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Alport’s Syndrome

What is Alport’s Syndrome?

Alport’s Syndrome is an inherited condition that causes abnormal development of the kidney. This abnormal development allows damage to occur to the capillary membranes of the glomeruli. These structures act as filters, removing excess water and waste from the blood. The damage is gradual and leads to kidney failure.

Who gets Alport’s Syndrome?

As the condition is inherited, you can only get it through the genes you acquire from your parents. It is a disease that reveals itself in childhood. Boys are affected more severely than girls, who may not even know that they have the condition. Exactly how it is passed on is unclear. Daughters seem to get it more from fathers who have the condition, whereas mothers seem to pass it onto both sons and daughters.

What are the symptoms?

The disease usually presents with blood in the urine (haematuria). This can be picked up early during routine urine tests, but is usually seen for the first time when the blood is visible in the urine.

The other main symptom is hearing loss. As the blood in the urine is usually seen first, hearing loss is not generally noticeable at this time.

In order to confirm the diagnosis, the doctor will want to perform a renal biopsy in order to obtain a very small amount of kidney tissue. This tissue will be examined under the microscope to determine what the cause of the blood in the urine is.

What is the treatment for Alport’s Syndrome?

There is no cure for Alport’s Syndrome. The damage to the kidney is permanent.

However, it takes time for the whole kidney to be affected and for the kidneys to fail. A child might be diagnosed with the illness, develop deafness when he is 10 years old and kidney failure when he is 15 years old. During this time, treatment will be aimed at controlling raised blood pressure and ensuring that the correct diet is followed

What happens when the kidneys do fail?

When kidney failure finally occurs the child will need the function of the kidney to be replaced by other means. This takes the form of dialysis. The different options available for dialysis will be put forward with their pro and cons in order that a choice can be made.

In addition, anyone with Alport’s Syndrome, with kidney failure, can be placed on the waiting list for a kidney transplant. The condition will not affect any transplanted kidney.

Analgesic Nephropathy

What is Analgesic Nephropathy?

Pain-killing drugs are called analgesics. Some years ago it was found that taking large doses of one particular pain-killer, phenacetin, could cause permanent damage to the kidneys. As a result phenacetin was withdrawn from the market and is not available in the UK. There is some concern, however, that prolonged use of other pain-killers

like Brufen/Ibuprofen, Diclofenac/Voltarol etc and other medication such as those used for arthritis might occasionally have the same effect. It is important therefore not to take pain-killers for long periods i.e. several months or more without checking with your doctor. Paracetamol and tablets containing paracetamol like Co-codamol/Co-proxamol etc do not cause kidney trouble.

What happens if kidney damage has occurred?

If kidney damage is caused by drugs then stopping the drug is often followed by improvement in kidney function. Unfortunately the more damage that has occurred the less likely there will be a worthwhile improvement.

Autosomal Dominant Polycystic Kidney Disease (ADPKD)

This leaflet is a shortened version of a booklet on ADPKD prepared by the Institute of Nephrology, Institute of Medical Genetics and Department of Paediatric Nephrology, University of Wales College of Medicine, Cardiff, Wales. Please ask your consultant if you would like one.

What is Autosomal Dominant Polycystic Kidney Disease?

Autosomal dominant polycystic kidney disease (abbreviated as ADPKD) is an inherited disease in which cysts develop in both kidneys. In a proportion of people this condition will cause kidney failure in adult life.

What are Cysts?

A cyst is a cavity containing fluid like a blister or grape. The cyst is usually filled with clear fluid. Sometimes blood clots may develop in some of the cysts and, occasionally cysts may become infected. Polycystic means there are many cysts present. In ADPKD the cysts cause the kidneys to enlarge.

How does ADPKD affect the kidneys?

The most important effect is a slow loss of kidney function. This occurs over many years and may result in the slow development of kidney failure. Both kidneys are equally affected. Kidney failure is very rare before the age of 30 and, if it develops, usually occurs from 50 to 60 years of age. Up to a third of affected individuals, however, will reach the age of 70 years without serious kidney problems. Thus not everyone with ADPKD gets kidney failure.

What makes the cysts grow?

No one knows what makes the cysts develop and grow. As a result there is no known proven treatment which will prevent cysts developing in people who have the ADPKD gene.

Is it possible to predict who will develop kidney failure?

Not everyone with ADPKD will develop kidney failure. Unfortunately it is not possible to predict who will and who won't advance into difficulties with kidney function. Furthermore, tests to tell how a patient inherits the condition are not yet available as a routine. **It is important that anyone with the condition is seen regularly (about once a year) by a doctor** for a check on blood pressure and the measurement of waste product levels in the blood. This will allow detection of any changes in kidney function at an early age.

Can other parts of the body be affected?

Yes. It is very common for people with ADPKD to have cysts in the liver. These may cause a large liver but liver failure does not occur. Occasionally cysts can occur in the spleen or pancreas but these do not cause any symptoms.

What are the symptoms of ADPKD?

Some people may get no symptoms at all. Others may experience no symptoms until they develop kidney failure. Some will get a variety of problems including pain, bleeding, infection in the urine and kidney stones.

- **Pain** - A minority of people experience pain in the loins. Usually this occurs in attacks lasting only a few hours or days and then settles for a long time. The pain can sometimes be severe requiring strong painkillers and may be accompanied by an episode of blood in the urine. Less frequently there may be a constant dull ache in the loins going on for months or years.

- **Blood** - Blood in the urine is a very common finding in people with ADPKD. Often the blood is not visible to the naked eye but can only be detected by sensitive tests. Sometimes the urine is obviously discoloured pink, red or brown. Individuals may develop pain in the loins and blood in the urine. When this occurs it is thought to be due to the occurrence of bleeding from a cyst. Treatment in this case consists of plenty of liquids to drink, painkillers and rest. Very occasionally a blood transfusion may be necessary but the attacks will always stop eventually.

- **Urine infection** - Studies have shown that people with ADPKD are liable to infection in the urine. Usually the attacks can be treated by antibiotics. Very occasionally infection can occur in the cysts themselves. In this case the antibiotics may need to be given through a vein to be effective. Occasionally it may also be necessary to remove any fluid or infected material from the cysts using a fine needle.
- **Kidney stones** - Kidney stones can occur in patients with ADPKD. Usually there are no symptoms associated with stones located in the kidney. Occasionally, the stones may move and cause symptoms such as waves of pain coming from the loin and moving around and down to the groin on the same side. Pain like this is called renal colic and may be associated with the appearance of blood or traces of stone in the urine.

How is it inherited?

The condition is hereditary which means it is caused by an altered gene. An alteration within a gene is generally referred to as a mutation. The gene mutation may be passed on from an affected parent to a child. Genes are the codes for the messages which tell the body how to develop, grow and work normally. Each gene codes for a different message. Genes are grouped together on structures called chromosomes. Humans have 23 pairs of chromosomes. Twenty two pairs are called autosomes. The last pair are called sex chromosomes and determine the sex of an individual. The A in ADPKD stands for autosomal. This means the condition is inherited on one of the autosomes. Because the gene is not on a sex chromosome males and females have an equal chance of having the disease. The first D in ADPKD stands for dominant. This means that if a person has the abnormal gene mutation then he or she will develop cysts in the kidney.

When a child is born to a parent with the condition there is a 1 in 2 chance that the child will inherit the mutation responsible for ADPKD. This is just like tossing a coin where there is a 50% chance of getting a head and a 50% chance of getting a tail. Sometimes 5 or 6 heads may occur in a row, however, if the coin is tossed often enough eventually there will be roughly equal numbers of heads and tails. The same is true in families with ADPKD. One family may have all affected children and another have none affected but on average there will be half affected and half unaffected. Everyone who has the gene for ADPKD will eventually develop kidney cysts, although the rate of cyst development is variable from one person to another. It is important however, to realise that if a child does not inherit the gene, he or she cannot transmit the condition to their children. The ADPKD gene does not skip generations, although it may appear to do so in some families. When this appears to have occurred it is because someone with the gene has had very few symptoms and may never have known that they had the condition.

How is the diagnosis made?

A person may discover they have ADPKD in a number of ways.

Firstly, they may be screened because someone else in the family has the condition. Usually this means having a test called an ultrasound scan.

Secondly, the condition may be picked up by chance when a person is seen for another condition either by a doctor feeling enlarged kidneys when examining the abdomen or as a result of some type of scan being done because of some other abdominal problem.

Finally, the condition may be diagnosed because the patient has symptoms suggestive of kidney disease or kidney failure.

Who should be tested?

In medical terms, there are a number of important potential benefits that arise from an early diagnosis of ADPKD. People with the condition are at increased risk of a number of complications which can remain hidden but which benefit greatly from early detection and treatment. The commonest and most important of these treatable complications is raised blood pressure (hypertension). This occurs as a result of cysts in the kidneys and is responsible for premature deaths from heart attack, stroke or a further deterioration of kidney function. Occasionally, infection can develop in one or a number of kidney cysts, causing further kidney damage.

While there are some beneficial effects that may arise from an early diagnosis, there are also a number of more negative aspects that need to be considered. Many people express concern about the potential psychological difficulties that may be encountered after learning that the condition may be present. These psychological issues may be even greater when a child is diagnosed as having ADPKD as a result of testing arranged because of the known background family history. One the other hand, some people experience considerable relief after learning as much as they can about the condition instead of having only partial understanding which often creates the potential for some more frightening misunderstandings. Occasionally, there are other surprising consequences which can arise from diagnosing ADPKD. Many people find that life insurance is more difficult to obtain and sometimes there can be employment consequences, particularly when an employer requires a medical examination prior to commencing a new job. Overall, we would suggest that it is important for each person to decide for themselves whether or not they wish to be tested bearing in mind their own particular circumstances.

Is there any treatment?

At present there is no proven treatment that will stop the cysts developing and growing. More importantly there is no proven treatment that will prevent a patient from developing kidney failure. However, there is evidence that if high blood pressure occurs as a complication of ADPKD then lowering the blood pressure will slow the rate at which the kidneys deteriorate. If kidney failure occurs, patients can be treated by dialysis or a kidney transplant and the results of these treatments are as good as with any other cause of kidney failure.

What should I do if I have ADPKD?

The important thing to remember is that most people with the condition should be able to live a normal life for many years. It is highly advisable to have an annual examination. This means having the blood pressure checked and a blood test to check on kidney function. If the blood pressure is found to be raised this can be treated by one or more drugs. Once the blood pressure is controlled it should be re-checked at frequent intervals, about once a month. This can be done by your family doctor or a nurse.

The blood tests measure the level of waste products. The two main waste products are urea and creatinine. If the levels of these substances start to rise this suggests the kidney function is deteriorating. If the blood urea and creatinine are found to be raised, testing is done more frequently. If kidney function is significantly reduced then a the blood count, which checks for anaemia, and other tests to assess calcium and the bones will also be done. If found, correction of these later complications of developing kidney failure will often bring benefits such as an improvement in energy levels and sense of well-being.

An introduction to diabetes and kidney disease

Diabetes is the most common cause of end stage renal failure (ESRF). Although most people with diabetes do not develop kidney damage that is severe enough to cause ESRF, diabetes is responsible for up to a third of all new kidney disease cases.

The factors that lead to kidney disease in people with diabetes is not fully understood. It seems that heredity, diet, and other medical conditions, such as high blood pressure are important. High blood pressure and high levels of blood sugar certainly increase the risk that a person with diabetes will develop kidney failure.

What is diabetes?

In diabetes, also called diabetes mellitus or DM, the body is unable to use certain foods effectively, especially carbohydrates. The human body normally converts carbohydrates (complex sugars found in starchy foods) into glucose (the simple sugar that is the main source of energy for the body's cells). To enter cells, glucose needs the help of insulin, a hormone produced by the body in the pancreas. When a person does not produce enough insulin, or the body is unable to use the insulin that is present, the glucose is unable to enter the cells and it builds up in the bloodstream. Measuring the level of glucose in the bloodstream provides the diagnosis of diabetes. It is also the

high levels of glucose in the bloodstream that causes the damage to the body.

There are two types of diabetes mellitus: Type I, or insulin dependent diabetes and Type II, non-insulin dependent diabetes.

- **Type I -** insulin dependent diabetes

Type I diabetes, insulin dependent diabetes (IDDM), is the more severe of the disease but is much less common than Type II. Type I occurs more in children and young adults and is less common in adults. In IDDM, the pancreas produces little or no insulin. As a result, people with IDDM must receive daily insulin injections to replace their normal production.

- **Type II** - non-insulin dependent diabetes

Most people with diabetes have non-insulin dependent diabetes (NIDDM), or Type II diabetes. It occurs more often in people over the age of 40. In NIDDM the pancreas is still producing insulin, but may not be making enough or for some reason, the body is unable to use it properly.

Type II diabetes is associated with being overweight. Therefore, it can be controlled by careful selection of foods and exercise leading to weight loss. However, some people require tablets to stimulate production of insulin by the pancreas within their body or slow down the absorption of sugars from the stomach and gut into the blood stream. Even so, severe cases can be treated with insulin, although they are not technically Type I diabetics.

Unfortunately both types of diabetes can lead to kidney disease, although Type I is more likely to cause it than Type II.

How does diabetes cause kidney disease?

The damage to kidneys caused by diabetes is called diabetic nephropathy. The kidneys are affected in two ways:

1. Damage to the glomeruli of the kidneys

The high levels of glucose in the bloodstream causes damage to the glomeruli, the microscopic blood filters of the kidneys. The damage reduces the efficiency with which the kidneys filter the blood. The damage can range from mild to severe. Symptoms can include fluid retention in the form of swelling of the limbs, loss of sleep, tiredness, poor appetite, upset stomach, vomiting, weakness, and difficulty concentrating.

2. Damage to the kidney that affects its role in controlling blood pressure

The high levels of glucose in the blood affect the kidneys role in controlling blood pressure. Sensors in the kidney falsely detect lower blood pressure because of damage that blocks the tiny vessels carrying blood through the kidney. These sensors then trigger a chain of chemical actions in the body which leads to the body raising blood pressure unnecessarily. In turn, the high blood pressure interferes with the function of the kidney by causing more damage to the glomeruli.

Unfortunately, the symptoms of kidney failure usually occur only in the late stages of the disease, when the kidneys have been reduced to working at less than a quarter of their normal level. This is because the kidneys work to make up for the failing capillaries and hide the problem.

In order to reduce the chance of damage it is important to control diabetes, by maintaining healthy blood sugar levels, as carefully as possible. Good control may slow the progression of the disease so that, although affected, the kidneys can still work well enough without medical intervention.

Mild damage might cause only swelling of the kidneys and the loss of tiny amounts of protein from the blood as the filters do not work quite as well as they should. Severe damage in advanced kidney disease related to diabetes will cause high blood pressure, increasing levels of waste products in the blood stream and possibly total kidney failure.

Who is affected by kidney disease?

It can take a long period of time to develop kidney failure from diabetes, as much as 20 or more years. Men with diabetes are more likely to get kidney disease than women. Control of blood sugar levels and the effective treatment of high blood pressure are important in maintaining kidney function. Kidney failure is not an inevitable result of diabetes.

How does high blood pressure affect the kidneys?

High blood pressure (hypertension), is a major factor in the development of kidney problems in people with diabetes. The glomeruli, the filters of the kidney, do not work effectively in the presence of high blood pressure as it damages and scars their delicate structure. Therefore, less excess water and fewer waste products are removed. These build up in the body causing the symptoms of kidney failure.

A family history of high blood pressure and the presence of high blood pressure increases the chances of developing kidney disease. High blood pressure will make any kidney damage worse where it already exists.

What is high blood pressure?

Blood pressure is measured in millimetres of mercury. Normal blood pressure is about 120 millimetres of mercury systolic over 70 millimetres of mercury diastolic but varies according to the gender, height and weight of a person. The term ‘systolic’ refers to the pressure in the arteries when the heart contracts or beats and ‘diastolic’ refers to the pressure between heartbeats when it is refilling before the next beat. High blood pressure is usually taken as any reading with a systolic greater than 140 mm/hg and a diastolic greater than 90 mm/hg. This is usually stated as 140 over 90.

As noted above, diabetes itself can lead to hypertension as a result of damage to the kidney caused by the disease. The combination of high blood pressure damaging the kidneys and damage to the kidneys causing high blood pressure creates a vicious cycle. Therefore, the early detection and treatment of even mild hypertension are essential for people with diabetes.

How can high blood pressure be treated?

There are a large number of drugs available now to treat high blood pressure. These drugs, commonly known as anti-hypertensives, can slow the progression of kidney disease significantly. If you have high blood pressure you may already be using one of these. There are two types commonly in use, ACE (angiotensin-converting enzyme) inhibitors e.g. captopril and calcium channel blockers e.g. nifedipine. ACE inhibitors also seem to play a role in protecting the glomeruli from damage.

Your doctor will prescribe these or other medicines for you if you need them as part of blood pressure control.

What happens to people with diabetes with end stage renal failure?

When somebody with diabetes reaches end stage kidney failure they will require medical help to replace the function of the kidney. This is called renal replacement therapy and is provided in the form of dialysis or a kidney transplant. Having diabetes does not mean that you cannot have dialysis and/or a kidney/pancreas transplant.

How successful is renal replacement therapy?

Patients with diabetes are transplanted as successfully as those without diabetes. Dialysis for people with diabetes is as successful in the short term as it is for patients without diabetes. However, because of the other complications of diabetes, damage to other organs such as the heart, the eyes and nerves, patients with diabetes who receive renal replacement therapy do experience higher rates of illness and death.

Can the pancreas be transplanted with the kidney?

For people who are insulin dependent diabetics where the pancreas no longer produces insulin there is sometimes the possibility of transplanting the pancreas with the kidney from the donor. The pancreas can be transplanted on its own. However, pancreases transplanted together with a kidney have a higher success rate than a pancreas transplanted alone.

If the operation is successful, the patient will no longer have diabetes, will not need insulin or blood sugar monitoring and is unlikely to develop diabetes again, unless the transplant fails. However, damage to other organs, such as the eyes or nerves, will not be reversed by a pancreas transplant

, but new injury is prevented.

Glomerulonephritis

What is glomerulonephritis?

Each kidney consists of about a million tiny filters, called glomeruli each connected to a fine tube called the tubule. Blood is filtered through the glomeruli and the tubules change this fluid into urine. Diseases of the glomeruli are called glomerulonephritis. There are several types of glomerulonephritis. Sometimes the condition is confined to the glomeruli. On other occasions the glomeruli may be involved as part of a more widespread disease such as lupus or vasculitis (see these sections in this library). Glomerulonephritis may come on suddenly, so called acute glomerulonephritis, or fairly quickly over a few weeks or months. This is called rapidly progressive glomerulonephritis. In many patients the condition may persist for a long time and is then known as chronic glomerulonephritis.

How is glomerulonephritis diagnosed?

When there is glomerulonephritis present the urine will almost invariably contain blood and/or protein when tested with paper strips. Sometimes the patient may develop swelling due to losing a lot of protein (see nephrotic syndrome). The commonest type of glomerulonephritis is IgA nephropathy. Often the best way to confirm the diagnosis and determine which condition has affected the glomeruli is to perform a kidney biopsy.

How is glomerulonephritis treated?

Treatment is available for some of the causes of glomerulonephritis and may involve the use of steroids and/or other drugs such as cyclophosphamide. For a number of patients the condition will deteriorate causing kidney failure with the need for dialysis and if there is no recovery a possible renal transplant.

Gout in kidney patients

What is gout?

Gout is a type of arthritis. It is caused by raised levels of uric acid in the bloodstream (hyperuricaemia) which crystallise and are deposited in the joint tissues of the body. These crystals cause a local reaction leading to inflammation which in turn causes enormous pain to the sufferer. The joints most commonly affected are the smaller joints of the hands and feet, but other joints can also be involved.

What are the symptoms of gout?

The onset of gout can be sudden, classically appearing during the night or early morning. The affected area becomes swollen and painful, to the point where even a sheet resting on the joint, e.g. the toe, can be too painful to bear

Which kidney patients are affected by gout?

- **Pre-dialysis & dialysis patients**

Gout occasionally occurs in people with poor kidney function not yet on dialysis and in dialysis patients. Uric acid builds up in the blood because the damaged kidneys are unable to remove it. Also, many of these patients take water tablets (diuretics) which can cause gout themselves.

These patients are more often affected by a similar condition called pseudogout, where the inflammation is caused by the deposition of calcium pyrophosphate crystals. This can be the result of renal bone disease due to kidney failure but may be due to other causes. Pseudogout has similar symptoms to gout but tends to affect large or medium sized joints such as knees, hips, wrists and shoulders.

- **Transplant patients**

Transplant patients taking cyclosporin (Neoral) are affected by gout particularly if they are taking water tablets (diuretics) as well. The cyclosporin reduces the kidney’s ability to clear uric acid from the blood.

What is the treatment for gout?

1. Treatment of acute gout

The aim of treatment for the acute phase of gout is to reduce inflammation and pain in the joints. The traditional first line of attack is with nonsteroidal anti-inflammatory drugs (NSAIDS) such as sulindac, diclofenac, ibuprofen, or naproxen. However, these drugs are often not given to kidney patients because they can cause a decline in kidney function and fluid retention. In dialysis patients, preservation of kidney function by avoiding NSAIDs is less important but the drugs would still be used with caution.

The main drug therapy for acute gout in kidney patients is colchicine. It does not share the problems of NSAIDs but the dose may need to be adjusted carefully depending on kidney function and side-effects experienced (nausea, vomiting, diarrhoea & abdominal pain are common). Colchicine is an effective treatment but it may take around 24 hours for the full benefit to be seen.

2. Long term treatment

Some people will need to be given drugs to prevent them getting further attacks of acute gout. The drug used is called allopurinol and it works by reducing the levels of uric acid in the blood. The drug needs to be taken regularly to make an attack less likely. Allopurinol is started after the acute phase has been treated. Starting sooner can worsen or prolong the acute attack. The most common side-effect of allopurinol is a skin rash, which should be reported to your doctor who may need to reduce the dosage or stop it temporarily.

Hypertension/High Blood Pressure

What is blood pressure?

Blood pressure means literally the pressure of blood in the arteries of the body. It is usually measured as two numbers. The first one is always higher than the second one. This is because the first number given is always the measurement of the pressure of blood in the arteries when blood is pumped out of the heart.

The arteries take the blood from the heart to the organs and tissues of the body. They have to be able to cope with the extra blood temporarily pushed out of the heart until the heart fills up again. As a result, there is a temporary surge or rise in pressure. This exists only until the heart refills itself from the blood supply brought back to it by the body’s main vein. The arteries of the body have to be able to withstand this rise in pressure every time the heart beats. The first number is called the systolic pressure.

The second, lower, number is simply the lowest pressure of blood in the arteries when the heart is refilling, releasing the extra pressure, allowing blood to move through the arteries and veins back into the other side of the heart before it is pushed out again. This number is therefore always lower. It is known as the diastolic pressure.

What is normal blood pressure?

Like most things normal can vary quite a lot. Children have lower blood pressure than younger adults, who usually have lower blood pressure than older adults. Average adult blood pressure measured in mm/hg (millimetres of mercury) is about 120/70 mm/hg. The systolic pressure as the heart contracts and pushes blood out into the arteries is 120 mm/hg, the diastolic blood pressure as the heart refills from blood brought back to it by the veins is 70 mm/hg. However, this can vary on how fit you are (top class athletes have low blood pressure) or how well you are: people with kidney disease often have high blood pressure, no matter how old they are.

What is the connection between the kidneys and blood pressure?

The kidneys are important in the control of blood pressure and are very sensitive to changes in blood pressure, particularly where they are already damaged.

If the kidneys are damaged e.g. by infection or inflammation, they are not able to help the body to control blood pressure. Normally, they do this by removing excess fluid from the blood. If the excess fluid is not taken out by the kidneys, and stays in the blood, it leads to raised blood pressure. In turn, the raised blood pressure will cause further damage to the delicate filters of the kidney that remove the water. Kidney failure may result.

Damage may also occur if there is not enough blood flowing through the kidney.

But there are other causes of high blood pressure. If these are not controlled, healthy kidneys can be damaged. In fact, high blood pressure is the second most important cause of end-stage renal failure.

Who gets high blood pressure?

Hypertension is more common in women than men. However, men seem to cope with it worse. It is associated with obesity, smoking and high blood fat levels. People of Afro-Caribbean ethnic origin are more likely to have high blood pressure.

How do you know if you have high blood pressure?

Most people have no symptoms. They find out only when their blood pressure is checked. Your blood pressure is considered high if it goes over 140/90 mm/hg. A one-off reading is not enough to confirm high blood pressure. The sight of a doctor is enough to give some people high blood pressure without any real cause. It needs to be consistently raised over a series of readings.

What is the treatment for high blood pressure?

Treating hypertension depends on the cause. There are several groups of drugs that are used. These include: ACE inhibitors, calcium channel blockers, diuretics and beta- blockers. You can talk to your GP, hospital doctor or pharmacist, or local chemist about these medications.

What can I do to control my blood pressure?

There are four key steps that anyone can take to help control their blood pressure:

- Control your weight
- Limit the amount of salt you use in your diet or add to your food at mealtimes
- Get plenty of exercise

- Don’t drink too much alcohol

Hyperparathyroidism & renal bone disease in kidney patients

What is hyperparathyroidism?

This is the term used to describe the condition that results when parathyroid glands work harder then normal.

What are the parathyroid glands?

We normally have 4 or 5 parathyroid glands. These are tiny oval bodies situated in the neck behind the thyroid gland, near to the voice box, underneath the Adam’s Apple.

What do they do?

The parathyroid glands play an important role, together with the kidneys, in keeping a normal balance of calcium and phosphate in the body. Normal calcium and phosphate balance helps to make bones strong and keeps them healthy.

In a healthy person this happens as follows:

The parathyroid glands produce a hormone called PTH (parathyroid hormone). Together with vitamin D, produced by the kidneys, it helps the gut to absorb calcium into the bloodstream from the food that we eat. This means that there is plenty of calcium available to maintain healthy bones and teeth and for the body to perform other functions in which calcium is important.

PTH also helps the kidneys to get rid of waste phosphate in the blood into the urine.

What happens to normal calcium balance when your kidneys are not working?

When there is kidney damage, the kidneys may stop making active vitamin D and are unable to get rid of waste phosphates into the urine. This has 2 effects:

Firstly, the gut is unable to absorb as much calcium as before. Unable to detect enough calcium in the bloodstream, the parathyroid gland produces more and more PTH. In order to find enough calcium, in response to the extra PTH, the body robs it from the next best source, your bones, making them weak, causing 'renal bone disease'. This, in turn, releases more phosphate into the bloodstream because bones are made not only of calcium but also of phosphate.

Secondly, the extra levels of phosphate in your bloodstream disguises real calcium levels in your blood making them appear lower, leading the parathyroid glands to demand more calcium and therefore produce even more PTH and leading to further breakdown of your bones.

How can calcium levels be controlled in kidney failure?

Your doctor will want to control your PTH levels carefully. Depending on the individual, this can take several forms. For example, by giving you extra calcium, controlling the level of phosphate in your bloodstream with tablets or giving you active vitamin D. However, if PTH is not controlled, your doctor may recommend that the parathyroid glands are surgically removed. To learn about surgery to remove the parathyroid glands please look at the leaflet on parathyroidectomy

IgA Nephropathy

What is it?

IgA nephropathy, also known as IgA Disease or Berger’s Disease after the doctor who first recognised it, is the commonest of a group of conditions, which have the general name glomerulonephritis. Glomerulonephritis is an inflammation of the kidneys, in particular the glomeruli, the microscopic filters which allow the kidney to clear waste products and excess water from the blood.

IgA is an antibody. Antibodies are a part of the body’s natural defences against infection. Everyone has IgA. It is usually found in our blood, the inner lining of the intestine and the airways of the lungs. If you have IgA nephropathy, a very small amount of the IgA has stuck in your kidneys causing inflammation and is stopping the kidneys working properly. The rest of your IgA will be working quite normally, defending you against infection.

It is not yet known why the IgA sticks in the kidney.

What are the symptoms of IgA nephropathy?

The commonest symptom of IgA nephropathy is episodes of blood in the urine (haematuria*)*. This often coincides with a sore throat or respiratory infection. Sometimes the episodes of blood appear to be caused by a bowel infection or even exercise. The urine may look like anything from slightly smoky, through tea without milk (most common), to bright red. It is not usual to see blood clots. It is usually painless, although may be accompanied by kidney discomfort.

Between these episodes of visible blood in the urine, there will still be blood in the urine, which will show if the urine is tested. Some people never get visible blood in their urine.

Sometimes the damage to the kidney causes protein to be lost into the urine.

This will show on urine tests. If there is a lot of protein loss, the patient may have fluid retention, which will appear as ankle swelling. This is also called nephrotic syndrome. This is not very common.

Some patients may develop high blood pressure as a result of the kidneys not working properly.

How is it diagnosed?

The above symptoms may suggest IgA nephropathy to your doctor. In order to confirm the diagnosis a renal biopsy will be required. Only a very small specimen of the kidney is taken to be examined in the laboratory for IgA. This is to rule out other possible causes for the symptoms. Only one kidney needs to be sampled.

Who gets IgA nephropathy?

The condition is three times as common in men than women. Nobody yet knows why this is. It is most common in children and young adults, but can develop at any age. Older people are less likely to have the visible blood in their urine, but more likely to have protein and blood in their urine when it is tested. They are also more likely to have high blood pressure and other symptoms of kidney failure. This is because they may have had the disease for longer before it was diagnosed as blood was not visible in the urine.

Very occasionally, a family will have more than one member affected by IgA nephropathy. This is very unusual. As the great majority of patients with IgA nephropathy are the only ones in their families to have the condition, there is no need to test other family members.

What is the risk of kidney failure?

The function of many people’s kidneys with IgA nephropathy does not get worse. However, about a quarter of all patients with the disease will develop impaired kidney function and, eventually, kidney failure. But, this may take 20 years or more.

Patients who have more severe symptoms, protein as well as blood in the urine, high blood pressure and high creatinine levels in the blood (a measure of kidney function), are more likely to develop kidney failure. The biopsy will show how much the inflammation has scarred and damaged the kidney. If you have blood in your urine and the biopsy shows just the deposits of IgA stuck in the kidney and very little other damage, the chance of kidney failure is small.

Although it is possible to predict what may happen for each person, it is not possible to be certain. For this reason, IgA nephropathy patients are always monitored regularly, either in the hospital outpatients department or at the GP’s surgery.

Does it ever get better?

Yes, it can. For some people, even the invisible blood in the urine will disappear, leaving no sign of the disease. However, the IgA can still be in the kidney. Although further episodes are unlikely, the blood in the urine can return. The regular check-ups are still needed.

What happens if I have repeated episodes of blood in the urine?

Most people get a few episodes of blood in their urine. There is not a close relationship between the number of attacks and the chance of getting kidney failure later. The attacks do get less frequent, although blood will still be found in the urine on testing.

Just occasionally, an attack will lead to a sudden worsening of the kidneys’ ability to work normally. Normal function is usually restored within a week or two.

Does IgA nephropathy affect any other part of the body?

No, it does not. There is another condition, called HSP (Henoch-Schonlein purpura), which is similar. Patients with this condition not only have a kidney problem, but also have a skin rash, aches and pains in their joints and abdominal pain. In HSP, IgA is found in the skin as well as the kidneys. The skin, joint and abdominal problems often go away after a few weeks, but the kidney problem can stay much longer and may lead to kidney failure. HSP can occur at any age but is most commonly seen in children.

If I have IgA nephropathy, should I change my lifestyle?

No!

- Food - No foods are known to cause IgA nephropathy. Continue to eat a normal, healthy diet.
- Alcohol - Alcohol has no effect on kidney disease. You may continue to drink alcohol, in moderation, of course.
- Exercise – If you are a patient who finds that exercise does seem to produce visible blood in the urine, it may be sensible to avoid those activities that cause this. Otherwise, all physical activity can be pursued as normal.

How is IgA nephropathy treated?

There are several approaches to consider:

1. Removing IgA stuck in the kidneys and preventing further deposits

This not yet possible. Research is continuing to look at how this might be achieved, but until it is understood why IgA sticks in the kidneys a treatment will remain unfound.

2. Treating the episodes of blood in the urine

Blood in the urine can be a dramatic and frightening symptom. Although it looks like a lot, a small amount of blood can colour urine very effectively. It is very unusual to become anaemic from IgA nephropathy. The haematuria will usually settle down in a few days, without any help. Consequently, there is no specific treatment for haematuria.

If the attack started with a sore throat or respiratory infection, the treatment for those infections should be no different to usual. For example, if you have a bacterial sore throat, antibiotics may be required. If it is viral, it will get better on its own.

If you have many attacks due to tonsillitis, you may want to have your tonsils out. But this decision should be based on the amount of trouble that your tonsils are giving you, as there is no proof that this will reduce the chance of kidney failure.

3. Treating IgA nephropathy with steroids and immunosuppressants

It was once thought that, as the condition is caused by the immune system going slightly wrong, giving drugs to suppress the immune system would work. There is no evidence that this treatment option provides any long-term help. Only in a small number of patients with rapidly deteriorating kidneys is this a useful possibility. The drugs have serious potential side effects and the pros and cons need to be discussed with the treating doctor.

A few patients with a lot of protein in the urine (nephrotic syndrome) may be helped with steroids. They can stop the protein loss rapidly, make the patient feel better and perhaps reduce the chance of kidney failure.

4. Treating blood pressure

Raised blood pressure is common in IgA nephropathy and can occur early on when kidney damage is mild. There are two very important reasons for controlling blood pressure.

- General health – you are more at risk of stroke and heart attack and a younger age if you have uncontrolled blood pressure.

- Protecting your kidneys – damaged kidneys are very sensitive to raised blood pressure. They will deteriorate more rapidly if blood pressure is uncontrolled. Therefore, controlled blood pressure can delay kidney failure in IgA nephropathy.

Blood pressure control using tablets is the best way of reducing the risk of kidney failure from IgA nephropathy

5. Treating Kidney Failure

A quarter of all IgA nephropathy patients eventually develop kidney failure. This happens gradually, usually over a twenty-year period.

When this does happen, patients need a treatment that will replace the function of their kidneys. Different forms of dialysis are offered to patients for them to choose that which best matches their needs. For many, if it can be achieved, the best form of treatment is a kidney transplant. IgA nephropathy does not affect the range of options that are available.

If I have a kidney transplant, will IgA nephropathy damage the new kidney?

IgA may stick in the new kidney. The immunosuppressants that transplant patients take will not prevent this from happening. This is not as serious as it first appears. The IgA may stick but it will not cause much in the way of inflammation or scarring. Some patients have lost their transplants because of recurrence of the disease in the new kidney. However, if it does happen, it happens slowly as it would have done in your original kidneys. The chance of a successful transplant are not reduced if the cause of your original kidney failure was IgA nephropathy.

Lupus - Systemic Lupus Erythematosus (SLE) & Lupus Nephritis

This leaflet is intended as a brief introduction to lupus. Further information and help may be obtained from the organisations listed at the end of this leaflet.

What is Lupus?

Lupus is an autoimmune disease. This is where the body’s own immune system, rather than producing antibodies (immunoglobulins) to attack invading bacteria and viruses, becomes confused and produces antibodies that attack the body’s own cells. In the case of lupus, it is the arteries and connective tissues e.g. skin, joints, kidneys, lungs, heart and gastrointestinal tract that are affected. The disease is unpredictable, it comes and goes unexpectedly.

Who can get lupus?

Lupus is not a rare disorder. Although it can affect anybody of any age, it mostly affects women of child bearing age (15-50). There does appear to be a genetic predisposition to lupus. If you have family with lupus there is more of a chance of developing lupus yourself. Among children, lupus occurs three times more commonly in females than in males and in adults the ratio of women to men is even higher. The people most at risk of from this disease are those of Afro-Caribbean origin, particularly women. It is also more commonly seen in people of Asian origin.

What are the symptoms of lupus?

Most people with lupus present with skin or joint problems but symptoms can vary enormously because of the different organs that can be affected. This means that it is difficult to diagnose and can be confused with other disorders such as rheumatoid arthritis, multiple sclerosis and ME.

Rashes, alopecia (hair loss), fatigue, weakness, aching and painful joints particularly of the fingers, hands wrists and knees or arthritis are commonly seen. Patients may present with a fever and single organ involvement such as glomerulonephritis where the microscopic filters, the glomeruli are affected leading to kidney failure or, more rarely, with multi-organ involvement.

The symptoms are caused by inflammation, the body's reaction to damaged tissue. Inflammation can cause visible swelling, redness, warmth and pain. Tissues can be left scarred and permanently damaged.

What is the treatment for lupus?

There is no cure available yet for lupus. Medical treatment is aimed at controlling the specific problems that a person with the disorder has. Inflammation is treated with non-steroidal anti-inflammatory drugs in milder disease, anti-malarial medicines are used for mild to moderate disease and steroids and, if necessary, cytotoxic drugs like cyclophosphamide are employed in serious cases. All these medications can have powerful side-effects and people taking them need to understand them and have regular follow up in outpatients or with their GP.

In addition to drugs, it is important that people with lupus get plenty of rest and sleep and take it easy when they have a flare up of the disease. This can mean major changes to a person's lifestyle affecting those around them. It may need help from partners, family members and employers.

Certain things can provoke an exacerbation of the disease. These factors should be avoided e.g. sun, excessive heat, fatigue and some medications and infections. Any early symptoms of flare up should be reported promptly to the doctor.

Lupus and kidney disease (lupus nephritis/lupus glomerulonephritis)

The kidneys are affected by lupus in about a third of all people with the condition. For some, the disease may be very mild and come and go. For others, the problems may be worse, with a decline in kidney function that may lead to kidney failure.

- **What is lupus nephritis/lupus glomerulonephritis?**

Lupus affects the glomeruli, the tiny delicate filter structures of the kidney that are responsible for cleaning the blood of excess water and waste products such as urea and creatinine. They become inflamed and scarred leading to a loss of function. In particular, they allow too much protein from the body to leak out into the urine.

- **What are the symptoms of lupus nephritis?**

The most common symptom is puffiness in the legs, ankles and/or fingers. This is caused by water retained in the body because of the loss of protein. A patient might notice weight gain also from the extra water retained in the body. There is no pain from the kidneys or when passing water that is caused by the disease. As the disease can be very mild there may be no symptoms at all. In these cases it is usually identified during routine screening of urine when higher than normal amounts of protein are found in the urine.

- **How is lupus nephritis diagnosed?**

Urine testing – identifies the presence of protein and blood cells in the urine that have leaked through the damaged filters into the urine. These signs can be caused by other problems, therefore, to determine the cause of the problem, other tests are necessary. A 24 hour urine collection may be needed to measure exactly how much protein is being lost and how much creatinine is being removed by the kidneys. If you know that you have lupus you should have your urine checked regularly for protein and blood by your doctor.

Blood testing – will show how well the kidneys are working by checking the level of waste products in the blood. If the kidneys are not working as well, there will be higher levels of urea and creatinine in the blood. Levels of essential chemicals such as sodium and potassium will also be affected. Protein levels may also be measured. A test can be performed to detect abnormalities in the immune system.

Kidney biopsy – taking a tiny specimen of the kidney itself is the only way of absolutely confirming the diagnosis of lupus nephritis and it may be required. This allows the specimen of kidney to be looked at under a microscope to find out how much damage there is. This information allows the doctor to tailor treatment to the individual needs of the patient.

- **What is the treatment for lupus nephritis?**

For people with very mild lupus nephritis, no treatment is necessary, however, it is important to monitor kidney function regularly in case of the disease worsening.

For those that require help, treatment takes two forms. Firstly controlling the effects of any kidney failure, for example giving drugs to control blood pressure and water tablets to help to remove the excess water. Secondly, to control the inflammation within the kidney. This is usually done with high dose steroids. It is important to be aware that these drugs have side-effects that may be unwelcome and anyone starting treatment needs to know what the effects may be.

For some people, the steroids are not effective. These patients are offered drugs to suppress the bodies immune system, to stop further damage to the kidneys. Again, these medicines are very powerful and can have serious side-effects. Anyone starting treatment needs to know what these effects may be.

- **Is there a cure for lupus nephritis?**

There is no cure for lupus or lupus nephritis at the present. The aim of treatment is to control the disease. Unfortunately, some patients may develop end stage renal failure and require renal replacement therapy in the form of haemodialysis or peritoneal dialysis. Patients with lupus who have end stage renal disease may also opt for kidney transplantation. This has been done successfully. However, because the disease can recur, it is important to have the disease well controlled before a patient can be placed onto the transplant waiting list for a suitably matched kidney.

What support exists for people with lupus?

People with lupus are fortunate to have a very active patient association called Lupus UK. Lupus UK has a network of regional support groups across the UK. It provides welfare support for people with lupus, information (books, videos, fact sheets), advice and counselling for people with lupus. It works to educate and inform health care workers about lupus. It raises awareness in the general public through its annual Lupus Awareness Week each April. It raises funds for research, publishes a quarterly magazine for members and produces posters and other publicity materials. You can contact them at their head office:

Lupus UK

St James House, Romford, Essex RM1 3NH

Tel: 01708 731251, Fax: 01708 731252

or the local group:

South Wales Lupus Group

Ella P. Hetherington, Group Secretary, 7 Clos-yr-Wenallt, Rhiwbina, Cardiff CF4 6TW

Tel: (029) 2062 4511

Myeloma

This leaflet is intended as an introduction to myeloma. You can find out more about this disease by contacting the organisations listed at the end of the document.

What is Myeloma?

Myeloma is a cancer of the white blood cells.

White blood cells are responsible for the production of antibodies or immunoglobulins which circulate in the blood and attack any bacteria and viruses that invade the body. White blood cells are produced by one white blood cell dividing into two. This is normally a continuous but controlled process that takes place in the bone marrow, the spongy tissue inside bones.

In a cancer of the white blood cells, the reproduction of the cells becomes out of control, with abnormal cells multiplying, producing myeloma cells. These cells fill up the bone marrow interfering with the normal processes of the marrow such as the production of normal white cells, red cells and platelets.

In addition the myeloma cells have other effects. They produce abnormal antibodies that are unable to fight invading infections, but stick to the kidney filters [glomeruli] and affect the kidneys' ability to filter waste products and excess water from the body. These abnormal antibodies slow the production of normal antibodies, making the body more vulnerable to infections. The myeloma cells also invade the outer casing of the bone, causing holes to appear.

The cause of myeloma is not known. It is not, however, infectious and cannot be spread from one person to another.

Who gets myeloma?

Myeloma is not usually seen in younger people. It is most common in those of middle age – over 50 and the elderly. It is most unusual to see it in adults under 40 years of age.

What are the symptoms of myeloma?

The symptoms of myeloma are related to the effect of the abnormal cells on the body.

- The most commonly reported is back pain which may affect the ribs, the neck and the pelvis.
- The suppression of red blood cell production can cause anaemia which may appear as tiredness and lethargy.
- Tiredness and lethargy may also be the result of a kidney problem as waste products build up in the body.
- A patient may notice repeated minor infections like colds and coughs, because of the body’s impaired ability to fight off infection.
- The erosion of bone will cause high blood calcium levels which can lead to nausea, constipation, loss of appetite and even depression and drowsiness.
- Sometimes bruises can appear without injury and the patient suffers from gum bleeding and nose bleeds as the platelets in the blood that are responsible for clotting are not produced in sufficient numbers.

How is Myeloma diagnosed?

Myeloma is initially diagnosed by testing the blood and urine for the abnormal antibodies produced by the myeloma cells. These antibodies are called paraproteins. They are difficult to trace and the tests take about a week to complete.

If your tests suggest that you have myeloma, your hospital doctor will want to run more tests in order to be certain of the diagnosis and better plan any treatment that will be recommended to you. These will consist of:

- X rays to assess your body for bone damage
- A 24 hour collection of urine for a paraprotein called Bence Jones protein
- A regular series of blood tests to measure the level of paraproteins and to monitor for anaemia or kidney failure
- A bone marrow sample to see if it there are myeloma cells present in the marrow. This is done to confirm the diagnosis.

The tests may take some time to complete, and it may be several days or weeks before you get the final results.

How is myeloma treated?

There are two aims in the treatment of myeloma: to fight the disease and to control the symptoms of the disease.

Treatment of the disease may consist of one or a combination of:

- chemotherapy which aims to destroy the myeloma cells using powerful drugs
- steroids which in combination with chemotherapy are aimed at destroying the cancerous cells
- interferon which helps to further control the disease after chemotherapy
- radiotherapy which can destroy myeloma cells in specific locations in the bone, but not for the whole body

All these treatments have side effects which it is important to be aware of before starting treatment.

Treatment is tailored to the specific needs of a patient. Myeloma affects people differently and so different treatments are needed to match individual needs. Factors such as age, general health and the extent of the disease have to be considered and discussed with the patient..

Not everyone can be cured of myeloma, however the symptoms can be controlled and the spread of the disease slowed for a considerable time.

How are the symptoms controlled?

Unsurprisingly, treatment of the symptoms depends on the symptoms. The more common symptoms and their treatments are as follows:

- Anaemia is treated with blood transfusions in order to stop you feeling tired and breathless
- Infections are treated with antibiotics where possible. It is important to see your doctor at the first sign of any infection or fever
- Pain is controlled using chemotherapy and radiotherapy. Painkillers are prescribed until these treatments have an effect.
- Bone damage may need to be repaired with surgery in order to apply metal pins or plates for weakened bones
- Kidney problems may require treatment from a kidney specialist. It is important to drink plenty to allow the kidneys to work properly.
- Calcium in the blood is treated by giving patients extra fluids to enable the kidneys to filter out the calcium and flush it from the body in the urine and by drugs which slow down the rate of loss of calcium from the bone.

What other help is there?

There are support organisations locally and nationally dedicated to giving people with cancer the help they need, as much as anything to help themselves. Below are some useful contact addresses, they will be able to tell you about other groups that may be more local to you:

Tenovus Cancer Information Centre

College Buildings, Courtenay Road, Splott, Cardiff CF1 1SA

Welsh and English information service on all aspects of cancer, together with emotional support for patients and their families.

Tel: Freephone 0800 526527, 01222 497700

BACUP

3 Bath Place, Rivington St, London, EC2A 3JR

BACUP provides information on all aspects of cancer together with emotional support for patients and their families. They provide an information service free of charge to patients and families and a counselling service.

Cancer Information Service: London – 0171 613 2121

Out of London - Freephone 0800 181199

Cancer Counselling Service: 0171 696 9000

BACUP Scotland Cancer Counselling Service: 0141 553 1553

The Ulster Cancer Foundation

40-42 Eglantine Avenue, Belfast BT9 6DX

Has a helpline service and a resource centre. Runs support groups for patients and relatives.

Helpline: 01232 663439

Admin: 01232 663281

Nephrotic Syndrome

What do the kidneys do?

The main job of the kidneys, is to clean the blood, removing waste material that is produced by the body and any water that is not needed. They turn these things into urine. The kidneys also ensure that the things that are important for the body, like protein and blood are not lost through the urine. Thus the kidney filters selectively lose waste products and retain required products.

What is Nephrotic Syndrome?

Nephrotic Syndrome is caused by the kidneys not working properly, allowing a lot of protein to leak from the blood into the urine and failing to filter out other waste products such as sodium (salt).

What causes Nephrotic Syndrome?

The failure of the kidneys to work properly is caused by inflammation of a part of the kidney called the glomeruli allowing the leakage of proteins from the blood into the urine and stopping its ability to let sodium through. There are several conditions that can lead to this. It might be an infection, part of diabetic kidney disease, a reaction to a drug, or part of an inflammatory illness affecting the whole body such as Systemic Lupus Erythematosus.

What are the symptoms of Nephrotic Syndrome?

The main symptom is caused by the result of the body not cleaning out the sodium it does not require and leaking too much protein. This in turn holds water in the body that would normally be removed by the kidney. This water builds up, causing swelling or oedema of the ankles, legs and arms that worsens gradually.

What is the treatment for this condition?

There are two parts to the treatment. Firstly, diagnosing the condition and its cause. Secondly, giving medicines to control it and reduce the risk of it happening again.

- **Diagnosis**

Blood and urine specimens are obtained from the patient and sent to the laboratory. If it is Nephrotic Syndrome, the urine will show high levels of protein and the blood high levels of lipids (fats) and low levels of protein.

In addition, the Doctors will often want to perform a renal biopsy in order to obtain a very small piece of the kidney. Looking at this under the microscope will confirm the diagnosis and help them to choose the right treatment.

- **Treatment**

Any treatment will depend on the cause of the inflammation in the kidney. Some cases can be treated with steroids to reduce the inflammation in the kidney, allowing it to work normally. The swelling may take time to reduce. A relapse, where the symptoms come back, can occur.

Sometimes the inflammation is caused by the body’s own defence mechanism, the autoimmune system. Immunosuppressant drugs may be needed that reduce the power of the body’s natural defence systems long enough to allow the inflammation of the kidney to settle.

If the cause is a reaction to drugs, removing that drug from a patients prescription may help the patient to get better. Treating or removing a growth that has caused the condition will also help.

Patients with diabetic renal disease as the cause and others who do not respond to steroids are offered diuretics to control the swelling. In severe cases, these may have to be given directly into the body by injection.

Certain blood pressure tablets [ACE inhibitors like Perindopril, Captopril etc] reduce the amount of protein lost by the kidneys and these may be given to try to reduce the amount of protein in the urine but not necessarily affecting the underlying condition.

A low sodium, high calorie diet for all Nephrotic Syndrome patients is important. Reducing salt intake will prevent swelling from getting worse and high calories will replace the lost protein. In severe cases protein may be given directly into the body by a drip.

What can I do to help?

It is important that advice given about controlling salt in you eat is put into practice in hospital and at home. Make sure your family and friends understand your needs

You will be followed up, closely, in your outpatients clinic. It is important to attend these clinic appointments. If you are unable to, please let the hospital know and book another. Your Doctor will want to take blood samples regularly. This is done to check that your kidneys are working as well as they can and that your treatment is working. Your doctor will be able to tailor your treatment according to the results of the blood tests.

Relapses in ceratin kidney conditions are recognised. You can help by keeping an eye on your weight. If it starts to rise and you notice swelling in your legs you need to contact your doctor again. You should contact your doctor if you get the symptoms of kidney failure – tiredness, sickness, and breathlessness

Obstructive Uropathy

What is Obstructive Uropathy?

If the flow of urine from the kidney or bladder is partially or completely blocked there is back pressure on the kidneys leading to a deterioration in kidney function. This then causes kidney failure. This condition is called obstructive uropathy and it can occur at any age.

What causes Obstructive Uropathy?

There are many different causes. In young children it can be caused by a valve in the urethra, the pipe that empties the bladder. In middle age certain types of cancer can block the ureters and in old age a large prostate may have the same effect. If the blockage is above the bladder then kidney failure only occurs if both ureters are obstructed.

How is Obstructive Uropathy diagnosed?

The diagnosis is usually made by ultrasound which will show the kidneys to be very swollen.

How is Obstructive Uropathy treated?

The treatment is often by surgery to remove the cause of the blockage. Temporary relief and improvement in kidney function is achieved by draining the urine from behind the blockage. This may be via a catheter in the bladder or a tube going directly into the kidney through the loin called a nephrostomy. Once urine is flowing freely kidney function will improve quickly though it may not return to normal if the back pressure has caused permanent damage.

Pain-killers and the kidney

How do pain-killers affect the kidney?

It is not uncommon for patients with kidney problems to need pain-killing drugs. These are called analgesics. Prolonged use of analgesics can sometimes cause permanent kidney damage (see Analgesic Nephropathy). Perhaps more important is the fact that if kidney function is impaired analgesics may make kidney function worse.

Which pain-killers affect the kidney?

The drugs most likely to do this are called non-steroidal anti-inflammatory drugs or NSAID. These are often used to treat arthritis and include Ibuprofen (Brufen), Indomethacin (Indocid) etc. It is important therefore not to take this type of drug without medical advice if you have any kidney damage. Even if prescribed it may be necessary to have frequent checks on kidney function. Please do not buy this type of drug over the counter e.g. Nurofen.

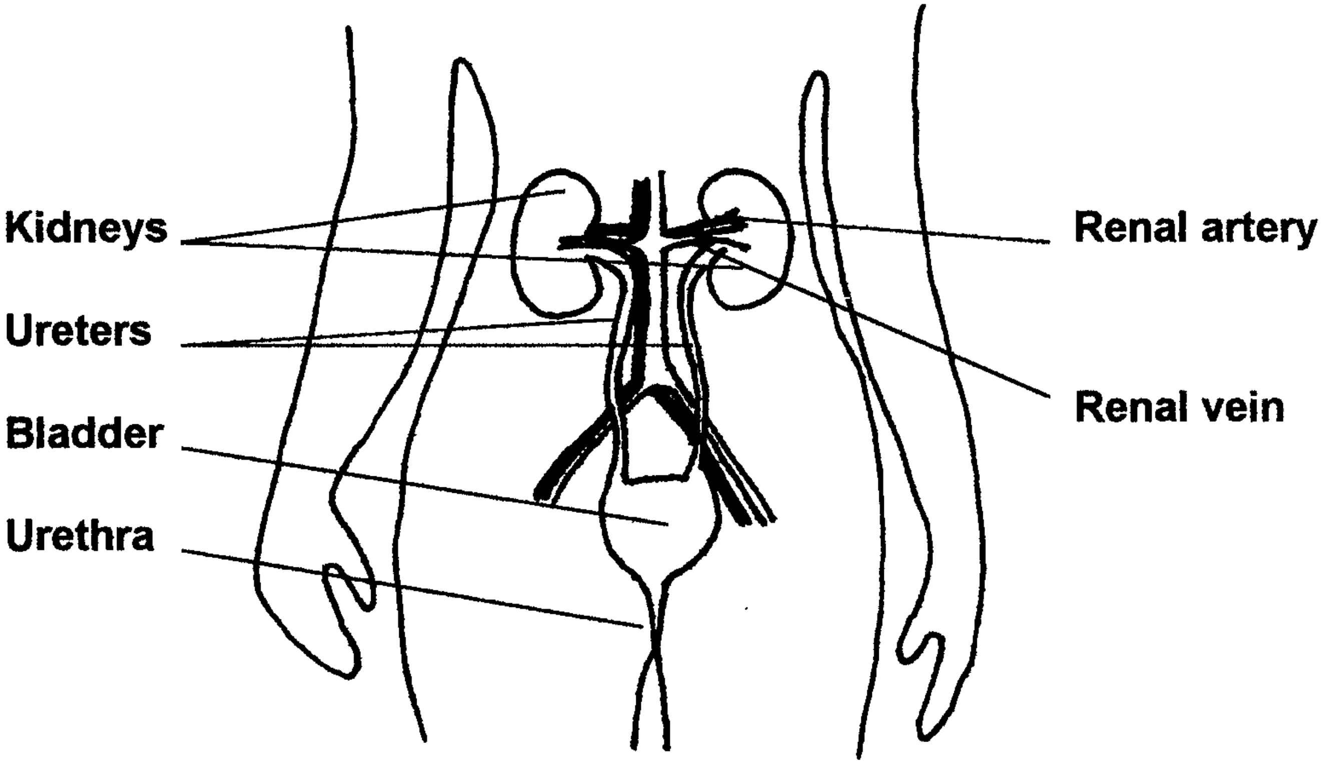
Which pain-killers can be taken?

Codeine and related drugs will not affect kidney function, are relatively safe and are often just as good at relieving pain. Paracetamol is also safe from the kidney point of view if 8 or less tablets are taken daily.

Pyelonephritis & Reflux Nephropathy

What do the kidneys do?

Most people have two kidneys and they are found at the back of the abdomen, level with the bottom rib on either side of the body. The main job of the kidneys, is to clean the blood, removing waste material that is produced by the body and any water that is not needed. These waste products are turned into urine. From the kidneys, the urine moves down a tube called the ureter into the bladder. When you go to the toilet, the urine is passed out of the body by contractions of the bladder through a single tube called the urethra.



What are the symptoms?

This urinary system (kidneys, ureters, bladder and urethra) can get infected. Infection of the kidneys is called pyelonephritis. One or both kidneys can be infected The symptoms you may feel if you have a kidney infection include back pain, side pain and loin pain. You may have a desire to pass urine frequently and urgently. You may experience pain or burning when you do pass urine. You may feel sick and you may also have a temperature.

How do kidneys get infected?

Pyelonephritis is caused by bacteria, most often from the bowel, entering the urinary system from the outside, up the urethra, into the bladder and then up one or both ureters to the kidneys. Prostatism and kidney stones can also cause infection as they prevent efficient flow of urine from the bladder.

Who gets this kind of infection?

The infection occurs more frequently in women than in men simply because the opening of the urethra in women is closer to the anus and the bacteria from the bowel.

How does it start?

- **Reflux nephropathy**

For some children and adults kidney damage is caused by a condition called reflux nephropathy. This is a combination of two problems that make infection more likely to occur.

Firstly, there are little valves at the ends of the two ureters where they join the bladder. These are supposed to prevent urine that has drained from the kidneys being allowed back up the ureters to the kidneys. These valves do not always work properly. When the bladder contracts to push the urine out of the body through the urethra, they allow some urine to escape up into the kidneys again.

Secondly, the bladder may not empty properly each time the child goes to the toilet. With the stale urine that has not emptied out going up, into to the kidneys, the chances of infection are increased causing pyelonephritis.

- **Urinary tract infections**

For others the damage is caused by infections of the kidney in childhood that went unnoticed at the time. The body may not fight off the infection entirely and it can remain, without causing any symptoms that you would be aware of, for a number of years. However, its presence causes scarring of the kidney which distorts and destroys parts of the kidney. For most children, teenagers and women the infection does not progress and it is eradicated by the body. The damage done does not affect the ability of the kidneys to do their job. But, in a few people, the continuous destruction of the kidney leads to chronic renal failure which will require treatment.

What is the treatment for this condition?

There are two parts to the treatment. Firstly, the Doctor finds out exactly which bacteria is causing the infection in order to kill it and stop further damage. Secondly, the Doctor finds out how the infection happened in order to reduce the risk of another occurring and to assess how much damage has been caused.

- Treating the infection

In order to discover the type of bacteria the patient is asked to give a specimen of urine. This is sent to the laboratory which identifies the bacteria allowing the Doctor to prescribe the right antibiotic.

- Finding the cause

Once treatment has started the Doctor will want the patient to have a couple of tests to find out why the infection happened and any damage that may have occurred. Usually, the patient is sent for an ultrasound scan or an x-ray of the kidneys. Ultrasound is a painless procedure that uses sound waves to build up a picture of your kidneys. The x-ray involves injecting a special dye into a vein in the arm. The body naturally removes the dye from the blood through the kidneys into the urine. The dye shows up the structure of the kidney when an x-ray is taken as this is happening.

What happens if the infection is not treated?

Untreated infection can sometimes stop on its own but, if it persists, it may lead to scarring and damage of the kidneys. Damaged kidneys can cause other conditions, for example, high blood pressure which can be the result of kidney disease. For some, chronic renal failure may be the result, requiring frequent medical attention in adult life.

Simple Kidney Cysts

What are they?

Simple kidney cysts are abnormal pouches containing fluid. The simple cyst is the most common form of kidney cyst. Cysts may be single or multiple. A kidney cyst does **not** mean there is cancer in the kidneys.

How do they affect people?

Most often, simple cysts do not cause symptoms or harm the kidney. In some cases, however, pain can occur when cysts enlarge and press on other organs around the kidney . Sometimes, cysts become infected or suddenly start to bleed. Less often, the cysts impair kidney function. Simple cysts can also cause high blood pressure. If only a few cysts are present they do not affect the efficiency of the kidney function.

How are they treated?

Kidney cysts are found by taking pictures by x-ray or ultrasound of the kidneys. When simple cysts are found, and there are no complications, no treatment is needed. If cysts cause symptoms, surgery may be needed.

Urinary Tract Infection (UTI)

What is the urinary tract?

It is the system of tubes, pipes and the bladder that carries urine from the kidneys via the bladder to the outside world.

What causes the infection?

Germs (bacteria) are able to enter the urinary tract from the outside. They are often bacteria, which live naturally in the bowel. They can spread from the bottom to the groins and enter the urethra and gain entry to the urinary tract.

Who is affected?

UTIs are more common in women than men. This is because men have longer urethras making it difficult for the bacteria to travel up to the bladder. Some women suffer from repeated UTIs. It is not clear why some should suffer more and others not.

Sexual intercourse and abnormality of the urinary tract place people at more risk of developing UTIs. Men with enlarged prostate glands, which prevent the bladder emptying properly, can develop infections in the stagnant urine retained in the bladder longer than normal.

What treatment exists for UTI?

Treatment depends on the bacteria causing the infection. A mid-stream urine sample is taken. This is incubated in the laboratory to see what type of bacteria grows. The doctor is then able to commence a patient on the correct antibiotic for those bacteria. The course is usually for 5-7 days. It is important that you drink plenty of fluids if possible. Symptoms should improve within 2-3 days; however; the full course of antibiotics should be completed.

What happens if you have repeated UTIs?

In some people, UTI recurs even if everything else is normal. In some cases, a longer course of antibiotics may be required. In most cases, repeated urinary tract infection does not cause kidney failure or affect kidney function.

What can women do to reduce the chances of repeat infections?

Good personal hygiene is important in reducing the risk of repeat infection.

- Always wipe yourself from front to back after using the toilet to prevent the spread of bacteria
- Wash the genital area daily especially before and after sexual intercourse

Urinate after sexual intercourse

Drink plenty of water

Make sure that you empty your bladder completely when urinating.

Do not put off urinating when you feel the need

Avoid using perfumes, deodorants, feminine hygiene sprays etc. in the genital area

Wear cotton underpants - they are absorbent whereas nylons are not and can irritate

Vasculitis

What is Vasculitis?

Vasculitis means inflammation of blood vessels, usually small arteries. It is not a common condition but it can occur at any age. It affects arteries anywhere in the body but usually involves the kidneys causing inflammation of the glomeruli, the tiny filters that clean the blood. Other parts of the body frequently affected are the lungs, the ears, nose and throat.

The cause of vasculitis is unknown. The inflammation can persist for long periods of time.

What happens if you get vasculitis?

When the kidneys are involved, kidney function is lost rapidly over a few weeks or months. If the lungs are affected, the patient often coughs up blood and may become breathless.

How is the disease diagnosed?

If your doctor thinks from your symptoms that you have vasculitis, a blood test will be performed. This test looks for the presence of an antibody against the body’s white blood cells called ANCA. The level of ANCA will enable the doctor to assess the activity of the disease. Other markers of inflammation will also be checked. The diagnosis is often confirmed by doing a kidney biopsy [see leaflet – on kidney biopsy] if there are any indications that the kidneys are involved.

What is the treatment for vasculitis?

Treatment consists of steroids and a drug called cyclophosphamide. The treatment helps to damp down the inflammation and prevent the production of antibodies such as ANCA by the body.

The main side effect of the drugs is a reduced resistance to infection. The level of white blood cells may fall in the blood. These are measured, therefore, at frequent intervals with further blood tests.

Drug treatment may be required for a long time, possibly several years.

Even if the drugs are stopped, it is necessary to continue to monitor patients in outpatients. Vasculitis can flare up again after several years of remission.

Sometimes a technique called plasmapheresis is used. This is similar to treatment with an artificial kidney as seen in haemodialysis. The patient’s blood is filtered through a machine with a special filter that removes plasma from the blood. Antibodies in the plasma are removed at the same time, helping to get rid of them. In order to perform plasmapheresis, it is necessary to install a temporary line or access into the patient. This is a narrow tube introduced into the body’s main vein under local anaesthetic.

Plasmapheresis is given as one or two courses of ten sessions each over a period of several weeks.

What happens if the kidneys stop working?

If kidney function is lost, dialysis is used to replace it. Sometimes, with treatment, the kidneys will recover although not always back to normal. Sometimes dialysis will have to continue long term. If the disease has died down, it is possible to be considered for a kidney transplant. The disease can affect the transplanted kidney, but this is most unusual.

What happens if the lungs are not working properly?

If the lungs are very badly affected, a period on a breathing machine (ventilator) may be necessary to ensure that the body gets enough oxygen.

What is the prognosis for patients with vasculitis?

There is no actual cure for vasculitis. Many patients do return to normal lives even if they have to continue to take drugs. For a few patients, the condition will continue to be very serious.

CHAPTER 3 TREATMENTS & INVESTIGATIONS

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 3. Treatments & Investigations

- Cyclophosphamide Injection
- Cystoscopy
- Kidney Biopsy - after transplant
- Kidney Biopsy - non transplant
- Kidney Ultrasound
- Nephrostomy tube care
- Parathyroidectomy
- Renal Angiogram
- Renograms
- Understanding your Blood Results

Cyclophosphamide Injection

Why you need it

The immune system in health protects your body against “bugs” like bacteria and viruses. It does this by recognising these invaders as “foreign” while recognising our own body cells as “self”. Sometimes this recognition process malfunctions and the immune system fights one or more organ systems causing disease. If the kidneys bear the brunt of this attack they may fail.

What it does

Cyclophosphamide is an immunosuppressant drug. It suppresses your immune system, stopping your immune cells from attacking your kidney [and/or other organs]. Depending on the type and severity of the condition, cyclophosphamide is administered as tablets or IV injections.

What the treatment involves

You will need to attend the hospital once a month for 6 months. A needle will be inserted into a vein in your arm and the cyclophosphamide given through the needle. Each visit will last 1½- 2 hours. You will also need to attend one or more times between each treatment for a blood test to check your white cell count. During treatment, if you experience any pain or burning sensation at the needle site please inform the staff.

Precautions

1. Cyclophosphamide may cause nausea and vomiting. You will be given an injection to help prevent this before your treatment and some anti-sickness tablets to take home. The nausea and vomiting may last a day or two.
2. Due to the affect of the cyclophosphamide lowering your white cell count which normally helps to protect you from infection, you will have an increased

risk of picking up infections. Tell your doctor if you get a fever, sore throat, skin rash or mouth ulcers.

> If you have had an infection since your last visit please inform the staff **when you arrive** for your treatment even if you have been treated for it by your GP.

3. Cyclophosphamide can sometimes cause irritation to your bladder. To help prevent this you will have a small infusion of a drug called mesna before the cyclophosphamide and two mesna tablets to take later that day. If you notice any blood in your urine or your urine appears darker than usual, inform your doctor.
4. Cyclophosphamide may cause hair loss but this is reversible when treatment is completed.
5. Cyclophosphamide can sometimes affect your blood clotting and cause anaemia. Tell your doctor if you get any unexplained bleeding or bruising.
6. Cyclophosphamide carries with it a very small increased risk that you may develop cancer. It may also cause infertility. In women, fertility may return to normal within 3 months to 1 year or you may continue to have reduced fertility. Male sterility can be permanent. Contraception is still advisable for patients and their partners during treatment as pregnancy may result in damage to the foetus.

Cystoscopy

What is it?

A cystoscopy is a procedure that allows visualisation of the inside of the bladder in order to diagnose and treat urethral and bladder disorders.

A narrow tube called a "cystoscope" is passed up the urethra. This allows the doctor to see inside the bladder, take specimens and pictures if required.

Two types of cystoscopy are carried out, flexible and rigid. Rigid cystoscopies are usually carried out under general anaesthetic; flexible cystoscopies are usually carried out using a local anaesthetic jelly applied to the urethra.

What preparation is needed?

- **inpatients**

The day before your test the doctor will obtain your consent to the procedure. Before you give consent you should have received a full explanation of the reasons for the test, the risks and the benefits. An anaesthetist will visit you before the procedure to examine you and decide the best type of anaesthetic for you (general, spinal or local) depending on the exact type of cystoscopy you are having.

- **Outpatient flexible cystoscopies**

Sometimes, flexible cystoscopy is performed as a day case. For this you will be asked to come in to hospital in the morning, have the procedure under local anaesthetic and go home the same day. It is possible that you will not be able to drive after the investigation if you need to have an injection to relax you. It is advised that you do bring somebody with you to take you home afterwards.

On the day

You will be asked not to eat or drink for a few hours before the procedure. If you are in hospital, you will be asked to have a bath and put on a theatre gown. Staff will check that you have the correct identification bands on and will run through a checklist to ensure that you are correctly prepared.

At some point, theatre staff will collect you from the ward area and take you for the investigation on a trolley.

In theatre

Once you are in theatre, further checks will be made by theatre nursing staff that you are prepared for the investigation. You will be taken to the anaesthetic room where the anaesthetist will administer the anaesthetic if you are to have a general anaesthetic. From there, you are taken into theatre for the procedure.

In theatre there will be the doctor who will perform the procedure, a nurse to help this doctor, another nurse assisting plus the anaesthetist and possibly an anaesthetic assistant.

You will be moved from the trolley onto the theatre table, your legs carefully placed in stirrups. At this point the doctor will apply local anaesthetic gel to the urethra, clean the skin around your urethra after which sterile towels will be placed over your stomach and legs. It takes a little while for the local anaesthetic to work. If you are conscious there will be somebody to talk to, hold hands with if necessary, throughout the preparation and the actual investigation. When you have been prepared, the doctor will proceed with the main investigation.

The investigation

If you are having local anaesthetic, you will be aware of what is happening. You may feel a little discomfort as the cystoscope is introduced, particularly at the point when it enters the bladder but this should be momentary. You can ask questions if you wish during the procedure. Please tell the doctor if you find the procedure to be more uncomfortable than you think it should be.

After the investigation

When the doctor is finished you will be taken to the recovery area where a nurse will look after you until you are ready to return to the ward.

On the ward, nursing staff will continue to monitor your pulse and blood pressure and keep you comfortable. If you require pain control, they will administer this for you. If you have had a local or spinal anaesthetic, you can eat and drink immediately. If you have had a general, it is advisable to start with a few sips of water.

It is likely, that if you have bad a spinal anaesthetic, you will need to lie flat initially, gradually sitting up as you feel able. Some patients do get a headache after spinal anaesthetic. Painkillers will be available if you need them.

After-effects

Most patients have no problems after a cystoscopy. You may experience some mild discomfort, for example, a slight burning when you pass water but this should improve over a couple of days. Sometimes, patients notice a little blood in their water. This is usually the result of small specimens of the bladder being taken during the investigation for examination in the laboratory. Occasionally, a patient does get a water infection after cystoscopy. If you experience temperature, pain, continuing burning or bleeding please contact your doctor.

Getting the results

Your results will be discussed with you prior to your discharge or at your next outpatients clinic appointment.

Kidney biopsy – after transplant

What is a biopsy?

A biopsy is the removal of a small piece of tissue from an organ of the body. It allows the tissue removed to be examined under a microscope in a laboratory in order to see if there are any changes to the blood vessels and cells of the kidney.

Why is a biopsy required?

After a transplant, it is necessary to monitor changes in the kidney closely. There are two main indications for biopsy: firstly, an increase in creatinine in the first few days after transplantation when it is possible the kidney is "sleeping". This needs to be monitored closely to ensure that there is no damage to the kidney, and a biopsy is required for this; secondly, at later stages, it is necessary to confirm the diagnosis of rejection in order for treatment to commence promptly.

What preparations are made before a renal biopsy?

You will be asked for your consent to the biopsy and the risks explained to you before you give that consent.

You blood will be sampled in order to check that it is clotting normally.

How is the biopsy performed?

The procedure for transplant biopsy is the same as that for non-transplant kidney biopsy, except that you will be asked to lie on your back.

The position of the graft kidney is then checked using an ultrasound scan. When the doctor is ready to proceed, the skin of the back will be cleaned with an antiseptic solution and green towels placed over the area and a painkilling injection will be given to numb the area. It takes a little while for this to work. When it is working, you will be asked to keep still. At this moment a special biopsy needle is introduced through the skin into the kidney to take the small sample. This will make a short sharp sound. This part of the procedure is very quick but may be repeated more than once to get sufficient tissue for analysis.

What happens after the biopsy has been performed?

Once the sample has been taken and a small dressing applied to the biopsy site you will be asked to stay lying on a bed for a period of time, usually about six hours. Your blood pressure and pulse will be monitored frequently and the wound site dressing checked to make sure that everything is well after the biopsy. Some people see some blood in their urine after a biopsy, this is not unusual and is not a cause for concern. Painkillers will be prescribed for you if you need them. If you are having a biopsy as a day patient, you should be ready to go home after about six hours.

What are the complications of a renal biopsy?

Any medical or surgical procedure carries risks. Patients are only asked to undergo procedures because it is felt that the risks are outweighed by the benefits of diagnosis and treatment. For example, rarely, a patient might have a small bleed in or around the kidney after a biopsy which may cause blood in the urine. All possible precautions are taken to prevent bleeding. When it does occur, patients are observed closely and treated according to their needs.

What happens in the days following the biopsy?

After the initial bed rest you will be allowed to get up and walk about slowly. No lifting heavy objects or strenuous exercise is advised for the first 24 – 48hrs days, but after that there should be no reason why normal activities could not be restarted. The dressing over the wound site should be kept dry and intact for 24 to 48 hours. After this you may remove it and shower or bath providing that the wound is dry.

If you experience dizziness, blood in your urine or any signs of infection such as a raised temperature, bleeding, swelling, redness or increased pain from the wound site, please contact the Renal Unit.

Getting the results

The results of a transplant biopsy are usually available in a few hours so that appropriate treatment can be started as soon as possible

Kidney biopsy – non-transplant

What is a biopsy?

A biopsy is the removal of a small piece of tissue from an organ of the body. It allows the tissue removed to be examined under a microscope in a laboratory in order to see if there are any problems with it.

Why biopsy a kidney?

When kidneys stop working properly, doctors want to find out why. In some instances this can only be done by taking a small specimen from one of a person's kidneys and looking at it to see if it can reveal what is causing the kidney failure. This in turn helps the doctors to decide on the best of the treating the underlying condition.

What preparations are made before a renal biopsy?

Before the procedure can start the medical team will make sure that it is safe to proceed. Your blood pressure will be checked and a blood sample taken. These tests will tell the team how well your kidneys are working and help them to be sure that there is only the smallest risk of any bleeding after the biopsy has been performed. You will be asked for your consent to the biopsy and the risks explained to you before you give that consent.

It is advisable to eat only a light meal before the procedure.

You will be asked to wear a theatre gown.

How is the biopsy performed?

Biopsies usually take place in either the Hospital's Day Surgery Unit or X-ray Department.

The patient is asked to lie on their front with a hard pillow under the stomach. This allows the doctor easier access to the kidneys which are found in the back of the abdomen on either side of the spine. The position of the kidneys is then checked using an ultrasound scan. When the doctor is ready to proceed, the skin of the back will be cleaned with an antiseptic solution and green towels placed over the area and a painkilling injection will be given to numb the area. It takes a little while for this to work. When it is working, you will be asked to hold your breath and keep still. At this moment a special biopsy needle is introduced through the skin into the kidney to take the small sample. Only one kidney will be sampled. This part of the procedure is very quick but may be repeated more than once to get sufficient tissue for analysis.

What happens after the biopsy has been performed?

Once the sample has been taken and a small dressing applied to the biopsy site you will be asked to stay lying on a bed for a period of time, usually about six hours. Your blood pressure and pulse will be monitored frequently and the dressing checked to make sure that everything is well after the biopsy. Some people see some blood in their urine after a biopsy, this is not unusual and is not a cause for concern. If you are having a biopsy as a day patient, you should be ready to go home after about six hours.

What are the complications of a renal biopsy?

Rarely, a patient might have a bleed after a biopsy. Any medical or surgical procedure carries risks. Patients are only asked to undergo procedures because it is felt that the risks are outweighed by the benefits. All possible precautions are taken to prevent bleeding. When it does occur, patients are observed closely and treated according to their needs and will not be discharged until it is safe to do so.

What happens in the days following the biopsy?

Patients going home after a biopsy should rest and take it easy for 48 hours. As the effect of the pain killer wears off, a sensation of discomfort around the biopsy site may appear. Paracetamol can be taken to reduce any discomfort. After the first 48 hours, there should be no reason why normal activities could not be restarted.

However, if you experience dizziness, blood in your urine or severe pain, please contact your GP at once. They will contact the hospital.

Getting the results

It takes a couple of weeks for tests to be returned. Usually, patients are given an outpatient clinic appointment for 2-3 weeks after the biopsy to discuss the results. However, if you are an inpatient a preliminary report may be available within 1 or 2 days.

Kidney (renal) ultrasound scan

What is an ultrasound scan?

Ultrasound is a painless procedure that uses high frequency sound waves to build up a picture of your kidneys. The waves are sent out and the reflected echoes received by a single hand held instrument that moves across the skin. A computer then builds up the received waves and creates a picture on a small monitor that can be viewed by the operator. The images can be printed out and are stored on computer disk.

Ultrasound scans are used to check the shape & size of internal organs as well as to look for abnormalities in the organs like cysts, growths and infection. The same test is also used to monitor babies growing in the womb of pregnant women.

What preparations are needed for renal ultrasound?

In order to be able to view the kidneys better, it is important to have a full bladder before the investigation, if possible.

You may also be asked to wear a gown.

What happens during the test?

If you are attending as an outpatient you will need to report to X-Ray Reception. From there, you will be sent to a waiting area from where you will be called to the Ultrasound Room.

Helping you with the scan will be an x-ray nurse or radiographer and a doctor who will perform the scan. The room will be darkened but not totally in order that the picture on the computer screen may be seen more easily. You will be made comfortable on a couch and asked to remove or pull up clothing so that the Doctor can carry out the scan. A gel will be applied to the skin. This makes it easier for the hand-held ultrasound probe to move over the skin. It wipes off easily after the test. The scan should take about 15 minutes.

The scan is painless but you may feel some mild discomfort if the doctor has to press more firmly to get a better picture.

You may have to wait for a short period before having your scan. This is because emergencies come first.

Are there any after effects?

There are no after effects related to ultrasound. If you are an outpatient, you will be able to go home and eat and drink normally.

When will I get the results?

If you are an outpatient the results will be discussed with you at your next appointment with your consultant's team. If you are an inpatient, the results should be available to discuss with your doctor within 24 hours.

Parathyroidectomy

What is parathyroid hormone?

The parathyroid hormone is produced in the parathyroid glands and is responsible for maintaining the balance of calcium and phosphate salts in the blood. This balance can be disturbed during renal failure and it is not always corrected after transplantation. It may be necessary to remove the parathyroid glands in order to correct this problem. You will find more information on the role of the parathyroid gland in the leaflet titled ‘Hyperparathyroidism and renal bone disease’

What is a parathyroidectomy?

Parathyroidectomy is the name given to the surgical operation to remove the parathyroid glands from the body.

What preparations are needed before the operation?

Admission for parathyroidectomy is planned in advance. Before admission you may be prescribed alfa-calcidol tablets (vitamin D) and you will require your vocal cords to be checked.

What happens during the operation?

An incision is made above the collar bone, approximately 4 inches in length. The 4 parathyroid glands are located by the surgeon and removed, a drain inserted at either end of the incision and either sutures (stitches) or surgical clips are inserted.

What happens after the operation?

The drains are removed on the following day and sutures removed in 3 to 4 days

or they may soluble. The scar heals well, as the area is well supplied with blood vessels, although some bruising is inevitable. Some hoarseness of the voice may be noted after surgery, this is caused by swelling of the vocal cords but should improve over the few days after the operation.

Following surgery, it is necessary to monitor your blood levels of calcium and phosphate

regularly. Supplements may be required either as tablets or sometimes given intravenously. If your calcium level drops too low you may experience tingling of the hands or face. Please tell the ward staff if you experience these symptoms.

You will stay in hospital for between 5 and 7 days or until the balance between your calcium and phosphate levels are re-established. After discharge your these levels will be monitored closely on dialysis or as an out-patient for a few weeks and medication changed as appropriate.

Renal angiogram

(also known as renal arteriogram)

What is an angiogram?

An angiogram is a picture of the blood supply to an organ of the body obtained using x-ray equipment. A picture of the blood supply to the kidneys is called a renal angiogram. To obtain a picture, a radio-opaque dye is injected into the bloodstream via the groin or forearm. As the dye reaches the kidneys, the blood vessels of the kidneys are shown up when an x-ray picture is taken.

Why take a picture of the blood supply of the kidneys?

When kidneys stop working properly, doctors want to find out why. A renal angiogram will show the medical team if the reason for kidney failure is related to problems occurring with the blood supply to the kidneys. For people who want to donate a kidney, it is important to make sure that their kidneys are suitable for donation and that the kidney left after the operation will be able to go on working.

What preparation is required?

Before you can have a renal angiogram, you will be asked for your written consent. In order to obtain consent the doctor will explain the test, what it is for, what happens and the risks and benefits of having the test and answer any questions that you or your family may have about the test. Please tell the doctor if you take warfarin or have asthma.

You will be asked not to eat for six hours prior to the angiogram but you may drink. You may be prescribed a sedative to help you relax if this is necessary.

As the dye is usually injected into the bloodstream through the groin, it is necessary to shave this area. This is often carried out by the nursing staff, but you may do it yourself if you wish.

You will be required to wear a theatre gown and paper, disposable underwear.

How is the angiogram performed?

Angiograms are performed in the X-ray Department. They can be performed as an inpatient or outpatient procedure. If you are an outpatient you will be asked to come to the main ward or a day case ward in the morning where a bed will be available for you. From the ward, you will be taken to the X-ray Department.

In X-ray department investigation room, you will be asked to lie on your back on a table. The doctor who will perform the test will clean your groin with an antiseptic solution. Sterile green towels are then placed over the area and a pain killing injection will be given to numb the skin of the groin. The doctor will ask you if you can feel any pain in the area before proceeding. At this point the doctor will use a special needle to introduce a narrow tube (catheter) into the artery in your groin. This tube is fed into the artery under x-ray guidance until it reaches the point at which the dye (contrast medium) can be injected through the tube into the blood vessels supplying the kidneys.

You may have a feeling of warmth as the dye is injected, starting at the tip of the catheter and going around your body. You may briefly feel as if you are passing water, however, this is a momentary sensation.

Once the dye has been injected, a series of x-ray pictures of the kidneys will be taken by the radiographer. When this is completed, the catheter is carefully removed and pressure is applied to the groin site for about 10 minutes to prevent bleeding. A dressing will be applied to the site.

Having an angioplasty after the angiogram

If the angiogram shows a narrowing of the renal artery, you may be asked if you wish to have an angioplasty straightaway. This is a very similar procedure where a catheter is inserted into the artery. This catheter has a small balloon on the end of it, which is inflated, at the narrowing in the artery in order to enlarge the artery by gently stretching it. Some discomfort can be felt. However, the improved blood flow that this allows may lead to an improvement of kidney function and/or blood pressure. You will be asked about proceeding to angioplasty straightaway as part of the consent procedure if it is appropriate. Some people will have the angioplasty as a second procedure at a later date if required.

What happens after the test has been carried out?

Once the test has been completed and it is safe for you to leave X-ray, you will return to the ward where you will be asked to remain in bed for between 4 and 6 hours, keeping your leg relatively still. You will be advised to press on the wound dressing when you sneeze, cough or do move. Your blood pressure and pulse will be measured frequently and the dressing and groin checked for any sign of bleeding or swelling.

You may be asked to drink fluids to flush out the dye from your system. It may be the next morning before you can use your leg properly.

What are the complications of a renal angiogram?

The most common problem associated with an angiogram is bruising, oozing or bleeding from the puncture site where the catheter was inserted. This is why you stay on bed rest after the procedure and nursing staff check the groin area regularly. The area will be bruised, swollen and possibly painful for a few days.

You should not drive or lift heavy objects for 2 days after the procedure after which time your groin should have healed.

The dye may affect your kidney function causing a temporary rise in creatinine. For this reason you are asked to drink plenty in order to flush the dye from your bloodstream.

When do I get the results of the test?

If you are an outpatient, the results will be explained to you by your doctor at your next outpatient’s appointment or earlier if indicated.

If you are in hospital, the results should be available almost immediately as the radiologist will write a report of the investigation in your medical notes.

Renograms

What is a renogram?

A renogram is a scan that enables medical staff to look at kidney function. It is useful in highlighting conditions that affect either the blood supply or the drainage system of the kidney/s.

How is it performed?

The test takes place in the x-ray department. A mildly radioactive dye (isotope) is injected into a vein in the arm of the patient. The patient is then asked to lie down. A ‘gamma’ camera is placed close to the patient and the passage of the dye is followed ‘on camera’ through the kidneys.

The isotope should pass through the kidney within a certain length of time. Any delay may indicate abnormalities. If there is a delay, drugs may be injected through a vein during the procedure to see if they improve how the kidney works.

The whole test takes between 30 minutes and an hour.

Are any special preparations needed for this test?

The preparations for the test are straightforward.

- The reasons for having the renogram will be discussed with you by your doctor before you are asked to sign a consent form. Very rarely, patients experience an allergic reaction to the dye or the other drugs that are injected during the test. These reactions can be treated. If you are allergic to anything, please inform your doctor.
- If you are not on a fluid restriction, it is important that you have drunk plenty before the test begins.
- A needle (cannula) will be placed into your arm. This is to allow the

dye and other drugs to be administered during the test if necessary.

- You will be asked to empty your bladder immediately before the test
- Women of child bearing age are advised to tell the medical staff if there is any likelihood of them being pregnant before the renogram. If necessary a pregnancy test may be performed before proceeding to the X-ray department.

What happens after the test?

The nurses will monitor you to ensure that you have suffered no adverse reactions, checking your blood pressure and pulse at regular intervals and observing you for any signs of reaction to the dye and drugs. You may have to rest on the bed for a few hours until the effects of any drugs have worn off. Although the dye is mildly radioactive, it is not harmful and will have disappeared entirely in 24 hours. Some of it is excreted in your urine, but only normal hygiene precautions are necessary, for example, hand washing and clearance of urine spillage.

When will the results of the test be available?

Inpatients will be able to learn the results of their test within 24 hours. If you came for the test as an outpatient you will be told the result at your next clinic appointment. If there are abnormalities that need to be discussed before then, your doctor will contact you.

Understanding your blood results for dialysis & transplant patients

This leaflet has been written to help you to understand your blood results. It will explain the different types of basic blood tests used in renal & transplant medicine. It will tell you why the components of the blood that are tested are important to your body. You will find the normal levels for these blood tests listed on the last page.

Before we start, a warning - blood results in kidney patients are frequently **not normal.** Do not be alarmed by this. To understand your blood results better, you must talk to your doctor or nurse about them. They will help you to understand their meaning, not this leaflet!

1. FBC - full blood count

A full blood count provides your medical team with a range of information on the components of your blood. The three most significant are your white blood cell count, your haemoglobin level, and your platelet count.

- **White cell count** – there are 5 different types of white cells. They are part of the body's defence systems against invading germs. A higher than normal count suggests that you have an infection caused by germs as the body releases more white cells to counter the threat caused by the invaders. A lower than normal count suggests that you are more at risk of infection.
- **Haemoglobin** – is a component of the red blood cells, which allows the red blood cells to carry oxygen from the lungs to the body's tissues and carbon dioxide from the body's tissues to the lungs.
- **Platelets** – are by comparison to red and white blood cells much smaller. Their job is to stop bleeding when damage occurs to small blood vessels, preventing blood from flowing into tissues and they play an important part in blood clotting processes after injury to larger vessels
- **Haematocrit or Packed Cell Volume (PCV)** – is a measurement of the

percentage of blood that is red blood cells. For example, in an average adult man every 100 mls of blood would consist of about 45 mls (0.45) of red blood cells and 55 mls of plasma. A high haematocrit can be an indication for venesection where the patient is bled deliberately in order to lose red blood cells.

2. Urea & Electrolytes (U & Es)

U & Es provide your medical team with an account of your basic blood chemistry, the different mixture of chemicals in the bloodstream. About 5 mls of blood are needed. The most important things measured are:

- **Sodium** - sodium is important in maintaining the balance of water in your body. It attracts water to it, binding with it. Too much sodium in the body and you will retain too much water in your body. In kidney failure, the damaged kidneys are unable to eliminate excess sodium leading to fluid (water) retention. The symptoms of fluid retention are swollen ankles and extremities, raised blood pressure and increasing breathlessness as the heart comes under pressure from having to cope with pumping the extra fluid in the bloodstream around the body. It is also important, with potassium, in the conduction of messages in nerve fibres.
- **Potassium** – an important electrolyte, allowing nerve fibres to conduct messages and muscle cells to work normally. Maintaining potassium levels correctly is essential. Fluctuations in potassium levels can affect the heart causing abnormal heartbeats or even make it stop beating.
- **Urea & creatinine** – are waste products from normal body processes that turn food into energy in the cells of the body. When your kidneys fail you are unable to get rid of these waste products and they build up in the body. Eventually, they are poisonous to the body and you will suffer the symptoms of 'uraemia'. These include nausea, sickness, skin irritation, loss of appetite.

> Creatinine is used by doctors to assess the extent of kidney failure. It is a more reliable measure than urea. Creatinine may be measured in the blood but more accurate estimates of kidney function are obtained by measuring creatinine in the urine as well (a 24 hour urine collection for creatinine clearance).

3. Other tests

Other substances are measured in your blood which are important to renal patients. These are described below:

- **Calcium** – is vital for having good strong bones. It is also an important electrolyte, associated with the control of fluid in the body and functioning of nerves and muscles.
- **Phosphate** - a mineral that is also important in the maintenance of strong bones. Phosphate and calcium need to be in balance in the body. If phosphate levels in the blood become too high, the body strips calcium from the bones to balance things up in the blood, weakening the bones. In kidney failure, excess phosphate is not removed from the blood. Dialysis is unable to control phosphate levels easily. Therefore, calcium tablets may be given to you to bind with the phosphate in your food and stop it being absorbed into the body from the gut. This stops permanent damage being caused to your bones.
- **Albumin** – albumin is a protein found in the blood that helps to carry other materials in the bloodstream. For example, it can combine with fatty acids. These are concentrated sources of energy broken down from the food you eat and released into the bloodstream. When they combine with albumin they can be moved to cell tissues where they can be broken down and converted into energy to allow the cell to work properly.

  Albumin is monitored by medical staff to check for protein loss in the normal process of peritoneal dialysis. The dietitian often requests high protein diets for PD patients as a result. It is also a marker for poor nutritional status particularly in haemodialysis patients and is closely monitored by dietitians.

- **Lipids** – lipids are a group of fat molecules found in the body. Two important types of lipids are triglycerides and cholesterol. Triglycerides are the body’s most concentrated source of energy and cholesterol is important in the construction of cells and liver function. High levels of triglycerides and cholesterol are a risk factor for cardiovascular disease, although smoking and high blood pressure are more important. Low levels are a sign of poor food intake. It is difficult to give a normal range of results, particularly for cholesterol because lipids do vary according to factors such as age, weight and medical history.

4. INR - ‘International Normalised Ratio’

If you take the drug warfarin to prevent problems caused by blood clotting, you will have regular blood tests to check your INR. It is a measurement of the time that it takes for blood to clot. Your doctor will alter the dosage of warfarin according to the results of the test, as necessary.

When you first start warfarin, you will have your INR checked on an almost daily basis. As your results stabilise on a certain dosage, you will not need to have blood tests as frequently. Some people have checks once every one or two months.

Normal values - for blood tested at University of Hospital of Wales laboratories

These values give the statistical range that most healthy adult population will fall within when tested. As noted above, kidney patients will often find their blood results are not ‘normal’. This does not mean that they are bad. It is important to discuss your blood results with your doctor or nurse to understand what they mean to you as an individual.

• White blood cells (WBC)	4-11 × 10^9
• Haemoglobin (Hb)	men 13-16.5 grams per decilitre (g/dl) women 11.5-15.5 g/dl
• Platelets	150-400 × 10^9
• Ferritin	15-300 micrograms per litre (µ g/l)

• Haematocrit	men 0.34-0.50 (measured as index) women 0.30-0.48
• Sodium (Na)	33-144 millimoles per litre (mmol/l)
• Potassium (K)	3.4-5 mmol/l
• Urea	2.5-7.5 mmol/l
• Creatinine	70-120 µmol/l
• Calcium (Ca)	2.2-2.6 mmol/l
• Phosphate	0.8-1.45 mmol/l
• Albumin	35-50 grams per litre (g/l)
• Triglycerides	0.6–2.0 mmol/l
• Cholesterol	no normal value available

Nephrostomy and nephrostomy tube care

What is a nephrostomy ?

A nephrostomy is used as a temporary measure to drain urine from the kidney

(or transplant kidney). It is a tube inserted when the normal pathway from the kidney to the bladder has become blocked. One cause of kidney failure is a blockage to the flow of urine (see Obstructive Uropathy). The long term solution is to remove the blockage often by surgery. It is important, however, to get urine flowing freely as soon as possible in order that the kidney failure will improve. This converts an urgent situation into a more stable one so that the surgery can be planned with the patient in a much fitter state. If the blockage is above the bladder then the technique used to drain the urine is called a nephrostomy.

How is the tube inserted?

Using ultrasound (see renal ultrasound) one kidney is located and local anaesthetic is injected over the site of the kidney in the lower back. When the anaesthetic has taken effect, a fine needle is inserted into the drainage part of the kidney (the kidney pelvis). Sometimes x-ray dye is injected and an x-ray taken to show where the blockage is exactly. A fine wire is then threaded through the needle, which is then removed. A narrow tube is then inserted over the wire and gently pushed into the kidney pelvis. The wire is removed and after fixing the tube to the skin with a couple of stitches, a drainage bag is attached to the tube that can be emptied by nursing staff. You may need painkillers after the tube has been inserted, but the discomfort should soon subside.

How long will the nephrostomy be needed for?

Nephrostomy tubes are usually temporary but can stay in place for several weeks if necessary. The other kidney may also have a nephrostomy tube depending on the clinical need.

How do I look after the tube and drainage bag?

The tube and bag are normally cared for by the nurses on the ward. However, if you are going home with the tube in place you will be shown how to look after it or if necessary a district nurse will be arranged to support you at home with the tube.

It is important, at home or in hospital to inform ward staff if you are experiencing any of the following symptoms:

1. Continuous pain around the area of the tube
2. The skin around the tube is becoming wet or there is redness, swelling or the presence of pus
3. The urine has changed in appearance and smells offensive
4. You have noticed that there is not as much urine in the drainage bag or nothing has drained
5. You are experiencing cold-like symptoms associated with high temperature
6. The tube has become dislodged and has fallen out

For further advice, please do not hesitate to contact the ward on (029) 2074 4588/5495

CHAPTER 4 PERITONEAL DIALYSIS

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

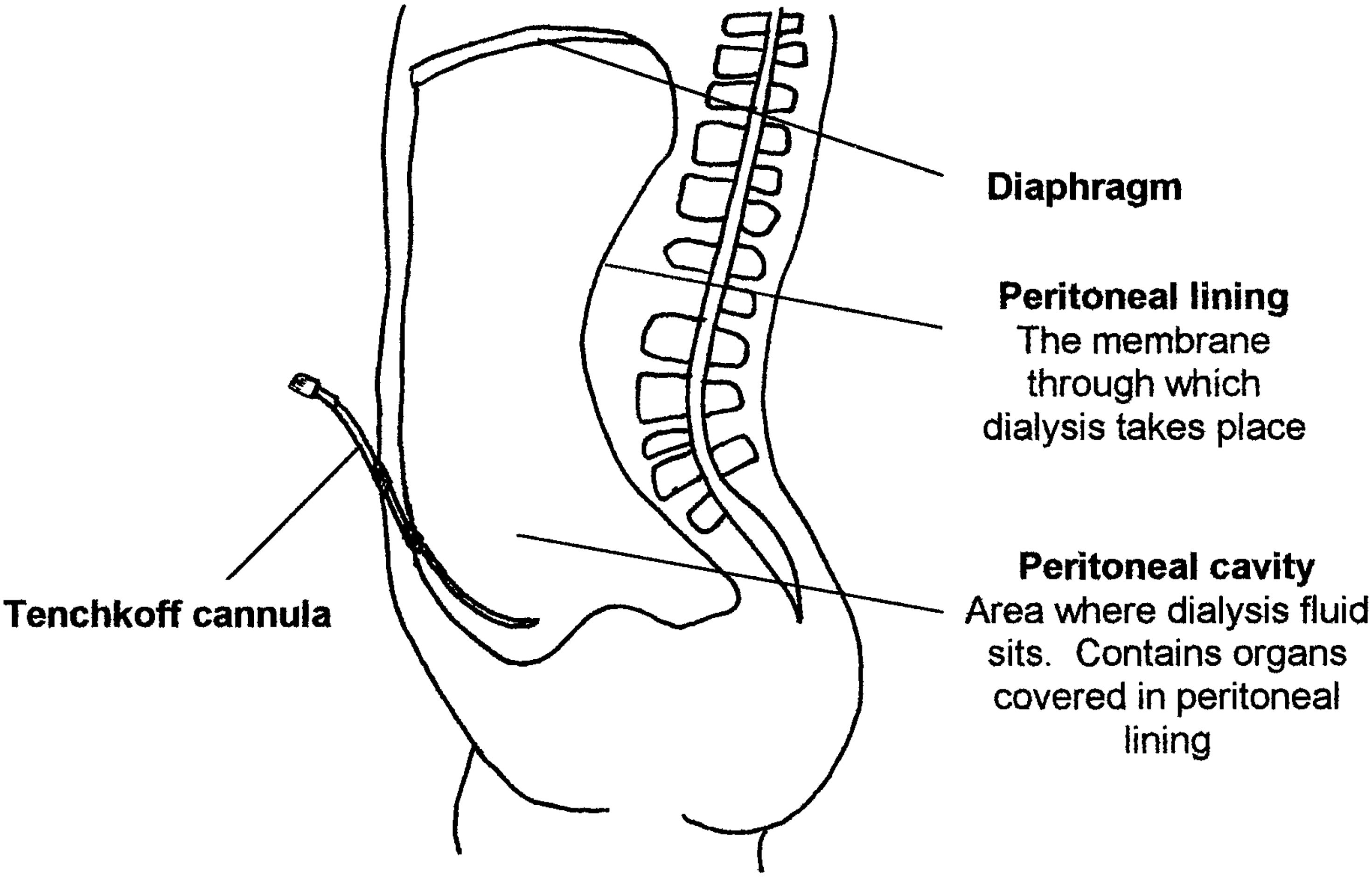
+ 4. Peritoneal Dialysis

Access for peritoneal dialysis

What is peritoneal dialysis access?

Peritoneal dialysis (PD) is a method of cleaning the blood without the blood leaving the body by using your peritoneal membrane, which consists of two layers, which lines the inside of your abdomen. Dialysis fluid is introduced into the space between these layers.

In order to do introduce the fluid, a soft plastic tube called a Tenckhoff catheter is inserted into the abdomen. Once in place the tube is permanent and should last for many years. It can be changed if necessary or removed if it is no longer required, for example, if you have a kidney transplant.



When will I need the Tenckhoff catheter to be inserted?

We aim to plan and prepare access for PD before the time for dialysis arrives, so that when it does everything is that much more straightforward.

You will be assessed by a PD specialist and a decision made as to whether you can have the procedure under local anaesthetic or under general anaesthetic. If a local anaesthetic is required, the PD doctor will arrange a date for you to come to the day surgery unit and it will be inserted as a day case. If you require general anaesthetic, you will be referred to a renal surgeon who will normally see you in outpatients and arrange a date for your operation.

What preparations need to be made prior to Tenckhoff insertion?

- You will need to arrange for 4 weeks off work after the operation
- You will not be able to drive after the operation, so please make appropriate arrangements for getting to and from the hospital.
- It is important that you are not constipated when the catheter is inserted. Therefore, you will be given a laxative to take a few days before the operation.

- If you are having the operation done as a day patient, going home at the end of the day, it is advisable to have someone stay with you at home overnight.

- If you are having a local anaesthetic, you may have a light meal e.g. tea an toast before coming into hospital. If you are having a general anaesthetic you will not be permitted to eat and drink for about 6 hours before you have the procedure.
- Before you can have any operation you must give your consent. In order to obtain consent the doctor will explain the procedure, what it is for, what happens and the risks and benefits of having it done and answer any questions that you or your family may have about the test before you sign the consent form.

Having the Tenckhoff put in

You will be admitted to the hospital for a day and possibly an overnight stay. If you need dialysis, this stay may be lengthened.

After the Tenckhoff has been put in

1. Initially the area will be well padded and the dressing left undisturbed for the first five days. Usually there are no sutures to remove.
2. You may experience some discomfort for the first couple of days, but the pain should be relieved with pain killing tablets
3. Carry on your normal life-style as you are able. However, straining on your stomach muscles, which may be caused by lifting heavy objects and sex is best avoided for the first 4 to 6 weeks.
4. You are advised to take 4 to 6 weeks off work and avoid driving for the first two weeks or until you are able to make an emergency stop comfortably.
5. Avoid wearing tight or restrictive clothing and belts that may cause friction over the dressing.
6. The CAPD nurse will see you and discuss the above points with you before you are discharged. You will also be given dates to attend the CAPD unit during the next 21 days for the changing of your dressing and the taking of blood samples
7. At the final visit, you will be either taught to change the dressing yourself or we will arrange for a district nurse to call. You will be supplied with the necessary equipment.
8. After the 21st day, if you do not need to start dialysis, you will continue to attend the outpatients department until there is further deterioration in your kidney function. At this stage, you will be informed of a date to start your training.

Information for patients about anaemia and its treatment

Introduction

If you have a kidney condition (whether you are on dialysis or not), you are likely to have anaemia. This is a decrease in the amount of haemoglobin found in the bloodstream, and can make you feel very weak and tired.

This leaflet will tell you what anaemia is, why it occurs and what treatment is available to control it

What is anaemia?

Oxygen is carried around the body by a substance called haemoglobin which is found in the red blood cells of the blood. If you do not have enough haemoglobin, your blood is unable to carry enough oxygen around the body. It is the reduction in the amount of oxygen going around the body that causes the symptoms of anaemia. Anaemia can occur for several different reasons, for example: after operations; during pregnancy; because of blood loss from an ulcer or not having enough iron in your diet.

How do I know if I have anaemia?

The symptoms appear gradually. You might feel more tired or lethargic. You will have less energy to do things. You might feel the cold more easily and feel out of breath doing things that do not normally make you breathless.

What causes anaemia in kidney failure?

Red blood cells are made in the bone marrow. Red blood cells are constantly being produced to replace those that are lost or die. These cells contain haemoglobin which carries oxygen. When the number of these cells drops in the bloodstream, less oxygen can be carried around the body causing anaemia.

The production of red blood cells is controlled by a hormone called erythropoietin (EPO). The kidneys make EPO in response to the level of oxygen in the bloodstream, the less oxygen from fewer red blood cells, the more EPO produced. In kidney failure, your kidneys cannot respond in this way and are unable to produce sufficient amounts of EPO when lower oxygen levels are detected.

To find out if you are anaemic, your doctor will order a blood test to measure your haemoglobin*.* This tells your doctor whether or not your are anaemic by measuring the amount of haemoglobin in your blood and if you need treatment. Chronic renal failure patients often have haemoglobin levels well below normal.

How is anaemia in chronic renal failure treated?

If you have kidney failure, it is likely that this is the cause of your anaemia. However, there other causes of anaemia and they need to be ruled out by investigations or treated as needed.

If your anaemia is caused by kidney failure, your doctor may give you EPO, an artificial form of the natural hormone. You may also require an iron supplement.

How is EPO made?

EPO is made outside of the body, in the laboratory, using genetic engineering. Artificial EPO is identical to the EPO our kidneys produce and acts in the same way, stimulating red blood cell production.

How do I take EPO?

If you are to start EPO you will be given advice and support by an anaemia co-ordinator or a link nurse specialising in this treatment. The nurse will be able to tell you about the treatment and answer your questions.

EPO is given as a subcutaneous (under the skin) injection. Most people are able to give this injection to themselves once they have been shown. The best places for these injections are in the thigh or tummy. Usually, you will need about 2 or 3 injections a week. Some people have their EPO given during dialysis.

All the equipment you need will be supplied to you, including sharps boxes to put used needles in as they must not be discarded with general waste. EPO needs to be kept refrigerated until half an hour before you use it, to give it time to warm up to room temperature.

How long before I feel better?

Your doctor will prescribe enough EPO to gradually increase your haemoglobin levels closer to normal. The aim is usually for a haemoglobin level of at least 10 - 12 g/dl. This may take weeks or months. Your improvement will be gradual; it takes time for the new red blood cells to replace the lost cells. Once your haemoglobin is stabilised your doctor may need to adjust your dosage. You may not need as much EPO or to take it as frequently. Occasionally, a break from EPO may be possible. However, as long as you have kidney failure, the anaemia is likely to return when treatment is discontinued. Regular blood tests will be required to monitor progress.

What are the side effects from taking EPO?

EPO generally causes few problems. However, some side effects have been noted. Blood pressure rises are the most important. You will need to have your blood pressure monitored regularly from the beginning of your EPO treatment. In the beginning, just once or twice a week. If your blood pressure goes up consistently, it will need to be treated and any existing medicines you are taking for high blood pressure may be adjusted. If you get bad headaches when you take your EPO, please tell your nurse or doctor. This may be a symptom of high blood pressure.

Some people have also experienced ‘flu like symptoms after injection and for a few days. Occasionally, a rash or redness is noted around the injection site but usually clears up quickly.

Iron therapy

Iron is a vital building block in the production of red blood cells. Unfortunately, a little iron is lost during each haemodialysis session contributing to anaemia in kidney failure. Dialysis patients and some transplant recipients can also suffer from iron deficiency. You may already be taking an iron supplement by mouth. When treatment with EPO is started the body uses up its’ remaining store of iron very quickly. Without extra iron, the EPO may not work properly. Iron can be prescribed as a tablet or given intravenously if necessary.

How do I know if I have enough iron?

A blood test will indicate if you are lacking enough iron. On the basis of this test, your doctor will prescribe either tablets or injections given intravenously (if you are on haemodialysis this can be given during a session). Patients who are not on dialysis may receive intravenous iron on a weekly basis in the renal unit.

What side effects does iron therapy have?

It may be necessary to try different amounts and kinds of iron supplements before the right dosage is found. Iron tablets may cause stomach problems such as loose stools, diarrhoea, constipation and stomach aches. If you have stomach problems caused by iron tablets, please tell your doctor. Do not take iron tablets with milk or tea or at the same time of day as antacids, titralac and calcichew. These medicines will interfere with the body’s ability to absorb the iron.

Do I need to take anything else?

Vitamin B and Folic Acid also help in red blood cell production and may be prescribed by your doctor.

What are the benefits of these treatments?

The chief benefit of EPO and Iron treatments is that they are effective in treating the symptoms of anaemia. Many patients notice a great difference in the way they feel, having more energy and better levels of concentration. In addition, these patients may not need blood transfusions to correct their anaemia.

Taking EPO will not affect your need for dialysis, but it should improve your quality of life.

A guide to your diet if you are on peritoneal dialysis

When you are established on peritoneal dialysis, it is important that you eat a healthy diet to get the maximum benefit from your treatment. The principles of a healthy diet on peritoneal dialysis (PD) are as follows:

Protein

It is important that you have a good protein intake whilst you are on peritoneal dialysis as some will be lost in your exchanges. Therefore, you need to eat enough protein to replace these losses.

Protein is essential for many functions in the body such as repair of your muscles, skin and other tissues. If you do not eat enough protein it will show as a low blood albumin (protein) level, muscle breakdown and weakness.

Protein rich foods include meat, fish, eggs, dairy products and pulses.

Calories (energy)

The dialysis fluid used in PD is normally a sugar solution, some of which is absorbed by the body. Too many calories absorbed this way may lead to undesirable weight gain. You may therefore need to reduce the fat and sugar containing foods in your diet e.g. butter, cakes, biscuits, pies and pasties.

Fluid

As kidney function deteriorates many patients pass less urine over time. Fluid intake needs to be matched to the amount of fluid you can pass as urine. Drinking more than you can pass will result in fluid overload. Fluid overload can lead to shortness of breath, swollen ankles and it can put a strain on your heart. Your doctor or PD nurse will be able to tell you how much to drink to avoid these problems. The dietitian can suggest ways to help you manage your fluid restriction.

Sodium (salt)

The more salt you eat in your diet, the thirstier you will feel. This can make it difficult for you to comply with a fluid restriction. Salt intake can also contribute to high blood pressure. It is therefore sensible to keep the salt in your food to a minimum. Foods that are high in salt include soup, salted crisps and salted nuts.

Fibre

Fibre is important in preventing constipation which can reduce the effectiveness of your dialysis. Fibre is contained in whole grain products, pulses, fruit and vegetables.

Phosphate

In renal failure, the kidneys are unable to remove excess phosphate from the body. High levels of phosphate can lead to your bones being weakened and may affect your circulation.

A way of keeping phosphate levels normal is to take phosphate binders e.g. titralac, calcichew. These drugs bind to the phosphate in the food you eat in your stomach and prevent it from being absorbed into the bloodstream. Ideally, binders should be taken 10 – 15 minutes before a meal. Your dietitian can advise you further on this.

Potassium

Potassium is a type of salt that builds up in the bloodstream in kidney failure. When you are established on PD, it is unlikely that potassium will build up to a high level because PD provides continuous dialysis. You should, therefore, not need to restrict potassium in your diet.

Peritonitis

If you develop peritonitis you will lose more protein than usual into the PD fluid. You will need to eat more protein at this time to replace these losses. If you feel that you have lost your appetite, the dietitian will advise you on what to do.

When will I see the dietitian?

You will be given individual advice about your diet during your PD training. The dietitian will give you practical advice on how to adapt your diet to follow these guidelines.

A dietitian is available in the PD clinic and will be happy to talk to you about any aspect of your diet that concerns you.

Introduction to Peritoneal Dialysis (PD)

What do my kidneys do?

The main role of normal kidneys is to get rid of waste products and water in the blood. They achieve this by filtering the blood and turning the waste into urine. They also produce certain hormones.

- **Making Urine**

The kidneys filter the blood. In this way they get rid of waste products such as urea and creatinine and excess water from the body and therefore maintain a normal balance of water and salts in the body. They also remove excess acid made in the body.

- **Producing hormones**

The second role of the kidneys is to produce a hormone called erythropoietin or EPO. This helps the body to make and maintain a normal level of red blood cells in the bloodstream.

The kidneys convert vitamin D into an active form that is important in maintaining a normal balance of calcium in the body and, as a result, keeping teeth and bones healthy.

The kidneys also play a role in maintaining normal blood pressure. Receptors in the kidney detect falls in blood pressure and causing the kidneys to release a hormone called renin which activates a series of chemical actions in the body leading to a rise in blood pressure.

What happens when my kidneys fail?

- **They stop making enough urine**
    1. They fail to remove excess waste products from the blood. These

products are urea, creatinine, acid and excessive amounts of potassium. Waste products, such as urea and creatinine, build up in the blood and can reach toxic levels. The symptoms vary from person to person. Some people experience all the symptoms and some experience a few. Others will not suffer any symptoms at all, however, it is important to recognise that this does not mean that their kidneys are working. Symptoms include: lack of appetite, nausea, vomiting, metallic taste in the mouth, itching, drowsiness during the day, insomnia and restlessness at night, restless legs, leg cramps. These symptoms may also be caused by imbalances in the levels of salts such as potassium in the body.

2. They fail to remove enough excess water. This means that too much water stays in the body, this is known as ‘fluid overload’. Fluid overload causes swelling of the feet and ankles initially. In severe overload a patient may have shortness of breath. If overload is left untreated, it may put undue strain on the heart.

- **production of hormones is affected**
  1. The kidneys do not produce enough EPO in order to manufacture red blood cells. This causes anaemia and patients will experience symptoms according to the level of anaemia. Some of the symptoms are: lethargy, nausea, loss of appetite, lack of concentration, shortness of breath and feel the cold.
  2. The kidneys do not produce enough active vitamin D. This causes an imbalance between calcium and phosphate levels in the body resulting in weak and aching bones and itching.
  3. Damage to the kidneys may cause them to overproduce renin leading to high blood pressure. This often causes headaches and if left untreated places the patient at higher risk of having a stroke.

Why do I need to have dialysis?

The only way to control the build up of excess fluid and waste products is to filter the blood using artificial means. This is called dialysis. The problems caused by the changes in production of hormones are not directly helped by dialysis but will require drug therapy, for example, EPO can be given by a regular injection, vitamin D by a tablet and any blood pressure problems can be addressed using tablets.

How do I decide what type of dialysis to have?

Once you have been told that you need long term dialysis because your kidneys are failing you will need to decide what is the best treatment for you. You will be given information about the two types of dialysis, haemodialysis and peritoneal dialysis, and the opportunity to discuss them with members of the dialysis team. Both types of dialysis provide a good treatment. Unless you have a medical problem that prevents you having a particular type of dialysis you will have a choice between them.

Generally, people make a decision based on the information they are given and how one or other treatment fits in best with their lifestyle.

What is peritoneal dialysis?

Peritoneal dialysis is a method of cleaning the blood without the blood leaving the body. A clean ‘sugar’ solution (dialysate) is run through a tube called a Tenckhoff catheter into the abdominal cavity.

A thin membrane, called the peritoneum, lines this cavity. The membrane has tiny holes (or pores) in it, through which the waste products can pass from the bloodstream into the ‘sugar’ solution (dialysate). When this fluid is drained out through the catheter, the waste products drain out with it.

There are several different types of PD that use the abdominal cavity in this way, CAPD – the most common type used, APD & CCPD. The difference between them is the equipment and time they need to put the dialysate through the catheter into the abdomen.

How does peritoneal dialysis work?

This next section provides a fairly detailed account of how it works. It is not essential to know it but it may be of interest to you.

PD works by the process of the movement of water and particles across a semi-permeable membrane, the peritoneum, allowing excess water and waste products to be removed from the bloodstream.

This is possible because the theory behind peritoneal dialysis exploits two essential principles of physics and chemistry.

Firstly, diffusion. All molecules and ions, the particles referred to above, move continuously, whether in liquid, gas or solid form and they spread out throughout any substance they are in. If there is a barrier in the way such as a ‘semi-permeable’ membrane that allows smaller particles to pass but blocks larger particles, the small particles will pass through it and spread out, but the larger particles will not. (Imagine a sheet of cling film with holes in it and household sugar & salt on it. The smaller salt crystals can go through the holes but larger granulated sugar ones are too big, then imagine similar sized particles in a fluid trying to pass through the cling film). So if there is a liquid with more particles on one side (a higher concentration) than the other to start with, eventually, the particles that can pass through the membrane will be spread out evenly on both sides.

In PD, you place a fluid with no waste products in the abdominal cavity. The water is separated from the bloodstream by the peritoneum, a membrane that is semi-permeable allowing waste products to pass through it, but not larger particles and elements in the blood. The waste products diffuse into the dialysis fluid which is then drained out.

Secondly, osmosis. Osmosis is the movement of water through a membrane which allows the solutions on side of the membrane to be balanced with another. So, if particles are unable to pass through the membrane and diffuse out, then the water can and will move until the solutions on either side of the membrane are balanced equally.

In PD the fluid used to attract particles in it, is also a highly concentrated ‘sugar’ solution. The ‘sugar’ slowly passes through the peritoneum into the bloodstream, but in order to create balance, the water in the blood quickly crosses the membrane into the solution, weakening it until it is the same sugar concentration as the blood. Therefore, when you drain out the fluid, you get more than you put in because water, excess to overall body needs, is removed.

What is CAPD?

CAPD stands for:

Continuous – you are having dialysis all the time

Ambulatory – you are able to walk around while dialysing

Peritoneal – the inside of your tummy is used for dialysis

Dialysis – the process by which waste products and fluid are removed from the blood/body

In CAPD, the movement of water and waste products across your peritoneal membrane takes place over a period of several hours while the fluid stays in your peritoneal cavity. After a specific period of time the fluid reaches saturation point, full of water and waste products. At this time, the fluid is drained out and exchanged for fresh dialysis fluid. This will take place 4 times a day, for example, at breakfast, lunch, teatime and before going to bed.

The exact time that you choose to change your bag is entirely up to you, in order to allow you to fit dialysis around the planned activities of the day. You do need to space out exchanges evenly throughout the day, but there is room for flexibility.

What is APD?

APD stands for

Automated – a machine is used

Peritoneal - the inside of your tummy is used for dialysis

Dialysis – the process by which waste products and fluid are removed from the blood/body

In APD, a machine is used to perform the exchanges of dialysis fluid. Dialysis takes place overnight so that all the patient has to do is set up and programme the machine. During the night, the machine carefully measures and controls the amount of fluid passing in and out of the patient.

This form of PD is better suited to some patients than others because some patients receive better dialysis when the dialysis fluid is left inside them for a shorter period of time. This is achieved most easily during the night using a machine. Doing it during the day would require the patient to perform extra bag exchanges.

When will I have the Tenckhoff catheter inserted?

We aim to plan and prepare access for peritoneal dialysis before the time of dialysis arrives. You can find out more about Tenckhoff insertion if you read the leaflet on Access for Peritoneal Dialysis. It does require time off work and in a small number of cases an overnight stay in hospital is necessary.

After you have had a Tenckhoff inserted, you will be followed up by your renal consultant until the time has arrived for you to commence PD training

What does PD training consist of?

The length of time it takes to learn how to change peritoneal bags and the problem solving that goes with it can take between 2 – 4 days, depending on the individual. You will not be rushed and training sessions are taken at your own pace. Your P.D. training will take place in your own environment with the P.D. link nurse coming to your home.

What happens when the PD training is completed?

When you have completed your training, your P.D. team nurses will support and visit you in the community. In some instances, a district nurse will call to change the Tenckhoff dressing and record blood pressure for those unable to manage these procedures themselves.

Your first outpatients appointment will be 2 weeks after discharge from training. Most appointments, when established and settled on CAPD vary at intervals of between 1 and 3 months.

Will I need to restrict the fluids and the food I eat?

One of the purposes of dialysis is to remove excess water from the body because the kidneys are no longer able to do this. However, the amount of fluid that can be removed is limited and so you will be required to restrict your fluid intake.

The amount that you need to drink will be calculated when you start your PD training. You will be asked to complete a 24 hour urine collection, from which your fluid restriction will be worked out depending on how much urine you have passed.

The food you eat is as important as the dialysis itself. You will be seen by the renal dietitian who will discuss your dietary needs in detail with you and give you a comprehensive diet sheet and dietary advice. Generally, a PD diet needs to consist of high protein, low sugar, low cholesterol and moderate amounts of fibre. We strongly advise asking the dietitian if you have any concerns about your diet.

Will I be able to bathe or shower

You will be able to have a bath, but you must ensure that the bath is clean and the bath water is below the level of the catheter exit site. A shower is preferable to a bath as the water is fresh and running.

Will I be able to go on holiday?

Yes, you will be able to go on holidays in this country and abroad. You will be required to contact the Home Dialysis Administrators who will arrange for deliveries of fluids and stock to your hotel or holiday accommodation. Between 6 to 12 weeks notice is required in advance depending on where you are going. UK holidays can be arranged with about 2 weeks notice.

Will I be able to go swimming?

Yes, swimming is possible for people on PD, but only in a swimming pool, not in the sea. If you would like to go swimming please ask your PD trainer about it who will give you instructions about how this can be undertaken.

What are the possible complications of PD?

- Catheter or exit site infections

These can occur and are best prevented by cleaning the exit site on alternate days. Infections that do occur are treated with antibiotics.

- Peritonitis

This is an infection of the peritoneum. It is the major drawback with PD. The signs and symptoms are cloudy drainage fluid, temperature, pain, nausea and vomiting. Peritonitis is treated with antibiotics taken by mouth or given directly into the dialysate bags before running them into the abdomen. In some instances, if the infection is severe and does not respond, the catheter may need to be removed. Haemodialysis is used until a new catheter is inserted.

Peritonitis can be avoided by maintaining good standards of personal hygiene and hand washing.

- Leakage

This may occur when the catheter is first used. It means that the catheter is not fully healed into the skin. The catheter will be rested for another 10-14 days before trying PD again.

- Poor drainage

Sometimes drainage of fluid out of the abdomen during exchanges is poor. This may be caused by the catheter end pointing up in the abdomen as opposed to down towards the pelvis. It is also caused by constipation. Drainage may improve after the successful use of a laxative.

What are the main advantages and disadvantages of PD?

The main advantage of PD is mobility. It can be performed at home, work or on holiday. You do it on your own without help. You can do it at the times that most suit you and you don't need a machine and if you are using a machine overnight, it is easily portable. PD patients are independent and need only visit the hospital every 8 weeks or if there is a problem.

There are fewer dietary restrictions on PD than haemodialysis because the dialysis is continuous.

The main disadvantages are the complications associated with infection, particularly peritonitis, that it disrupts your daily routine and the time off work required for Tenckhoff insertion and training.

Some people who have undergone abdominal surgery can not have PD because the peritoneum has been scarred by surgery and cannot function as an effective semi-permeable membrane.

Can I have a kidney transplant?

You may be suitable for a kidney transplant. If you are interested in this option then you will need to discuss it with your consultant. You may do this before you start on dialysis and at anytime after you have started dialysis. You will be referred to a transplant surgeon for an assessment in outpatients clinic. Routine tests will be arranged to see if you are medically suitable. If you are suitable, your name will be placed on a transplant waiting list and when a kidney which matches your blood group and tissue type becomes available you will be given it.

It is important to realise that the length of time you are on the waiting list depends on the availability of a suitable kidney and not how long you have been waiting.

Some people may have relatives who wish to make a kidney donation. In this case you will need to discuss it with your consultant and an assessment for you and your potential donor will be arranged.

How do you know if you are receiving enough dialysis?

- Measuring the adequacy of dialysis

What do the kidneys do?

Normal kidneys have two jobs, to make urine and to produce certain hormones.

- **Making urine**

The kidneys help to get rid of waste products from the blood such as urea and creatinine, maintain a normal balance of water in the body, maintain a normal balance of salts in the body such as sodium and potassium and get rid of acid made in the body.

The kidneys filter the blood, removing the waste products and excess water which is excreted from the body as urine.

This role is known as an excretory function

- **Making hormones**

The second role of the kidneys is to make a hormone called erythropoietin or EPO. This helps the body to produce and maintain a normal level of red blood cells in the bloodstream.

The kidneys also convert vitamin D into an active form that is important in maintaining a normal balance of calcium in the body and, as a result, keeping teeth and bones healthy.

This role is known as an endocrine function

What is kidney failure?

When a patient has chronic kidney failure (or chronic renal failure - CRF), the kidneys’ ability to carry out these jobs gradually deteriorates. When so-called end-stage renal failure (ESRF) is reached dialysis is used to replace the work that the kidneys do. However, dialysis can only partly replace the excretory function, the removal of waste products and excess water from the blood. The endocrine function, the manufacture of hormones, has to be replaced when necessary in a different way by injections of EPO and tablets of active vitamin D.

What is adequacy?

When a patient is on dialysis it is important to know and ensure that they are receiving enough treatment. In general the rule is the more dialysis the better. This means that it is necessary to measure at intervals the adequacy of dialysis to find out if the treatment a patient is receiving is sufficient or adequate.

The doctors and nurses caring for the patient want to find out how well the treatment is replacing the excretory function of the kidneys, that is the removal of waste products and excess water.

There are three questions that need to be answered in order to find this out:

1. How well is the dialysis getting rid of the waste products e.g. urea and creatinine?

2. How normal is the fluid (water) and salt balance in the body? Fluid balance is closely related to salt balance.

3. How well is the acid being controlled?

How is the removal of waste products from the body measured?

Patients receiving haemodialysis (HD) will have this done during a treatment session. The level of urea in the blood is measured at the beginning and end of the dialysis session. The more the level drops, the more efficient has been the treatment.

Patients receiving peritoneal dialysis (PD) need to have all their bags collected for 24 hours. These are then sampled. In addition, the amount of urea and creatinine in the blood is also checked in order for the amount being removed to be calculated. If the patient is still passing reasonable quantities of urine this is also collected for 24 hours and the amount of waste products still being removed by the patients kidneys is measured also.

Because patients vary in height and weight, the results for both types of dialysis are usually corrected for a patient’s size. This allows comparisons between different patients to be made.

How is the balance of fluid and salts in the body measured?

A blood test will tell the doctor how much sodium and potassium is in the blood. However, it is more important to examine the patient. If there is any swelling (oedema) this usually means that there is excess salt and water in the body.

Once a patient is having dialysis, blood pressure also provides a guide. High blood pressure often means an excess of salt and water in the body and low blood pressure might mean that the patient is dehydrated.

One of the best guides to fluid balance is the weight of the patient. An increase in weight over a short period of time, a few hours or days, means increasing fluid in the body. A falling body weight means the opposite, that there is less fluid in the body.

How is the level of acid measured?

A simple blood test will quickly reveal the level of acid in the body.

What happens when dialysis adequacy has been measured?

If the tests show that the dialysis is adequate there will be no change in the treatment. For many patients, with time, there will be a need to alter dialysis. This usually means an increase in dialysis is necessary, particularly if there is a need to remove more waste products.

It is important to realise that all the evidence suggests that more dialysis is better because it means fewer medical problems and a longer life. For patients receiving haemodialysis increased dialysis can mean increasing the hours of treatment or increasing the pump speed or increasing the size of the dialyser (artificial kidney) or increasing the number of sessions per week. Often a combination of these changes will be necessary. If the tests continue to get worse this usually means that there is a problem with access, the fistula or line, which will need to be sorted out.

Peritoneal dialysis patients have their dialysis increased by increasing the size of the bags or increasing the number of the bags. A PD machine may be needed to give frequent cycles of treatment overnight. As with haemodialysis, a combination of these changes may be needed. To improve dialysis with PD it is essential to have fluid in the abdomen 24 hours a day, seven days a week.

Peritonitis - for peritoneal dialysis patients

What is peritonitis?

Peritonitis is a complication that may occur to a patient on peritoneal dialysis. It is an infection caused by bacteria (germs) that affects the peritoneal membrane (the lining) of the abdominal cavity. It should not be confused with the more serious peritonitis that occurs as a result of a ruptured bowel.

What are the symptoms?

Patients usually first notice that their bag appears cloudy when performing a bag exchange. They may also experience some abdominal discomfort and feel generally unwell. If you think you have peritonitis, please contact your peritoneal dialysis unit so that treatment can be started as soon as possible.

How is it treated?

Peritonitis can be treated with a course of antibiotics. Initially you will receive one dose added to a bag and be asked to take a course of antibiotic tablets by mouth. At the same time, a specimen is taken from a cloudy bag and sent for to the laboratory for analysis. When the results of this analysis are known your treatment may need be changed.

How can I prevent peritonitis?

Prevention is better than cure. During your PD training you will have been shown how to carry out exchanges using a technique designed to minimise infection. It is important that you never relax this technique. In general:

- Always wash your hands before and after performing a bag exchange. Good handwashing is an essential part of infection control.
- Ensure that you carry out your bag exchanges in a clean environment
- Always follow the procedure that you were taught for the equipment that you are using.

If you need a refresher course or advice, please contact your PD Unit who will be happy to help you.

How to control phosphate.

What is phosphate?

Phosphate is a chemical element which is found in many foods.

What does phosphate do?

Calcium and phosphate work together in the body to keep bones healthy and strong.

Why is too much phosphate in the blood a problem?

In renal failure the kidneys are unable to remove excess phosphate from the body. If phosphate levels rise too much calcium levels may fall, and **Renal Bone Disease** can occur as a result. This causes bones to become more brittle and even fracture.

What can be done to help?

- **Drugs**

A way of keeping phosphate levels normal is by taking tablets known as '**phosphate binders'*.*** Examples of these drugs include **Calichew,Renagel** and **Titralac.**

These drugs bind to phosphate in the stomach and prevent blood phosphate levels from rising.

- **Diet**

The foods that are high in phosphate are also high in protein. If you reduce your intake of phosphate containing foods, you will reduce your intake of protein. Adequate protein is essential to health and strength, so **do not** reduce your intake without discussion with the dietitian. It is especially important that you are taking the binders at the right time with the right foods.

- Binders should always be taken with foods high in phosphate, otherwise they do not work. Ideally, they should be taken 10-15 minutes before a meal (unless specifically told otherwise)
- Always take your full prescription of binders.
- Try and adjust the binders through the day depending on the phosphate content of the meals.

The foods that are high in phosphate include:

- Eggs.
- Dairy produce e.g. milk, cheese and yoghurt
- Fish which contain soft bones i.e. sardines, white bait.
- Meat

For example:

Mrs Jones has been prescribed 3 Titralacs/day. On a typical day this is what Mrs Jones would eat.

- **Breakfast.**

  2 slices of toast with spread and jam

  cup of tea

  glass of orange juice.

- **Mid Morning**

  2 digestive biscuits + a cup of tea.

- **Lunch**

egg or cheese on 2 slices of toast

a piece of fruit.

- **Evening Meal**

Chops or roast meat + 3 x boiled potatoes, carrots, peas.

- **Supper**

A cup of Horlicks made with milk.

Mrs Jones would get the best effect from the Titralac if she took one with lunch, one with her evening meal, and one with supper. This is because she takes a high phosphate food with all the above meals.

So…in summary

- the best way to control your phosphate is to take your full prescription of binders daily.
- The amount to be taken with each meal depends on the phosphate content of the meal.

If you are still unsure then ask to see the dietitian at clinic.

The Role of the Anaemia Co-ordinator

The Anaemia Co-ordinator is an experienced nurse who has specialised in the care of anaemic patients. Her role is to co-ordinate the proper treatment of anaemia for haemodialysis and peritoneal dialysis patients. If you are an anaemic patient in one of these groups you may or may not meet her, however, she will be involved in assessing your treatment needs. She will be instrumental in setting up a package of care to relieve your symptoms of anaemia.

However, if you have not yet started dialysis, your anaemia care will be coordinated by one of the Pre-Dialysis Clinical Nurse Specialists who will oversee this part of your care.

The Co-ordinator’s role includes:

- liaison with the community team of nurses and your GP to enlist their support in a shared care system.
- liaison with your medical team to ensure that appropriate treatment is organised.
- patient education which is a large feature of the co-ordinators job. If you are having EPO, you will be taught how to inject EPO and its relevant side-effects. This may be by the co-ordinator or by your link nurse (a nurse from your particular dialysis unit). The nurse will supply you with relevant education and provide you with an information pack about EPO and iron management.
- making arrangements for you to receive intravenous iron, if you need it.
- reviewing your blood tests with your doctor and link nurse and organising changes when they need to be made.
- acting as contact for you and your community team. She is able to provide education and support about anaemia and its treatment to patients, their families, GPs and community nurses.

If you need to contact the anaemia office, please telephone 029 2074 8453

and the administrator will direct your enquiry appropriately.

CHAPTER 5 HAEMODIALYSIS

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 5. Haemodialysis

Introduction to haemodialysis

What do my kidneys do?

The main role of normal kidneys is to get rid of waste products and water in the blood. They achieve this by filtering the blood and turning the waste into urine. They also produce certain hormones.

- **Making Urine**

The kidneys filter the blood. In this way they get rid of waste products such as urea and creatinine and excess water from the body and therefore maintain a normal balance of water and salts in the body. They also remove excess acid made in the body.

- **Producing hormones**

The second role of the kidneys is to produce a hormone called erythropoietin or EPO. This helps the body to make and maintain a normal level of red blood cells in the bloodstream.

The kidneys convert vitamin D into an active form that is important in maintaining a normal balance of calcium in the body and, as a result, keeping teeth and bones healthy.

The kidneys also play a role in maintaining normal blood pressure. Receptors in the kidney detect falls in blood pressure and causing the kidneys to release a hormone called renin which activates a series of chemical actions in the body leading to a rise in blood pressure.

What happens when my kidneys fail?

- **They stop making enough urine**
  1. They fail to remove excess waste products from the blood. These products are urea, creatinine, acid and excessive amounts of potassium. Waste products, such as urea and creatinine, build up in the blood and can reach toxic levels. The symptoms vary from person to person. Some people experience all the symptoms and some experience a few. Others will not suffer any symptoms at all, however, it is important to recognise that this does not mean that their kidneys are working. Symptoms include: lack of appetite, nausea, vomiting, metallic taste in the mouth, itching, drowsiness during the day, insomnia and restlessness at night, restless legs, leg cramps. These symptoms may also be caused by imbalances in the levels of salts such as potassium in the body.
  2. They fail to remove enough excess water. This means that too much water stays in the body, this is known as 'fluid overload'. Fluid overload causes swelling of the feet and ankles initially. In severe overload a patient may have shortness of breath. If overload is left untreated, it may put undue strain on the heart.

- **production of hormones is affected**
  1. The kidneys do not produce enough EPO in order to manufacture red blood cells. This causes anaemia and patients will experience symptoms according to the level of anaemia. Some of the symptoms are: lethargy, nausea, loss of appetite, lack of concentration, shortness of breath and feeling the cold.
  2. The kidneys do not produce enough active vitamin D. This causes an imbalance between calcium and phosphate levels in the body resulting in weak and aching bones and itching.
  3. Damage to the kidneys may cause them to overproduce renin leading to high blood pressure. This often causes headaches and if left untreated places the patient at higher risk of having a stroke.

Why do I need to have dialysis?

The only way to control the build up of excess fluid and waste products is to filter the blood using artificial means. This is called dialysis. The problems caused by the changes in production of hormones are not directly helped by dialysis but will require drug therapy, for example, EPO can be given by a regular injection, vitamin D by a tablet and any blood pressure problems can be addressed using tablets.

How do I decide what type of dialysis to have?

Once you have been told that you need long term dialysis because your kidneys are failing you will need to decide what is the best treatment for you. You will be given information about the two types of dialysis, haemodialysis and peritoneal dialysis, and the opportunity to discuss them with members of the dialysis team. Both types of dialysis provide a good treatment. Unless you have a medical problem that prevents you having a particular type of dialysis you will have a choice between them.

Generally, people make a decision based on the information they are given and how one or other treatment fits in best with their lifestyle.

What is haemodialysis? The basics

Haemodialysis is a word taken from Greek. It means literally ‘blood filtering’. Haemodialysis is a way of removing waste products from the bloodstream using an artificial filter in a machine. The blood is removed from the body by inserting two needles into a vein in the arm. The needles are attached to blood tubing on the dialysis machine. The blood comes out of the bottom needle, through the tubing, into the filter where it is cleaned. It comes out of the filter and is returned via the tubing into the top needle.

Because only a small amount of blood can be removed from the body at any one time, the blood needs to circulate through the filter many times before the waste products are removed. This takes, on average, four hours in order to bring the waste products in the blood down to an acceptable level.

When you start dialysis, your kidneys will not be functioning enough to keep the level of the waste products down and in a few days time they will have risen again. You will then need to have dialysis again. On average, you will need dialysis two or three times a week. It will not be less than twice a week and it is not usual for it to be more than three times a week.

Once you have started on dialysis, it will take a few months to settle down. You will be monitored during this time to see how well your dialysis is working. Depending on this, the number of hours and number of sessions a week will be tailored to suit your individual needs.

How am I attached to the dialysing machine?

As noted already, needles are placed into a vein immediately prior to dialysis and then removed immediately afterwards. Because our veins are not big enough for needles to be inserted regularly two or three times a week, a vein in the arm has to be made bigger. The vein is made bigger by performing a small operation on the wrist called a fistula. This will allow the nurses to insert the needles more easily.

The operation will be done as a day surgery outpatient, usually under local anaesthetic. It takes about six to eight weeks before the vein is ready to use after the operation. This operation can be performed well in advance of a patient needing dialysis. If you should need dialysis and the fistula has not been made or before the fistula is ready to use, you will be able to receive dialysis by way of a small catheter inserted into a large vein in the neck or shoulder. This may be a temporary measure and will be removed when your fistula is ready to be used, or if the veins are poor, a more permanent catheter may be inserted.

What can I do while I am on dialysis?

When you are dialysing, you will remain connected to the machine. You will be either sitting in a comfortable chair or lying on a bed and you will not be able to move from the bed or chair. However, there are activities you can carry out. Some patients chat, others watch TV, or read books and magazines. Others simply prefer to sleep. You may be able to drink and have a snack.

What will I feel when I am on dialysis?

During the dialysis you will not be aware of the blood circulating through the machine. However, there may be some problems that you will encounter whilst on dialysis which will affect the way you feel.

1. Low blood pressure

Sometimes, if fluid and waste products are removed too quickly from your blood, you may experience a drop in blood pressure. This could make you feel light headed, sweaty and sick. It is easily and quickly remedied by infusing fluid directly into the bloodstream through the machine or having a drink in order to replace the lost fluid an adjusting the controls on the machine.

2. Nausea

Nausea is sometimes experienced during and after dialysis because of changes in blood pressure.

3. Cramp

Cramp is sometimes experienced, usually in the legs. It is the result of rapid fluid loss or salt depletion. It can be remedied by replacing the fluid and salt.

4. Headaches

Headaches can occur towards the end of a dialysis session. They are the result of the removal of waste products and fluid. These problems can be controlled if you follow your fluid, diet and medication instructions.

When and where will I have my dialysis?

Dialysis takes place in a special dialysis unit. There are several different units. You will be asked to attend a unit where there is available space and time for your sessions. This may not always be the nearest unit to you; however, you may transfer at a later date when a space becomes available.

Normally, there are two sessions a day, morning and afternoon, every day, Monday to Saturday, though some units offer evening appointments, but transport is not available for this shift-(twilight). You will be asked to attend for either a morning or afternoon session depending on available times and days when you first start dialysis. These will be your regular times and days unless your treatment regime changes. If these are inconvenient for you, they may be changed as soon as another more convenient space is available.

How do I get to the dialysis unit?

Transport can be arranged by your dialysis unit. This might be ambulance, car or taxi. This will take you both to and from dialysis. However, there may be some delays in returning home, if other dialysis patients are using the same transport. If you decide at anytime to make your own arrangements to be picked up from or dropped at the unit, you need to let the unit know in advance so that they may let ambulance control know.

You may drive yourself back and forth for treatment along as you are feeling well enough.

Can I learn to dialyse myself?

When you have unit based dialysis, the nurses take the responsibility for dialysis. However, there are a number of patients who would like to learn to dialyse themselves at home. If you feel that you would like to do this you will need to discuss it with the unit staff. They will be able to advise you about dialysis at home. If you decide to go ahead, the nurses will train you to dialyse yourself. This training will take about three to six months depending on the individual. When you are confident that you know how to dialyse and the staff are also confident that you are able to dialyse safely then you will be able to have a machine at home.

Before this can happen, certain conditions have to be met. You would need to have facilities to dialyse at home, for example, a spare room. You will also need someone to support you, a partner, spouse, relative or friend committed to being there for every dialysis session. They would not be trained to dialyse you, but would be trained to assist you should specific problems occur.

Haemodialysis at home offers more flexibility than unit based dialysis. Although the number of hours and sessions would be no different, you will be able to arrange your dialysis time to fit in with your lifestyle. However, this needs to be discussed between you and the person who will support you as haemodialysis at home can be stressful in the first few months.

Can I go away?

Yes, you can, whether you dialyse at home or in the unit, though some medical conditions need to be met.

If you want to go away just for the day on a special occasion and it coincides with your dialysis, let the unit know well in advance and they may be able to change your dialysis day for you.

If you want to go on holiday, you can, as long as there is a dialysis unit within travelling distance.

If you inform your local dialysis unit at least one month in advance of where and when you want to go on holiday they will be able to tell you if there is a dialysis unit near and, if there is, will book your dialysis for you. If there is no dialysis unit near, you will have to choose another holiday venue.

For holidays in the UK and Europe, the dialysis cost is met by the health authority; however, if you go outside the European Union, you will have to meet the dialysis cost yourself.

For a list of holiday dialysis venues/units please contact the National Kidney Federation, 6 Stanley Street, Worksop, Notts, S81 7HX, Tel: 01909 487795 or the British Kidney Patients Association, Bordon, Hants, GU35 9JZ, Tel: 01420 472021. http://www.kidney.org.uk/holidays/index.html

Can I have a kidney transplant?

You may be suitable for a kidney transplant. If you are interested in this option then you will need to discuss it with your consultant. You may do this before you start on dialysis and at anytime after you have started dialysis. You will be referred to a transplant surgeon for an assessment in outpatients' clinic. Routine tests will be arranged to see if you are medically suitable. If you are suitable, your name will be placed on a transplant waiting register, and when a kidney which matches your blood group and tissue type becomes available you will be given offered the opportunity.

It is important to realise that the length of time you are on the register depends on the availability of a suitable kidney and not how long you have been waiting.

Some people may have relatives or others who wish to make a live kidney donation. In this case you will need to discuss it with your consultant, and your potential donor will be visited by the live donor transplant co-ordinator to provide information. This whole process will take up to 6 months to complete.

Vascular access for haemodialysis

What is vascular access for haemodialysis?

Haemodialysis is a long term treatment for kidney failure. It removes waste products and fluid from your blood because your kidneys can no longer do this. To circulate your blood through the dialysis machine, a special site or ‘access’ is needed to allow your blood to be removed, cleaned and returned to you. There are several ways this can be done. They all require a minor surgical procedure.

Is it permanent?

Access for dialysis can be temporary or permanent. Some people may have a temporary method until a permanent access site is ready for use. Good vascular access can last you for many years to come.

When will I need it?

We aim to plan and prepare vascular access before the time for dialysis arrives, so that when you commence your treatment it will be much less stressful and more planned. Having vascular access made, does not mean that you will have to start dialysis before it is necessary.

When the decision has been made that you need access for haemodialysis, you will be assessed by a surgeon who is an expert in making vascular access. You will need to attend the out patient clinic so that the surgeon can examine you and decide on the best type of access for you. Occasionally, the surgeon will organise a scan of your arms (a Doppler scan) to be done in order to help him decide the best place for your access. Following this assessment, your name will be placed on the surgical waiting list and your operation will be done in good time according to your clinical need. Your operation will normally take place in the Ambulatory Care unit at UHW where you will only stay in for the day usually. However, some patients may be required to be admitted to hospital depending on the type operation and their general clinical condition.

What are the different kinds of access?

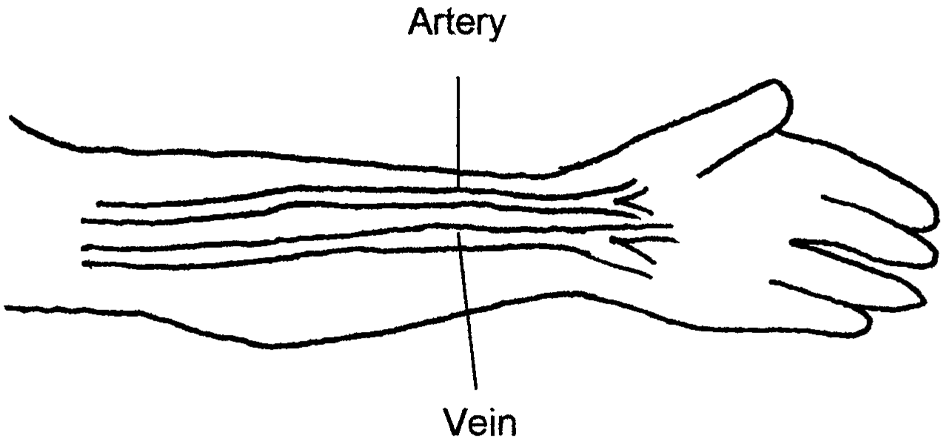
1. Fistula

What is a fistula?

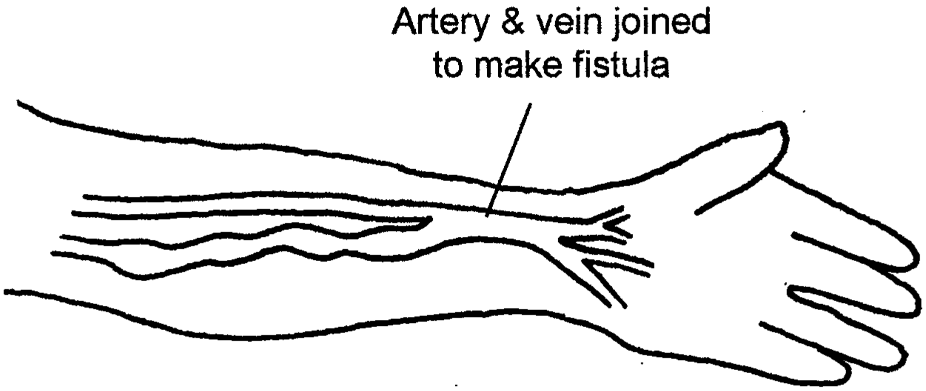
A fistula is the most common and best type of dialysis access. Creating a fistula involves a small operation on the wrist or arm to join together a vein and an artery. The procedure takes about an hour and is usually carried out under local anaesthetic which means you will be awake throughout but you should not feel any pain.

Joining a vein to an artery creates a faster and more turbulent flow of blood through the vein. This makes the vein thicker and it gets bigger. Eventually, it becomes visible under the skin and this makes it easier for needles to be introduced into it when dialysis is needed. When you touch it you can feel a ‘buzz’. This sensation is very important, because it means that the fistula is working properly. You should check your fistula every day and if it ever stops working, you must contact the hospital immediately.

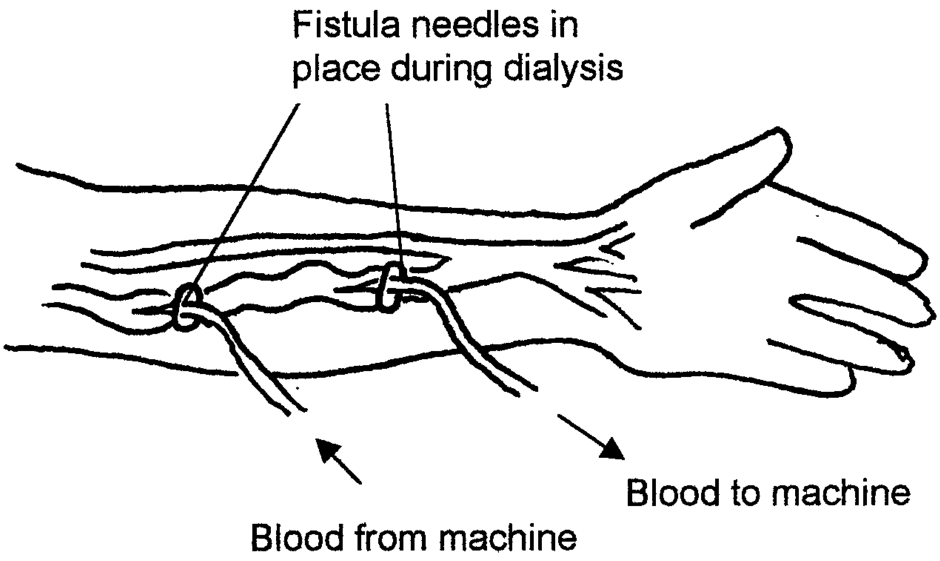
1. Forearm before access surgery



2. Forearm after surgery



3. Fistula in use 6 weeks after surgery



How does a fistula work?

This is the best and least troublesome method of access and many people learn to insert the needles themselves. Every time you have dialysis, two needles are inserted into the fistula and lines are attached that carry your blood through the machine and then return it to you. After dialysis the needles are removed leaving only a small puncture mark.

2. Synthetic graft

A graft is a soft, synthetic connecting tube used to connect an artery and a vein if a person's own veins are too small or weak to create a fistula for dialysis. A graft can be created both in the arm and top of the leg and is used in the same way as a fistula for dialysis. The graft is placed close to the surface of the skin for easier needling. The main drawback of this type of access however is the high risk of infection.

3. Temporary access

Some sort of temporary access may be needed if you have to have dialysis sooner than planned or if there is a problem with your permanent access. Temporary access will also be used for people requiring immediate unplanned dialysis treatment.

Temporary access is usually inserted as a procedure carried out in the treatment room of ward B5 at UHW. It is inserted under a local anaesthetic whereby you will be awake throughout the procedure but shouldn't feel any pain. This type of access will only be used for up to 3 weeks, and will then be replaced with a tunnelled line (or permcath as it is known) which will last until long term vascular access such as a fistula is established. The most common complications with temporary access are infection and blockage. There are two types of temporary lines; jugular lines which are inserted into a large blood vessel in the neck, and femoral lines which are inserted into a large blood vessel in the groin.

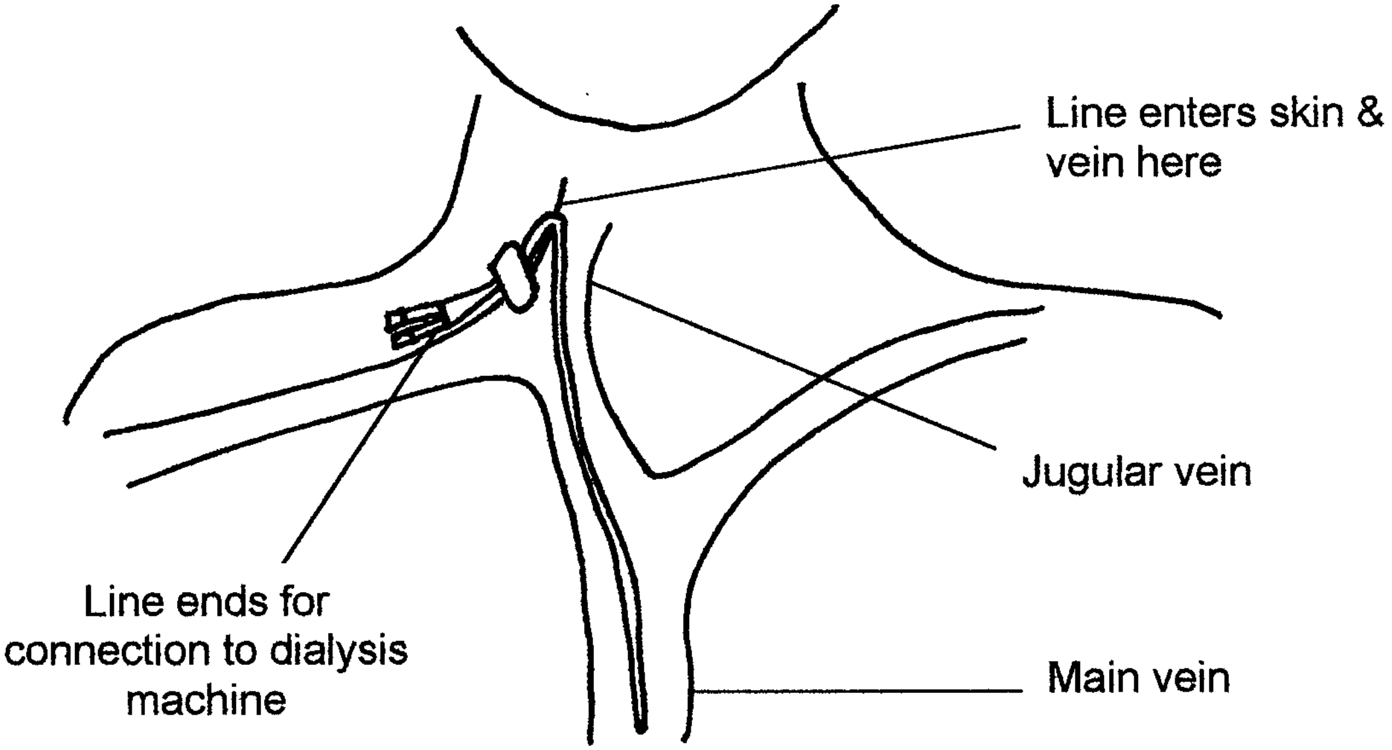
Jugular line

The procedure will be explained to you by the doctor prior to the insertion of the line and you must sign a consent form. During insertion of a jugular line you will need to lie flat, and the procedure takes about half an hour. A dressing is placed over the area where the line it enters the skin and this should be kept clean and dry. The dressing is changed each time you have dialysis. A chest x-ray is taken afterwards to ensure the line is correctly placed.

Femoral line

The insertion of a femoral line is similar to that of the jugular line, however you are able to sit up during the procedure and you will not require a chest x ray to confirm correct positioning of the line. Your mobility may be limited after insertion of a femoral line. It is very important that the area is kept clean and dry.

Both the femoral and jugular lines have two prongs at the end to allow blood to be removed and returned after being cleaned by the dialysis machine. After each dialysis session, the prongs are flushed with a solution to prevent clotting or blocking of the line, sealed with sterile caps and clamped to ensure blood is not able to leak out and germs are unable to enter in.

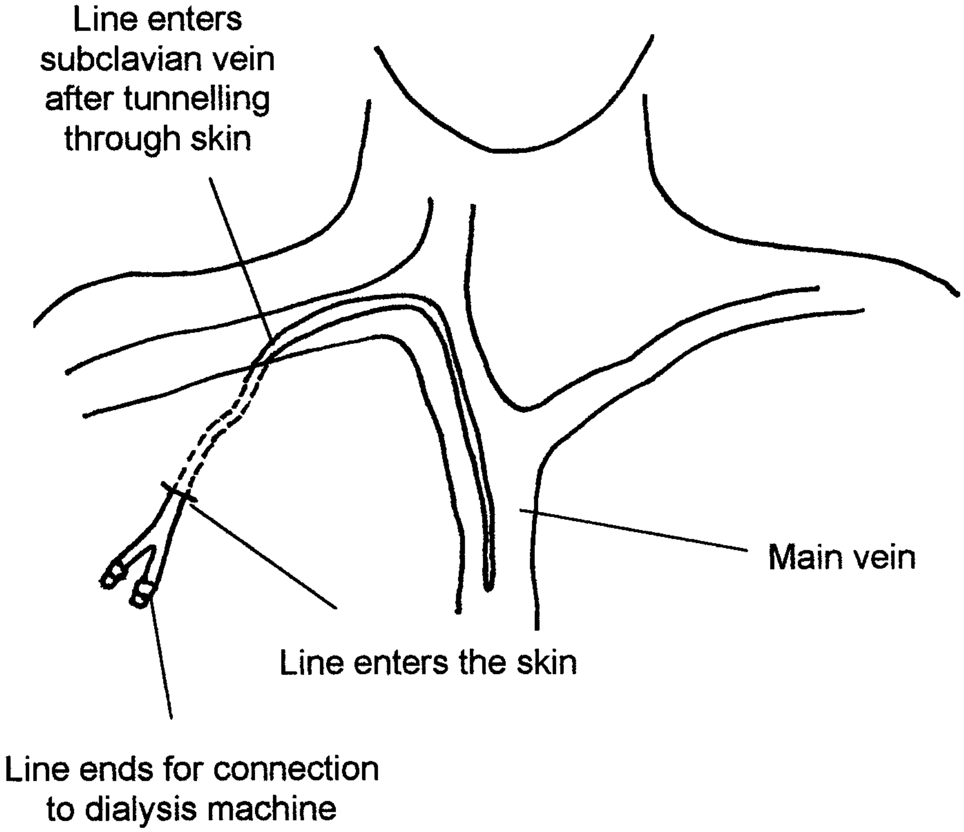


Temporary haemodialysis access

3. Permcath

What is a permcath?

A permcath will be a replacement to the temporary line, or in a small number of cases be used as a long term vascular access. (See additional section for full explanation of permcath)



Permanent access line for haemodialysis

How does a permcath work?

The permcath works in the same way as a temporary line for dialysis. It has two prongs at the end to allow blood to be removed and returned after being cleaned by the dialysis machine. After each dialysis session, the prongs are flushed with a solution to prevent clotting or blocking of the line, sealed with sterile caps and clamped to ensure blood is not able to leak out and germs are unable to enter in.

Vascular access is sometimes termed as “your life line”. You should look after it at all costs, and always check with your nurse or doctor if you are unsure about any aspects.

Information for patients about anaemia and its treatment

Introduction

If you have a kidney condition (whether you are on dialysis or not), you are likely to have anaemia. This is a decrease in the amount of haemoglobin found in the bloodstream, and can make you feel very weak and tired.

This leaflet will tell you what anaemia is, why it occurs and what treatment is available to control it

What is anaemia?

Oxygen is carried around the body by a substance called haemoglobin which is found in the red blood cells of the blood. If you do not have enough haemoglobin, your blood is unable to carry enough oxygen around the body. It is the reduction in the amount of oxygen going around the body that causes the symptoms of anaemia. Anaemia can occur for several different reasons, for example: after operations; during pregnancy; because of blood loss from an ulcer or not having enough iron in your diet.

How do I know if I have anaemia?

The symptoms appear gradually. You might feel more tired or lethargic. You will have less energy to do things. You might feel the cold more easily and feel out of breath doing things that do not normally make you breathless.

What causes anaemia in kidney failure?

Red blood cells are made in the bone marrow. Red blood cells are constantly being produced to replace those that are lost or die. These cells contain haemoglobin which carries oxygen. When the number of these cells drops in the bloodstream, less oxygen can be carried around the body causing anaemia.

The production of red blood cells is controlled by a hormone called erythropoietin (EPO). The kidneys make EPO in response to the level of oxygen in the bloodstream, the less oxygen from fewer red blood cells, the more EPO produced. In kidney failure, your kidneys cannot respond in this way and are unable to produce sufficient amounts of EPO when lower oxygen levels are detected.

To find out if you are anaemic, your doctor will order a blood test to measure your haemoglobin*.* This tells your doctor whether or not your are anaemic by measuring the amount of haemoglobin in your blood and if you need treatment. Chronic renal failure patients often have haemoglobin levels well below normal.

How is anaemia in chronic renal failure treated?

If you have kidney failure, it is likely that this is the cause of your anaemia. However, there other causes of anaemia and they need to be ruled out by investigations or treated as needed.

If your anaemia is caused by kidney failure, your doctor may give you EPO, an artificial form of the natural hormone. You may also require an iron supplement.

How is EPO made?

EPO is made outside of the body, in the laboratory, using genetic engineering. Artificial EPO is identical to the EPO our kidneys produce and acts in the same way, stimulating red blood cell production.

How do I take EPO?

If you are to start EPO you will be given advice and support by an anaemia co-ordinator or a link nurse specialising in this treatment. The nurse will be able to tell you about the treatment and answer your questions.

EPO is given as a subcutaneous (under the skin) injection. Most people are able to give this injection to themselves once they have had some practice. The best places for these injections are in the thigh or tummy. Usually, you will need about 2 or 3 injections a week. Some people have their EPO given during dialysis.

All the equipment you need will be supplied to you, including sharps boxes to put used needles in. EPO needs to be kept refrigerated until half an hour before you use it, to give it time to warm up to room temperature.

How long before I feel better?

Your doctor will prescribe enough EPO to gradually increase your haemoglobin levels closer to normal. The aim is usually for a haemoglobin level of at least 10 g/dl. This may take weeks or months. Your improvement will be gradual, it takes time for the new red blood cells to replace the lost cells. Once your haemoglobin is stabilised your doctor may need to adjust your dosage. You may not need as much EPO or to take it as frequently. Occasionally, a break from EPO may be possible. However, as long as you have kidney failure, the anaemia is likely to return when treatment is discontinued. Regular blood tests will be required to monitor progress.

What are the side-effects from taking EPO?

EPO generally causes few problems. However, some side-effects have been noted. Blood pressure rises are the most important. You will need to have your blood pressure monitored regularly from the beginning of your EPO treatment. In the beginning, just once or twice a week. If your blood pressure goes up consistently, it will need to be treated and any existing medicines you are taking for high blood pressure may be adjusted. If you get bad headaches when you take your EPO, please tell your nurse or doctor. This may be a symptom of high blood pressure.

Some people have also experienced ‘flu like symptoms after injection and for a few days. Occasionally, a rash or redness is noted around the injection site but usually clears up quickly.

Iron therapy

Iron is a vital building block in the production of red blood cells. Unfortunately, a little iron is lost during each haemodialysis session contributing to anaemia in kidney failure. Peritoneal dialysis patients can also suffer from iron deficiency. You may already be taking an iron supplement. When treatment with EPO is started the body uses up its remaining store of iron very quickly. Without extra iron, the EPO may not work properly. Iron can be prescribed as a tablet or given intravenously if necessary.

How do I know if I have enough iron?

A blood test will indicate if you are lacking enough iron. On the basis of this test, your doctor will prescribe either tablets or injections given intravenously (if you are on haemodialysis this can be given during a session). Patients who are not on dialysis or CAPD may receive intravenous iron on a weekly basis in the renal unit.

What side effects does iron therapy have?

It may be necessary to try different amounts and kinds of iron supplements before the right dosage is found. Iron tablets may cause stomach problems such as loose stools, diarrhoea, constipation and stomach aches. If you have stomach problems caused by iron tablets, please tell your doctor. Do not take iron tablets with milk or tea or at the same time of day as antacids, titralac and calcichew. These medicines will interfere with the body’s ability to absorb the iron.

Do I need to take anything else?

Vitamin B and Folic Acid also help in red blood cell production and may be prescribed by your doctor.

What are the benefits of these treatments?

The chief benefit of EPO and Iron treatments is that they are effective in treating the symptoms of anaemia. Many patients notice a great difference in the way they feel, having more energy and better levels of concentration. In addition, these patients may not need blood transfusions to correct their anaemia.

Taking EPO will not affect your need for dialysis, but it should improve your quality of life.

Diet and Haemodialysis

When Will I See The Dietitian?

Each dialysis unit has a Dietitian. Within 6 weeks of starting dialysis the Dietitian will arrange to see you to discuss your diet. It is important to know that every person is individual in their kidney condition and the way that they respond to haemodialysis. You should only make changes to the foods you eat if you have been **told** to do so by the Renal Dietitians. That is, do not change your diet just because the person in the station next to you has been told to do so. If you need to make any changes, the Dietitian will come and see you and advise you on what to change and why.

Following your first visit by the Dietitian on the haemodialysis unit you may be told that you do not need to make any changes to what you eat. However the dietitian may ask you to make changes during your time on haemodialysis as kidney function often deteriorates as time progresses.

Do I Need A Special Diet When I Am On Haemodialysis?

Not everybody will need to change the way they eat because they start haemodialysis. It is important to eat well as people who receive haemodialysis have a greater requirement for energy and protein.

Calories (energy)

Calories are used up during the haemodialysis process and so it is important that you eat enough to compensate for these losses. Try to eat 3 meals each day. If you are struggling with your appetite and your portion sizes have become smaller, try and have small frequent foods i.e.;3 small meals and 2-3 between meal snacks. If you are not meeting your energy needs your dry weight may fall and you may start to feel weak. The Dietitian will advise you if you need to increase the amount of energy in your diet.

Protein

Protein is lost during haemodialysis. This needs to be replaced. Foods that are rich in protein include meat, poultry, fish, eggs, dairy products and pluses. You should aim to have a protein food at each meal. If you are not eating enough protein this may show as a low blood albumin (protein) which may lead to muscle loss and muscle weakness.

Potassium

Potassium is a mineral that is found in many foods that we eat. The kidneys help usually remove excess potassium form the blood. However, if your urine output has fallen you will stat to rely more on the haemodialysis machine to remove any excess potassium in your blood. In this instance potassium level can build up between dialysis sessions. Your blood results will be checked every month and if your potassium levels go too high the Dietitian will advise you on a potassium restricted diet. **Do not restrict potassium unless you have been told to do so.**

Fluids

Fluid comes from the foods we eat as well as from drinks. As your kidneys begin to work less well you may find that you pass less urine. If this happens and you do not cut down the amount you drink you will become fluid overloaded. Being fluid overloaded can cause swollen ankles and shortness of breath. It also puts strain on your heart. Your doctor or dialysis nurse may set you a daily fluid allowance/ restriction. If this is the case the Dietitian will advise you on sources of fluid in the diet and on how to stick to your fluid allowance.

Salt (sodium)

As with general healthy eating advice the aim is to eat less salt. High salt diets have been associated with high blood pressure. In addition high salt diets can make you feel thirsty, making your fluid allowance difficult to comply with. Salt does not only include salt that we add to food in cooking and at the table, but it also includes salt hidden in foods. Try and go for foods that contain less than 0.25g salt (less than 0.1g Sodium).Also to cut down on salt try adding a little either in cooking or at the table i.e.; not at both places, and if foods are tasting bland try flavouring with herbs and spices.

Phosphate

Phosphate and calcium work together to keep bones healthy and strong. When kidneys fail they become less able to remove phosphate from the body. If phosphate levels remain too high for too long, it can chalk up and harden blood vessels and may cause weak bones. It can also cause red eyes and itchy skin.

Phosphate in the blood can be stopped from going too high by taking tablets called “Phosphate Binders”. These include Calcichew, Renagel, Phosex and Alu-Cap. It is important that these tablets are taken at the correct time and with the right foods. Your Dietitian will advise you on this.

What Should I Eat on Dialysis Days?

It is important to eat the same on dialysis days as on any other day. If you feel nauseous on dialysis, try snacking little and often.

Can I Eat Out?

Yes, all dialysis patients should feel free to eat out. If you are on a potassium restricted diet you may want to discuss low potassium options with the Dietitian first. You may also wish to phone ahead to the establishment and request a copy of the menu.

Can I Drink Alcohol?

This is up to your Doctor to decide. If you are allowed and you follow a fluid allowance, make sure alcoholic drinks are included in this. If you are on a potassium restricted diet the Dietitian will advise you on lower potassium drinks.

Having your fistula formed

Having the operation

A fistula is the most common and the best method to remove and return your blood during haemodialysis. It is formed by joining an artery and a vein, usually in the wrist, to allow easier access to your bloodstream. It is preferably created before you need to start dialysis so that the vein is larger, stronger and ready for use when you need it. However if you had to start dialysis unexpectedly you should have your fistula formed as soon as possible after you have commenced treatment.

You will usually need to spend the day in hospital for this minor surgical operation. It is normally performed under local anaesthetic, so you will be awake and should be not feel any pain, with the procedure lasting roughly about one hour.

After the operation

There will be a small cut mark at the site of the operation which will be covered in a dressing and a bandage. In time, as this heals, it will leave a small scar.

Immediately after the operation, extra padding and protection may also be placed around the wound site to keep it warm.

The nursing staff will check your dressing regularly after the operation. They will also listen to the buzzing (or ‘bruit’) created by the fistula. This is caused by the turbulent flow of blood in the vein caused by joining it to an artery. In the beginning this will only be heard by using a stethoscope, but in time, you will be able to feel it if you place your hand gently over the fistula.

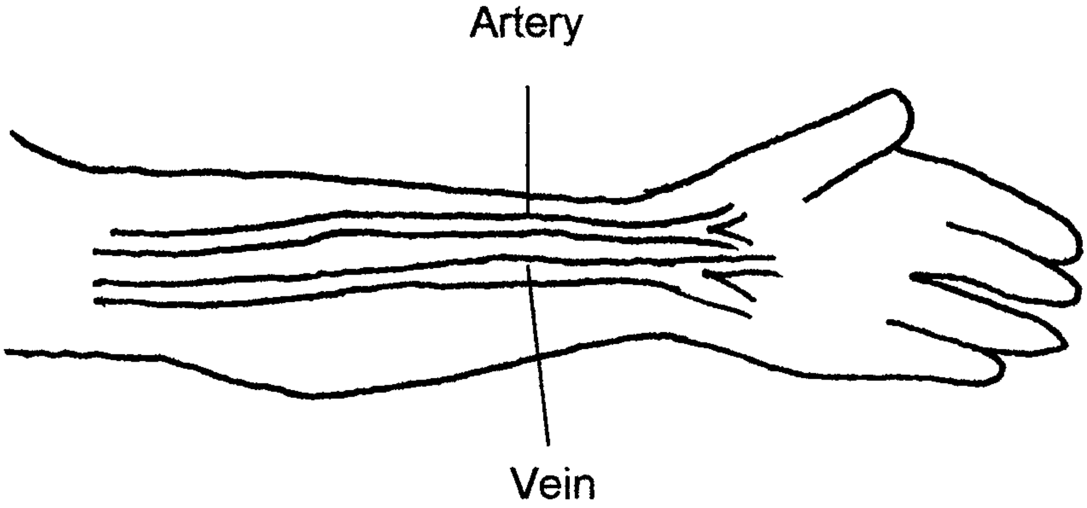
Sometimes, some blood oozes through the dressing after the operation, but it should not be excessive.

You may require simple pain killers following the operation.

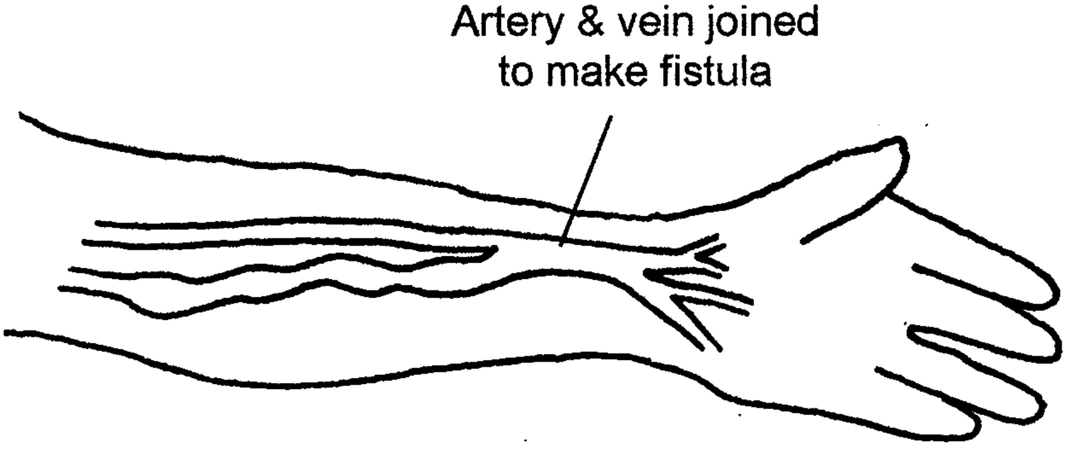
You should not drive for 2 weeks following your operation, so you should make arrangements for someone to take you home from hospital. It is also advisable that you have someone to stay overnight, particularly if you have only been in hospital for the day.

The fistula cannot be used for dialysis for at least 6 weeks. If you need dialysis during this time, you will require a temporary form of access. Having a fistula does not mean that you will start dialysis before you need it. Some people can have their fistula for many months before starting dialysis.

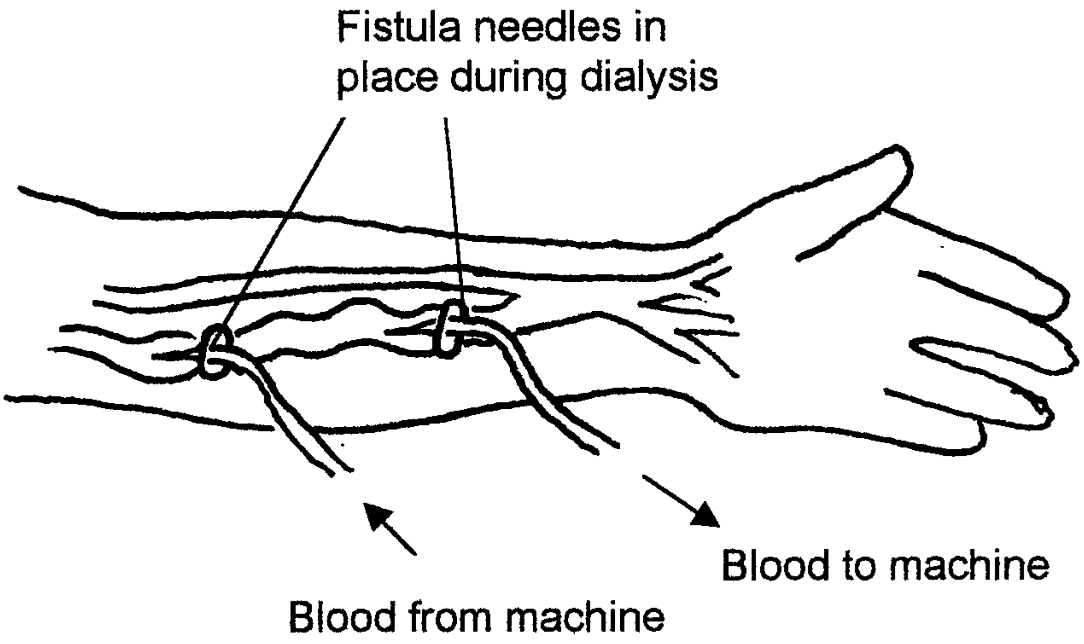
1. Forearm before access surgery



2. Forearm after surgery



3. Fistula in use 6 weeks after surgery



Looking after your fistula or graft

Points to remember after the operation and generally

1. Keep your fistula or graft site and dressing clean and dry.

2. The district nurse will call to check and change the dressing if necessary

3. You should take care with the following activities:

- ☐Driving - please seek advice from medical staff as to when it is safe to drive again

- ☐Avoid sports for at least 2 weeks and ask the doctor in clinic when you can resume these activities

- ☐Do not lift heavy objects for 2 weeks and when lifting, be careful not to take the weight of an object on your fistula arm.

4. Once you can feel the buzzing sensation in the fistula or graft, check it at least once a day. If you have any concerns about your fistula you should contact the hospital immediately.

5. If the fistula/arm shows any signs of infection such as redness, swelling, tenderness and pain you should contact the hospital immediately.

6. If you are not receiving dialysis, your fistula will be checked by your pre dialysis specialist nurse about 1-2 weeks following the operation. The stitches will dissolve, although sometimes but there may be a small knot left that will need to be trimmed. If you are on dialysis, your dialysis unit should check your fistula.

7. Never let anyone do the following with your fistula arm:

- take a blood pressure reading on it
- take blood from it
- give intravenous drugs into it.

8. Avoid wearing tight, constrictive clothing and jewellery such as bangles or watches.

9. Do not hang a bag over the arm or carry heavy objects on the fistula arm. This could block off the fistula.

Remember, your fistula is your life line and should be treated as such.

Having your permcath inserted

Having the operation

A permcath is a soft plastic tube, about the thickness of a pencil that allows us to gain immediate access to your blood for haemodialysis. It consists of two prongs emerging from the skin. Blood to be cleaned leaves one prong from the body and returns via the remaining prong.

A permcath is a semi permanent method of access for the majority of patients, and used usually when you are waiting for a fistula operation or have a fistula that is not yet ready to use. However, a *small* number of patients may require the permcath as their long term permanent access if they are unable to have any other form of vascular access.

- You will normally have you permcath procedure in the treatment room on the ward, however sometimes this may be carried out in the x ray department or the operating theatre.

- Specially trained doctors put the permcaths in place using a local anaesthetic.

- You will be awake while this happens, but you can have a light sedative if you prefer.

- You will need to wear an oxygen mask while the tube is being put in. A nursing assistant will stay with you during the half an hour this takes and will measure your blood pressure and pulse.

- You may eat and drink normally before your catheter is put in, unless you are having sedation.

- A blood sample will also be taken to check your blood clotting levels.

- Many people who have a permcath inserted already have a temporary dialysis line. It is normal for this line to be removed at the time that the permcath is inserted. Unlike the temporary access lines, a permcath is made of a softer, more comfortable material and it is carefully tunnelled under the skin by the doctor into place in order to prevent infection and to sit more comfortably.

After the operation

- You will find after the operation that about six inches of the permcath protrudes from the skin at the base of your neck. There will be a dressing over the site where it actually enters the skin.

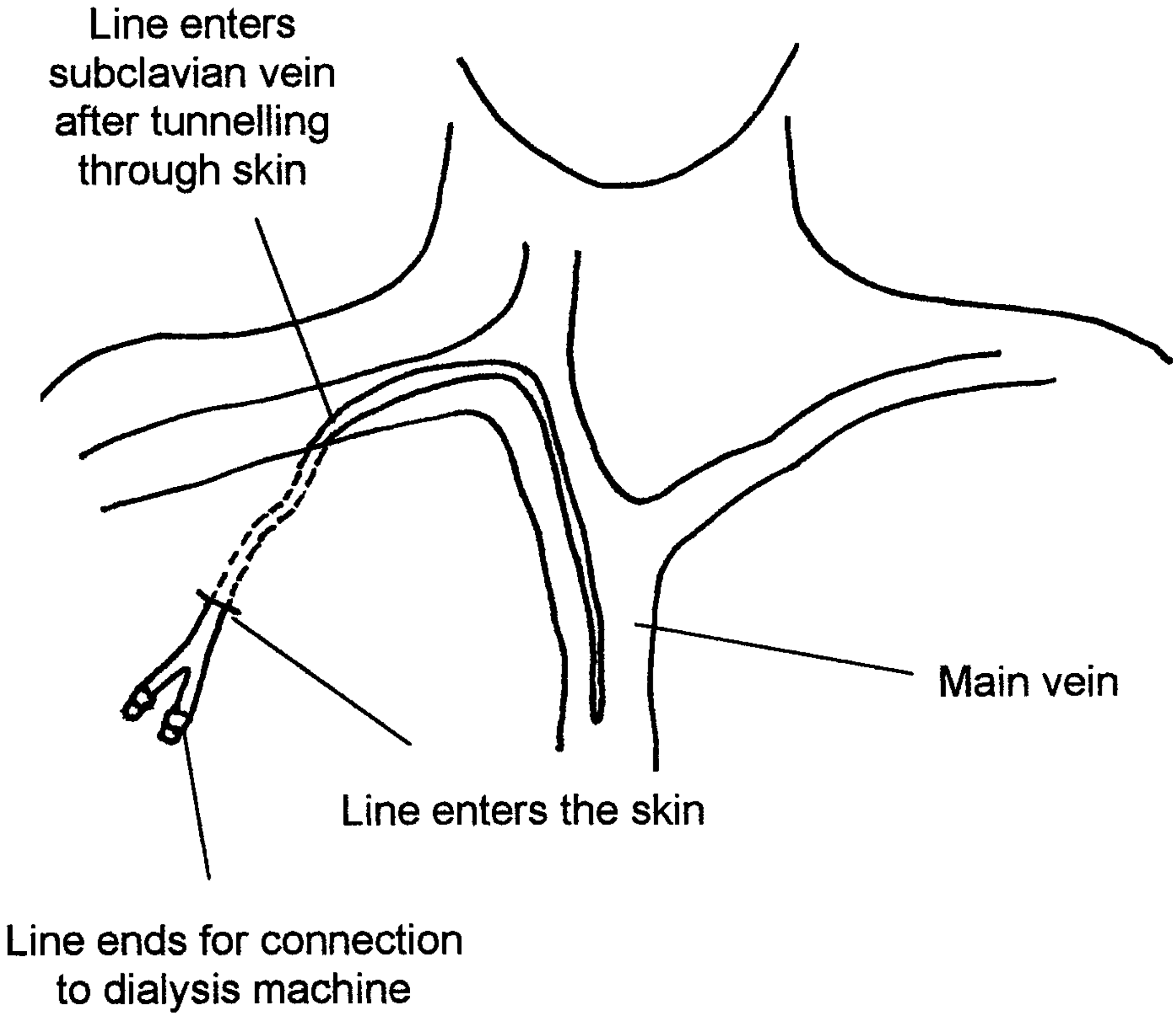
- You will have a chest x-ray taken to make sure your Permcath is in the right place.

- You will need to rest for at least an hour after the tube has been put in and possibly stay overnight in hospital.

- The permcath is held in place by a few stitches in you neck which will be removed by dialysis unit staff after 7 days, and some around the exit site of the permcath which will be removed after 4 weeks.

Complications are rare and we make every effort to reduce the risks during this procedure but all invasive procedures carry some degree of risk. These are some of the things that could happen:

1. During the procedure- Very mild bleeding may occur which can occasionally become more severe. You may feel some discomfort, like someone pushing and pulling, as the doctor inserts the catheter, however you should not feel pain.
2. Immediately after the procedure- Bleeding may occur, but this can be controlled by putting on a pressure dressing and usually stops within 24 hours. Occasionally bruising might occur- however this will fade in time.
3. Long term- Infection may occur when bacteria (bugs) are introduced to your blood from the catheter. If you have any flu like symptoms you must tell the nursing staff/doctor at the hospital.



Permanent access line for haemodialysis

Looking after your permcath

Points to remember after the operation and generally

1. Keep the dressing clean and dry

2. When bathing or taking a bath, do not let the dressing get wet. Some people hold the shower nozzle in their hand in order to direct it away from the permcath site

3. It may be easier to get someone to help you wash your hair over a sink or treat yourself to a trip to the hairdressers

4. The dressing will be changed each time you have dialysis

5. Do not use scissors anywhere near the dressing.

6. Infection can be a complication. If the area where the permcath enters your skin becomes tender, red or there is a visible discharge, or if you experience flu like symptoms you should contact the dialysis unit immediately

Using the permcath

The end of the catheter is forked. When you need dialysis, the lines to remove and return your blood are attached to the end of the permcath.

After each dialysis session, the permcath is flushed with a solution to prevent clotting or blocking of the line. Two small secure caps are placed on the end of the catheter until the next dialysis session.

How do you know if you are receiving enough dialysis?

- Measuring the adequacy of dialysis

What do the kidneys do?

Normal kidneys have two jobs, to make urine and to produce certain hormones.

- **Making urine**

The kidneys help to get rid of waste products from the blood such as urea and creatinine, maintain a normal balance of water in the body, maintain a normal balance of salts in the body such as sodium and potassium and get rid of acid made in the body.

The kidneys filter the blood, removing the waste products and excess water which is excreted from the body as urine.

This role is known as an excretory function

- **Making hormones**

The second role of the kidneys is to make a hormone called erythropoietin or EPO. This helps the body to produce and maintain a normal level of red blood cells in the bloodstream.

The kidneys also convert vitamin D into an active form that is important in maintaining a normal balance of calcium in the body and, as a result, keeping teeth and bones healthy.

This role is known as an endocrine function

What is kidney failure?

When a patient has chronic kidney failure (or chronic renal failure - CRF), the kidneys' ability to carry out these jobs gradually deteriorates. When so-called end-stage renal failure (ESRF) is reached dialysis is used to replace the work that the kidneys do. However, dialysis can only partly replace the excretory function, the removal of waste products and excess water from the blood. The endocrine function, the manufacture of hormones, has to be replaced when necessary in a different way by injections of EPO and tablets of active vitamin D.

What is adequacy?

When a patient is on dialysis it is important to know and ensure that they are receiving enough treatment. In general the rule is the more dialysis the better. This means that it is necessary to measure at intervals the adequacy of dialysis to find out if the treatment a patient is receiving is sufficient or adequate.

The doctors and nurses caring for the patient want to find out how well the treatment is replacing the excretory function of the kidneys, that is the removal of waste products and excess water.

There are three questions that need to be answered in order to find this out:

1. How well is the dialysis getting rid of the waste products e.g. urea and creatinine?
2. How normal is the fluid (water) and salt balance in the body? Fluid balance is closely related to salt balance.

3. How well is the acid being controlled?

How is the removal of waste products from the body measured?

Patients receiving haemodialysis (HD) will have this done during a treatment session. The level of urea in the blood is measured at the beginning and end of the dialysis session. The more the level drops, the more efficient has been the treatment.

Patients receiving peritoneal dialysis (PD) need to have all their bags collected for 24 hours. These are then sampled. In addition, the amount of urea and creatinine in the blood is also checked in order for the amount being removed to be calculated. If the patient is still passing reasonable quantities of urine this is also collected for 24 hours and the amount of waste products still being removed by the patients kidneys is measured also.

Because patients vary in height and weight, the results for both types of dialysis are usually corrected for a patient's size. This allows comparisons between different patients to be made.

How is the balance of fluid and salts in the body measured?

A blood test will tell the doctor how much sodium and potassium is in the blood. However, it is more important to examine the patient. If there is any swelling (oedema) this usually means that there is excess salt and water in the body.

Once a patient is having dialysis, blood pressure also provides a guide. High blood pressure often means an excess of salt and water in the body and low blood pressure might mean that the patient is dehydrated.

One of the best guides to fluid balance is the weight of the patient. An increase in weight over a short period of time, a few hours or days, means increasing fluid in the body. A falling body weight means the opposite, that there is less fluid in the body.

How is the level of acid measured?

A simple blood test will quickly reveal the level of acid in the body.

What happens when dialysis adequacy has been measured?

If the tests show that the dialysis is adequate there will be no change in the treatment. For many patients, with time, there will be a need to alter dialysis. This usually means an increase is necessary, particularly if there is a need to remove more waste products.

It is important to realise that all the evidence suggests that more dialysis is better because it means fewer medical problems and a longer life. For patients receiving haemodialysis increased dialysis can mean increasing the hours of treatment or increasing the pump speed or increasing the size of the dialyser (artificial kidney) or increasing the number of sessions per week. Often a combination of these changes will be necessary. If the tests continue to get worse this usually means that there is a problem with access, the fistula or line, which will need to be sorted out.

Peritoneal dialysis patients have their dialysis increased by increasing the size of the bags or increasing the number of the bags. Sometimes a PD machine may be needed to give frequent cycles of treatment overnight. As with haemodialysis, a combination of these changes may be needed. To improve dialysis with PD it is essential to have fluid in the abdomen 24 hours a day, seven days a week.

The Role of the Anaemia Co-ordinator

The Anaemia Co-ordinator is an experienced nurse who has specialised in the care of anaemic patients. Her role is to co-ordinate the proper treatment of anaemia for haemodialysis and peritoneal dialysis patients. If you are an anaemic patient in one of these groups you may or may not meet her, however, she will be involved in assessing your treatment needs. She will be instrumental in setting up a package of care to relieve your symptoms of anaemia.

However, if you have not yet started dialysis, your anaemia care will be coordinated by one of the Pre-Dialysis Clinical Nurse Specialists who will oversee this part of your care.

The Co-ordinator's role includes:

- liaison with the community team of nurses and your GP to enlist their support in a shared care system.
- liaison with your medical team to ensure that appropriate treatment is organised.
- patient education which is a large feature of the co-ordinators job. If you are having EPO, you will be taught how to inject EPO and its relevant side-effects. This may be by the co-ordinator or by your link nurse (a nurse from your particular dialysis unit). The nurse will supply you with relevant education and provide you with an information pack about EPO and iron management.
- making arrangements for you to receive intravenous iron, if you need it.
- reviewing your blood tests with your doctor and link nurse and organising changes when they need to be made.
- acting as contact for you and your community team. She is able to provide education and support about anaemia and its treatment to patients, their families, GPs and community nurses.

If you need to contact the anaemia office, please telephone 029 2074 8453

and the administrator will direct your enquiry appropriately.

The Chronic Dialysis Unit at University Hospital of Wales

Your team

The team is headed by Dr David Thomas your consultant. He is based at UHW and attends the unit at least twice a week, and holds clinic once a week.

The unit has a staff nephrologist, Dr Mohammed Ashraf, who attends the unit on a daily basis, Monday to Friday, looking after you and your dialysis with the nursing staff. She/he is available for dialysis and kidney problems but is not a substitute for your own GP who you should continue to consult for routine medical problems.

The nursing team is led by the unit manager, Rebecca Newman and consists of experienced dialysis nurses, auxiliary nurses and assistant technical officers (ATOs). All staff members are happy to help you and your family on any aspect of your care.

The unit receptionist is Julie Mercer. Julie works very closely with the transport office to ensure that your journey to and from the unit runs as smoothly as possible.

Visitors

For reasons of safety, privacy and maintaining the Renal Unit as a clean area we prefer that visits are kept to a minimum. However, when you first start on the unit or at times of illness or stress we will be happy to accommodate a relative or friend whom you wish to be with you during dialysis. Please do not visit if you are unwell e.g. cough or cold or if you have had contact with an infectious disease e.g. chicken pox.

We do not advocate visits from children under 12 years old. If children do visit, they must be closely supervised for safety.

Food & drink available

Morning patients:

Early morning - tea & biscuits

Lunch - sandwiches & tea

- hot meals available on request

Afternoon patients:

Teatime - sandwiches

- hot meals available on request

Small cold snacks may be brought in to eat whilst dialysing. We regret that we are not permitted to warm up any food brought in to the unit.

Entertainment facilities

Televisions providing terrestrial TV channels are available above almost every station in the unit. Please feel welcome to bring personal stereos, books and magazines to read. Please note that mobile phone operation is not allowed within the hospital and all mobiles phones should be turned off on entering the hospital.

Contact numbers

Main Unit: Direct line 029 2074 8465 7 a.m. – 10 p.m. Monday – Saturday

Dr Thomas' secretary Direct line 029 2074 6645

Ward B5 UHW Direct line 029 2074 2782/4588

Cardiff B Braun Renal Unit,

Pentwyn, Cardiff

At the Cardiff B Braun Renal Unit, we have a small team dedicated to providing your care.

The team is headed by Dr Richard Moore, your consultant. He is based at the University Hospital of Wales, Cardiff. He takes clinic every 2 weeks on a Wednesday. All patients attending the unit are scheduled to be seen every 4 months at this clinic. You will receive a letter by post to let you know the date of your appointment. The unit staff will arrange transport as required and changes in dialysis times to accommodate the appointment if required.

A clinical assistant from B5 attends the Renal Unit on a daily basis, looking after you and your dialysis with the nursing staff. She/he is available for dialysis and kidney problems but is not a substitute for your own GP who you should continue to consult for routine medical problems.

Your nursing team

The nursing team is led by the Head Nurse and the Senior Dialysis Nurse. The nursing team consists of a total 12 qualified nurses and 3 health care assistants. In addition there is a domestic attending the unit Monday to Friday in the early morning.

Nursing staff are organised via a system of patient allocation. One named nurse will oversee and plan your care but will not be available every time you dialyse. On a day to day basis any of the qualified nurses may be allocated to help you. This will be your named nurse when he/she is on duty.

Care assistants will provide blankets etc. and generally make sure that you are comfortable.

Visitors

For reasons of safety, privacy and maintaining the Renal Unit as a clean area we prefer that visits are kept to a minimum. However, when you first start on the unit or at times of illness or stress we will be happy to accommodate a relative or friend whom you wish to be with you during dialysis. Please do not visit if you are unwell e.g. cough or cold or if you have had contact with an infectious disease e.g. chicken pox.

We do not advocate visits from children under 12 years old. If children do visit, they must be closely supervised for safety.

Car parking

Limited car parking for patients only is provided outside the unit.

Entertainment

There is a TV, several walkmans, a radio-cassette unit, video and a small library of books available for your entertainment.

Food & drink available on the Cardiff B Braun Renal Unit.

With only a small kitchenette on the unit it is not possible to produce substantial meals. We supply tea and toast to all patients once they are settled on the dialysis machine and again, just before the end of their treatment. Two cups of tea is a moderate fluid intake and can easily be remove without too much risk by the machine.

Special occasions

Please feel free to bring in cakes for special occasions such as birthdays or anniversaries

Cardiff Baxter Renal Unit – Contact Numbers

Main Unit Direct Line 029 2054 5650

Fax 029 2054 5651

Dr Moore's secretary, UHW

Janet Undery Direct Line 029 2074 6646

Ward B5, UHW

Reception Direct Line 029 2074 4588/2782

Outpatients clinic co-ordinator, UHW

Direct Line 029 2074 6641

Baxter Dialysis Unit, Prince Charles Hospital,

Merthyr Tydfil

- ## Your team

At Merthyr, we have a small team dedicated to providing your care.

The team is headed by Dr David Thomas, your consultant. He is based at University Hospital of Wales, Cardiff and attends the unit at least once a week when he takes a clinic at the unit. All patients attending the unit are scheduled to be seen every 3 months at this clinic. A list is displayed in the reception area.

The unit has a clinical assistant, a doctor who attends the Renal Unit on a daily basis most lunchtimes, looking after you and your dialysis with the nursing staff. The doctor is available for dialysis and kidney problems but is not a substitute for your own GP who you should continue to consult for routine medical problems.

The nursing team is led by Head Nurse, her deputy and consists of 6 qualified nurses and 2 health care assistants. In addition we have a domestic who attends the unit Monday to Friday in the early afternoon.

- ## Visitors

For reasons of safety, privacy and maintaining the Renal Unit as a clean area we prefer that visits are kept to a minimum. However, when you first start on the unit or at times of illness or stress we will be happy to accommodate a relative or friend whom you wish to be with you during dialysis. Please do not visit if you are unwell e.g. cough or cold or if you have had contact with an infectious disease e.g. chicken pox.

We do not advocate visits from children under 12 years old. If children do visit, they must be closely supervised for safety.

- ## Entertainment

Entertainment provided includes a television and video plus a large selection of unit videos. You can, of course, bring your own in. We also have a Talking Book library for those who are visually impaired or who prefer to ‘listen’ to a good read. There are also many magazines of every shape and form.

- ## Our system of nursing

In order to maintain a high standard of individualised nursing care for everyone, we use primary nursing and patient allocation on a daily basis.

What this means for you is that one specific nurse is allocated to care for you and other patients on that day, both for the morning and for the afternoon shifts. When your allocated nurse has prepared your machine, only then can your care be delivered. This may mean waiting for afternoon dialysis until your nurse has finished caring for his/her morning patients.

All care is delivered as promptly and efficiently as possible. We do not work on a ‘first come, first served’ basis, as this would be against our philosophy of care and might potentially be dangerous.

- Delays in service

Any unavoidable delays are always explained to avoid anxiety. Delays may arise from medical emergencies, technical difficulties and on many occasions, transport problems which are beyond the control of the nursing staff.

We therefore ask that you please be tolerant during these times and considerate to others who may be less well than yourself.

Food & drink available at Merthyr Tydfil

At Merthyr, the food and drink available depends on the time of day that you dialyse. Diabetic patients are a priority and they will be offered early breakfasts, glucose gel or milk and glucose to maintain their blood sugar levels during dialysis

- Morning patients

Breakfast – toast and marmalade or biscuits with a choice of tea or squash

Lunch – choice of sandwiches (orders are taken at breakfast time), or toast or biscuits with a choice of tea or squash

Most patients prefer to take their sandwiches home and have just a drink with or without biscuits

- Afternoon patients - receive the same service as lunch for teatime
- Special occasions

On special occasions, birthdays etc. we have cake or gateaux offered to everyone with either a small tot of sherry or wine. At Easter we have a special Easter treat involving chocolate. At Christmas we have a finger buffet or assorted delights plus crackers and sherry

Contact Numbers

Main unit: Direct line: 01685 384609

Fax: 01685 384678

Internal line 01685 721721 ext. 8488

Ambulance Control Direct line: 01443 205331

Internal line: 01685 721721 ext. 8303

Renal secretary (PCH) Internal line: 01685 721721 ext. 8357

Dr Srivastava Direct line: 01685 384609

(Clinical Assistant)

Dr Thomas' secretary Direct line 029 2074 6645

Ward B5, UHW

Reception Direct Line 029 2074 4588/2782

Newport Renal Unit

Your team

Medical Staff

- Consultant

Professor John Williams is the principle doctor who is in charge of your care and will see you on a regular basis in the hospital and at clinic appointments. If you or your family need to speak to the Consultant and appointment can be arranged.

- Clinical Assistant

A senior doctor is based in the Renal Unit on a daily basis and will be looking after you and your dialysis with the nursing staff. She/he is available for dialysis and kidney problems but is not a substitute for your own GP who you should continue to consult for routine medical problems.

Nursing Staff

There is a team of nurses led by the Head Nurse and supported by additional highly qualified staff. We also have a team of renal Health Care Assistants who assist the nursing staff with your care.

N.B. Many other people may visit the Renal Unit - W you are unsure who they are or what their role is please ask a member of the Nursing Team.

How we work together

The Newport Renal Unit operates a named nurse scheme. A particular member of staff is assigned as your Primary Nurse. She/he will be responsible for planning your care and discussing any issues with you such as your dialysis, blood results, holidays etc. or any concerns that you might have.

Your Primary Nurse will not be able to look after you every session you come for dialysis. One nurse will be assigned to you and a number of other patents for a session. In time you will be looked after by all the nurses on the unit. Although you will have a particular nurse each session we work very much as a team. All staff are available to help you and are happy to do so.

Visitors

For reasons of safety, privacy and maintaining the Renal Unit as a clean area we prefer that visits are kept to a minimum. However, at specific times of illness or stress arrangements can be made for a relative or friend to be with you during dialysis. Please refer to the visitors guide available on the unit

Entertainment

Television and radios are available through out the Unit. TV's do have to be shared. And you can of course bring reading material, personal stereos, games etc.

Food & drink available at the Newport Renal Unit

- Morning Patients

Tea and Toast at 9.00am

Tea and Sandwiches at 12.00 noon

- Afternoon Patients

Tea and Sandwiches at 3.00 p.m.

Biscuits are also available as an alternative.

Patents are advised that all the above are snacks are not substitutes for a proper meal and that particularly those on an afternoon shift should have some sort of a meal prior to coming for dialysis.

Newport - Contact Numbers

Main Unit Direct Line 01633 656070

Fax 01633 656075

Professor William's secretary, Royal Gwent Hospital

Direct Line 01633 234978

Professor William's secretary, UHW

Direct Line 029 2074 6646

Ward B5, UHW

Reception Direct Line 029 2074 4588/2782

CHAPTER 6 TRANSPLANT

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 6. Transplant

Introduction to kidney transplant.

Undergoing a transplant can be an exiting and challenging time for everyone involved. It is a successful long-term treatment for kidney failure. It is associated with better quality of life than other forms of treatment which involve dialysis.

This leaflet is intended to provide an overview of transplantation. It is not a complete guide but will help you to prepare for a transplant. It will tell you about getting onto the transplant waiting list, where the organs come from and provides some guidelines as to what you can expect before and after the operation. In addition, it will tell you about the medicines and outpatient clinic appointments that are required after a transplant.

If you want to discuss transplantation further, please do not hesitate to contact the Recipient Nurse Specialist at University Hospital of Wales, who will be able to supply you with more information and answer any queries that you may have.

Where do donor organs come from?

There are two sources of donor organs, from a living person (living donation) or from a person who has died (deceased donation).

Who can be a living donor?

There are two types of living donors - related and unrelated. A living related donor is someone who has a blood relationship with the recipient, such as parent, child/children, siblings, aunt/uncle, etc. Live unrelated donors are usually those who are close to the recipient, such as their partner/spouse or friend.

How is a potential living donor assessed?

When people are considering living donation they have the opportunity to meet with the Live Donor Coordinator and talk about exactly what will be involved.

The first stage is to check the potential donor and recipient’s blood group compatibility. If they are compatible more blood tests will be taken to determine tissue typing and antibody cross-match. These blood tests will determine if it is possible to proceed further.

The potential living donor must be willing to donate a kidney and be in good health. They will be seen by a clinical psychologist and undergo checks on their physical fitness. The tests they will under go include blood and urine studies, chest x-rays, electrocardiograms (ECG) and a stress test (on a treadmill). A renal arteriogram is also performed. This is a type of x-ray to visualise the blood vessels in the kidneys. If the donor is medically suitable and the recipient wishes to receive the kidney, the operation is arranged at an appropriate time for both donor and recipient.

A donor may withdraw from donation **at any time** during the process if they wish and can expect their reasons for doing so to remain confidential. Donors must be donating of their own free will without payment or pressure from anybody and are protected under the law that stipulates this.

Will kidney donation affect the future for the living donor?

There is no reason why a person with one healthy kidney should not lead a full and active life.

How does someone receive a kidney from a deceased organ donor?

Most people requiring a kidney transplant will go on the National Transplant Waiting Register to receive a kidney from someone who has died. The National Transplant Waiting Register is not a waiting list which works on a ‘first come, first served basis’. Everyone in the UK waiting to have a transplant is registered by their transplant centre on the National Register maintained by UK Transplant (UKT). It is likely that the kidney you receive comes from another city in the UK or occasionally, from abroad.

When a kidney becomes available, anywhere in the UK, the donor’s blood group and tissue type is entered onto the computer at UKT. There are other factors taken into consideration when allocating kidneys too, including how long you have waited for a transplant, how long you have been dialysing, whether you have any antibodies, etc. The most suitably matched recipient will be identified and their local Transplant Coordinator will be informed.

The Transplant Coordinator will then call you to come to the hospital for your transplant. This is usually very sudden because we never know exactly when a kidney will become available.

Are there different types of deceased donors?

Yes, there are two types of deceased donor: heart beating and non-heart beating.

A heart beating donor is someone who has sustained such a severe brain injury that the brain-stem dies. No recovery is possible in this situation and the doctors pronounce the donor ‘brain-stem dead’. Organs for transplantation are removed while the donor is still on a breathing machine and their heart continues to pump blood through the body.

To increase the number of kidneys available, and therefore reduce the time that people have to wait for a transplant, we have implemented a non-heart beating donor programme here in Cardiff. A non-heart beating donor is someone who was not brain-stem dead but whose heart had stopped pumping blood. Organs for transplantation are removed after the blood circulation has stopped. With careful selection of the donors results have shown that the outcome for these kidneys, including improvements in individual’s quality of life is as good as that of the kidneys from ‘brain stem dead’ donors.

How does somebody get onto the National Transplant Waiting Register?

If you wish to be considered for a transplant, you will need to raise the matter with your consultant. This can be just before you start dialysis and at anytime once you are on dialysis. Your consultant will refer you to the transplant surgeons for assessment, which consists of appointments in the outpatient clinic and routine tests to see if you are medically fit for transplant. The transplant surgeon will explain what is involved in having a transplant and answer any questions you may have.

Transplantation is not suitable for all patients. Some people have other health problems that would make it too risky for them to have the transplant surgery. If this is true in your case, this will be discussed with you during the clinic appointment.

If you are found to be medically suitable for this treatment, your name will be placed on the National Transplant Waiting Register. Before you are ‘activated’ on the register we need to take several blood samples. Some are tested for your blood group and tissue type to match with a donor, and need repeating at least one week later. Others are screened for the following viruses:

- Human Immuno-deficiency Virus (HIV or AIDS virus)
- Hepatitis B
- Hepatitis C
- Syphilis antibody
- Toxoplasma gondii antibody
- Epstein-Barr Virus (glandular fever virus)
- Cytomegalovirus (CMV)
- Varicella Zoster Virus (Chicken pox virus)

All these blood tests are carried out on every potential transplant recipient to avoid any risk of illness after transplantation.

Your name will only be placed on the National Transplant Waiting Register when all the tests have been completed, which can take several weeks. The Recipient Nurse Specialist will contact you when this has happened and you are 'activated'.

Once you are on the National Transplant Register it is important to keep yourself as healthy as you can as it may help you recover quicker after your operation and increase the chances of success. For instance,

- if you smoke, now is a good time to stop;
- if you are dialysing, make sure you dialyse well and keep to your fluid and diet restrictions;
- exercise daily within your limits (if you are able) and watch your weight

If you develop any new illness while 'active' on the register please let the Recipient Nurse Specialist know. You may need to be 'suspended' from the register for a time to allow you a full recovery or for further treatment.

You will also need to have your blood checked regularly for antibodies. These antibodies may be formed in your blood following blood transfusion, a previous transplant or pregnancy. Antibodies can contribute to rejection of your newly transplanted kidney. It is therefore very important that we receive these blood samples every 10 – 12 weeks. If you have a blood transfusion we will need a fresh blood sample two weeks later. We can take these blood samples at your clinic visits here, in your local hospital, or in your dialysis unit (haemodialysis patients)

If you want to discuss transplantation with somebody first, please do not hesitate to contact the Recipient Nurse Specialist who will be happy to supply you with more information and answer any queries that you may have.

Is it possible to catch any illnesses from a transplanted kidney?

It is not possible to guarantee that a person will not develop an illness passed on to them from a transplanted organ. However, in much the same way as blood donors are screened, all donated organs and the people they come from are checked for the presence of certain diseases. All donors have their medical and social history checked to see if they are in a high risk category for certain diseases, to ensure that they do not have cancer, and tests are made for hepatitis, cytomegalovirus (CMV), HIV - the AIDS virus - as well as syphilis and toxoplasmosis.

How long does somebody wait for a kidney transplant?

If you are able to have a live transplant, the different tests will have to be completed before a day can be decided on for the operation. The health of the donor is of paramount concern and these tests can take several months.

If you are waiting for a deceased donor kidney, it may take time for a kidney to become available that is suitable for you. On average, in Cardiff, the wait for a transplant is about 2½ years. Some people are fortunate and have a transplant very quickly, others will spend longer waiting. Take time to think about what will happen when you receive a call for a transplant and then remain prepared and positive but get on with your life in the meantime.

What happens when somebody is called in for a transplant operation?

1. Getting the call

When a deceased donor kidney becomes available that MAY be suitable for you, the Transplant Coordinator will ring you. Please make sure that the Recipient Nurse Specialist has your phone numbers to give the Transplant Coordinator team so they can contact you at all times. Please remember they only have a short time to contact you in. We do not provide a pager so you may need to get a mobile phone so that you can be contacted when you are out of the house. If you are going to be away overnight or longer please let the Recipient Nurse Specialist know and give a contact number. Similarly, if you change your address or telephone number please let the Recipient Nurse Specialist know.

Think about how you will get to the hospital and who is going to look after your children or pets. If you need transport to the hospital from your home, this will be arranged. After you have got ready, make your way to the hospital and ward B5 where you will be admitted. Please bring a bag with nightwear, toiletries, something to read, change for the TV/telephone card etc. Please also bring your medicines with you. If you are coming from West Wales you will need to pick up your notes from Morriston hospital on your way to Cardiff.

For those who have travelled a long way to get to us, there are bed and breakfast accommodations nearby. We do not have the facilities for family members to stay overnight on the ward.

2. Admission to hospital

If it is planned for you to receive a kidney from a live donor, you will be asked to come to the hospital the week before the operation, to be seen on the ward by the doctors and the anaesthetist. You will then probably be able to go home and come back to the hospital a day before the operation.

When you have been called for a deceased donor transplant come to B5 where you will be seen by the doctors and anaesthetist who will examine you to make sure you are fit and healthy to undergo the surgery. You will have blood samples, a chest x-ray and ECG (heart tracing) taken. Depending on the results you may need further tests. If you are found not to be fit enough to undergo the transplant you will either be sent for further treatment or home.

For either donor kidney transplant you may be asked to take part in clinical research. This is not compulsory and if you decide not to take part it will not affect your treatment or care in any way.

3. Cross matching

When a kidney has been identified for you, what is known as the final ‘cross match test’ takes place to make sure that you do not have HLA antibodies against the kidney. It is this test which determines whether we can go ahead with the transplant or not. If you are having a live donor kidney we will do this test the week before the planned operation date.

The ‘cross match’ is one of the blood samples that will be taken when you arrive on the ward. It involves mixing serum (a part of the blood) from your blood with cells from the donor to see if there is a reaction and can take up to 6 hours. As soon as we have the results of this test you will be informed.

A negative cross match result means that we can go ahead with the transplant and we will get you prepared for theatre.

Unfortunately, but rarely, a positive cross match result occurs. This indicates there was a reaction against the donor cells caused by recipient HLA antibodies. If this happens the transplant will not be able to proceed as it means your body would immediately reject the kidney.

4. Before the operation

While we are waiting for the final cross match results we will also be checking your blood to see if it might be necessary for you to receive some dialysis or carry out a peritoneal dialysis exchange before undergoing surgery.

You will not be allowed to eat or drink for approximately 4-6 hours before the operation to reduce the risk of vomiting and choking. If you are a diabetic we will check your blood sugar levels regularly to make sure they don’t drop too low. Because we don’t know the exact time you will go to theatre we will not give you anything to eat or drink from the time you arrive on the ward.

You will be given a hospital gown and some TED stockings (help to prevent blood clots in the legs) to wear. You will also be given some tablets to take before the operation, which usually include the anti-rejection drugs.

The surgeon will examine the kidney to make sure that it is suitable to be used for transplantation.

5. The operation

You will be given a general anaesthetic for the operation, which will take about 2-4 hours. The donated kidney is placed just above the groin on the left or right side. The kidney’s artery and vein will be connected to your blood vessels; and it’s ureter (the tube that carries the urine from the kidney to the bladder) will be attached to your bladder. Your own kidneys will not normally be touched at all.

During the operation you will have some tubes inserted to help the nurses monitor you and your new kidney closely. These are:

Central line – inserted into a vein in your neck, that allows us to give you fluids and drugs, as well as measuring your vein's pressure to assess your fluid balance. This is usually taken out 2 or 3 days after the operation.

Intravenous drip – usually in the back of your hand so that you can give yourself pain relief (Patient Controlled Analgesia - PCA). A pain killer injection machine is attached to the drip and you press a button to give yourself a dose. You cannot overdose as the machine will only let you have 1 dose every 5 minutes no matter how many times you press the button. You cannot get addicted to the pain killer drug either as you are not getting more than you need to relieve the pain. We disconnect this drip 2 to 4 days after the operation depending on the degree of pain you feel. Before we stop it completely we start giving you tablet pain killers.

Urinary catheter – goes into your bladder so that the urine produced by the transplanted kidney can be measured each hour. This catheter will normally remain in for about 5 to 7 days.

Wound drain - with all major surgery there is a risk of bleeding. The drain allows any blood or fluid that collects at the operation site to drain out, and is usually removed 2 or 3 days after the operation. If the amount of blood loss is excessive another operation to stop the bleeding may be needed; you may also need a blood transfusion to replace any blood lost.

Stent – sometimes a tube is needed in the ureter to keep it open allowing the urine to flow freely. This is usually removed 8-12 weeks after the transplant operation in the Day Surgery Unit.

When the transplant operation is over you will be taken to the recovery area until you wake up and your condition is stable enough to return to the ward.

6. After the operation

On return to the ward you will be monitored very closely as there is a risk of complications. The transplant team will do their best to reduce your chance of having complications and to treat any problems or difficulties immediately. The main complications are:

Thrombosis – this is an occasional complication that occurs when a blood clot develops in the vein or artery of the transplanted kidney. As a result, blood cannot flow to the kidney and it fails. If this happens the kidney needs to be removed in another operation.

Bleeding – there is always a risk of bleeding with any major surgery and transplantation is no exception. If there is excessive bleeding another operation may be needed to try to stop it. On occasion, the kidney may need to be removed if the operation is not successful, despite all efforts.

Delayed function – not all kidneys work immediately but a delay in function alone is not a cause for alarm. It is quite common and requires patience on your part. Until the kidney is working well we may need to dialyse you. Daily blood tests will be performed in order to monitor the function of the kidney. It can take from several days up to several weeks for the kidney to resume working and we will not discharge you home until this happens. When it starts producing urine it is normal for it to be quite bloody at first.

Urine leak – occasionally the join between the bladder and ureter fails causing urine to leak into the abdomen. It usually means another operation to repair the leak.

Rejection – your body will recognise the new kidney as foreign and will try to destroy it. In spite of all precautions, rejection occurs in up to half of all kidney transplant recipients. See below for more information about rejection.

Diabetes – raised blood sugar can occur as a side effect of the anti-rejection drugs. It is usually treated by changes in medication or by diet, but occasionally insulin injections are needed.

Infection – the anti-rejection medications (immunosuppressants) interfere with your natural immunity so you are more likely to get infections after your transplant. You are more vulnerable to infections in the early stages when the drug doses need to be higher to protect your kidney from rejection. As a precaution we advise against visitors with a cough/cold/chest infection while you are recovering from your transplant operation. See below for more information about infection.

Constipation – this is common after surgery and can be very uncomfortable. We will give you medicines to prevent this but you can help by walking around as much as possible, when it is safe for you to do so.

Deep vein thrombosis (DVT) – following all surgery there is a risk of developing blood clots in the veins of the legs. This problem is not common but can still occur. To prevent this we will give you heparin injections under your skin for the first few days, as well as giving you the TED stockings to wear. Again you can help by walking around as much as possible, when it is safe for you to do so.

The average hospital stay after kidney transplant is about 10 – 14 days. If you have any difficulties your stay may be longer.

In the early days after the operation you will be seen by the physiotherapist who will assist you with deep breathing exercises to prevent chest infection. You will be assisted to get up and out of bed as soon as it is safe for you to do so, usually the day after the operation. You will be encouraged to walk around as much as you can safely do.

Good nutrition is important to help you heal and replace muscle tissue. Once your new kidney is working well you will be encouraged to drink a lot of fluid and you will be able to start to have normal food. The dietician will give you dietary advice before you go home.

The pharmacist will also see you to give you information and instruction about your new medicines.

The Transplant Nurse Specialist will see you before you are discharged to make sure you have had all the information you need to look after yourself at home.

6. Visitors

We would suggest that only close relatives and friends visit, especially during the first few days after your operation. We only allow 2 visitors at the bedside at any time as a precaution against infection and to ensure that the nursing staff have easy access to you, especially in case of an emergency.

On ward B5 the visiting times every day are:

2 – 4 pm

6 – 8 pm

If you wish to have visitors outside these times or you wish children to visit please ask the nurses who are caring for you. We would also ask that visitors do not bring flowers/plants to the ward.

What medicines are required after somebody has received a transplant?

At the time of your transplant all your medication will be reviewed and you will start taking anti-rejection (immunosuppressant) drugs. This is because the human body has a powerful natural defence system (the immune system) that can identify and take action against any foreign tissue that is introduced into it. Although donor organs are carefully matched to transplant patients, the body will still recognise the kidney as foreign and attempt to reject it. For this reason, transplant patients are given immunosuppressant medicines to reduce the power of the immune system and prevent rejection. The majority of transplant patients will experience some degree of acute rejection following transplantation.

- **acute rejection**

This is when the body puts up a degree of resistance to the kidney at an early stage. Acute rejection episodes are periodic and the first episode usually happens within the first 6 months. Acute kidney rejection does not necessarily mean kidney failure as most episodes can be treated with medications if detected early enough. In many cases there are no outward signs of acute rejection, but taking regular blood samples allows us to detect changes.

These episodes may require a further hospital stay and a biopsy of the kidney to have a look at what is happening to the tissue. When rejection occurs, it is usually treated with a course of high dose steroids but if the rejection does not respond more powerful treatments are available. Very occasionally, dialysis may be needed until the rejection subsides.

In a very small number of cases the rejection cannot be controlled and the transplanted kidney may need to be removed and the individual returns to dialysis.

- **chronic rejection**

This is a rejection that may occur anytime following a transplant. It could be one, five, ten or twenty years following the transplant. This type of rejection will be picked up from blood tests and you may not be aware that it is occurring. This type of rejection is more difficult to treat with drug therapy and may over time lead to the eventual failure of the kidney and a return to dialysis.

- You will need to continue taking immunosuppressant medicines for as long as your transplanted kidney is working. If you stop taking them, or take them irregularly you increase the chance of rejection and other complications happening which will cause permanent damage to the kidney and may lead to its failure.

What are the signs of rejection?

Decreased urine output is the most common sign of rejection. Weight gain or any unusual swelling of the hands or ankles are other indications to watch for. So it is advisable to keep an eye on your weight. Your blood pressure may go up and you can have a high temperature, often associated with chills and muscle aches, much like the ‘flu. If you experience any of these symptoms, you should inform your Transplant Nurse Specialist immediately. During this time your blood results will show a rise in creatinine and urea.

Are there any problems with using immunosuppressant drugs?

The suppression of the body’s immune system allows viral diseases that you may have caught a long time ago to reactivate and cause illness again. These viruses can make you feel quite unwell and in the early stages may be very similar to kidney rejection. These viruses include cytomegalovirus (CMV), usually a ‘flu-like’ illness that most of us shrug off without ever knowing we have had it; Epstein-Barr virus that causes glandular fever; herpes simplex (cold sores & genital herpes); and herpes zoster (chicken pox & shingles). All these viruses are treatable.

Sometimes people can catch these viruses from the donor kidney. Because it is possible to treat all these viruses, it is recognised that having a donor kidney known to have had CMV (for example) is better than not having a transplant at all.

Other problems related to immunosuppression e.g. catching infections from others, skin care, gum care, vaccination and pregnancy are discussed below.

- **side effects**

Immunosuppressants do have side-effects and it is normal for patients to experience these. Not everyone gets the same effects but it is important to be aware of them. The dose of the drugs will be adjusted to meet your individual needs and are normally reduced over the first few months. Side effects should reduce with the decrease in dosage.

- **medicines**

The table below shows some of the drugs you may require following a transplant and gives a little information on the side-effects that **may** occur.

Drug & preparation form	Purpose	When to take	Possible side effects
Aspirin 75mg	prevents blood clotting	daily after food	stomach irritation, bruise more easily
Azathioprine Variable dose	prevents rejection	once daily	nausea, high blood pressure, osteoporosis

Co-trimoxazole (Septrin) 480mg	antibiotic – prevents infection	once daily for 3 months	sore tongue, stomach irritation
Omeprazole (Losec) 20 mg	reduces stomach acid	once daily	stomach upset, headache
Mycophenolate mofetil (Cellcept or MMF) Variable dose	prevents rejection	two to four times daily	diarrhoea, nausea, bone marrow suppression
Myfortic Variable dose	prevents rejection	twice daily	bone marrow suppression
Neoral Variable dose	prevents rejection	twice daily avoid grapefruit juice	increased hair growth, sore gums, tremors, stomach irritation, increased risk of cancer
Nifedipine LA 20 mg tablet	controls blood pressure, protects the kidney	twice daily	flushes, headaches
Prednisolone plain Reducing dose	prevents rejection	morning with or after food	stomach irritation, bruise more easily, increased appetite & weight gain
Rapamune (Sirolimus) Variable dose	prevents rejection	once daily	skin rash, ulcers, high cholesterol
Tacrolimus (Prograf) Variable dose	prevents rejection	twice daily avoid grapefruit juice	tremor, gastric irritation, occasional headaches, increased risk of cancer

- **know your medicines**

You should make sure that you know what drugs you are taking, why you are taking them and what the current dosage is. You will be given a medicine card before you leave hospital and the drugs explained to you. Always take your medication record card with you to clinic appointments so that it can be updated as necessary.

All your medication is of equal importance and should not be stopped unless on doctor’s instructions. Always make sure that you have enough medication to last over holiday periods, e.g. bank holiday weekends, Easter & Christmas.

Finally, keep your medication in a safe place, out of the reach of children.

- **prescription charges**

As of April 1st 2007 Wales has free prescriptions.

How long will a transplanted kidney last?

We hope that every transplanted kidney will work for a long time but there can be no guarantees. Very occasionally, kidneys will not start to function or will only function for a short while. This is obviously very disappointing and can be difficult to cope with at the time but if this should occur there will be support for you from the transplant team.

When the kidney does eventually fail then you will need to return to dialysis. It may be possible, should you want to, to go back on the waiting list for a further kidney.

What happens to my old dialysis access?

- **Haemodialysis access** – your fistula will usually be left alone after the transplant, although they usually clot after a while if they are not used. Should this happen, do not worry but please inform your doctor/Transplant Nurse Specialist at your next clinic appointment.

  If you have a permcath, this will be removed, in the Day Surgery Unit, once it is clear that your new kidney is working satisfactorily.

- **Peritoneal dialysis access** – if you have a Tenckhoff line, it will be shortened prior to discharge, and providing you have no problems, it will be removed between 3 and 6 months post-transplant. Equally, your PD fluid stocks will be removed once it is clear that your new kidney is working satisfactorily.

You must continue your exit site care until the Tenckhoff is removed.

When do I go home?

You will, hopefully, be ready to leave hospital between 10 and 14 days after your surgery. Some people may take longer to recover and if you should have any problems then it may be necessary to stay in hospital until these are remedied.

What do I do when I get home?

- ## the first few weeks

Although you may have been feeling quite well and active during the last few days of hospitalisation, it is usual to feel quite tired once you get home. Once at home there are a few things that you are advised not to do.

You should not drive for 6 weeks after your operation. Your insurance is unlikely to cover you to drive during this period. If you have any queries, please ask before you leave the unit or whilst in the outpatient clinic.

There are a few other restrictions you should observe until the wound has had time to heal. These include lifting heavy objects, swimming or anything that is really strenuous. However, over time you should feel ready to become more active. Please ask the doctors/Transplant Nurse Specialist that you see in clinic for advice.

It is important particularly in the early days to be careful of coming into contact with anyone with coughs, colds or infectious diseases. If you have been exposed to any infections inform the Transplant Nurse Specialist.

What after-care is provided?

It takes about 6 months to a year for your transplant to settle down. During this time you will be closely monitored and followed up, in the first six months by your surgeon and then after that by one of the consultant transplant physicians and their team.

You will require regular outpatient appointments, several times a week initially, until your blood results have stabilised. It is a time when the doctors will be tailoring your drugs to suit you in order to find a reasonably stable, maintenance regime.

On clinic days, you will be asked not to take your morning immunosuppressant drugs – Neoral or Tacrolimus – but, instead, bring them with you to clinic to take after your blood tests. Depending on the test results your drug dosages may be altered. On some clinic days you may be asked to bring in a 24 hour urine collection which you should start the morning before clinic.

There will be minor setbacks and problems with most transplants as everybody reacts differently to the combination of essential drugs. At these times you will need to be followed up more closely than usual. You may also be asked to come in for investigations. Do not be alarmed as many are routine.

What else do I need to be aware of after transplant?

- **infections**

Following your transplant, you will be more at risk of picking up infections. This is due to the immunosuppressant drugs. They prevent rejection but also reduce your ability to fight infection.

It is important to avoid any childhood diseases that you are not already immune to, such as chicken pox, measles, etc. Contact the Transplant Nurse Specialist/ doctor if you do come into contact with a disease of this type.

- **diet**

You will be seen by the dietician before you leave hospital after the transplant. This is because now that you are free to eat and drink whatever you want to, perhaps for the first time in years, you may experience sudden weight gain.

Initially you may have flesh weight to regain after a period on dialysis, but it will soon become obvious if you start to put on weight.

Eating sensibly, keeping to low-fat foods, fresh fruit and vegetables and avoiding too much sugar and salt in your food can help you to keep fit and your weight steady.

- **skin care**

Transplant patients on immunosuppressant medication should avoid direct exposure to sunlight. This is to reduce the risk of abnormal changes to the skin which could potentially become cancerous. A high factor sun protection cream should be used (at least factor 30), a hat worn, particularly if your hair is thinning and clothing used to cover-up as much as possible if exposure is unavoidable. If you have moles on your skin, check them regularly for bleeding or changes in shape and/or colour.

Female transplant patients should check their breasts and have cervical smears regularly.

Male transplant patients should check their testicles regularly.

- **gum care**

Some people on immunosuppressants find that their gums can become swollen and sore. It is very important to look after your teeth and gums both before and after transplant. Make sure that you are registered with and visit a dentist regularly (at least 6 monthly) who will be able to help you with these problems.

- **vaccinations**

If you are going on holiday or need a vaccination for any purpose, please get advice from the Transplant Nurse Specialist or your consultant. You must not take any ‘live attenuated’ vaccines because your immune system is suppressed.

- **sex**

You can resume sexual activity whenever you feel ready. After transplant, many people feel a return of their sex drive and energy.

Women of child bearing age recover normal menstrual cycles and fertility. Both men and women need to be aware of birth control issues and plan contraception if necessary. The pill and intra-uterine devices (IUD) may not be appropriate and barrier methods are recommended initially. You can discuss these issues with the Transplant Nurse Specialist or doctor.

Some male patients may have suffered impotence during their time on dialysis or due to medication such as anti-hypertensive drugs. This may improve and can be discussed with the Transplant Nurse Specialist/doctor or an appropriate counsellor.

- **pregnancy**

It may be possible for women who are of childbearing age to become pregnant following a transplant. You would be advised to delay trying to become pregnant until your transplant has had an opportunity to settle down. We would recommend that if you wish to become pregnant that you discuss this first with your transplant consultant/Transplant Nurse Specialist who will be able to advise you on any of the risks associated with the medication you are taking.

Financial help

If you are claiming benefit, you must notify the DSS attendance unit at Warbreck House, Warbreck Hill, Blackpool, of the change in your circumstances. Please contact the social worker for further advice.

If you need financial assistance for travel to and from the hospital for appointments, please ask your social worker who can provide the forms and assist with supporting your claim.

Transport

When you attend clinic appointments, hospital transport provided by South & East Wales Ambulance Trust will be provided for all your appointments for the first 3 months after transplant if you wish. After that time, provided you are well enough and able to make your way to hospital independently, you should not expect to have ambulance transport booked for you.

May I contact the donor’s family?

The families of deceased donors are offered anonymity. It is, however, possible for the Transplant Coordinators to pass a letter from you expressing your gratitude for the gift of a transplant that you have received. If you would like further information about this following your transplant, please contact the Recipient Nurse Specialist or the Transplant Nurse Specialist.

Contact details for more information

Live Donor Coordinators: Ann Marsden or Rhian Cooke – 02920 746432

Live Donor Coordinator (West Wales): Helen Burt – 01792 702222 and ask to bleep

Transplant Recipient Nurse Specialists: Kymm O’Connor – 02920 742453

Tracy Hopkins – 02920 744857

Transplant Nurse Specialists: Eiddwen Glyn – 02920 744817

Sharon Warlow – 02920 742342

Transplant Nurse Specialist (West Wales): Cathy Blakemore – 01792 702222 and ask to bleep

Introduction to pancreas transplant.

Undergoing transplantation can be an exciting and challenging time for everyone involved.

This handout is intended to provide an overview of pancreatic transplantation. It is not a complete guide but will help you to prepare for a pancreas transplant. It will tell you about getting onto the National Transplant Waiting Register, where the pancreases come from and provides some guidelines as to what you can expect before and after the operation. In addition, it will tell you about the medicines and outpatient clinic appointments that are required after the transplant.

If you want to discuss transplantation further, please do not hesitate to contact the Recipient Nurse Specialist at University Hospital of Wales, who will be able to supply you with more information and answer any queries that you may have.

What is the pancreas?

The pancreas is an organ inside the abdomen. 2-3% of the pancreas consists of clusters (islets) of cells that secrete small amounts of hormones into the bloodstream. The most important of these hormones is insulin. A lack of insulin causes diabetes.

Why do pancreas transplants and who can have one?

Pancreas transplants treat diabetes but only people who have Type 1 diabetes are suitable for it. It is the only treatment that can restore complete insulin independence and normal blood sugar levels. After a successful pancreas transplant people do not need insulin injections, have no special dietary requirements, do not need to prick themselves regularly to check their blood sugar levels, and are not at risk of developing low blood sugar levels (hypoglycaemia).

It is also known that most of the complications of diabetes (retinopathy, neuropathy, foot ulcers, digestive problems, abnormalities of the heart rhythm, etc) are related to blood sugar control. Strict and good blood sugar control is known to delay the onset of these complications and their severity. There is no better means of blood sugar control in the diabetic person than a successful pancreas transplant. Hopefully this means that pancreas transplantation will benefit you by preventing or easing some of the long-term disabling complications of diabetes, although we cannot guarantee that.

If the complications are very advanced (e.g.: blindness, amputation, etc) and irreversible, they would not be influenced by pancreas transplantation.

Why don’t we offer pancreas transplantation to everyone with Type 1 diabetes?

Pancreas transplantation has risks and these must be taken into account when deciding whether this is a treatment that is right for you. Lifelong treatment with insulin injections is safer for most patients with Type 1 diabetes. Even if pancreas transplantation was made very much safer, there would be the problem of a shortage of organ donors to provide the number of pancreas transplants needed to meet the demand.

Having a pancreas transplant is a major operation. Like all operations this includes risk of complications, and even a small risk of death. Advances in surgical techniques and medications have greatly improved the safety of the pancreas transplant operation, so that 97 -98% of patients undergoing pancreas transplants will survive. Other complications such as bleeding, clotting, and infection, can occur. About 1 in 4 people may need another operation to deal with such complications after pancreas transplant.

Other risks are due to the drugs that are needed after transplantation. Transplantation involves the transfer of another person’s tissue type cells to the recipient. These foreign cells are normally rejected by the immune system. Therefore, we need to give drugs which suppress the immune system and prevent rejection. The medicines (immunosuppressants) have many potentially serious side effects, such as an increased risk of infection and even a small increase in the risk of developing cancer.

Where do donor pancreases come from?

Pancreases for transplantation come from a person who has died (deceased donor).

There are two types of deceased donor: heart beating and non-heart beating.

A heart beating donor is someone who has sustained such a severe brain injury that the brain-stem dies. No recovery is possible in this situation and the doctors pronounce the donor ‘brain-stem dead’. Organs for transplantation are removed while the donor is still on a breathing machine and their heart continues to pump blood through the body.

To increase the number of pancreases available, and therefore reduce the time that people have to wait for a transplant, we have implemented a non-heart beating donor programme here in Cardiff. A non-heart beating donor is someone who was not brain-stem dead but whose heart had stopped pumping blood. Organs for transplantation are removed after the blood circulation has stopped. With careful selection of the donors results have shown that the outcome for these pancreases, including improvements in individual’s quality of life is as good as that of the pancreases from ‘brain stem dead’ donors.

How does someone receive a pancreas from a deceased organ donor?

Most people requiring a pancreas transplant will go on the National Transplant Waiting Register to receive a pancreas from someone who has died. The National Transplant Waiting Register is not a waiting list which works on a ‘first come, first served basis’. Everyone in the UK waiting to have a transplant is registered by their transplant centre on the National Register maintained by UK Transplant (UKT). When a pancreas becomes available, anywhere in the UK, the donor’s blood group is entered onto the computer at UKT. The most suitably matched recipient will be identified and their local Transplant Coordinator will be informed. It is likely that the pancreas you receive comes from another city in the UK or even, occasionally, from abroad.

The call to come to the hospital for your transplant usually is very sudden. This is because we never know exactly when a pancreas will become available.

How does somebody get onto the National Transplant Waiting Register?

If you wish to be considered for a transplant, you will need to raise the matter with your consultant. They will refer you to the transplant team for assessment. This can happen just before you start dialysis, at any time once you are on dialysis, or a year after you had a kidney transplant. The transplant assessment consists of appointments in the outpatient clinic with the transplant surgeon and some routine tests to see if you are medically suitable. He will explain what is involved in having a transplant and answer any questions you may have.

Pancreas transplantation is not suitable for all patients. Some people have other health problems that would make it too risky for them to have transplant surgery. If it is considered that undergoing transplant surgery will be too high risk for you to benefit from, this will be discussed with you during the clinic appointment.

If you are considered suitable, you will have several blood samples taken. Some are tested for your blood group and tissue type to match with a donor, and need repeating at least one week later. Others are screened for the following viruses:

- Human Immuno-deficiency Virus (HIV or AIDS virus)
- Hepatitis B
- Hepatitis C
- Syphilis antibody
- Toxoplasma gondii antibody
- Epstein-Barr Virus (glandular fever virus)
- Cytomegalovirus (CMV)
- Varicella Zoster Virus (Chicken pox virus)

All these blood tests are carried out on every potential transplant recipient to avoid any risk of illness after transplantation.

Your name will be placed on the National Transplant Waiting Register for a pancreas that matches your blood group and tissue type when all the tests have been completed. This can take several weeks. The Recipient Nurse Specialist will contact you when you are ‘activated’.

Once you are on the National Transplant Register it is important to keep yourself as healthy as you can as it may help you recover quicker after your operation and increase the chances of success. For instance,

- if you smoke, now is a good time to stop;
- if you are dialysing, make sure you dialyse well and keep to your fluid and

diet restrictions;

- exercise daily within your limits (if you are able) and watch your weight

If you develop any new illnesses while ‘active’ on the register please let the Recipient Nurse Specialist know. You may need to be ‘suspended’ from the register for a time to allow you a full recovery or for further treatment.

You will also need to have your blood checked regularly for antibodies. These antibodies may be formed in your blood following blood transfusion, a previous transplant or pregnancy. Antibodies can contribute to rejection of your newly transplanted pancreas. It is therefore very important that we receive these blood samples every 10 – 12 weeks. If you have a blood transfusion we will need a fresh blood sample two weeks later. We can take these blood samples at your clinic visits here, in your local hospital, or in your dialysis unit (haemodialysis patients).

How long does somebody wait for a pancreas transplant?

It may take time for a pancreas to become available that is suitable for you. In the UK the average wait is about 1½ years. Some people are fortunate and have a transplant sooner than this, others will spend longer waiting. Take time to think about what will happen when you receive a call for a transplant and then remain prepared and positive but get on with your life in the meantime.

Is it possible to catch any illnesses from a transplanted pancreas?

It is not possible to guarantee that a person will not develop an illness passed on to them from a transplanted organ. However, in much the same way as you were screened, all donated organs and the people they come from are checked for the presence of certain diseases. All donors have their medical and social history checked to see if they are in a high risk category for certain diseases and to ensure that they do not have cancer. Tests are also made for hepatitis, cytomegalovirus (CMV), HIV - the AIDS virus - as well as syphilis and toxoplasmosis.

What happens when somebody is called in for a transplant operation?

1. Admission to hospital

When you have been matched for a deceased donor pancreas, you will be called by the Transplant Coordinator. Please make sure that the Recipient Nurse Specialist has your phone numbers to give the Transplant Coordinators so they can contact you at all times. We do not provide a pager so you may need to get a mobile phone so that you can be contacted when you are out of the house. If you are going to be away overnight please let the Recipient Nurse Specialist know and give a contact number.

After you have got ready, make your way to the hospital and ward B5 where you will be admitted. Once on B5 you will be seen by the doctors and anaesthetist to check your fitness for surgery. You will have blood samples, a chest x-ray and ECG (heart tracing) taken. Depending on these results you may need further tests. If you are found not to be fit enough to undergo the transplant you will either be sent for treatment or home.

You may also be asked to take part in clinical research. This is not compulsory and if you decide not to take part it will not affect your treatment or care in any way.

2. Cross matching

When a pancreas has been identified for you, what is known as the "cross match test" takes place to make sure that you do not have HLA antibodies against the pancreas.

The ‘cross match’ is a blood test that will be taken when you arrive on ward B5. It involves mixing serum (a part of the blood) from your blood with cells from the donor to see if there is a reaction.

A positive cross match result indicates there was a reaction against the pancreas caused by recipient HLA antibodies. If antibodies against the pancreas are present then the operation will not be able to proceed.

3. Before the operation

You will not be allowed to eat or drink for approximately 4-6 hours before the operation, so have a cup of tea before leaving home, unless the Transplant Coordinator who rings you tells you otherwise. Because we don’t know the exact time you will go to theatre we will not give you anything to eat or drink when you arrive on B5.

You may need to have some dialysis (haemodialysis or a peritoneal dialysis exchange) before undergoing surgery.

You will be given a hospital gown and some TED stockings (help to prevent blood clots in the legs) to wear. You will also be given some tablets to take before the operation, which usually include the anti-rejection drugs.

4. The operation

The actual operation will take about 4-5 hours.

During the operation, the donated pancreas is placed in the abdomen on the left or right side. It will be connected to blood vessels and to your bowel.

5. After the operation

The new pancreas usually works immediately. So we can monitor how well the pancreas is working, daily blood tests will be taken.

As there is a risk of a blood clot developing in the vein or the artery of the transplanted pancreas, we check the blood flow in the pancreas using an ultrasound scan. If this shows a lack of blood flow to the pancreas it usually means it has failed and needs to be removed in a further operation.

You will have a tube that passes through your nostril to your stomach. This is called a naso-gastric tube and allows us to keep your stomach fairly empty to rest it after your operation. It also helps in reducing any feelings of sickness (nausea) you may have.

You will have a tube called a catheter in place so that the urine output may be measured each hour. This catheter will normally remain in for about 3 to 5 days.

Like all major surgery there is a risk of bleeding, so you will have a ‘drain’ tube leading from the transplant wound. The drain allows any blood or fluid that collects at the operation site to drain out, and is usually removed 2 or 3 days after the operation. If the amount of blood loss is excessive another operation to stop the bleeding may be needed; you may also need a blood transfusion to replace any blood lost.

You will have a drip in a vein in your arm so that you can give yourself pain relief (Patient Controlled Analgesia - PCA). A pain killer injection machine is attached to the drip and you press a button to give yourself a dose. You cannot overdose as the machine will only let you have 1 dose every 5 minutes no matter how many times you press the button. You cannot get addicted to the pain killer drug either as you are not getting more than you need to relieve the pain. We disconnect this drip 2 to 4 days after the operation depending on the degree of pain you feel. Before we stop it completely we start giving you tablet pain killers.

You will also have a drip in a neck vein that allows us to give you fluids and drugs, as well as measuring your vein’s blood pressure. This is usually taken out 2 or 3 days after the operation.

You will be seen by the physiotherapist who will assist you with deep breathing exercises to prevent chest infection. You will be assisted to get up and out of bed as soon as it is safe for you to do so.

Good nutrition is important to help you heal and replace muscle tissue. Once your new pancreas is working well you will be encouraged to drink a lot of fluids and you will be able to start to have normal food.

6. Visitors

We would suggest that only close relatives and friends visit, especially during the first few days after your operation.

On ward B5 the visiting times every day are:

2 – 4 pm

6 – 8 pm

If you wish to have visitors outside these times or you wish children to visit please ask the nurses who are caring for you. It is also best if visitors who have a cold or any other infection do not attend the ward. We also ask that visitors do not bring flowers/ plants for you.

What medicines are required after somebody has received a transplant?

At the time of your transplant all your medication will be reviewed and you will start anti-rejection (immunosuppressant) drugs. This is because the human body has a powerful natural defence system that can identify and take action against any foreign tissue that is introduced into it. Although donor organs are carefully matched to transplant recipients, the body will still recognise the pancreas tissue as foreign and attempt to reject it. The majority of transplant patients will experience some degree of rejection following transplantation.

You will need to continue taking immunosuppressant drugs for as long as your transplanted pancreas is working. If you stop taking them, or take them irregularly you increase the chance of rejection and other complications happening which will cause permanent damage to the pancreas and may lead to its failure.

What is rejection?

There are 2 types of rejection:

- **acute rejection**

This is when the body puts up a degree of resistance to the pancreas at an early stage. These episodes can normally be treated with changes to the drug therapy. They may require a further hospital stay and a biopsy of the pancreas to have a look at what is happening to the tissue.

Acute rejection episodes are periodic. They occur most commonly in the first 6 months after transplantation. When rejection occurs, it is treated with extra immunosuppressants, given intravenously. Other medications may be changed and a restriction on fluid and food types may be required.

- **chronic rejection**

This is a rejection that may occur anytime following a transplant. It could be one, five, ten or twenty years following the surgery. This type of rejection will be picked up from blood tests and you may not be aware that it is occurring. This type of rejection is more difficult to treat with drug therapy and may over time lead to the failing of the pancreas and a return to insulin therapy.

- **Are there any problems with using immunosuppressant drugs?**

The suppression of the body’s immune system allows viral diseases that you may have caught a long time ago to reactivate and cause illness again. These viruses can make you feel quite unwell. These viruses include cytomegalovirus (CMV), usually a ‘flu-like illness that most of us shrug off without ever knowing we have had it, Epstein-Barr virus that causes glandular fever and herpes simplex (cold sores & genital herpes) and herpes zoster (chicken pox & shingles). These viruses are treatable.

Other problems related to immunosuppression e.g. catching infections from others, skin care, gum care, vaccination and pregnancy are discussed below.

- **side effects**

These medications do have side-effects and it is normal for patients to experience these. Not everyone gets the same effects but it is important to be aware of them. The dose of the drugs will be adjusted to meet your individual needs and are normally reduced over the first few months. Side effects should reduce with the decrease in dosage.

- **medicines**

The table below shows some of the drugs you may require following a transplant and gives a little information on the side-effects that **may** occur.

Drug & preparation form	**Purpose**	**When to take**	**Possible side effects**
Aspirin 75mg	prevents blood clotting	daily after food	stomach irritation, bruise more easily
Azathioprine Variable dose	prevents rejection	once daily	nausea, high blood pressure, osteoporosis
Co-trimoxazole (Septrin) 480mg	antibiotic – prevents infection	once daily for 3 months	sore tongue, stomach irritation
Omeprazole (Losec) 20 mg	reduces stomach acid	once daily	stomach upset, headache
Mycophenolate mofetil (Cellcept or MMF) Variable dose	prevents rejection	two to four times daily	diarrhoea, nausea, bone marrow suppression
Myfortic Variable dose	prevents rejection	twice daily	bone marrow suppression

Neoral Variable dose	prevents rejection	twice daily avoid grapefruit juice	increased hair growth, sore gums, tremors, stomach irritation, increased risk of cancer
Nifedipine LA 20 mg tablet	controls blood pressure, protects the kidney	twice daily	flushes, headaches
Rapamune (Sirolimus) Variable dose	prevents rejection	once daily	skin rash, ulcers, high cholesterol
Tacrolimus (Prograf) Variable dose	prevents rejection	twice daily avoid grapefruit juice	tremor, gastric irritation, occasional headaches, increased risk of cancer

- **know your medicines**

You should make sure that you know what drugs you are taking, why you are taking them and what the current dosage is. The drugs will be explained to you and you will be given a medicine card before you leave hospital. Always take your medication record card with you to clinic appointments so that it can be changed as necessary.

All your medication is of equal importance and should not be stopped unless on doctor’s instructions. Always make sure that you have enough medication to last over holiday periods, e.g. bank holiday weekends, Easter & Christmas.

Finally, keep your medication in a safe place, out of the reach of children.

- **prescription charges**

As of April 1st 2007, Wales has free prescriptions.

How long will a transplanted pancreas last?

We hope that every transplanted pancreas will work for a long time but there can be no guarantees. Very occasionally, pancreases will not start to function or will only function for a short while. This is obviously very disappointing and can be difficult to cope with at the time but if this should occur there will be support for you from the transplant team.

The success rate of pancreas transplants is around 85% at one year after the operation. The average time deceased donor pancreases last is approximately 10 years, if all goes well.

If your transplanted pancreas fails you will need to return to insulin therapy. It may be possible, should you want to, to go back on the waiting register for another pancreas.

When do I go home?

You will, hopefully, be ready to leave hospital between 7 and 14 days after your surgery. Some people may take longer to recover and if you should have any problems then it may be necessary to stay in hospital until these are remedied.

What do I do when I get home?

- ## the first few weeks

Although you may have been feeling quite well and active during the last few days of your hospital stay, it is usual to feel quite tired once you get home. Once at home there are a few things that you are advised not to do. You should not drive for 6 weeks after your operation. Your insurance is unlikely to cover you to drive during this period. If you have any queries, please ask before you leave the unit or whilst in outpatients.

There are a few other restrictions you should observe until the wound has had time to heal. These include lifting heavy objects, swimming or anything that is really strenuous. However, over time you should feel ready to become more active. Please ask the doctors that you see in clinic for advice.

It is important, particularly in the early days, to be careful of coming into contact with anyone with coughs, colds or infectious diseases, especially shingles/chicken pox. If you have been exposed to any infections inform the Transplant Nurse Specialist.

What after-care is provided?

It takes about 6 months to a year for your transplant to settle down. During this time you will be closely monitored and followed up, in the first six months by your surgeon and then after that by one of the consultant transplant physicians and their team.

You will require regular outpatient appointments, several times a week initially, until your blood results have stabilised. It is a time when the doctors will be tailoring your drugs to suit you in order to find a reasonably stable, maintenance regime.

On clinic days, you will be asked not to take your morning immunosuppressant drugs – Neoral or Tacrolimus – but, instead, bring it with you to clinic to take after your blood tests. Depending on the test results your drug doses may be altered.

There will be minor setbacks and problems with most transplants as everybody reacts differently to the combination of essential drugs. At these times you will need to be followed up more closely than usual. You may also be asked to come in for investigations. Do not be alarmed as many are routine.

What else do I need to be aware of after transplant?

- **infections**

Following your transplant, you will be more at risk of picking up infections. This is due to the immunosuppressant drugs. They prevent rejection but also reduce your ability to fight infection.

It is important to avoid any childhood diseases that you are not already immune to, such as chicken pox, measles, etc. Contact the Transplant Nurse Specialist or doctor if you do come into contact with a disease of this type.

- **diet**

You will be seen by the dietician before you leave hospital after the transplant. This is because now that you are free to eat and drink whatever you want to, perhaps for the first time in years, you may experience sudden weight gain. Initially you may have flesh weight to regain after a period on dialysis, but it will soon become obvious if you start to put on weight.

Eating sensibly, keeping to low-fat foods, fresh fruit and vegetables and avoiding too much sugar and salt in your food can help you to keep fit and your weight steady.

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Transplant patients on immunosuppressant medication should avoid direct exposure to sunlight. This is to reduce the risk of abnormal changes to the skin which could potentially become cancerous. A high factor sun protection cream should be used (at least factor 35), a hat worn, particularly if your hair is thinning and clothing used to cover-up as much as possible if exposure is unavoidable. If you have moles on your skin, check them regularly for bleeding or changes in shape and/or colour. Report any changes to your Transplant Nurse Specialist or consultant as soon as possible.

Female transplant patients should check their breasts and have cervical smears regularly.

Male patients should carry out regular testicular self examinations.

- **gum care**

Some patients on immunosuppressants find that their gums can become swollen and sore. It is very important to look after your teeth and gums both before and after transplant. Make sure that you are registered with and visit a dentist regularly (at least 6 monthly) who will be able to help you with these problems.

- **vaccinations**

If you are going on holiday or need a vaccination for any purpose, please check with your Transplant Nurse Specialist or your consultant. You must not take any ‘live attenuated’ vaccines because your immune system is suppressed.

- **sex**

You can resume sexual activity whenever you feel ready. After transplant, many people feel a return of their sex drive and energy. Women of child bearing age recover normal menstrual cycles and fertility. Both men and women need to be aware of birth control issues and plan contraception if necessary. The pill and intra-uterine devices (IUD) may not be appropriate and barrier methods are recommended initially. You can discuss these issues with the Transplant Nurse Specialist or doctor.

Some male patients may have suffered impotence during their time on dialysis or due to medication such as anti-hypertensive drugs. This may improve and can be discussed with medical staff or the Transplant Nurse Specialist.

- **pregnancy**

It may be possible for women who are of childbearing age to become pregnant following a transplant. You would be advised to delay trying to become pregnant until your transplant has had an opportunity to settle down. We would recommend that if you wish to become pregnant that you discuss this first with your transplant consultant who will be able to advise you on any of the risks associated with the medication you are taking.

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May I contact the donor’s family?

The families of deceased donors are offered anonymity. It is, however, possible for the Transplant Coordinators to pass a letter from you expressing your gratitude for the gift of a transplant that you have received. If you would like further information about this following your transplant, please talk to the Transplant Nurse Specialist/Recipient Nurse Specialist.

Contact details for further information

Recipient Nurse Specialists: Kymm O’Connor – Tel: 02920 742453

Tracy Hopkins – Tel: 02920 744857

Transplant Nurse Specialists: Eiddwen Glyn – Tel: 02920 744817

Sharon Warlow – Tel: 02920 742342

Living Kidney Donation.

Ann Marsden
Live Donor Transplant Co-ordinator
University Hospital of Wales, Cardiff
Tel 02920746432
Email: ann.marsden@cardiffandvale.wales.nhs.uk

Introduction

Increasingly, since the first living donor transplant fifty years ago, living donation is becoming, by necessity, a more commonplace event in the field of renal transplantation. The number of patients waiting for kidney transplantation continues to increase, whilst the number of organs available from cadaveric (deceased) donors is decreasing and therefore not meeting the demand. It is generally accepted that a healthy individual should not suffer any long-term ill effects from the donation and that recipient outcomes are expected to be superior to other forms of renal replacement therapy, particularly if the live transplant can be performed pre-emptively i.e. before starting dialysis.

Kidney failure affects the whole family but nevertheless the decision to offer to donate a kidney is a major undertaking and one that requires careful consideration. The primary role of the Living Donor Transplant Co-ordinator is to act as the advocate of the donor, to give information to and to support the potential living donor and their family throughout the work-up process whether or not donation is possible.

What is living donation?

Living donation is the process whereby a healthy individual, who is willing and physically able to donate, undergoes surgery to remove a kidney for transplantation. Living donors may be genetically related to the recipient or have a close personal relationship. There is no particular upper age limit for suitability for donation, rather physical fitness to donate. Living donation is purely voluntary on the part of the donor. The donor should not be subject to any coercion by the recipient or any other person and is free to withdraw at any time throughout the whole process.

Why do we do living donor transplants?

A recipient, not wishing to put a family member or close friend through the trauma of donating a kidney, often considers kidney transplantation from a cadaveric donor more desirable. Asking a loved one to donate a kidney is the most difficult question a recipient could face asking; fearing a negative response, possibly could feel rejected or that people don’t care enough.
However, in the UK there is a considerable shortfall of organs available for transplantation from this source. Therefore, in order to increase the number of kidneys available for transplantation, living donation is explored more vigorously. Living kidney donation offers the potential for a superior form of treatment and kidneys transplanted from living donors have the potential to work better and to last longer than transplants from cadaveric donors.

From the recipient perspective, living kidney donation offers potentially the most positive outcome, however it is important to focus on the needs of and potential risks for the living donor.

Who can be a living donor?

Someone who is genetically related or who has a close personal relationship with the recipient and wishes to donate can be considered. Certain medical conditions would exclude someone from donating eg diabetes, heart disease, and cancer.

How do I go about it?

The process of preparing to be a living kidney donor is lengthy and arduous, and in some circumstances the donor may be unable to donate their kidney for a variety of reasons. An initial discussion with the Live Donor Transplant Co-ordinator takes place either in the hospital or in the home, explaining fully the benefits and the short and long term risks of donation and outlining all the tests and investigations to be completed, to ensure that the donor is fully prepared.

What tests would I expect to undergo?

Stage 1

Compatibility

A simple blood test will establish whether the potential donor is blood group compatible with the recipient. In most centres this is still a requirement in order to proceed to donation. However, a procedure to desensitise the recipient from antibodies against the donor's blood group, is currently being explored in some centres and has the potential to enable us to proceed with blood group incompatible donors.

- Blood Group Compatibility

Recipient's blood group	Possible blood group of potential donor
O	O
A	O or A
B	O or B
AB	O or A or B or AB

Figure 1
Showing blood group compatibility

- Tissue Type Compatibility

Tissue type testing involves further, more in depth screening of the donors genetic make up, and comparing this with the tissue type of the recipient. Human Leucocyte Antigens (HLA) are 'marker' cells that are present on the surface of all the cells in the body. These 'markers' can be varied and the higher the percentage of these that match between donor and recipient, the greater the chances of successful transplantation in the long term. Donor and recipient pairs who are genetically related are likely to have a chance of better matching, however increasing numbers of transplants are successfully being performed between genetically unrelated pairs where the level of matching is not so good. The advantage of having a ‘live’ transplant outweighs the inferior matching.

Some recipients may have developed antibodies, either from pregnancy, blood transfusion or a previous transplant, or rarely from a virus. Sometimes it can be more difficult for such patients to receive a well-matched transplant from a cadaveric donor and therefore a live donor may offer a better option.
Once the tissue match has been established, a cross-match test is performed to ascertain whether the recipient has any antibodies to the mismatched antigens of the donor. In the UK, a positive cross-match is usually a contra-indication to donation however it is likely in the future that some centres will be able to proceed with transplants of this nature following desensitisation of the recipient.

Stage 2

Medical Tests and Investigations

Once the first stage is completed and it is established that a potential living donor is compatible, the second stage of the work-up process begins to establish the potential donors’ medical suitability to go through major surgery, to live the rest of their life with one kidney and to be sure that it is a good kidney to donate to their recipient.

- Blood & urine tests - analysis of blood and urine samples are performed to rule out any abnormality. Specifically, to ensure optimal kidney function now, and exclude as far as possible any risk for the future.
- Chest X-Ray
- ECG
- CT Angiography – establish that the kidneys appear normal and to view the blood supply to the kidneys. The scan will also detect any gross abnormality within the abdomen.
- Cardiological review
- Psychological assessment (donor & recipient)

The Consultant Nephrologist, discusses the potential risks and hazards of living donation, performs a physical examination and reviews the results. Once all these tests and investigations have been completed it may be necessary to further evaluate, using different methodology, any abnormal results that have been detected. Sometimes the donor may face the distressing fact that they have a medical problem that they were unaware of. Once the Consultant Nephrologist has established medical suitability, then the donor is referred on for surgical evaluation by the Consultant Surgeon.

Surgical Assessment

This involves a review of the results of the medical evaluation together with a lengthy explanation of the operative procedure and the risks involved. During this consultation the potential donor will be told of the small but not insignificant risks of having a major operation. This includes the risk of death of less than 3 in 10,000, and a less than 5% chance of other complications i.e. haemorrhage, thrombosis other more minor risks such as infection, wound pain. Review of the CT angiogram will enable the Surgeon to decide the most appropriate surgical procedure to remove the kidney. In our centre the options for surgery are; the conventional open retro-peritoneal approach or hand-assisted laparoscopic (keyhole) surgery. If both surgical procedures are possible then the patient is offered the choice. The traditional operation is performed via a short incision on the side. The laparoscopic procedure is performed with the assistance of a hand inserted into the abdomen and two additional ports for the instruments. This procedure is less invasive and appears to shorten recovery time. At this consultation the date will be set for the operation.

How will the donation affect me?

Emotionally

The process of living kidney donation can be an emotional ‘roller coaster’, both for the donor and recipient, with feelings often very difficult to deal with. The donor quite normally will have periods of fear, anxiety, ambivalence and pressure about the impending donation. Appropriate time should be given to potential donor and recipient to assimilate and express their fears and concerns. It is a situation, which has the potential to put additional pressure, not only on the potential donor and recipient, but also on their families. It is important for the donor to understand that they can withdraw from the process at any stage. No explanation will need to be given and no pressure should be brought from any member of the family or the transplant team.

Physically

If the tests and investigations conclude that the donor is fit enough to donate then there should be no reason not live a normal healthy life afterwards. It has been noted that kidney donors may have an increased potential for requiring medication for blood pressure in the future, and may have some leakage of protein into the urine, which is usually not significant. There have been a few reported cases of the donor experiencing long-term pain.

How long will it take me to recover?

Every individual is different and no two people recover in the same way. Following discharge from hospital, it is advisable to take the appropriate length of time to recover. This may mean having help for housework, shopping, childcare, gardening etc for the first month, and after that, slowly resuming normal activities. It may be 2-3 months before feeling completely back to normal and going back to work (depending on the nature of the work and the physical demand).

Follow-up appointments are given for post-operative review two weeks after the operation, at three months and annually thereafter to ensure continued good health.

Will I lose out financially?

Throughout the work-up process there will be a time commitment, to attend the hospital for the various appointments. This necessitates time from work, which may have a financial implication. The operation involves a hospital stay of 4-7 days and afterwards a recuperation period of 6-12 weeks. It is possible for the donor to claim for compensation for loss of earnings, to make up any shortfall in his income, attributable to the donation.

Are there any special precautions I need to take in the future?

Although there is no reason not to maintain a normal healthy existence following donation, it should be stressed that it is important to take care of oneself by not smoking and by maintaining an ideal weight. Healthy eating, drinking and exercise promote good health and help to ensure a long and healthy future.

Living donation and the Law

Following the introduction of The Human Tissue Act 2006, all prospective living donors and their recipients will have a consultation with a third party assessor, following completion of their work up and prior to the transplant taking place. The purpose of this is to be sure that both donor and recipient are fully informed about the intended procedure, that both are happy to continue and know that they can withdraw at any time should they wish to, and finally, that neither donor or recipient are being coerced.

Live donation is continuing to increase and over the next few years is likely to develop in the following areas:

1. Altruistic Donation – where a motivated, healthy person donates one of his kidneys to the ‘waiting list’

2. Paired donation – where kidneys are ‘swapped’ between two couples who are incompatible with their own recipient but compatible with another.

3. Kidneys from living donors who are either blood group incompatible or cross-match positive, may be transplanted successfully following desensitisation of the recipient.

The increasing numbers of living donor transplants performed in the UK, makes all the more important the meticulous follow-up of the donors and the rigorous maintenance of a donor registry.

Key Points

- Living donor transplantation offers the best possible treatment for end-stage renal failure.
- This can be performed safely and with minimal risk to a healthy donor.
- It is an emotionally charged situation for both donor and recipient.
- The Live Donor Co-ordinator will be happy to answer any questions or arrange for you to have a consultation to discuss this treatment option further
  Tel 02920746432

This is to confirm that the enclosed photographs have been taken with the consent of all those people involved.

Ann Marsden
Live Donor Transplant Co-ordinator
University Hospital of Wales, Cardiff.

Diet after Kidney Transplant

Do I Need To Be On A Special Diet?

If your transplant has been successful there is no need for you to be on any special diets that you may have followed before your transplant for example a low potassium diet or high protein diet. You can now eat a healthy balanced diet.

However, if after your transplant your kidney is not functioning well the potassium in your blood may become too high and you may need to follow a low potassium diet. Your Doctor will inform you of this and refer you to the Dietitians for further advice.

Food Safety

You have been prescribed anti-rejection tablets which help stop your body from rejecting your new kidney. These tablets can make your body less able to fight infections and therefore you are more likely to become unwell from a food related illness. The Dietitian will see you when you on the ward after your transplant and advise you on which foods to avoid and how to handle and store food safely to reduce this risk.

Healthy Eating

It is common to gain weight after a transplant, as you may no longer be on a restricted diet and your appetite will probably improve. Also, you have been given steroids as part of your anti-rejection tablets which can also make you gain weight. It is important to try and keep a healthy weight.

The anti-rejection tablets you need to take can also increase the levels of lipids (cholesterol and triglycerides) and sugars in your blood.

Following a healthy diet will help you to control your weight and lower your blood lipid and sugar levels. The principles of a healthy diet are:

- Aim for 5 portions of fruit and vegetables a day
- Reduce the fat in your diet particularly animal fat.
- Increase fibre from wholemeal, whole-wheat foods, fruit and vegetables.
- Decrease sugar and sugary foods in your diet
- Watch your intake of salt and salty foods, which will help reduce blood pressure
- Limit your alcohol intake to a safe level (1-2 units/day for women, 2-3 units/day for men) One unit is ½ pint of beer, or a small glass of wine or a pub measure of spirits.

If you require any more diet advice once you have been discharged from the ward your doctor will refer you to the Dietitians for an out-patient appointment.

Gum overgrowth and mouth care following

transplant surgery

What is gum overgrowth?

A few of the drugs commonly prescribed to transplant patients have a side effect which induces gum overgrowth (gingival hypertrophy/hyperplasia). The principal drugs involved include the immunosuppressant ciclosporin A (Neoral) and the anti-blood pressure medicine nifedipine. The mechanism which causes the overgrowth is not understood but causes the gums to increase in bulk and in severe cases cover the tooth surfaces. This may interfere with eating and speaking and therefore can also be uncomfortable and unsightly. The effect of gum overgrowth may be made worse by plaque building on the teeth causing gum inflammation (gingivitis).

How often does the problem occur?

It is a widespread problem associated with these medicines after transplant. Children and young adults seem to suffer from the problem more than older adults. The condition normally occurs within 3-6 months of commencing the drugs, but may occur at any time. It would be preferable to find an alternative medicine to these drugs and the condition will regress on change of medication.

How can I prevent the problem?

As the medications can not be altered easily, it is important to make sure that your teeth and gums are kept in the best possible condition to avoid the problems caused by plaque and poor oral hygiene. This should start before transplant surgery in order to reduce the likelihood of gum overgrowth by keeping plaque at bay.

Teeth and gums should be kept scrupulously clean to control plaque. You should have regular check ups with your dentist before and after your transplant. Your dentist will be able to advise you further on how to look after your teeth and gums. If gum overgrowth does occur, it may be recommended that you are seen more frequently than previously by your dentist and hygienist.

What treatment exists if the gum overgrowth is not prevented?

The severity of gum overgrowth is very variable. At its most severe the excess tissue may need to be surgically removed. Unfortunately, as the drugs causing the problem are still being taken, recurrence will occur. However, if scrupulous oral hygiene is maintained, it may not be as severe as before. Recurrence normally occurs within 2-5 years. Less severe overgrowth may simply require regular dental hygiene treatment, often 2-3 monthly. Meticulous tooth brushing and flossing at home is essential to control the problem.

What happens if the condition goes untreated?

Because untreated gum overgrowth makes tooth cleaning more difficult there may be an increase risk of dental problems such as tooth decay and gum disease. The build up of plaque on teeth can also lead to bad breath (halitosis) and bad taste.

If this gum overgrowth is a problem, please contact us, to see if it is appropriate for you to consider a change in medication – do not stop your tablets without contacting the transplant nurse or doctor.

Occasionally transplant recipients get mouth infections such as thrush or ulcers- either due to the immunosuppression or antibiotic treatment. These infections need to be treated – thrush – with nystatin liquid, and ulcers with topical Bonjela or similar product. If the infections persist, contact your GP or transplant nurse specialist.

Immunosuppressive drugs

after transplant

Why are immunosuppressive drugs so important?

Immunosuppressive drugs (also called anti-rejection drugs) are important because they prevent the body rejecting a transplanted kidney. Rejection occurs when the body recognises the new kidney as ‘foreign’ and switches on the immune system of the body setting off a chain of events that can damage the kidney. This damage can occur early after transplant and is known as acute rejection, or it can occur over a long period of time, known as chronic rejection. Rejection may happen despite close matching of the donated kidney and the transplant patient, and the patient has no symptoms.

Immunosuppressive drugs greatly reduce the risks of rejection, protecting the kidney and preserving its function. These drugs aim to block the immune system so that it is less likely to react against the transplanted kidney. A variety of drugs achieves this same basic aim but work in different ways to reduce the rejection.

What are the names of the immunosuppressive drugs?

These are the oral medications currently used in kidney transplantation for immunosuppression:

1 Ciclosporin – taken 12 hourly

2 Tacrolimus – taken 12 hourly

2 Azathioprine – taken once daily

4 Mycophenolate mofetil or Myfortic – taken twice daily

5 Prednisolone taken once daily (with a reduction protocol post transplant)

6 Rapamune (Sirolimus) taken once daily

At the time of transplant you may also be given intravenous medication to provide extra immunosuppression, especially if you have a pancreas transplant, a transplant from a Non- heart beating donor, or have many antibodies.

How many immunosuppressive drugs need to be taken and for how long?

Most people start on a combination of drugs after their transplant, e.g. tacrolimus, azathioprine and prednisolone. Over a period of time the doses of each drug and the number of drugs taken may be reduced as the risks of rejection decline. However, everyone must take medication for the rest of their lives to maintain function. If medication is not taken, the transplant will not function.

To get the maximum benefit from the drugs, it is vital that they are taken regularly.

How are the immunosuppressive drugs monitored?

Anti-rejection drug regimes need to be closely monitored. For example, blood levels of Ciclosporin, tacrolimus and rapamune are checked regularly at each clinic visit, prior to the morning dose being taken. If the levels of a drug in the blood are too low the doctor or nurse may increase the dose of the drug to ensure that the kidney is protected from rejection. If the levels are too high your nurse or doctor may decrease the dose of the drug. Kidney function, white blood cell count and adverse reactions to drugs will also be checked.

Can other drugs be taken safely with immunosuppressive drugs?

Some drugs may have an adverse effect on immunosuppressive therapy. This is particularly important for people taking Ciclosporin, tacrolimus and rapamune. Some drugs can cause the blood levels of the immunosuppressives to rise, while others can cause the blood levels to fall. Before taking any new drugs, even ones bought over the counter from the chemist, please check with a doctor, transplant nurse or pharmacist first. Homeopathic drugs are not recommended. Grapefruit juice reacts with these medications, therefore is discouraged.

What are the side effects of immunosuppressive drugs?

For information on the side effects of specific drugs please refer to the manufacturer's 'patient information leaflet' which will be found in the drug packaging or to the drug information cards available in this library in the drugs section. Alternatively, speak to your doctor, nurse or pharmacist for advice.

- **Increased risk of infection** – is a common side effect of all the immunosuppressives. The body's immune system protects us from infections and when the immune system is suppressed we are more likely to pick up infections. Taking antibiotics such as co-trimoxazole for 6 months post transplant prevents one of these infections. It is very important to report the signs of infection, such as fever, to your doctor or nurse, so that the appropriate treatment can be started as quickly as possible. Some transplant recipients also require protection from a virus known as cytomegalovirus (CMV) for the first 3 months post transplant. Whilst this virus is not harmful to the general population, it can be to transplant recipients. The virus can be activated by transfer from the donor, or conversion of the recipient's blood to being the active form of the virus from the antibody already in the recipient.
- **Slightly increased risk of cancer -** the immune system also plays a role in protecting the body against some forms of cancer. With long term use of immunosuppressive drugs there is, by comparison with the general population, an increased risk of developing skin cancer -caused by a combination of the drugs and exposure to sunlight (see the leaflet on skin

care after transplant) – and a form of lymphoma- usually presenting as unexplained illness or swelling in the lymph glands. If you do notice any swelling in the glands that is unexplained or persistent, please contact the transplant nurse specialist and we will arrange to see you promptly.

Kidney rejection after transplant

What is rejection?

The human body possesses a powerful natural defence system that can identify and take action against any foreign body that is introduced into it. This reaction could be in response to a germ, a blood transfusion or to an organ, in the case of transplantation. Although a donor organ is carefully matched to the transplant patient by tissue typing and cross matching, the body will still recognise it as foreign and attempt to reject it. For this reason, transplant patients are given medicines to reduce the response of the immune system and prevent rejection. Even so, most transplant patients experience mild episodes of rejection at some stage.

There are 2 types of rejection that may result from the body’s response to donor organs: acute and chronic.

1. Acute rejection

Acute rejection episodes can occur at any time after transplantation. However, it is most commonly seen in the first 7 - 14 days after transplantation and less frequently after the first three months. For this reason outpatient monitoring is very important after discharge from hospital following a transplant. Patients are routinely admitted to hospital during rejection episodes for monitoring and treatment.

Diagnosing acute rejection

Blood tests may reveal that the creatinine and urea levels are raised, as the kidney is not working as well. A biopsy of the transplanted kidney may be taken to confirm the diagnosis of acute rejection, and to establish how severe this rejection is. You may not have any symptoms. A biopsy is undertaken in the Xray department, using local anaesthetic. An ultrasound scan is also done to exclude any changes to the blood supply of the kidney, and to check the urinary tract. Following the biopsy you will need to be on bedrest for 6 hours, and may see a small amount of blood in the urine for the next few hours, which will gradually clear. The dressing can be removed the next day.

Treating acute rejection

Normally, the first line of treatment for acute rejection is a course of steroids. (500 mg daily intravenously for 3 days).This may be repeated if necessary up to 3 times. Hopefully the blood results will return to near previous levels. If there is severe or persistent rejection more powerful agents may be required. These are known as antibodies, and would require a longer stay in hospital. These medications have a different side effect profile that can be discussed with patients on an individual basis.

2. Chronic rejection (chronic graft nephropathy)

Chronic rejection is the term used to describe slow, progressive loss of function in a transplanted kidney. Transplant research shows that transplanted kidneys steadily lose function over the long term. How quickly a particular organ deteriorates is affected by factors such as how well an organ is matched to the recipient, the age of the donor, the length of time between the retrieval of the organ to the time it was transplanted, subsequent events during the years that follow, blood pressure control and the likelihood of the original disease recurring – which can happen in some cases.

Chronic rejection will normally be detected by a steady decline in renal function, with changes seen in the creatinine levels and an increase in protein loss into the urine. Sometimes a biopsy may be taken of the transplanted kidney. It may take several years for the kidney function to decline to a level where it would be necessary to return to dialysis or plan for another transplant.

Chronic rejection may be accelerated by events that are likely to cause damage to the kidney for example: certain drugs that are damaging to the kidney such as anti inflammatory drugs: e.g. Brufen, uncontrolled high blood pressure, non compliance with medication regimes.

The effect of immunosuppressive drugs

The immunosuppressive medications prescribed after transplantation are essential to prevent acute rejection occurring, but they can also damage the kidney. To maximise the function of the transplanted kidney it might be necessary to adjust the amounts of the drugs prescribed, or to change to a different immunosuppressive drug.

Treating chronic rejection

If chronic rejection is occurring, the treatment is aimed at maintaining the kidney for as long as possible. Medication may be altered to control blood pressure and slow kidney deterioration such as changes to the immunosuppressive drug treatment.

A patient with chronic rejection needs to be prepared for an eventual return to dialysis and another possible transplant with the implications that has for the way they live.

Religion & Organ Donation

Outlined below is information regarding the attitudes of some of the major religions towards organ donation. Most religions have no objections to, and are supportive of organ donation in principle.

Buddhism

Helping others is fundamental to Buddhist beliefs. In general, supportive of organ donation

Christianity

No objections to organ donation

Jehovah's Witnesses

Members are advised that organ donation and transplantation is a matter of individual choice. What is objected to is the transfer of blood

Hinduism

No objections to organ donation

Judaism

No objection to the principle of organ donation and transplantation.

Islam

In 1995, the Muslim Law Council UK issued a directive in support of organ donation and transplantation

Sikhism

No objections to organ donation

Further information is available from the appropriate religious advisers.

http://www.uktransplant.org.uk/ukt/newsroom/fact_sheets/religious_leaflets/general_religious_lflet-2005.pdf

Skin care after transplant

Why is skin care important after transplant?

In order to prevent your body rejecting your kidney after transplant, it is necessary for you to take immunosuppressive medicines. These medicines reduce the chances of the body recognising the donated kidney as foreign, and prevent rejection. However, this means that people receiving transplants are more vulnerable to infections in general.

The immune system is also responsible for identifying and destroying abnormal cells in the body that can lead to cancer. The main source of abnormal cells is damage to the skin caused by the sun's ultraviolet rays. With a weakened immune system, it is very important to prevent any changes to the cells of the skin.

What can be done to prevent skin problems?

☐ **Stay out of the sun**

It is important to keep out of direct sunlight as much as possible. Do **not** sunbathe and do **not** use a sun bed. Avoid exposure to the sun when it is brightest between the hours of 11 a.m. and 3 p.m. This advice applies particularly on skiing holidays where the sun's rays are reflected back by the snow. If you want to go on holiday to a hot country, sit in the shade. If you want a sun tanned complexion – buy it as a lotion or spray! There are plenty of choices.

☐ **Cover-up**

If exposure to direct sunlight cannot be avoided always apply a high factor sun protection cream - at least **Factor 30** - ensuring that it is a cream effective against both UVA **and** UVB rays. These are available in your chemists or from your GP e.g. 'Uvistat'. Wear a hat, particularly if your hair is thinning, and cover up with loose cool clothing as much as possible. Consider wearing gloves if you are driving in sunny weather.

☐ **Check your skin**

It is important to check your skin for any changes, and not just those areas that are exposed to the sun e.g. hands, face, ears and the scalp. If you have any moles check them regularly for bleeding or changes in shape and colour. If you are unable to do this at home with a mirror, please ask in clinic for assistance.

Women should check their breasts and have cervical smear tests regularly.

☐ **Report changes promptly**

Most changes are not dangerous; however, they may need treatment. It is important to tell your doctor or transplant nurse specialist about any changes that you notice. The British Association of Dermatologists suggest an A B C D E approach to checking moles –

Asymmetry – if the 2 halves differ in shape

Border – if the edges are irregular or blurred

Colour – if uneven or different shades

Diameter – report any changes in size

Expert – if in doubt check it out!

What other skin problems can transplant patient’s experience?

Fortunately, most skin problems that transplant patients encounter are relatively harmless and some are naturally attributable to normal ageing processes. However, transplant patients are at increased risk of viral and fungal skin infections that will need treatment.

Warts are a viral infection and in isolation may respond well to wart paints available from the chemist. If more widespread and persistent, they may need to be treated with cryotherapy (freeze treatment) or be surgically removed. Please discuss any problems you have with your doctor or nurse to ensure correct treatment or for referral to dermatology clinic. Some patients may have access to a transplant skin surveillance clinic.

Fungal infection of the skin or nail beds may respond to topical creams, if not oral medication may required, but needs to be monitored closely as it may interact with other medications.

Tattooing and body piercing are not encouraged due to risks of infection.

Useful websites: http://www.bad.org.uk/public/leaflets/transplant.asp

http://www.bad.org.uk/public/leaflets/awaiting_transplant.asp

Useful tel: number 0207 3916355

Successful pregnancies after kidney transplant

Research suggests that approximately 1 in 50 women of childbearing age will want to try for a baby after successful kidney transplantation. Indeed, world-wide there have been many hundreds of successful pregnancies and in Cardiff we have had several happy mothers.

There are no specific reasons why a woman of childbearing age should not have a child after transplant. However, it is recommended that the decision is made carefully and after discussion with the transplant consultant.

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How soon after transplant can I try for a baby?

Following transplant, many people experience a return of libido (sex drive). Women of child bearing age recover normal menstrual cycle and fertility within a few months. During this time it is important to continue using contraception. Barrier methods are recommended such as condoms, diaphragms and spermicidal jellies, as these also reduce the risk of sexually transmitted infections. Some patients may use the low dose contraceptive pill, but this needs to be discussed with your nurse or doctor. Occasionally the Mirena coil is used on advice from the gynaecologist. Pregnancy is not recommended until at least 1 year after transplant. Men may find that sexual function recovers, but in some instances may have erectile dysfunction due to a variety of reasons such as physical problems or as a side effect of some medications. Various treatments are available such as Caverject, Muse or oral medication if medically suitable.

Planning for pregnancy

Before considering pregnancy you need have:

- Stable and good renal function
- Well controlled blood pressure
- Well controlled blood glucose if diabetic
- Good general health including being of normal weight and a non-smoker

Careful planning is essential. If you want to try for a baby let your transplant consultant or nurse know in plenty of time so that they can help you by adjusting your medication as some tablets are contra-indicated in pregnancy, and may harm the unborn baby. Once you are pregnant plans can be made with your obstetric team to monitor your baby. Monitoring the baby in the womb is very important. Babies born to mothers with transplants are often premature and small but there is no reason why you should not have a normal delivery.

In addition your transplant consultant will want to keep a close eye on you throughout the pregnancy. There is an increased risk of kidney rejection together with rises in blood pressure and an increased risk of urinary infections associated with any pregnancy that may affect your kidney. Therefore, it will be necessary for you to have closer monitoring of your blood levels during pregnancy.

After the birth, breast-feeding is not recommended. This is because some of the drugs used in immunosuppression are found in breast milk.

Donor Transplant Co-ordinators

The co-ordinators offer a 24 hour 365 day a year on-call service and are responsible for organising the retrieval of organs and tissues for transplantation from people who have died. Medical and nursing staff who have been involved in providing care for somebody who has died and been identified as a potential donor will contact the transplant co-ordinator. The co-ordinators will discuss organ and tissue donation with the family and make all the necessary arrangements for the retrieval of organs or tissues and their transfer to the transplant centres. The transplant co-ordinators provide support for the staff who have been involved in the donation. There is also ongoing bereavement support provided for the donor families.

The co-ordinators provide education about organ donation and transplantation to doctors, nurses, schools, police and other members of the general public.

A thanksgiving service is held every two years for donor families, transplant recipients and staff. The service alternates between the cities of Swansea and Cardiff.

How the Transplant Co-ordinators contact you!

The co-ordinator will contact the patient who is waiting on the kidney/pancreas waiting list to inform them that there is a suitable kidney/pancreas available for them

When we have a kidney available for transplant we need to be able to contact the recipient at any time day or night to bring him or her into ward B5, University Hospital of Wales as soon as possible.

In order to do this it is important that we are provided with contact numbers. Where appropriate we require home and mobile phone numbers. It is also helpful to have phone numbers for relatives, friends and work

Holidays

We are always pleased to hear that people are off on their holidays but please remember to keep Kymm O'Connor the transplant recipient nurse specialist informed.

Where possible please provide details of:

- dates of travel, you will be temporarily suspended fro the list but automatically reinstated once you are home.

Contacting the Transplant Co-ordinators

The transplant co-ordinators can be contacted directly as follows:

Kymm O'Connor – (029) 2074 2453

Tracy Hopkins - (029) 2074 4857

If your call is urgent then the switchboard could page whoever is on-call.

The transplant co-ordinators can be contacted by post at :

Transplant Co-ordinators Office, Room DS9, Lower Ground Floor, Nephrology & Transplant, University Hospital of Wales, Heath Park, Cardiff CF14 4XW

Vaccination for kidney transplant patients

This leaflet will give you straightforward advice about vaccination if you have had a kidney and/or pancreas transplant. It will give you essential advice on what to take and what not to take, general advice on immunisation and travel overseas and finally, a brief explanation of vaccination, what it is and how the different types work.

It is important to remember that vaccines and vaccination advice is constantly being updated. For this reason, **you should always check with your doctor, nurse or travel clinic before travelling abroad or having a vaccination.**

. What is vaccination?

The aim of vaccination is to give a person protection (immunity) against specific diseases. There are two types of protection – active and passive.

- **Active immunity**

A person is given active immunity by getting the body to react to a vaccine in a way that when it meets the real disease it will recognise it immediately and be able to fight it before that disease can become established.

Two types of vaccines are used to give active immunity: live attenuated vaccines and inactivated vaccines.

a. Live attenuated vaccines

These vaccines consist of a very small amount of live disease organisms that have been specially altered to make sure that they cannot cause illness, although a patient may have mild symptoms of the disease after vaccination. The body is able to recognise these weakened organisms, destroy them but remember them so that should it meet the real thing it will be able to fight it off.

It is recommended that kidney and pancreatic transplant patients **DO NOT** receive these kinds of vaccines. This is because there is a risk that even though the vaccines contain weakened organisms these could still cause serious illness in a person whose immune system is suppressed by medication. For this reason, too, it is recommended that children of patients do not receive oral polio vaccine (an injected form does exist) because of the risk of exposure of transplant patients to droplet infection of the weakened organism from the child.

b. Inactivated vaccines

These are vaccines made up of dead disease organisms. Again, the body is able to recognise these dead organisms and responds to them. However, because they are dead the response is not as vigorous and several doses of an inactivated vaccine may be necessary to give immunity.

Kidney and pancreas transplant patients may be given these. However, because of the immunosuppressants that you are taking, your response will not be as good and you may not receive adequate protection.

- **Passive immunity**

Another way of giving a resistance to an illness is to use vaccines of human antibodies (immunoglobulins) that are prepared from donated blood. Antibodies are produced by the body. They recognise foreign substances, bind to them to either inactivate them or mark them so that other parts of the human defence system can dispose of them.

Antibodies for specific illnesses can be collected and given as injections. The protection they give is temporary, the length of time depends on the specific type. Vaccines exist for measles, hepatitis A, hepatitis B, tetanus, rabies and chicken pox. As they do not involve exposure to the organism causing the disease in anyway, transplant patients can receive this type of vaccine.

What you cannot take

It is recommended that kidney and pancreas transplant patients on immunosuppressant medication do not receive **live attenuated vaccines**. These are:

MMR – measles, mumps and rubella

BCG – tuberculosis

Polio (by mouth), but there is an inactive vaccination available

Yellow fever

It is recommended that oral polio vaccine should not be given to the families of kidney and pancreas transplant patients

What you can take

Kidney and pancreas transplant patients may have **inactivated or ‘dead’ vaccines**. However, these should not be taken during acute illness and should be discussed with your doctor, nurse or GP prior to arranging vaccination. These vaccines are:

Influenza – it is recommended that transplant patients on immunosuppressant medication receive this vaccine annually

Polio – inactivated form exists as an injection

Diphtheria

HiB - Haemophilus Influenzae type B

Meningococcal - meningitis

Pertussis - whooping cough

Pneumovax – pneumonia – recommended every 5 years for transplant recipients

Rabies

Tetanus

Typhoid

Varicella - chicken pox/shingles

Hepatitis A

Hepatitis B

Inactivated vaccines are not dangerous but may not be effective in patients on immunosuppressant medication as they do not respond to the vaccine in the same way as the general population.

General information on immunisation and travel

- Countries where no specific immunisation is required:

USA, Europe, Australia & New Zealand – however, childhood immunisations should be up to date

- Countries where vaccination may be required:

Non-European areas of the Mediterranean, Africa, Middle East, Asia, Central and South America

Other vaccine notes:

Yellow fever: Recommended for travel to Africa and South America

Meningococcal: Recommended for travel to areas around and including Delhi, Nepal, Bhutan, Pakistan, Mecca – especially during and prior to Haj, and areas of central Africa.

Rabies: may be required for Central/South America, Africa, Asia, the Caribbean.

Cholera: Vaccine is no longer available

You may also need to take medication to prevent malaria if travelling to some countries, which is available in tablet form.

If you are travelling abroad, please plan your journey, you need travel insurance, EHIC if travelling in Europe, and be aware of the health care facilities in the country you plan to visit, sanitation, food preparation (do not buy food from street vendors etc), water supply and take a generous supply of medication with you, some with you and some in the luggage.

Further information is available from ‘Health Advice for Travellers’, a booklet produced by the Department of Health and available from travel agents and post offices or the government web site for travellers: http://www.dh.gov.uk/PolicyAndGuidance/HealthAdviceForTravellers/EssentialInformationOnMajorDiseases/fs/en

Viral infections after transplant

The suppression of the body’s immune defence system allows viral diseases that you may have caught or been exposed to a long time ago to reactivate and cause illness again. These viruses can make you feel quite unwell and in the early stages the symptoms may be very similar to kidney rejection. The virus that is most frequently seen is cytomegalovirus (CMV), usually a ‘flu-like’ illness that most of us shrug off without ever knowing we have had it. This leaflet will tell you more about CMV. Other viruses that may re-emerge are the Epstein-Barr virus that causes glandular fever, herpes simplex virus (cold sores & genital herpes) and herpes zoster virus (chicken pox & shingles). These viruses are all treatable, though they may cause some anxiety. If you are in contact with others who have a virus such as chicken pox, you may need to have preventative medication.

Sometimes these viruses are present in the donor kidney. These kidneys are still transplanted because these viruses can be controlled or treated effectively.

What is CMV?

CMV is a very common viral infection in the general population. It causes 'flu-like symptoms and does not need any specific treatment in people with normal immune function.

CMV is a member of the herpes virus family which is responsible for conditions such as cold sores and chicken pox. Like other viruses it infects cells by attaching itself to a cell, invading it and taking over the cell, causing the cell to produce virus rather than whatever it is supposed to do.

It is the result of the infected cells bursting open to release new virus to infect other cells and the body’s own reaction to the infection that makes us feel unwell. The number of infected cells and the level of the body’s reaction will determine how you feel.

What parts of the body does CMV affect?

It can affect almost any organ of the body, the kidney, liver, heart, lungs, eye, stomach, bowel and brain, causing inflammation.

What are the symptoms of CMV?

In immunosuppressed patients, i.e. transplanted patients, CMV symptoms can vary enormously from mild to very severe because it can affect almost any organ. When it affects the kidney (CMV nephritis) in a kidney transplant patient it may cause elevated creatinine levels. Some times it can present with a reduction in the number of white cells in This can be confused with kidney transplant rejection.

How is CMV spread?

CMV is spread by contact with the secretions of an infected person or from the donor organ. Once a person has been infected with the virus they never lose it. In healthy humans, CMV does not cause a problem because its activity is combated by the body's natural defence systems and it remains dormant. However, because the body fights viruses in the same way it tries to reject a new transplant, the immunosuppressant drugs that transplant patients take to stop rejection impair the body's ability to fight the virus and symptoms can occur.

As mentioned earlier, CMV is a common viral infection and many donors may have had exposure to the CMV virus. This infection may be passed on to the recipient of the kidney after transplantation. The wait for a CMV negative kidney can be very long and there is effective preventative medication and treatment for CMV infection. Therefore, it is not uncommon to transplant a CMV positive kidney into a recipient who has not had exposure to the CMV virus before.

Both the donor and the recipient of a transplant organ are tested for CMV antibodies when admitted to the waiting list and before the operation in order to anticipate the need for preventative treatment of CMV after the transplant. The recipient is also tested after surgery.

How is CMV diagnosed?

CMV can be difficult to diagnose as the symptoms are so varied. There are two main tests for CMV, checking for the presence of the virus in the bloodstream or taking a biopsy of the infected organ. However, these tests may not be conclusive and repeat tests may be needed.

What is the treatment for CMV?

A 14 - 21 day course of a powerful antiviral drug called ganciclovir is the treatment of choice for active CMV, though occasionally oral medication is sufficient if the patient is feeling well. If it is given intravenously, directly into the patient's vein, a hospital admission is required. However, if it is appropriate, a patient can be treated at home if there is the required nursing support. Occasionally CMV can recur.

CHAPTER 7 LIVING WITH KIDNEY DISEASE

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 7. Living With Kidney Disease

- **Sexuality and kidney disease**
- **Holiday facilities for people needing dialysis**
- **Patient & carer support Groups**
- **Kidney Patients' Befriending Service**

Sexuality & kidney disease

Many people with renal failure experience changes and difficulties in their emotional and sexual lives. People with kidney disease are not unique in this. Living with dialysis or having a transplant adds complexities to life that may cause problems for both themselves and a partner. Whatever their nature, be they physical changes or in body function or adjustments in lifestyle to adapt to kidney disease, for each individual the effect of any change is different. For some the changes do not cause a problem, for others, they may create severe difficulties in the way they see themselves and in their relationships with their partner or with other people close to them.

This leaflet is about the kinds of sexual and emotional difficulties people experience and the sort of help that is available. Whatever problems you may be experiencing, there will always be someone on your renal unit who will be either willing to listen and discuss these with you or knows somebody who can. Sometimes, the reassurance gained by talking about it may be all that is required.

The demands of dialysis

- The effect of stress

The demands of a life on dialysis may be stressful. Regular dialysis, taking tablets and keeping to a diet and fluid restriction, can cause people to feel anxious and depressed. Equally, the impact that dialysis can have on work, income and plans that have been made for life ahead, can lead to emotional difficulties that affect not just the person on dialysis but their partner and family also. Some people have emotions that develop as a result of losing their old way of life and self, suffering a sort of grief. This can be expressed by a variety of emotional states. If you feel this way it is important to take the opportunity to talk to somebody. Your nurse or doctor can help you to get in touch with somebody who is qualified to help with these kinds of difficulties.

One thing that some people on dialysis experience is moodiness. This can be the consequence of the dialysis and the drugs used in treating kidney failure. If you do get moody, it is important that your partner understands that it is not them but the way you feel that causes your mood swings.

- Changes in sexual function

There are physical difficulties relating to sex that people experience on dialysis which may affect their relationships.

- People often report a lack of interest in sex. Men may not be able to have or sustain an erection or reach orgasm. Women may find it difficult to become sexually aroused and reach orgasm. Many people feel tired and lethargic from the process of the dialysis. One major cause of this is anaemia, a lack of red blood cells in the blood stream that carries oxygen around the body. You may already be taking EPO and iron to combat this. But tiredness can also be caused by the dialysis itself.

  It can take a little while to adjust to dialysis and some people then find that they recover their sex drive and have more energy.

- If you are having difficulty achieving or sustaining an erection, it may be appropriate to refer you, for specialist help, to an erectile dysfunction clinic. It may not be always be appropriate for renal patients to be prescribed Viagra because of side-effects and interactions with other drugs. There are other treatments available for impotency in men including the vacuum pump, injections and oral medications – these need to be discussed with your nurse or doctor, as are not suitable for every one.

- Drugs for treating high blood pressure can reduce sexual interest and, if you are a man, affect your ability to have an erection. Changing to another type of drug may help and your doctor will be happy to talk about this kind of problem.

Whatever the sexual difficulty you may be having, it is a good idea to check with your doctor to see if there is a medical cause.

- Peritoneal dialysis (PD)

There is some medical evidence that starting treatment with peritoneal dialysis may be better in terms of health and quality of life. People on PD, however, are still at risk of developing emotional and sexual difficulties which can affect their relationships. These difficulties do not necessarily have the same physical causes as those reported by haemodialysis patients. For instance, people on PD do not have the same degree of anaemia as people on haemodialysis. However, PD patients have to cope with a catheter in their abdomen. This can get in the way during lovemaking and can cause either partner to be concerned about the harm that might be suffered by the person with the catheter or damage to the tube itself as a result of love making. In practice, it is unlikely that any serious harm or damage will occur.

It is important to talk together about these sorts of worries, to find answers together that will avoid upset on either part or perhaps experiment during love making with different positions that suit you both.

If either partner is finding sex to be unpleasurable there is plenty that can be done to sustain a close relationship. The natural tenderness that partners show through touch and caress are invaluable ways of showing how you feel toward one another. Such expressions of closeness can provide their own satisfaction and are a larger part of a caring relationship, perhaps more vital than achieving an orgasm. Intercourse is not the only way of enjoying a sensual relationship.

Your changing self

Individuals on dialysis, in addition to experiencing great changes to their lifestyle, will also experience changes in the appearance of their body. Loss of weight, scars and having a fistula or a catheter for dialysis access, may make some people feel less attractive. Not being able to pass water can make some men feel less masculine. People may also be affected by changes in their complexion, which can become pale and sallow, and notice changes in the way their breath smells. These changes can affect both the way you feel about yourself and, as a consequence the way you act toward your partner.

PD patients can be affected by the presence of the catheter or by weight gain (consequence of absorbing sugar from the dialysis fluid).

Experiencing any of these changes may prove difficult to accept. Try to remember that any mark or blemish we have concerns us far more than it will those who love us. Be positive about your appearance and look after yourself in any way that you can.

Feeling frightened

Being unwell and living with the treatment for kidney failure can be frightening. Hospital admission, tests, minor operations and the worries caused by the uncertainty of these things can cause upset. It is important to take the time to discuss these concerns with your partner. Some people find that knowing more about their condition and treatment by reading and asking questions allows them to feel more in control. Try to bring your concerns and fears to the nurse or doctor who cares for you.

Fertility and having children on dialysis

Many women on dialysis find that menstruation is either irregular or stops altogether. However ovulation may continue. For those who are irregular or have ceased their periods altogether, the opportunity to conceive a child remains, although it is an uncommon occurrence. The chances of any pregnancy reaching full term with a normal size baby are low. There is a high level of spontaneous abortion. Pregnancy also carries risks to the mother. Together, these things mean that women on dialysis are normally recommended to use a method of birth control. You can get advice on contraception from your doctor.

Men on haemodialysis may not be able to achieve an erection or reach orgasm and their sperm count will be lower. For men on PD where there are fewer physical causes of sexual difficulties, fertility is higher and the likelihood of conception greater. Contraceptive care and advice regarding conception is also available to men and their partners from the doctors on the renal unit.

Having a baby whilst living with dialysis is something that has to be thought through carefully whether you are a man or a woman on dialysis or PD. The pros and cons need to be discussed with your doctor. If you do not wish to have a baby, you should seek advice on contraception.

Having children after transplant

If you have a transplant the opportunities for having a baby are greatly increased. For both men and women fertility will usually return to normal once their health has stabilised. Many people postpone pregnancy until after they have had a transplant. If, on the other hand, you do not wish to start a family or have any more children, it is essential that you discuss contraception with your doctor or nurse to find the most suitable form for you.

Pregnancy is not recommended until you are stable on your medication after transplant, usually about a year after the transplant itself. It is very important that you discuss the possibility of pregnancy with your doctor or nurse before conception so that you can get the help and support you will need. For instance, it may be necessary to change a drug for blood pressure before conception to prevent a risk to the baby. You can read more about pregnancy after transplant in the leaflet in this library on ‘Successful Pregnancy after Transplant’.

Talking about problems – looking ahead

People with kidney disease can feel tired, worried, anxious, frightened and worried about themselves and how they look. Any of these things can reduce the energy you have available to display and demonstrate your affection to your partner. This can affect your relationship more than any loss of sexual contact. It can also mean that you have little energy to communicate how you feel about other things.

Talking about problems, sharing anxieties and fears will give you the opportunity to get help and to work through them. It is important to deal with emotions even about those things that may seem morbid, such as dying. Many people find that they actually feel better once they have done something, for example, ensuring that their affairs are in order in case of their death because it has allowed them to be positive and take some control back into their lives. It may be useful to set goals, no matter how small, in order to start to look to the future.

If you feel you need to talk to somebody, in confidence, about how you are coping your nurse or doctor are your first point of contact, but, if appropriate, they can also put you in touch with the clinical psychology service. You can read about the role of the clinical psychologist elsewhere within the library. For certain difficulties or concerns the social worker may also be able to provide appropriate assistance or a confidential listening ear.

A useful web site and phone number for advice is: http://www.sda.uk.net/ Sexual Dysfunction Association- Tel: 0870 7743571 or the National Kidney Federation website: http://www.kidney.org.uk/Medical-Info/sex-problems/index.html

Holiday facilities for people needing dialysis

Arranging holidays

- **Haemodialysis**

If you are on dialysis you can go holiday. There are a very large number of dialysis units around the UK and abroad that offer the chance to escape from home for more than a couple of days at a time.

If there is somewhere within the UK you wish to go to, your local unit should have access to a Critical Care Directory which will identify a dialysis unit local to the area you wish to visit that can be contacted to see if they take holiday patients. In addition, the list below offers a variety of venues and accommodation, which may be useful. It has been drawn from a number of sources, including the National Kidney Federation Holiday Booklet. The NKF helpline (0845 601 0209) and the Welsh Kidney Patients Association (029 2074 2735) can also provide information. Additionally, Global Dialysis (www.globaldialysis.com) is a useful website to visit providing extensive travel information for dialysis patients.

It does take time to organise holidays for people needing dialysis and you must talk to your local dialysis unit who will be able to tell you how long it takes and supply you with essential guidelines on the preparations that have to be made. You will probably have to allow about 2 months for holidays in the UK and longer for overseas.

- **Peritoneal dialysis**

It is much easier to travel when you are on PD. Arrangements can be made for deliveries to your holiday destination, both in the UK and overseas through your supplier. Contact your Home Dialysis Administrator and they will advise you on the procedures required, but you should be able to travel to almost any popular holiday destination without too much difficulty.

You will need to provide your Home Dialysis Administration office with the address and telephone number of your destination and the dates of the holiday. You can go anywhere in the UK at about 2 weeks notice (4 weeks if you are a Fresenius patient) but you will need to allow anywhere between 6 weeks and three months (8 weeks to 3 months for Fresenius patients) when you travel abroad, particularly if your supplies have to be shipped out.

- **Travel insurance**

Your local dialysis unit and home dialysis administration office may be able to give you advice and contact numbers.

Check with your tour operator first. They may provide insurance with a letter from or form signed by your GP.

The National Kidney Federation membership services offers travel insurance packages especially tailored to kidney patients and their families. Tel: 01277 23155 quoting your membership number.

You must make sure that your insurance covers pre-existing illnesses.

Going abroad?

If you are hoping to travel abroad, you need to be aware that some of the clinics will charge, whilst others, if they are state run and within the European Community, will provide free treatment if they accept form E111.

- **Form E111**

This is available from your local DHSS office. It needs to be filled out; one part handed in before you go on holiday and the other taken with you on holiday

- **Blood tests**

You will need a full set of blood tests for hepatitis B & C and HIV before you go. Units offering holiday dialysis will not accept you without a negative HIV test result and many will not accept you unless you are also hepatitis negative.

- **Transplant waiting list**

If you are on the transplant waiting list there are three alternatives to consider if you are going abroad:

1. Ask the transplant co-ordinators to suspend your name on the list
2. Insure yourself for a flight home in the event of contact. This is likely to be expensive
3. Be prepared to pay for a flight back at short notice

- **Pre-booking checklist**

Before you finally book a holiday, you will need to have the answer to the following questions

☐ Does the unit you want to go to accept visitors?

☐ Can they dialyse you during the period that you intend to be there, meeting the number of sessions and hours that you require?

☐ Will there be a charge or do they accept form E111 for free treatment

☐ Do they accept patients who have tested positive for Hepatitis and HIV? It is not recommended that you dialyse in a unit that does accept these patients

☐ Is there at least one English speaking nurse or doctor at the unit who will be available during your stay should medical problems arise?

☐ Is your dialysis unit happy with the dialysis unit you want to go to?

If these questions are answered satisfactorily, there should be no reason why you cannot go ahead. Your local unit will help you to make the arrangements as the dialysis unit that you want to go to will need medical details and require an E111D filled in by your doctor (some units have their own form instead). The arrangements can take some time. You will need to allow at least 3 months for the arrangements to be made satisfactorily.

- **Other tips**

  ☐ Leave a contact address and telephone number with your local unit

  ☐ Do not expect things to be the same as in your own unit

  ☐ In hotter climates, the dialysis mixture you need may be stronger than you are used to.

  ☐ You may wish to take your own lignocaine, as some units do not offer this before needling.

  ☐ In hotter climates you may sweat more which means that you may need to drink a little more. It is sensible to discuss this with your doctor before you go

  ☐ Beware of ice in drinks! It needs to be made from bottled water

  ☐ You will probably have to take your own EPO with you if you are taking it. To keep it cool, use a jiffy large enough to take a freezer block, put the EPO and the block together in the jiffy bag and seal it up

  ☐ Take all your drugs, including the EPO as hand luggage. Do not put them in your main luggage!

Organisations providing holiday opportunities

British Kidney Patients Association

The BKPA can help with destinations and may be able to help with grants to meet costs

Contact: BKPA, Bordon, Hants GU35 9JZ

Tel 01420 472021

Butlins UK Dialysis Holiday Centres

Bognor Regis & Skegness

For availability & details telephone: 0181 942 9555

Local Kidney Patient Associations (KPAs)

Many local KPAs have holiday facilities for their own members. Please ask your local association for details

Scout Holiday Home Trust

Provides caravans & chalets at Barrow, Bracklesham Bay, Exmouth, Felixstowe, Kidwelly, New Milton, Paignton, Poole, St Austell, Skipsea & North Wales. Accommodation can be up to 6 people. Standard design wheelchairs catered for. Reductions for families with a disabled member or special needs e. g. elderly, one parent, low income.

Contact: The Scout Holiday Home Trust, Baden-Powell House, Queen’s Gate, London SW7 5JS

Tel: 0171 584 7030

Destinations

The accuracy of the following list of centres cannot be guaranteed. You will need to double check the details with the advertised unit to ensure that a holiday service remains available and what requirements the unit has e.g. equipment you need to bring and cost, before you discuss booking through your local dialysis unit.

Some of the addresses are simply accommodation requiring you to make your own dialysis arrangements.

Centres in the United Kingdom & Ireland

Broadstairs, Kent

Barts Renal Patients Association Holiday House

Two self-contained flats in a single house, 5 minutes from the sea and shops.

Contact: John & Dorothy Leeson, 10 Queens Gardens, Rainham, Essex, RM13 8EB

Tel: 01708 501055

Blackpool, Lancashire

Devonshire Road Hospital

A minimal care unit in the community hospital. Open all year round. Staffed by 4 nurses with support of consultant physician at the local District General Hospital.

Contact: Sister, Renal Dialysis Unit, Devonshire Road Hospital, Devonshire Road, Blackpool, FY3 8AZ

Tel: 01253 303307

Bristol, Avon

BUPA Hospital

Contact: Grace Stimson, Dialysis Manager, ‘The Glen’, Redland Hill, Durdham Down, Bristol, BS6 7JJ

Tel: 0117 973 2562

Cotswolds, Gloucestershire

Triple C Healthcare

Contact: Cotswold Dialysis Centre, Gloucestershire Royal Hospital Campus, Horton Road, Gloucester GL1 3NJ

Tel: 01452 394848 Fax: 01452 394849

Emsworth, Hampshire

Charing Cross Holiday Dialysis Trust

Single house converted into 2 self-catering flats, with large garden including heated outdoor swimming pool, games room, barbecue area and full laundry facilities. Resident wardens, 2 dialysis cabins in gardens close to house. Full time qualified nurse, dialysis trained.

Contact: Sister Ellie Faber, tel: 01243 374497

Exeter area

Exeter Kidney Unit & Torbay Satellite Units

Units in Exeter, Newton Abbot & Barnstaple

Contact: Sister P. Woodhams, Clinical Nurse Manager, Exeter Kidney Unit, Royal Devon & Exeter Hospital (Wonford), Barrack Road, Exeter, Devon EX2 5DW

Tel: 01392 402519 Fax: 01392 402527

Jersey

Dialysis unit - Portelet Bay

Run by BKPA. Sessions are mornings Sunday to Fridays, from May to September.

Contact: Christine Barnett, BKPA, Bordon, Hants GU35 9JZ

Tel 01420 472021

Ludlow, Shropshire

Holiday cottage

Cottage with superb views across farmland to Clee Hills. One twin bedroom, french windows to sun terrace, bathroom with shower, TV, wood burner, double bed sofa & garden. Owner is on CAPD therefore used to dealing with fluid deliveries.

Contact: Krystina & Michael Wills, Brookrow Cottage, Coreley, Ludlow, SY8 3AW Tel: 01584 890146

Norman’s Bay (between Eastbourne & Hastings)

South Eastern KPA caravan

Quiet private site by Norman’s Bay. Only a few minutes walk from the railway station & the sea. Caravan has mains services & calor gas, TV, microwave.

Contact: Peter Sumners, 2 Kings Road, Haywards Heath, West Sussex, RH16 4EJ

Tel: 01444 413303

Norwich

Jubilee Renal Unit, West Norwich Hospital

Contact: Mr Eric Tan, Jubilee Renal Unit, West Norwich Hospital, Bowthorpe Road, Norwich, NR2 3TU

Tel: 01603 288246

Plymouth

Derriford Hospital

Modern purpose built dialysis unit.

Contact: Linda Durbridge, Dialysis Unit, Durbridge Hospital, Derriford Road, Plymouth PL6 8DH

Tel: 01752 792464

St Ives, Cornwall

Channings Hotel

Provides service for resident & non-resident haemodialysis patients and resident peritoneal dialysis patients (facilities for receipt & storage of fluids, exchange facilities en suite & waste disposal). Haemodialysis unit has its own qualified nurses assisting with haemodialysis with support from local GPs and renal unit.

Contact: Dorothy Juggins, Tel: 01736 796681

Overseas destinations

1. International Dialysis Network (IDN)

The International Dialysis Network is a membership organisation open to all dialysis centres that accept travel patients and who meet certain standards of patient care

Worldwide Headquarters

Michel Botton, 8 rue de Fauborg, Poissonniere, 75010 Paris, France

Tel: 00 33 1 44 83 02 60 Fax: 0033 1 44 83 02 50

European Headquarters

Mrs Dominique Ponsard, Friedrichstrasse 10, 45458 Mulhbeim/Ruhr, Germany

Tel: 00 49 208 33 059 Fax: 00 49 208 38 0214

French Office

M. Jean-Christophe Bourrie, 10 rue Jean Mermoz, 77210 Avon, France

Tel: 00 33 1 64 22 60 67 Fax: 00 33 1 60 72 50 62

US Representative

Dr. S. Aswad, Renal Care International, Hacienda Heights, CA 91745-0416, USA

Tel: 00 1 818 336 1810 Fax: 00 1 818 336 5555

Asian Representative

Ms Linda Tan, 322-B King George’s Avenue, Singapore 0820

Tel: 00 65 737 0071 Fax: 00 65 737 8167

Japanese Representative

Mr S. Nishimoto, Osaka Tours Co. Ltd.

Tel: 00 81 6 325 1111 Fax: 00 81 6 326 0505

2. IDN Destinations

Balearic Islands

Dr Nizar, Ibidialyse

Tel: 00 34 731 33 64 94 Fax: 00 34 71 33 64 60

Canada

Mr Igal Holtzer, Director, Dialysis Management Cliniques Inc., 4394 Steeles Avenue East, Suite 220, Markham, Ontario, Canada L3R 9V8

Tel: 00 1 416 783 43 35 Fax: 00 1 416 785 83 28

Canaries

Dr Monzon, Club Hemodialysis Maspolomas, Centio Commercial NILO, Playa de Los Ingles, Gran Canaria

Tel: 00 34 28 76 43 49 Fax: 00 34 28 76 51 36

Corsica

Dr Marraoui, Clinique De l’Ospedale, RN 198 Carrefour de l’Ospedale, 20137 Porto Vecchio.

Tel: 00 33 95 73 80 00 Fax: 00 33 95 70 15 54

France

- **Paris**

Dr X. Picart, Unit René Moreau-Andra, 31 rue d’Amsterdam, 75008, Paris

Tel: 00 33 1 40 16 90 94 Fax: 00 33 1 42 82 13 57

- **Hauteville**

Dr Genevive Bianchi, Regina Medical Center, Avenue Felix Mangind, 01110 Hauteville

Tel: 00 33 74 40 29 18 Fax: 00 33 74 35 39 52

N.B. - membership pending

- **Nice**

Centre de la Riviera, 50 avenue de Nice, 06600 Antibes

Tel: 00 33 93 95 12 93 Fax: 00 33 93 33 37 63

N.B. - membership pending

- **Serena**

Dr Robert, 83830 Figanieres

Tel: 00 33 94 67 26 96 Fax: 00 33 94 60 43 39

Germany - Munich

Dr Nattermamm, Dialyse im Zentrum, Lindwurmstrar 23, 80337 Munchen, Germany

Tel: 00 49 89 54 39 009 Fax: 00 49 89 54 39 099

Hungary

Dialysis Center Sorpon, Dr V. Lios, Holiday Services International

Tel: 00 39 373 97 43 18 Fax: 00 39 373 97 42 01

Indonesia

Dr R C Sulling, Mediros Hospital, JL Perintis Kemerkelcann Kav 149, Jakarta, Timur 13260, Indonesia

Tel: 00 62 21 488 0042 Fax: 00 62 21 489 19 37

Italy

- **Chiavari, Tuscany**

Centro Dialysis Chiavari, J. Peronna, Holiday Services International

Tel: 00 39 373 97 43 18 Fax: 00 39 373 97 42 01

- **Falconara**

Centro Dialysis Falconara, Manuela Moretti, Holiday Services International

Tel: 00 39 373 97 43 18 Fax: 00 39 373 97 42 01

- **Verona**

Azienda Ospedaliera Di Verona, Dr V De Blasé, Servizio Dialysis O. C>M, Piazzale Stefani 37126, Verona, Italy

Tel: 00 39 45 808 26 49 Fax: 00 39 45 807 3129

Israel, Tel Aviv

Mr Ariel Margalit, Renal Medical Service, 31 Altase, Tel Eviv, Israel

Tel: 00 972 3 681 79 36 Fax: 00 973 682 43 91

Japan

Mr S. Nishimoto, Osaka Tours Co. Ltd.

Tel: 00 81 6 325 1111 Fax: 00 81 6 326 0505

Morocco, Agadir

Dr H Zamare & Dr Mounie, Centre D'Hemodialyse D'Agadur, Villa n 10 ext X BP 3152, 8005 Agadir, Morocco

Tel: 00 212 8 82 15 83 Fax: 00 212 8 84 33 00

Mauritius

Dr Mrs J Rampol, AURAM, Hospital SSRN, Pamplemoussees District, Mauritius

Tel: 00 230 243 41 82 Fax: 00 230 243 41 96

Mexico, Monterrey

Mrs A Gonzalez de Perez, Cenro Renal De Monterry, Carlos M Alayan no 2306, Col Lomas CP, 64030 Monterrey, Nuevo Leon, Mexico, 64030

Tel: 00 52 8 348 16 91

Poland, Cracow

Dr A Milkowski, Cracow Dialysis Department, Rydygier Hospital

Tel: 00 48 12 47 05 45 Fax: 00 48 12 47 41 30

Russia, Moscow

Dr A Denisov, Moscow Central Clinic Hospital

Tel: 00 7 95 414 06 64 Fax: 00 7 95 405 03 54

Spain, Almeira, Cadiz, Ciudad Real, Madrid, Malaga, Sevilla, Teruel

Ms Ana Conejo, Amex

Tel: 00 34 1 433 87 13 Fax: 00 34 1 433 46 08

NB Membership pending

Taiwan

Ms Jackie Lee, Manager, Leisure Travel Service Corp

Tel: 00 886 2 504 44 19 Fax: 00 886 2 594 79 97

Tunisia

- Clinique El Manar, Mr Jean Pallau

Tel: 00 216 1 885 000 Fax: 00 216 1 885 100

- Centre De Dialyse Hammamet, Nabeul, Dr Amir Douad, Km 9 Route d’Hammamet, BP 12 – 8050 Mammamet, Tunisia

Tel: 00 216 2 282 670 Fax: 00 216 2 280 677

USA

- **Florida**

Ms Patsy Anders, Renex, 2222 Ponce de Leon Boulevard, Suite 300 Coral Gables, Florida 33134

Tel: 00 1 3305 448 2044 Fax: 00 1 305 448 1154

- **Hawaii**

Mr Craig Chapman, Dialysis Center Honolulu,

Tel: 00 1 808 293 17 36 Fax: 00 1 808 293 20 66

- **Las Vegas**

Mr Paul Maine, Dialysis System Inc, 2300 McDaniel Street, Las Vegas, Nevada 89102

Tel: 00 1 702 878 09 08 Fax: 00 1 212 725 35 38

- **Los Angeles**

Dr. S. Aswad, Renal Care International, 14831 East Whittler Boulevard, Whittler, CA 90605, USA

Tel: 00 1 818 336 1810 Fax: 00 1 818 336 5555

3. Other European Destinations

Greek Islands

- Rhodes

Dialysis unit run by American trained doctor. Free treatment with E111

Contact: Dr Marai Volanakis, Nephrology Dept, Rhodes General Hospital, Rhodes Town, Rhodes 85100, Greece

Tel: 00 30 241 22 222

Portugal

- Lisbon

Travel agency in Lisbon with excellent relations with Medicassis dialysis centre at Estoril. They can book transfers, hotels, restaurants & guarantee dialysis treatment

Contact: Vimeca Viag. E Turismo

Tel: 00 351 1 411 3939 Fax: 00 351 1 411 2551

- Port Imaio, Algarve

Contact: Chris Gleadell, Freedom Travel & Apartments Ltd, 1 Middlefield Road, Cossington, Leicester LE7 4UT

Tel: 01509 815999 Fax: 01509 815889

Italy, Chiavari, Tuscany

Centro Dialisi Golfo Del Tigullio

Run by Fresenius. BKPA can arrange group or individual holidays. Special hotel rates organised through Fresenius. Holiday grants may be available on application to BKPA. Special facilities for Hepatitis positive patients

Contact: Christine Barnett at BKPA, tel: o1420 472021

Spanish Islands

- **Majorca**

Fully equipped private clinic in Palma (including restaurant & swimming pool for partners who prefer to wait at the clinic) and satellite units at Manacor and Inca. Free treatment with E111. Booking fee £40.

All patients must be Hep B (AA) & HIV negative. Treatments available morning

& afternoon, open year round, mid-week bookings available. You book your own flight and accommodation.

Contact: Nephco International, 10 High Street, Totton, Southampton, Hants, SO4 4HN

Tel: 01703 868411/ 871003 Fax: 01703 872107

or Chris Gleadell, Freedom Travel & Apartments Ltd, 1 Middlefield Road, Cossington, Leicester LE7 4UT

Tel: 01509 815999 Fax: 01509 815889. No booking fee

- Tenerife, Puerto de la Cruz & Playa de las Americas

Free treatment with E111, open year round. All patients must be Hep B (AA) & HIV negative

Contact: Chris Gleadell, Freedom Travel & Apartments Ltd, 1 Middlefield Road, Cossington, Leicester LE7 4UT

Tel: 01509 815999 Fax: 01509 815889

Turkey, Larakent

Private clinic charging per dialysis session. CAPD available also. Credit cards accepted

Contact: ECE Holiday Dialysis Centre Ofo Caddesi, Larakent, Sitesi 14, 07003 Antalya, Turkey

Tel: 00 90 242 349 2004 Fax: 00 90 242 349 2005

4. Other world-wide destinations

Australia, Central Australia

Red Centre Dialysis Services provide facilities for those wishing to dialyse in Central Australia, providing a service for patients in the comfort of their own accommodation. They employ qualified nursing personnel, have access to a renal physician and local hospital backup if needed.

Contact: Red Centre Dialysis Services, 46 Bokhara Street, Alice Springs, Northern Territories, Australia

Tel: 61 89 550 250

USA

Facilities are available across the USA. For further details by State please contact the National Kidney Federation tel: 01909 487 795

5. Cruises

- **Dialysis at Sea Cruises**

An agency providing cruise travel opportunities for people on dialysis

Contact: Unique Reservations Inc, 107 13th Street, PO Box 218, Indian Rocks Beach, Florida 33785

Tel: 00 1 813 596 0203

Patient Associations & Support Groups

The following alphabetical list of self-help and support groups for patients and carers has been assem
from a variety of sources.

The information provided below was accurate at the time of compilation.

Renal groups / Associations / Websites

British Kidney Patient Association (BKPA)

BKPA,

Bordon,

HANTS

GU35 9JZ

Tel: 01420 472021/2 **Website:** www.britishkidney-pa.co.uk

The BKPA is a national organisation providing financial aid to kidney patients where possible e.g.

contribution towards holiday costs / covering fees for further education and training etc. to help kidney patients live an active and productive life.

They have special arrangements with certain holiday dialysis centres for children and adults, and a ra
educational leaflets on a variety of kidney diseases and problems.

British Organ Donor Society (BODY)

Balsham,

CAMBRIDGE

CB1 6DL

Tel: 01223 893636 **Website:** www.bodyuk.org email: Mbody@bodyuk.orgail

BODY provides help & support for organ donor and recipient/potential recipient families

EdREN

Website: www.edren.org email: mrenal@ed.ac.uka

EdREN is an informative website of the Renal Unit at Edinburgh Royal Infirmary.

Particularly useful is the EdrenINFO section, which deals with kidney tests, diseases and related renal issues.

Global Dialysis

PO Box 12821,

Solihull,

B91 9BT **Website**: www.globaldialysis.com

This comprehensive website is for dialysis patients who want to travel nationally and internationally.

It has a database directory of over 12,500 dialysis centres in over 141 countries and offers useful trave information and tips.

Kidney Research UK

Kings Chambers,

Priestgate,

Peterborough,

CAMBS, PE1 1FG

Tel: 0845 070 7601

National Kidney Helpline: 0845 300 1499 **Website:** www.kidneyresearchuk.org e
mailto:mcommunications@kidneyresearchuk.orgai

Kidney Research UK (formally NKRF) was founded in 1961 and is the leading UK charity funding rese
into the prevention, treatment and management of kidney disease.

They provide funding for projects with some 20-30 new grants each year, and a commitment of over £
million at any one time to ongoing research.

A significant proportion of expenditure is allocated for fellowship grants to train scientists and clinician
renal science and medicine.

Kidney Research UK also assists with pilot studies and work in partnership with other research funder
the pharmaceutical industry to support clinical trials.

The charity also aims to improve patient care and raise awareness of kidney disease.

They offer a Kidney Health Information service to kidney patients, and provide patient support grants
individual basis.

Kidney Wales Foundation

1-3 Museum Place,

CARDIFF

CF10 3BD

Tel: 029 2034 3940/343951 **Website:** www.kidneywales.com email**:** mailt
minfo@kidneywales.comai

Fax: 029 2034 4130

Kidney Wales Foundation (formally KRUF) is Wales' only national charity supporting kidney research
kidney patient welfare in Wales.

It supports research in the Institute of Nephrology in the University of Wales College of Medicine and w with the WKPA for the benefit of kidney patients.

It raises funds for specific Welsh renal projects and campaigns to increase public awareness of kidney disease and the need for organ donation.

It is hoped that Welsh kidney patients will support its activities.

National Kidney Federation (NKF)

6 Stanley Street,

Worksop,

NOTTS

S81 7HX

Tel: 01909 487795

NKF Patient's Helpline: 0845 601 02 09 **Website:** http://www.kidney.org.uk

The NKF is a UK wide organisation formed by the combination of affiliated local patient groups e.g. W Kidney Patients Association (WKPA).

It exists to promote throughout the UK the welfare of persons suffering from kidney disease or failure.

The Federation was formed in 1978 when facilities for kidney patients were still scarce in order to repr the interests of all kidney patients in developing services.

The NKF undertakes a wide range of activities in support of patients including:

- lobbying for the expansion of renal dialysis facilities
- representing kidney patients' interests to government and statutory bodies
- promoting awareness amongst the general public of organ donation as the 'gift of life'
- offering advice and information to patients and their families
- providing educational material for kidney patients through a series of leaflets and an information magazine 'kidney life'
- organising an annual patients' conference
- working closely with professional bodies such as the Renal Association to ensure high quality and

standards of care

- offering a range of financial services designed for kidney patients and their families

Transplant Kids

email: mailto:minfo@transplantkids.co.uka **Website:** **http://www.transplantkids.co.**

This is an informative and fun website written for children who are waiting for/have received organ trar

Transplant Support Network (TSN)

6 Kings Meadow Drive,

Wetherby,

WEST YORKSHIRE

LS22 7FS

Tel: 01937 585 434

Support line: 0800 027 4490 /4491 (free)

Website: www.transplantsupportnetwork.org.uk email: tsnetwork@tiscali.co.uk

TSN supports patients, families and carers of all organ transplants with advice and assistance, often o
one-to-one basis.

It provides a regular newsletter for members and useful contacts.

Welsh Kidney Patients Association

The Chairman,

WKPA,

Lakeside offices,

University Hospital of Wales,

Heath Park,

CARDIFF CF14 4XW

Tel: 029 2074 2735

(answer machine)

Website: **www.wkpa.org.uk** **N**orth **W**ales**:** www.renalcareglanclw

(Glan Clwyd Renal Unit, Bodelwyddan)

carrington57.tripod.com/pacamaks (Pacamaks KPA, Wrexham)

Affiliated to the National Kidney Federation (NKF), the WKPA is the largest patient association in Wale chronic renal failure patients.

It is run by patients and carers, for patients and carers.

The WKPA provides an information service to kidney patients and carers, and a Befriender service an listening ear whenever necessary, at both Cardiff and Swansea renal units.

The Association has support/self-help groups in some areas of Wales.

These groups provide opportunities for kidney patients, their carers, family and friends to meet social exchange ideas, information and experiences.

Many patients find that their local WKPA group helps to break down the sense of isolation which often accompanies home dialysis.

The Association is a pressure group active in improving services for kidney patients in Wales, attendin meetings with AM's on the All Party Kidney Group at the Welsh Assembly.

The Association supports the Welsh Transplant Team to compete at the British Transplant Games. T Association provides a free magazine, which is distributed three times a year.

There is a children's section for children with renal failure, awaiting transplant or who have parents wi kidney disease.

Other useful UK organisations

Age Concern - Cymru

13-14 Neptune Court,

Vanguard Way,

CARDIFF CF24 5PJ

Tel: 029 2043 1555

Helpline: 0800 00 99 66 (free) **Website:** www.accymru.org.uk

AC Bridgend:	01656 669288
AC Cardiff & Vale:	029 2052 1052 /01446 795632
AC Gwent:	01633 763330 / 240190
AC Morgannwg:	01443 485505
AC Pembrokeshire:	01437 769972
AC Sir Gar:	01554 784080
AC Swansea:	01792 648866
AC Torfaen:	01495 762151

Age Concern is a national organisation committed to providing direct services, information, support an advocacy by working with and on behalf of older people.

They have offices in most areas, often based in local hospitals.

Age Concern also offers travel insurance for pre-existing medical conditions.

Cancerbackup

3 Bath Place,

Rivington St,

London EC2A 3JR

Tel: 020 7696 9003

Helpline: 0808 800 1234 (free) **Website:** **http://www.cancerbacku uk**

Cancerbackup provides up-to-date information on all aspects of cancer, together with practical advice emotional support and a counselling service for patients and their families.

Carers UK - Wales

River House,

Ynsbridge Court,

Gwaelod -y-Garth,

CARDIFF

CF15 9SS

Tel: 029 2081 1370

Helpline: 029 2022 1421 **Website:** **http://www.carerswales.**

Bridgend:	01656 658479
Caerphilly:	01495 231731

Carmarthen: 01267 236436

Haverfordwest: 01437 767762

Merthyr Tydfil: 01685 353954

Swansea: 01792 653344 / 418002

The national voice of carers, Carers UK (formally CNA) advocates on behalf of carers throughout the

raising awareness of the needs of carers and campaigning on their behalf at all levels of local and nat
government.

With approximately 350,000 carers in Wales, Carers Wales, with its head office in Cardiff, offers exten
locally based help and support throughout Wales.

Cruse Bereavement Care

Cruse House,

126 Sheen Road,

Richmond,SURREY

TW9 1UR

Tel: 020 8939 9530

Helpline: 0870 167 1677 **Website:** http://www.crusebereavementcare.org.uk

Cardiff & Vale: 029 2022 6166

Gwent: 01633 238162

Morgannwg: 01792 462845

West Wales: 01970 625621

A bereavement counselling service providing a national helpline and local counsellors who can visit.

Diabetes UK

Argyle House,

Castlebridge,

Cowbridge Road East,

CARDIFF CF11 9AB

Tel: 029 2066 8276

Careline: 0845 120 2960 (lo-call rate) **Website:** www.diabetes.org.uk

Diabetes UK is the largest organisation in the UK working for people with diabetes, funding research, campaigning and helping people live with the condition.

Diabetes UK Careline provides information and support on diabetes and access to a translation servic to 100 languages.

Diabetes UK Cymru offers a bilingual service and has many voluntary support groups throughout Wal

The website is available in several languages and has a good selection of recipes.

Lupus UK

St. James House,

Eastern Road,

Romford,

ESSEX

RM1 3NH

Tel: 01708 731251 **Website:** http://www.lupusuk.org.uk

Lupus UK aims to give sufferers support and raise awareness of Lupus nationally, with contacts in mo
areas of the country.

They produce information leaflets for sufferers, a quarterly magazine for members, and support resea
Lupus through fund-raising and grant awards.

There is a South Wales regional group, who provide advice and understanding of the immune system
disease, and where possible, welfare support.

They also organize social events/ fund-raising activities – contact the above number for details.

Myeloma UK

Lower Ground Floor,
37 York Place,
EDINBURGH EH1 3HP

Infoline: 0800 980 3332 (free) **Website:** www.myeloma.org.uk

Myeloma UK is the only organisation in the UK that deals exclusively with Myeloma and its related dis

They inform and support people affected by Myeloma and help to improve treatment and standards of
through research, education and awareness.

Samaritans

Tel: 08457 90 90 90 (local rate) **Website:** www.samaritans.org.uk **email:** mailto:mJo@samaritans.org (for deaf/hard of hearing) Textphone: 08457 90 91 92

Confidential phone line for those in crisis - available 24 hours a day, 7 days a week. There are 9 branc
across Wales, many offering face-to-face support.

Tenovus Cancer Information Centre (TCIC)

TCIC,

Velindre Hospital,

Whitchurch,

CARDIFF

CF14 2TL

Tel: 029 2019 6100

Helpline: 0808 808 1010 (free) **Website:** www.tenovus.com

Tenovus offers an information service on all aspects of cancer, together with emotional support and counselling for patients and their families.

They are committed to quality research, and to control and treat various cancers.

Kidney Patients' Befriending Service

The Befriending Service is offered to people with kidney disease, their families and carers for those living in South Wales.

What is a Befriender?

A befriender is a patient or carer of a patient, who is willing to talk to other patients or carers, to provide support and understanding and to share experiences. This is not the same as a counsellor who has been formally trained in counselling on an established course.

What is the Kidney Patient's Befriending Service?

The Befriending Service has been founded by the WKPA with the support of Nephrology & Transplant at UHW and Morriston. All the people in this service have received some training in this role and will be supervised in their work by professionals within the service.

Befriending can be offered by telephone, face to face, or by letter. A single contact may be sufficient for some people but others may need more. For other people just knowing that someone is available is all the help they need.

Confidentiality is the corner stone of this service.

How to Make Contact?

Pick up a copy of the Befriending Service Directory leaflet from your local renal unit or request a copy by telephoning the WKPA on **(029) 2074 2735** and leave a message on the answer phone. The WKPA will then contact a befriender on your behalf to ask them to contact you as soon as is possible. Alternatively, ask the staff in your local area. You may also consider becoming a befriender yourself- if so, please contact the WKPA or the psychology service on 02920 746432.

CHAPTER 8 SUPPORT SERVICES

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 8. Support Services

Dialysis Technical Services

Who we are

Dialysis Technical Services (DTS) is a team of technical officers aiming to provide you with a quality service in support of your dialysis equipment at home. We also provide support for dialysis equipment throughout the Trust and other external sources within the catchment area.

The service is part of Clinical Engineering in Cardiff and the Vale NHS Trust and is currently based at The Quadrant Centre, Cardiff Business Park, Llanishen Cardiff CF14 5QQ.

Team Members

Jim Blackie Head of Dialysis Technical Services

Mark Bolton	Service Technician
Adrian Bragger	Service Technician
Simon	Service Technician
Steve	Service Technician

What we do for patients with home dialysis

Ø Educational support before home dialysis

If you have decided to have dialysis at home you will need technical support from DTS. About three weeks before you are due to start treatment at home, you will be given appropriate training, by a member of the DTS team, in the operation of your dialysis equipment. You will be provided with written notes to take home. The training is designed to resolve any problems that may exist in your understanding of the technical aspects of dialysis, recognising that you are already familiar with the equipment.

Ø Installation of equipment

- **Haemodialysis**

During the training period, your home will be prepared for the equipment you will need. Either a room in your house will be converted or you can have a portacabin in your garden. You will also need to have a specially adapted water supply, a separately metered electricity supply and sealed drainage outlets fitted.

This work is carried out to our specifications by a private company that specialises in home dialysis installations. To ensure a consistently good standard of workmanship, the installation will be inspected by us on completion.

The equipment will consist of a Dialysis Machine fed by a Water Treatment Unit. The installation of this equipment is carried out by our DTS technicians and is usually completed in one day.

- **Peritoneal dialysis**

Installation of peritoneal dialysis equipment normally requires only a special protected mains socket for the electricity supply.

Support for first dialysis at home

Ø Haemodialysis

A technician and a member of the nursing staff will be with you at home during the time you prepare your equipment and connect your blood lines in case you should encounter any problems.

Ø Peritoneal dialysis

It will not be necessary for a technician to attend at your first dialysis at home.

Maintaining the equipment

While you are dialysing at home, it is our aim to maintain your equipment to a standard that will cause the least possible inconvenience to you within the constraints of the service.

We provide two types of service: **routine** and **non-routine**

Ø Routine services

In order to ensure the safe working of your equipment, routine services will be carried out at pre-planned intervals. Breakdowns are reduced by inspection and testing of function using instruments calibrated to a known and acceptable standard. All equipment receives a yearly check for electrical safety.

Ø Non-routine services

If technical problems do occur between routine service visits, please call the switchboard at UHW on (029) 2074 7747 and ask to be put through to the Dialysis Technicians.

Telephone advice to help solve minor problems is available at all times.

Often advice over the telephone will be sufficient to solve problems but if a visit to your home is needed, your problem will be dealt with promptly. It is sometimes necessary to prioritise visits depending on urgency. Night visiting is not available, but when the need for service is urgent and your call is received during the night, the problem will always be dealt with by the following mid-morning. For urgent calls received during the day, every effort will be made to correct the problem the same day, provided it is possible to get a technician to your home before 4 p.m.

During office hours Monday to Friday, your calls will be directed by the UHW switchboard to a member of the DTS team.

Outside working hours, the operator will contact the on-call technician who will then phone you as soon as possible on your home number.

These arrangements apply every day of the year with the exception of Christmas Day when telephone cover only is maintained.

Quality Control

As part of our programme to provide you with a quality service, a yearly check on the condition of your equipment and installation will be carried out by one of the managers from DTS. Please use this visit as an opportunity to comment on the service we provide.

Your views provide important feedback on the quality of service we aim to deliver

Quality management

In order to help us to provide you with a professional quality service we have developed formal, documented policies and procedures that help us to manage our work. We are registered with the British Standards Institute under their BS EN ISO 9002 programme and were the first NHS organisation in Wales to do so. We are now inspected at six monthly intervals to check that we continue to operate according to the British Standard.

Contact point:

Dialysis Technical Services

The Quadrant Centre

Cardiff Business Park

Llanishen

Cardiff

CF14 5QQ

Tel: (029) 2074 7747

Home Dialysis Administration Department

Who we are

Mrs Michelle Haytack – Home Dialysis Administrator

Ms Mitzi Fairbrother – Home Dialysis Administrator

Mr Malcolm Gregory – Storeman/Driver

How to contact us

Based at UHW

Telephone: (029) 2074 8457/8458

Fax: (029) 2074 3525

Office hours 9 a.m. to 5 p.m. Answerphone service out of hours

What we do

☐ arrange deliveries of dialysis supplies to patients' homes via the pharmaceutical company 'Unicare Limited'

☐ inform Unicare of changes to patient stock needs, arrange top ups if necessary

☐ arrange room adaptation for home haemodialysis patients.

☐ arrange weekly collection of dialysis waste from homes

- ☐ arrange re-imbursement of patients’ telephone rental charges
- ☐ arrange re-imbursement of electricity costs associated with home haemodialysis installations
- ☐ arrange delivery of supplies to holiday destinations for PD patients.

If you have any problems

Please direct any queries or problems that you may have on the above duties to the Home Dialysis Administration Team. We can ensure a prompt response to meet your needs. Please do not refer problems and queries on the above duties to the wards or dialysis units. They will not be able to help you.

The Clinical Psychology and Counselling Service for renal & transplant patients and their families

Psychological care is an important part of treatment for people who suffer from chronic renal failure. It is recognised that people with renal failure can experience a wide range of potentially difficult or confusing emotional reactions to their condition. The way in which a person responds to the illness and its treatments inevitably has an influence on their emotional well-being and quality of life. It can also impact upon physical health.

What is psychological care?

Psychological care involves looking after the patient’s emotional well being. Psychological care includes supporting the patient and their family during all stages of the illness and treatments. This may include advice and support to help the patient to integrate the treatment into daily life, cope with changes in the way they see themselves and any relationship difficulties that may occur.

Who provides psychological care?

All health care staff can and do provide some degree of psychological care. Many of the nursing staff have counselling qualifications and are able to provide emotional support.

What is psychological treatment?

Not everyone experiences psychological difficulties as a consequence of their renal difficulties. However, for some people there are times when they may need specialised help with a particular problem relating to their adjustment or psychological well being. Clinical and Counselling Psychologists can help with these difficulties. Common problems can include: depression, anxiety, anger and resentment, difficulties adjusting to life style changes, personal relationship/sexual difficulties and changes in family relationships. The Clinical and Counselling Psychologists can provide talking therapies and psychological interventions which can help people to cope with their difficulties. It is a confidential service and is available for people at any stage during their care. In some cases the Clinical Psychologist works together with the Consultant Liaison Psychiatrist to provide comprehensive management of a mental health problem.

The Clinical Psychology and Counselling Service is made up of a Consultant Clinical Psychologist, Clinical Psychologist and a Counselling Psychologist in Training, who are all employed on a part time basis. Referrals to the Clinical Psychology and Counselling Service are made usually by the Consultant.

Role of the Pre Dialysis Service

Our role

As a key part of the multi disciplinary team, the pre dialysis specialist nurse aims to empower kidney patients and their families and carers to learn about kidney disease and all types of treatment options. This includes patients who do not wish to have dialysis, those who have suddenly developed kidney failure and started dialysis as emergencies, as well as known patients referred from the out patient clinic.

The role includes provision of expert advice, education and support to patients, and helping them to making informed choices and decisions about their care. In addition, counselling and support is provided to help patients and carers cope with the psychological and emotional effects of the transition from health to chronic illness and its treatment.

When will I be referred?

You will be referred to a specialist nurse when your kidney function reaches around 25%, and the specialist nurse will arrange to visit you at home for an initial discussion about your condition and the various treatment options. Following the visit, you will have the opportunity to attend our “low clearance clinic” at UHW where you can learn more about dialysis and transplantation. You will be supported until you commence dialysis or transplantation when your care will be handed over to a different team.

To further complement your care, we run a patient support group three times a year. This is a 5 week course for patients who wish to increase their knowledge and understanding of chronic kidney disease and learn how best to manage their health.

Where to find us

The pre dialysis nursing team are located at the University Hospital of Wales; however, patients are referred to us from clinics at;

Prince Charles Hospital

Royal Glamorgan Hospital

Royal Gwent Hospital

Princess of Wales Hospital

Team Profile

Lead Consultant Nephrologist

4 Specialist Pre Dialysis Nurses covering different geographical areas

Secretary

Team Availability

The nursing team are available between 8am and 4pm Monday to Friday. We can be contacted through our secretary on 02920 745854.

The Role of the Anaemia Co-ordinator

The Anaemia Co-ordinator is an experienced nurse who has specialised in the care of anaemic patients. Her role is to co-ordinate the proper treatment of anaemia for haemodialysis and peritoneal dialysis patients. If you are an anaemic patient in one of these groups you may or may not meet her, however, she will be involved in assessing your treatment needs. She will be instrumental in setting up a package of care to relieve your symptoms of anaemia.

However, if you have not yet started dialysis, your anaemia care will be coordinated by one of the Pre-Dialysis Clinical Nurse Specialists who will oversee this part of your care.

The Co-ordinator’s role includes:

- liaison with the community team of nurses and your GP to enlist their support in a shared care system.
- liaison with your medical team to ensure that appropriate treatment is organised.
- patient education which is a large feature of the co-ordinators job. If you are having EPO, you will be taught how to inject EPO and its relevant side-effects. This may be by the co-ordinator or by your link nurse (a nurse from your particular dialysis unit). The nurse will supply you with relevant education and provide you with an information pack about EPO and iron management.
- making arrangements for you to receive intravenous iron, if you need it.
- reviewing your blood tests with your doctor and link nurse and organising changes when they need to be made.
- acting as contact for you and your community team. She is able to provide education and support about anaemia and its treatment to patients, their families, GPs and community nurses.

If you need to contact the anaemia office, please telephone 029 2074 8453

and the administrator will direct your enquiry appropriately.

INFORMATION FOR RENAL PATIENTS AND THEIR FAMILIES

December 2005

Produced with thanks to Age Concern Cardiff & the Vale of Glamorgan

INTRODUCTION

The purpose of this booklet is to let you know a little about the ways in which you can obtain practical and financial help.

On reading this booklet you may decide that you need to discuss some issues relating to dialysis and it's problems. The Renal Social Worker Elin Owen is based at :-

Social Work Department
University Hospital of Wales
Heath Park
Cardiff Tel: 029 2074 2098 / 2766

We would be pleased to have any comments on whether you found this booklet useful and if there are any additions you might find helpful

Community Care Services

Councils can provide a wide range of social care services such as care in your home, aids and adaptations, meals on wheels, day services and residential care. Demand for services is heavy and each council has a limited amount of money and has to make sure that the services that it provides are given to the people with the greatest need and who are most at risk. Eligibility for a service is based on Welsh Assembly Guidelines for Fair Access to Care, known as FACS. If you are having problems managing, as a renal patient you are entitled to request an assessment of your needs by Health and Social Services whether you are at home or waiting to go home from hospital. If you are a carer you are also entitled to ask Health and Social Services to talk to you about your needs in relation to the care that you give. These needs will include your own health and well being. In recent years the National Assembly of Wales has given annual funding to local authorities for services explicitly for carers and especially to provide breaks. Contact your local Social Services or Carers Centre for further information. Carers UK Wales will also have details of local carers services. Carers Centres can give carers support and lots of helpful information. They can also link you in with self help groups of carers and former carers who meet together for mutual support, relaxation, information sharing and campaigning.

Private Services

Lists for cleaning services can normally be provided by your local Social Services. Shopping can be provided as part of a package of care or you may be able to order direct from Wiltshire Farm Foods who deliver frozen foods fortnightly and cater for all special diets. Tel. 01633 871007 or free phone 0800 773773 for a catalogue. Website orders: www.wiltshirefarmfoods.com

Agencies who may be able to provide a **cleaning and shopping service:**

Cardiff:

All Care	029 20415000
Cardiff Care & Support	029 20235426
Caring 2000	029 20640001
Derwen Care	029 20396831
Evercare	029 20455300
Lynton Community Care	029 20405678
Somebody Cares	029 20252869
Freedom Choice	029 20455555
Mansfield Domestic Duties Agency	029 20653407

Lists for agencies outside Cardiff can normally be provided by your local Social Services.

Supermarket Home Deliveries

Asda	**www.asda.co.uk** (online only)
Iceland	0870 2422242 or **www.iceland.co.uk**
Sainsbury’s	0845 3012020 (Thornhill store, covers all Cardiff)

www.sainsburystoyou.com

Tescos **www.tesco.com/superstore** (not taking new telephone customers at present

State Benefits
Income Support

Income Support is an income related benefit for people aged 16-60 who are on a low income. It is made up of:

- Money for you
- Money for your partner, if you have one
- Extra money for people if their expenses are higher then others, for example, disabled people
- Money for certain housing costs that are not covered by Housing Benefit.

If you are living alone, or with a disabled partner and you are claiming Attendance Allowance or the middle or high rate of Disability Living Allowance for care, you may be able to claim a Severe Disability Premium. This may give you extra money on top of your existing Income Support or may make you eligible for Income Support if you weren't previously.

Savings over £3,000, usually affect how much Income Support you can get. Savings over £8,000 mean you usually cannot get Income Support (unless your partner if you have one is 60 or over)

To claim: complete forms A1 available from Benefit Agency offices.

Mortgages and Income Support

Claimants or potential claimants of Income Support need to register a claim straight away. You may get help with mortgage interest rates with certain restrictions:

a) Mortgages taken out before 21/10/95 - no help for the first 8 weeks, then 50% for the next 18 weeks.
b) Mortgages taken out after 2/10/95 – no help with interest for the first 39 weeks of a claim.

During the waiting period it is best to negotiate a ‘freeze’ with the mortgage company.

Pension Credit

This is for people aged 60 and over. Couples can apply if one is under 60. Pension Credit has two parts: the Guarantee Credit helps with daily living expenses by topping your weekly income up to a certain level set by the government. The Savings Credit provides additional money for people aged 65 and over who have income over a certain level from sources such as private pensions and savings.

If you are living alone, or with a disabled partner and you are claiming Attendance Allowance or the middle or high rate of Disability Living Allowance for care, you may be able to claim a

Severe Disability Premium. This may give you extra money on top of your existing Pension Credit or may make you eligible for Pension Credit if weren't previously

There is no upper savings limit and savings of up to £6,000 will be ignored.

To claim: phone the Pension Service's application line 0800 991234 (free phone) or complete form PC1 available from the Pension Service.

Mortgages and Guaranteed Pension Credit:

For pensioners with mortgages or having to take out mortgages, you would need to apply for Pension Credit and complete the first half of form MI12. The second half then needs to be completed by your mortgage lender. Pensioners who are eligible can have the interest on their mortgages paid.

Attendance Allowance

Attendance Allowance is a non means tested, non taxable benefit for people who are aged 65 or over with an illness or disability and who need help with personal care.

You can claim Attendance Allowance if you have needed help for 6 months or more, although there are special rules for people with a terminal illness.

Attendance Allowance is paid at different rates depending on your care needs. Claiming Attendance Allowance may increase other benefits you are getting, eg. Pension Credit/Income Support, Housing/Council Tax Benefit.

To apply complete form AA1 available from you local benefit agency.

Disability Living Allowance

Disability Living Allowance (DLA) is a tax free benefit for people with an illness or disability who need help with getting around and/or help with personal care and who are aged 65 and under. The care component has 3 rates depending on the degree of personal care needed and the mobility component has 2 rates depending on the level of walking ability or need for supervision.

The qualifying period for DLA is 3 months. Being in hospital dialysis prior to going home counts towards the 3 month waiting period.

DLA is paid in addition to any other benefits or income you may be receiving and is not affected by savings you might have.

Renal Dialysis and Attendance Allowance (AA) and Disability Living Allowance (DLA).

Specific rules for some kidney patients help them qualify for the middle rate of the care component of DLA. In general, if you are on home haemodialysis or intermittent peritoneal dialysis you will satisfy the rules. Depending on when and where you dialyse, you will be treated as satisfying part of the disability test. You must show that:

a) you undergo renal dialysis 2 or more times a week, and

b) the dialysis is of the type which normally requires the help or supervision of another person, or

c) because of your particular circumstances (eg age or visual impairment) you need the help of another person in order to avoid danger to yourself.

If you are dialysing as an out patient and getting help from hospital staff, you won't automatically satisfy the disability test. If the help you get is from someone not employed by the hospital, this will pass the disability test. Certain types of dialysis are designed to be carried out without help. These include continuous peritoneal dialysis (CAPD), continuous cycle peritoneal dialysis (CCPD) and peritoneal rapid overnight dialysis (PROD). You will only satisfy the disability test with these types of dialysis if you need help from another person due to a disability or frailty.

Carers Allowance

If you have an informal carer or relative who looks after you for 35 hours a week or more and you claim Attendance Allowance or Disability Living Allowance (at the middle or high rate of care), they may be able to claim Carers Allowance for looking after you.

Carers Allowance is not affected by savings but is affected by earnings. Certain benefits such as Income Support/Pension Credit may be affected if someone claims Carers Allowance for looking after you, it may be worth seeking advice before claiming.

Claiming Carers Allowance will protect the carers National Insurance contributions. An added incentive for the carer is the Carers Premium, which may increase the amount of Income Support, Pension Credit, and Housing Benefit/ Council Tax Benefit payable.

Statutory Sick Pay (SSP) and Incapacity Benefit

Statutory Sick Pay is paid for 28 weeks if you have been working for an employer when you became sick, and been sick for at least 4 days in a row including weekends or bank holidays.

When SSP ends and you are still unable to work through sickness you may be able to claim Incapacity Benefit.
If you are self employed or unemployed you should claim Incapacity Benefit on form SC1. People who have special medical treatment may get Incapacity Benefit instead of SSP even when they work for an employer. “Special medical treatment” can include dialysis.

You can find out more about incapacity Benefit in leaflet IB1 from your local Job Centre Plus

Social Fund

The Social Fund is a scheme to help people with exceptional expenses which are difficult for them to pay from their regular income. There are crisis loans, community care grants and budgeting loans. Forms are available from your local Benefit Agency.

Cold Weather Payments

You are eligible for a Cold Weather Payment if you or your partner are getting Pension Credit, Income Support or Income Based Jobseeker's Allowance, which includes either a premium for being over 60 or one for being disabled or long term sick. Payments will be sent out automatically to those who qualify if the average temperature is (or is forecast to be) zero degrees Celsius for seven consecutive days.

Council Tax Band

For those dialysing at home with equipment and stock occupying a room the family previously used as a bedroom or dining room, etc., it may be possible to claim a reduction in Council tax (i.e. one band lower). From April 2000 Band A properties may also qualify for a reduction in Council Tax. Contact your local Council Tax Department for further information once the dialysis equipment and stores are in place

Prescription Charges

Many pharmacies can, with you consent, arrange for the collection and delivery of your prescription.

a) Exemption on Medical grounds

All patients with a working fistula, permanent catheter or with a permanent cannula are entitled to free prescriptions. Other medical conditions include diabetes, epilepsy and "people who have a continuing physical disability which means they cannot go out without the help of another person". Transplant patients are not automatically eligible but may still be exempt on medical grounds if they still have a working fistula or permanent cannula. Please complete FP92A available from your Doctors surgery or tel. 01495 332000

b) Exemption on Income Grounds

People in receipt of Income Support or Income Based Jobseekers Allowance automatically qualify. If you are in receipt of Working Tax Credits or Child Tax Credits you may be entitled to help with prescription charges. For further information please ring 0845 6095000. Other people on a low income may be eligible but will have to apply on form HC1.

c) Exemption for other Reasons

Children under 16 (18 if in full time education), people over 60, pregnant women and those who have had a baby during the last 12 months are entitled to free prescriptions. In Wales you also get free prescriptions if you are under 25 and your prescription is dispensed in Wales.

For further information see the information leaflet HC11 Help with Health Costs

Those who are not exempt can save money by taking out a pre payment certificate. Pre payment and

exemption forms can be requested and returned to:

Business Services Centre
Cwmbran House
Macmillan Park Estate
Pontypool
S E Wales
NP4 0XS
Tel: 01495 332000

Welfare Rights Advice

For older people (aged 60 plus)

- Age Concern Cardiff & the Vale of Glamorgan has the only dedicated Welfare Rights Service
  02920 567883
- Age Concern Gwent's Hospital Discharge Service will give advice and fill out forms
  01633 763330
- Age Concern Morgannwg has an Information Service that

gives advice regarding state benefits and offers help with forms. 01685 353910

- Age Concern Neath Port Talbot has an Information and Advice service that offers advice and form filling 01792 81772

For other services please contact your local **Citizens Advice Bureau** who may be able to help you with a range of issues, including welfare benefits, housing and debt etc. Some are able to do home visits if you are too unwell to visit their offices. It is hoped that the Citizens Advice Bureau will be providing a welfare rights clinic as an integral part of the UHW renal clinic (at suite 18) on Friday afternoons. This will be a pilot scheme, initially for those who cannot access the help that they need locally. Appointments will need to be made in advance and an ambulance can be booked, as necessary under the auspices of the renal clinic.

Local Authority Housing Helplines

Some renal patients find that they need to be rehoused on medical grounds. Most county councils now have a housing help department, listed in the phone book. They can send an application form or a transfer form and also a list of local authority housing associations. Most can give advice to prevent homelessness and can help you to negotiate with mortgage companies and landlords and give advice on housing benefit (for tenants) and council tax benefits.

Car Insurance

We suggest that dialysis patients who wish to continue driving contact their car insurance company. Failure to notify your insurance company that you are receiving dialysis and treatment may invalidate you policy.

Employment

Hopefully before too long you may be well enough to return to work. It may be that some people find that there is a problem with this, e.g. if your work is too heavy or vigorous or there is no hygienic place to do a bag change (CAPD patients).

Some large firms are able to offer employees alternative employment within their organisations and this is often the best course.

For others it may be that the services of the Disability Employment Advisors (DEA) will help you to find suitable alternative work. The DEA is based at your local Job Centre and is there to help anyone with health problems that are looking for work. The DEA may also be able to help you retrain for work more suitable to your circumstances.

Blue Badge for the Car

This scheme provides a national arrangement of parking concessions for people with severe walking difficulties, people who are registered blind, or people with severe upper limb disabilities who travel either as drivers or passengers. The badge allows the holder to park closer to their destination. Badges are issued by the local authority Social Service Department on behalf of the Department of Transport.

If you receive the higher rate of the mobility component of Disability Living Allowance your application for a Blue Badge will be automatically accepted.

Holidays

If you are feeling well and your renal consultant is in agreement, there is no reason why you cannot go on holiday.

CAPD patients need to have hygienic conditions for bag changes. If the dialysis administrator is given plenty of notice, they can arrange for supplies to be delivered to your holiday destination.

Information on holidays for haemodialysis patients:
The British Kidney Patients Association (BKPA)
01420 472021/2
Welsh Kidney Patients Association 02920 742735
The National Kidney Patients Federation 01909 487795

Travelling Expenses for Hospital Treatment

If you are travelling to and from the University Hospital of Wales (UHW) for treatment you may be able to reclaim your travel expenses.

a) You may get help with fares or other travel expenses if you receive Income Support/ Income Based Jobseekers Allowance or the Guarantee Credit of Pension Credit.
b) Or if you receive Working Tax Credits with a disability element, or are getting Child Tax Credits but are not eligible for Working Tax Credits and your gross annual income is below a certain level.
c) Or if you are in receipt of a low income, you can apply to the Health Benefits Division on form HC1 for help with NHS costs.

To be able to claim you must take proof of the above benefits to the cash desk based in the concourse area at UHW

For further information about help with health costs contact the Health Costs Advice Line: 0845 850 1166

Fares for Relatives to Visit Patients

Relatives on Income Support, Income Based Jobseekers Allowance, Pension Credit (Guarantee Credit), may be able to get help towards travelling expenses for visiting close relatives in hospital from their local Benefit Agency. If the Benefit Agency is unable to help and the cost of travelling to visit is causing hardship then please contact the Social Work department, as we may be able to obtain help from other sources.

Bus Passes

Senior Citizens can normally obtain application forms for a Senior Citizens Bus Pass from the local post office. Younger people who are on the higher rate of the mobility component of Disability Living Allowance or are registered blind/ partially sighted can also apply for a disabled person's free bus pass.

Discretionary Funds

If you experience hardship as a direct result of your illness, we may be able to apply to other sources of help on your behalf eg. The British Kidney Patients Association (BPKA), The National Kidney Research Fund or The Welsh Kidney Patients Association. Please ask the Renal Social Worker for further information, application forms, etc.

Welsh Kidney Patients Association (WKPA)

The W.K.P.A is the patient's own organisation covering most of Wales. Membership is free and open to all dialysis and transplant patients and carers. They have a quarterly newsletter and help develop self-help groups for support and to enable people to meet socially to exchange ideas, information and experiences. They have worked with the UHW Renal Unit to develop an information library designed for kidney patients and you can look at it on the computers in the outpatient's clinic at UHW or on ward B5 or through the W.K.P.A. For more information on W.K.P.A. please contact them at Lakeside Offices, UHW, Heath Park, Cardiff CF14 4XW
Phone/fax :029 2074 2735 or at their web site address www.wkpa.org.uk/

Telephones

All patients on home-based dialysis must have a telephone so that they can contact their unit at any time in an emergency. The Home Dialysis Administrator can make arrangements for the rental to be paid.

Other patients may be eligible for installation of a telephone via their local Social Services Department but the qualifying conditions are usually very stringent e.g. people who live alone and are likely to need to contact a doctor in an emergency.

Useful Addresses and Telephone Numbers

Benefit Enquiry Line (for people with disabilities)	0800 882200
Over 60's Pension and Pension Credit Helpline	0845 6060265
Benefit Agency	
Cardiff East (Eastgate House)	029 20423400
Cardiff West (Cowbridge Rd)	029 2042 3200
Cardiff Central (Southgate House)	029 2042 8000
Disability Benefit Centre, Gabalfa (For Attendance Allowance and Disability Living Allowance)	029 2058 6002
Attendance Allowance/ Disability Living Allowance Helpline	08457 123456
Carers UK Wales	029 20811370
British Kidney Patients Association	01420 472021/2
National Kidney Federation (NKF)	01909 487795
National Kidney Federation packs for Kidney Patients	0845 601 0209
Welsh Kidney Patients Association	029 20742735
National Kidney Research Fund	0845 070 7601
Social Work Department, University Hospital of Wales	

029 20742768

Disclaimer: The information given in this booklet does not reflect the views of Social Services and is given in good faith. No responsibility can be accepted for inaccuracies.

CHAPTER 9 DIET.

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 9. Diet

- **Diet & Haemodialysis**
- **Diet & Kidney faliure**
- **Diet & Peritoneal Dialysis**
- **Diet & Transplant**
- **Low Potassium Recipies**

Diet and Haemodialysis

When Will I See The Dietitian?

Each dialysis unit has a Dietitian. Within 6 weeks of starting dialysis the Dietitian will arrange to see you to discuss your diet. It is important to know that every person is individual in their kidney condition and the way that they respond to haemodialysis. You should only make changes to the foods you eat if you have been **told** to do so by the Renal Dietitians. That is, do not change your diet just because the person in the station next to you has been told to do so. If you need to make any changes, the Dietitian will come and see you and advise you on what to change and why.

Following your first visit by the Dietitian on the haemodialysis unit you may be told that you do not need to make any changes to what you eat. However the dietitian may ask you to make changes during your time on haemodialysis as kidney function often deteriorates as time progresses.

Do I Need A Special Diet When I Am On Haemodialysis?

Not everybody will need to change the way they eat because they start haemodialysis. It is important to eat well as people who receive haemodialysis have a greater requirement for energy and protein.

Calories (energy)

Calories are used up during the haemodialysis process and so it is important that you eat enough to compensate for these losses. Try to eat 3 meals each day. If you are struggling with your appetite and your portion sizes have become smaller, try and have small frequent foods i.e.;3 small meals and 2-3 between meal snacks. If you are not meeting your energy needs your dry weight may fall and you may start to feel weak. The Dietitian will advise you if you need to increase the amount of energy in your diet.

Protein

Protein is lost during haemodialysis. This needs to be replaced. Foods that are rich in protein include meat, poultry, fish, eggs, dairy products and pluses. You should aim to have a protein food at each meal. If you are not eating enough protein this may show as a low blood albumin (protein) which may lead to muscle loss and muscle weakness.

Potassium

Potassium is a mineral that is found in many foods that we eat. The kidneys help usually remove excess potassium form the blood. However, if your urine output has fallen you will stat to rely more on the haemodialysis machine to remove any excess potassium in your blood. In this instance potassium level can build up between dialysis sessions. Your blood results will be checked every month and if your potassium levels go too high the Dietitian will advise you on a potassium restricted diet. **Do not restrict potassium unless you have been told to do so.**

Fluids

Fluid comes from the foods we eat as well as from drinks. As your kidneys begin to work less well you may find that you pass less urine. If this happens and you do not cut down the amount you drink you will become fluid overloaded. Being fluid overloaded can cause swollen ankles and shortness of breath. It also puts strain on your heart. Your doctor or dialysis nurse may set you a daily fluid allowance/ restriction. If this is the case the Dietitian will advise you on sources of fluid in the diet and on how to stick to your fluid allowance.

Salt (sodium)

As with general healthy eating advice the aim is to eat less salt. High salt diets have been associated with high blood pressure. In addition high salt diets can make you feel thirsty, making your fluid allowance difficult to comply with. Salt does not only include salt that we add to food in cooking and at the table, but it also includes salt hidden in foods. Try and go for foods that contain less than 0.25g salt (less than 0.1g Sodium).Also to cut down on salt try adding a little either in cooking or at the table i.e.; not at both places, and if foods are tasting bland try flavouring with herbs and spices.

Phosphate

Phosphate and calcium work together to keep bones healthy and strong. When kidneys fail they become less able to remove phosphate from the body. If phosphate levels remain too high for too long, it can chalk up and harden blood vessels and may cause weak bones. It can also cause red eyes and itchy skin.

Phosphate in the blood can be stopped from going too high by taking tablets called “Phosphate Binders”. These include Calcichew, Renagel, Phosex and Alu-Cap. It is important that these tablets are taken at the correct time and with the right foods. Your Dietitian will advise you on this.

What Should I Eat on Dialysis Days?

It is important to eat the same on dialysis days as on any other day. If you feel nauseous on dialysis, try snacking little and often.

Can I Eat Out?

Yes, all dialysis patients should feel free to eat out. If you are on a potassium restricted diet you may want to discuss low potassium options with the Dietitian first. You may also wish to phone ahead to the establishment and request a copy of the menu.

Can I Drink Alcohol?

This is up to your Doctor to decide. If you are allowed and you follow a fluid allowance, make sure alcoholic drinks are included in this. If you are on a potassium restricted diet the Dietitian will advise you on lower potassium drinks.

Diet and Kidney Failure

Do I Need To Follow A Special Diet?

If your kidneys are failing you may be wondering if you need to follow a ‘special diet’.

Healthy kidneys help your body get rid of waste products however when they are not working these waste products can build up in your blood. One such waste product is potassium. Potassium is a mineral found in food. You may need to watch the amount of potassium you are eating if your potassium level in your blood becomes too high. Examples of foods that are high in potassium include many fruit and vegetables, coffee and chocolate.

It is very important to remember that everyone has different dietary needs and these needs can change as your kidney function changes. What is good for one person may be harmful for another. It is therefore very important that you **do not restrict** your diet unless advised to do so by your Doctor or Dietitian. If you need a special diet you will be referred to the Dietitians for dietary advice.

Will I Need To Restrict How Much I Drink?

Healthy kidneys control the level of fluid in your body. Drinking more increases urine production and drinking less reduces how much urine the kidneys make. As your kidneys fail they may no longer able to control the amount of fluid in your body and it becomes important to watch the amount of fluid you drink. The Doctor may set a ‘fluid allowance’ for you which may be less than you are used to drinking. To help you keep to your daily fluid allowance the Dietitian can offer suggestions on how you can best manage your fluid intake.

What Other Advice Can The Dietitian Give Me?

People with kidney failure may feel sick, experience taste changes and a loss of appetite. These side effects can result in you becoming very tired, eating less and losing weight. The Dietitians can make suggestions on how to help you with these symptoms.

When Will I See The Dietitian?

If you need to be seen by a Dietitian your Doctor will refer you. If you are an inpatient you will be seen by a Dietitian on the ward. If you are an outpatient you will be offered an outpatient clinic appointment.

Diet and Peritoneal Dialysis

It is important to eat well when on peritoneal dialysis (PD) to remain healthy and to get the maximum benefit from your treatment.

The principles of a healthy diet on PD are as follows:

Protein

It is important to have a good protein intake whilst on PD as you lose protein every time you drain a bag out. Therefore, you need to eat more protein foods to replace these losses.
If you do not eat enough protein it may show as a low blood albumin (protein) level and you may experience muscle breakdown and muscle weakness.
Foods which are a good source of protein include poultry, fish, eggs, red meat, cheese, milk, yogurt, quorn, tofu and pulses. You should aim to have a portion of protein food at each meal.

Calories (energy)

The dialysis fluid used in PD contains sugar (glucose) and some of it is absorbed by the body. This may lead to weight gain so you may need to cut down the amount of fat and sugar in your diet. For example a 2 litre weak bag may provide 76Kcal.

Fluid

As kidney function deteriorates you may find that you pass less urine and if you do not reduce the amount you drink, this may lead to you becoming fluid overloaded. Fluid overload can lead to shortness of breath, swollen ankles and can put a strain on your heart. Your doctor or PD nurse will advise you on how much fluid you can drink per day to avoid these problems. The Dietitian can advise you on ways to keep within your daily fluid allowance.

Sodium (salt)

Salt is also called sodium chloride. It is found in many foods and if you eat a lot of salt and/or salty foods it can make you thirstier. This will make it difficult to keep to your daily fluid allowance. Salt can also contribute to high blood pressure. It is a good idea to keep the salt in your diet to a minimum, this can be achieved by not adding salt to your food at the table and avoiding processed foods where possible. The dietitian can advise you further on how to do this.

Fibre

Fibre is important to keep your bowels healthy and in preventing constipation. Constipation is a common problem with people on PD and it can cause difficulties draining your PD fluid in and out. Eating more foods high in fibre such as wholegrain products e.g. bread, pasta and breakfast cereals, beans, pulses, fruit and vegetables can help.

Phosphate

In renal failure, the kidneys are unable to remove excess phosphate from your body. Over a long time high blood phosphate levels can cause hardening of your blood vessels and may result in renal bone disease, but short term you may experience itching, red eyes and joint pain.
To keep blood phosphate levels normal phosphate binders e.g. calcichew, renagel, phosex or alucap may

be prescribed. These drugs bind to the phosphate found in food in your stomach and prevent it going into your blood. It is important that these tablets are taken at the right time and with the right foods. The Dietitian will be able to advise you further.

Potassium

In renal failure, the kidneys are unable to remove excess potassium from your body. Dialysis helps remove potassium from your blood. When you are on PD it is unlikely that your blood potassium will increase to a high level as PD provides continuous daily dialysis, therefore you should not need to restrict the potassium in your diet. Only follow a low potassium diet when on PD if advised to do so by your Doctor, PD Nurse or Dietitian.

Peritonitis

If you develop peritonitis you will lose more protein than usual into your PD fluid. It is important that you try and eat more protein than usual to cover these losses. If your appetite is not affected then try and increase the protein portion at mealtimes, however if your appetite is reduced you may find it easier to have smaller more frequent meals throughout the day ensuring a protein portion at each meal/snack. The dietitian will be able to provide further advice and it may be necessary to have nutritional supplements for a short period until you appetite returns.

When will I see the Dietitian

The Dietitian will give you individual and practical advice on how to change your diet, to include these guidelines after your PD training.

The Dietitian is available in the PD clinic and will be happy to discuss any dietary issues you may have.

Diet after Kidney Transplant

Do I Need To Be On A Special Diet?

If your transplant has been successful there is no need for you to be on any special diets that you may have followed before your transplant for example a low potassium diet or high protein diet. You can now eat a healthy balanced diet.

However, if after your transplant your kidney is not functioning well the potassium in your blood may become too high and you may need to follow a low potassium diet. Your Doctor will inform you of this and refer you to the Dietitians for further advice.

Food Safety

You have been prescribed anti-rejection tablets which help stop your body from rejecting your new kidney. These tablets can make your body less able to fight infections and therefore you are more likely to become unwell from a food related illness. The Dietitian will see you when you on the ward after your transplant and advise you on which foods to avoid and how to handle and store food safely to reduce this risk.

Healthy Eating

It is common to gain weight after a transplant, as you may no longer be on a restricted diet and your appetite will probably improve. Also, you have been given steroids as part of your anti-rejection tablets which can also make you gain weight. It is important to try and keep a healthy weight.

The anti-rejection tablets you need to take can also increase the levels of lipids (cholesterol and triglycerides) and sugars in your blood.

Following a healthy diet will help you to control your weight and lower your blood lipid and sugar levels. The principles of a healthy diet are:

- Aim for 5 portions of fruit and vegetables a day
- Reduce the fat in your diet particularly animal fat.
- Increase fibre from wholemeal, whole-wheat foods, fruit and vegetables.
- Decrease sugar and sugary foods in your diet
- Watch your intake of salt and salty foods, which will help reduce blood pressure
- Limit your alcohol intake to a safe level (1-2 units/day for women, 2-3 units/day for men) One unit is ½ pint of beer, or a small glass of wine or a pub measure of spirits.

If you require any more diet advice once you have been discharged from the ward your doctor will refer you to the Dietitians for an out-patient appointment.

Low potassium recipes

Department of Dietetics

University Hospital of Wales, Cardiff

Contents

1. Sweet and Sour Pork

Serves 2

8oz lean pork cut into 1" cubes

1 teaspoon olive oil

black pepper

1 level teaspoon ground ginger

oil for deep frying (preferably polyunsaturated)

Batter

6oz plain flour

1 small egg

½ pint water

½ teaspoon oil

Sweet & Sour Sauce

2 tablespoons white sugar

black pepper

6 tablespoons vinegar

a few drops of red food colouring

1/3 pint water

2 heaped teaspoons cornflour

2 tablespoons pineapple juice (which can be drained from tinned pineapple)

To make the batter

Sift the flour into a basin and make a well in the centre. Drop in the egg, then gradually add and beat in the water. Stir in the oil and set aside for 20 minutes to ‘rest’.

To make the sauce

Place the sugar, pepper, vinegar, water and pineapple juice into a saucepan and bring to the boil.

Blend the cornflour with 2 dessertspoonfuls of cold water and stir into the sauce and continue boiling for 2 minutes. Keep hot.

The meat

Place the pork cubes into a basin and add the olive oil, pepper and ground ginger. Mix well.

Coat the pork in 2 tablespoons of plain flour, removing any excess flour. Drop the meat into the batter.

Heat the cooking oil in a deep pan until hot, but not smoking. Drop the pork into it and cook for 8 - 9 minutes or until golden brown.

Drain on absorbent paper, place in a heated serving dish and pour the sauce over. Serve with plain or boiled rice.

Recipe adaptations

1. This recipe can be made with chicken instead of pork.

2. If you do not wish to deep fry, omit the batter and shallow fry the coated meat with a few slices of onion and green pepper. Serve with the sweet and sour sauce and rice.

Note

Although this recipe contains pineapple juice, normally forbidden on a low potassium diet, the quantity used is small. As the dish is served with rice which is low in potassium, it is acceptable on such a diet.

2. Cannelloni

Serves 4

8oz cannelloni (8 pieces)

10oz cooked minced beef

1½ oz fresh white breadcrumbs

2oz grated Parmesan cheese

1 beaten egg

pinch ground nutmeg

a little gravy from the minced beef

pinch of salt and black pepper to taste

1oz butter

¼ pint water

Cook the cannelloni in boiling water for 8 - 10 minutes. Drain thoroughly. When cooled slightly, split each one lengthways and open out. Alternatively, use instant cannelloni, which does not need cooking, and simply fill with a spoon or piping bag fitted with a large plain nozzle.

To make the stuffing, combine the minced beef, breadcrumbs, half the cheese, egg and nutmeg together. Bind with a little gravy, then season to taste.

Divide the mixture into 8 and place in the cannelloni shells. Roll up like sausages. Place in a row in a shallow, buttered ovenproof dish. Dot with butter, then sprinkle with the rest of the cheese. Pour the water into the dish then re-heat in the centre of a moderate oven (350ºF, 180ºC, Gas mark 4) for 25 - 30 - minutes.

3. Sweet & Sour Chicken Stir-fry

Serves 4

1 lb chicken, cut into small pieces

1 tablespoon vegetable oil

ground black pepper

8oz tin crushed pineapple, drained of juice

2 teaspoons lemon juice

2 teaspoons honey

paprika pepper for decorating

Heat the oil in a non-stick frying pan and add the chicken and black pepper. Stir over a high heat until the chicken begins to turn brown.

Mix together the pineapple and honey and add to the pan. Cook for a further 3 minutes. Remove the pan from the heat and stir into the lemon juice.

Serve immediately and shake on a little paprika to decorate

Serve with plain boiled rice or pasta.

4. Beef Bolognaise Sauce

Serves 4

The tomato in this recipe will count as 1 vegetable serving in the K^+/ LK diet.

448g (1lb) minced beef

1 tbsp vegetable oil

1 small onion, finely chopped 112g (4oz)

1 clove garlic

14g (½ oz) cornflour

300ml (½ pint) stock Beef stock cube x 1

Black pepper, salt

2 tsp dried oregano

196g (7oz) drained chopped tinned tomatoes

Heat the oil in a saucepan and sweat the onion lightly. Add the mince and **finely** chopped garlic until browned and softened, stirring continuously. Add the stock and simmer for 20 minutes. Add oregano, salt and pepper. Add drained tomatoes. Stir and cook for further 2 minutes.

Mix the cornflour with a little cold water and add to the pan stirring continuously. Simmer for 10 minutes.

5. Tuna & Potato Bake

Serves 4

The potato content of this meal counts as the potato allowance. No other potato should be served with this meal

448g (1lb) double boiled potatoes

1 medium onion, sliced

Juice of ½ lemon

420g (15oz) drained tuna fish

4 eggs beaten

Black pepper

2 pinches nutmeg

Butter/margarine

Boil the onion for 10 minutes

Mash the double boiled potato and onion together. Add the pepper, nutmeg, lemon juice and beaten eggs.

Flake the tuna and stir into the potato mixture.

Place mixture into well greased ovenproof dish and brush the top with melted butter or margarine. Bake in a hot oven (450°F, 230°C, Gas Mark 6) for about 30 minutes until brown on top.

6. Savoury Mince

The vegetable content of this dish will count as one vegetable serving in the K^+/LK^+ diet.

448g (1lb) minced beef

1 tbsp vegetable oil

1 small onion, finely chopped 112g

100g (3½ oz) drained, tinned tomato, chopped

336g (12 oz carrots, chopped)

14g(½ oz) cornflour

450 ml (¾ pint) stock

Salt and pepper

Parsley to garnish

Parboil the carrots for 10 minutes and place to one side.

Heat the saucepan and fry the onion until browned and softened. Add the mince and cook until browned. Add the stock and bring to the boil. Boil for 2 minutes. Skim off any fat. Add the drained, chopped tomato. Mix the cornfour with a little cold water and add to the pan stirring continuously. Add the par-boiled carrots and allow to cook for a further 10 minutes. If necessary add a little extra stock. Season with pepper and a little salt.

Garnish with parsley.

7. Corned Beef Hash

Serves 4

The potato in this recipe will count as the potato allowance for this meal. No other potato should be allowed with meal.

336g (12oz) corned beef, diced

1 medium onion, peeled and chopped 150g

448g (1lb) double boiled potatoes, mashed with a little milk and butter seasoned with pepper only.

Butter or margarine.

Semi-skimmed mil 30 ml

Flora 20g

Boil the onion for ten minutes.

Mix the corned beef, onion and double boiled potato together and put into well buttered ovenproof dish.

Brush the top with melted butter or margarine and bake in a hot oven (450° F, 230° C, Gas Mark 6) for approximately 30 minutes until brown on top.

8. Lamb casserole

Serves 4

The vegetable content of this dish will count as one vegetable serving for the K^+/LK^+ diet.

448g (1lb) lamb pieces cut into 1" cubes

168g (6oz) carrots, sliced

140g (5oz) swede, chopped

196g (7oz) onion, chopped

50g (1¾) drained, chopped, tinned tomatoes

28g (1oz) plain flour

450 ml (¾ pint) beef stock

1½ tbsp vegetable oil

Bouquet garni

½ tsp dried Rosemary

Salt & Pepper

1 tsp fresh dried Parsley

Par boil the swede in a large pan of slightly salted water for 5 minutes. Add the carrots and onion and boil for a further 5 minutes.

Place the vegetables to one side.

Fry the lamb in the vegetable oil until browned. Remove lamb with a slotted spoon and set aside. Add the flour and cook for 2 - 3 minutes to make a roux. Add the stock, stirring continuously. Bring to the boil for 2 - 3 minutes. Return lamb to the pan with the bouquet garni, rosemary and drained chopped tomatoes, cover and simmer on a low heat until the lamb is tender.

Drain the vegetables and add to the pan. Cook for a further 20 minutes adding extra stock or water as required.

Adjust seasoning. Remove bouquet garni and garnish with parsley.

CHAPTER 10 DRUGS

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 10. Drugs

- Ciprofloxacin
- Clonazepam
- Clopidogrel
- Colchicine
- Co-Trimoxazole
- Cyclophosphamide
- Cyclosporin
- Ciclosporin
- Digoxin
- Domperidone
- Doxazosin
- EPO
- Eprex
- Fludrocortisone
- Furosemide
- GTN Patch
- GTN Spray
- GTN Tab
- Iron
- Ketovite
- Lactulose
- Lansoprazole
- Metolazone
- Methylprednisolone
- Metoclopramide
- Minoxidil

- Moxonidine
- Mycophenolate Mofetil
- Mycophenolate sodium
- Neorecormon
- Nifedipine
- Nitrates
- OKT3
- Omeprazole
- Penicillin
- Phenytoin
- Potassium Supplement
- Prednisolone
- Quinine
- Ranitidine
- Senna
- Sevelamer
- Simvastatin
- Sirolimus
- Sodium bicarbonate
- Sulphonylureas
- Thyroxine
- Tacrolimus
- Trimethoprim
- Valganciclovir
- Vancomycin
- Verapamil

- **Warfarin**

Drug Information Cards

Introduction

The Drug Information Cards have been designed by the Pharmacy Department at the University Hospital of Wales, Cardiff, to give you some facts about your medicines. They aim to answer some of the most commonly asked questions, for example:

- Why do I need to take this drug?
- How does this drug work?
- What are the common side-effects of this drug?
- Are there any special precautions that I need to know about when taking this drug?

Some of the cards are specifically for people with kidney failure or who have had a kidney transplant, whereas others are relevant to many more people. A card has not been written for every drug and you may be taking a drug for which a drug information card is not available.

Large amounts of detailed information will not be found on the cards but, hopefully, you will have a better understanding of your drug treatment after reading them.

If you have any further questions or concerns about medicines prescribed by your doctor or purchased over the counter at a pharmacy shop, then your pharmacist or doctor will be happy to advise you.

click here to view the list of drugs

A2R blocker

(for renal patients)

The proper name of your drug is:

What it does

The drug may be used to treat high blood pressure. It can also relieve the strain on a weak heart by improving the circulation of the blood. This medication can also help people with protein in the urine.

Precautions

Most people taking this drug feel very well, but sometimes it causes a rash, headache or dizziness.

A2R blockers can increase potassium levels in the blood.

This drug is usually started in a very small dose; this helps to avoid dizziness.

If you get any of these problems or if you feel unwell, do not stop taking your tablets but do tell your doctor.

Other information

It is important to take it at regular intervals. If you forget a dose, take it as soon as you remember but do not take two doses within three hours of each other.

You may take this drug with or without food.

ACE inhibitor

(for renal patients)

The proper name of your drug is:

What it does

This medicine may be used to treat high blood pressure. It can also relieve the strain on a weak heart by improving the circulation of the blood. This medication can also help people with protein in the urine.

Precautions

Most people taking this medicine feel very well, but sometimes it causes a rash, headache or dizziness or a dry cough.

ACE inhibitors can increase potassium levels in the blood.

This drug is usually started in a very small dose; this helps to avoid dizziness.

If you get any of these problems or if you feel unwell, do not stop taking your tablets but do tell your doctor.

Other information

It is important to take this medicine at regular intervals. If you forget a dose, take it as soon as you remember but do not take two doses within three hours of each other.

You may take this drug with or without food.

Aciclovir

What it does

Aciclovir is used to treat or prevent infections caused by certain types of virus.

Precautions

Aciclovir tablets or injection may cause stomach upset, rash and can make you fell dizzy.

Aciclovir cream may cause itching and a burning sensation on the skin.

Other information

Keep taking the drug until your doctor tells you to stop or until the course of treatment is finished.

Alfacalcidol (for renal patients)

What it does

Alfacalcidol is a form of vitamin D. It helps your body to absorb calcium from food. Alfacalcidol also helps to lower your parathyroid hormone (PTH) level.

If your kidneys are damaged you may have low vitamin D levels, high PTH levels and low calcium levels. All can make your bones weak. As alfacalcidol increases your calcium and lowers your PTH, it keeps your bones strong.

Precautions

Most people taking alfacalcidol feel very well. Tell your doctor if you feel sick or vomit, get diarrhoea, need to pass water frequently or feel more tired than usual. These symptoms may mean that you have too much calcium in the blood.

Aluminium hydroxide (Alu-cap®)

(for renal patients)

What it does

Alu-cap ® is a phosphate binder. It reduces the absorption of phosphate from food, so it treats high levels of phosphate in the blood (hyperphosphataemia). Too much phosphate in the blood can cause itching, red, sore eyes and may make your bones weak.

Precautions

Most people taking Alu-cap ® feel very well. Some people get constipation.

Other information

Alu-cap ® capsules must be swallowed whole with meals. Phosphate binders **only** need to be taken at mealtimes.

Amiodarone

What it does

Amiodarone is used to control certain fast or irregular heart rhythms. The drug is very effective in treating certain serious disturbances in heart rhythm.

Precautions

Most people taking this drug feel very well. Rarely, it causes headaches, tiredness, dizziness or a metallic taste in the mouth. It makes some people sensitive to sunlight so you should shield your skin from direct sun, using clothes or a sun block with a high 'protection factor'. Occasionally, sunlight will cause the skin to discolour slightly.

Other very rare side effects may occur if you take the drug for a long time. These include shortness of breath, thyroid problems and minor eye problems but eyesight is not affected. These side effects should all go away when the drug is stopped.

Your doctor will carry out regular checks for side effects. If you notice increasing shortness of breath, an unusual change in weight, restlessness or tiredness do not stop taking these tablets but do tell your doctor.

Other information

- It takes at least three weeks for the right level of amiodarone to build up in your body. Your doctor may therefore ask you to take a higher dose in the first few weeks and cut it down later.
- You may take this drug with or without food.

Anti-inflammatory analgesic drug

The proper name of your drug is:

What it does

This drug helps to relieve pain, particularly where inflammation (swelling) is also present.

Precautions

Before taking this drug tell your doctor if you have ever had asthma, if you are allergic to aspirin or you have ever had a stomach-ulcer.

Some people taking this drug feel sick, or get an upset stomach or indigestion. You can reduce the chance of these side-effects if you take the drug with food or milk.

Tell your doctor if:

- you get indigestion or stomach discomfort after taking this drug
- you vomit blood or pass black motions
- you get dizzy, short of breath or ringing in your ears

Other information

This drug usually works within a few days of taking it. Tell your doctor if it has not worked after taking it for a week. With some conditions you will need to take it for up to three weeks to tell if it is working.

Antihistamines

(for renal patients)

The name of your antihistamine is

……………………………………

What it does

People take antihistamines for many reasons, for example to relieve symptoms of hay fever and other allergies. Kidney patients often need antihistamines. Damaged kidneys are unable to remove the body’s waste products, which will build up in the blood causing itching. Antihistamines can relieve itching.

Precautions

Some antihistamines cause drowsiness. Your doctor or pharmacist will tell you if your particular antihistamine will make you feel tired. These drugs occasionally cause dry mouth or blurred vision.

Other information

Alcohol enhances the drowsiness caused by antihistamines.

Aranesp®

(Erythropoetin = EPO)

(for renal patients)

What it does

EPO is a hormone made by the kidneys. It helps the body to make healthy red blood cells. If your kidneys are not working you may become anaemic (measured by low haemoglobin level in the blood) because there is less EPO in your body.

Anaemia has many consequences, such as tiredness, shortness of breath and may cause heart problems, such as angina.

Your EPO injection is called Aranesp®.

Precautions

Most people on Aranesp® feel very well. Some people get ‘flu-like symptoms at the start of treatment. Others may get a rise in blood pressure.

Other information

- Aranesp® is injected, usually underneath the skin on the thigh or in the tummy. For those people who have haemodialysis, Aranesp® can be injected into the dialysis machine.
- The drug will not work straight away. It may take a few weeks for you to

feel better.

- Aranesp® must be kept in a fridge.

Aspirin (for renal patients)

What it does

A low dose of aspirin reduces the chances of clotting in narrowed blood vessels in the heart (causing angina) or brain (causing a stroke). Aspirin helps to prevent these problems getting any worse.

Low dose aspirin can also reduce the chances of clotting in blood vessels supplying a kidney transplant and in the fistulas or lines of haemodialysis patients.

Precautions

Aspirin may cause stomach upsets, but this is very unusual with the low dose you are taking. It is even less likely if you take your aspirin with food.

Azathioprine (for renal patients)

What it does

Azathioprine is an immunosuppressant drug. By blocking your body's immune system, azathioprine reduces the risk of your kidney transplant rejecting.

It can also be used to treat a variety of other conditions which require immunosuppression.

Precautions

The drug can cause stomach upset. This is less likely if you take it with food. You are also at increased risk of picking up infections.

A few people may be allergic to azathioprine. Tell your doctor if you get a fever, skin rash, sore throat, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs such as azathioprine cause an increased risk of developing certain forms of cancer when taken for a long period of time.

Other information

- Do not take a drug called allopurinol while you are taking azathioprine without checking that it is safe to do so with your doctor or pharmacist.
- Take your azathioprine at regular times each day. Do not stop unless your doctor tells you to.

Beta-blocker

The proper name of your drug is:

What it does

This drug reduces the work of the heart. It may be used to treat angina, control the heart rhythm or reduce high blood pressure- depending on the dose.

Precautions

It is a very safe drug. Rarely it causes cold hands or feet, stomach upsets or sleeping problems. This drug has to be used with caution by people with asthma or respiratory problems.

While taking this drug, a few men have difficulties with sexual intercourse because they cannot get an erection. This problem does go away if you stop taking the drug, but only do so after contacting your doctor.

Other information

This drug can be taken with or without food.

Bumetanide (for renal patients)

What it does

Bumetanide is a water tablet (diuretic). Bumetanide removes salt and water from the body. It is used to treat a build-up of fluid.

It works rapidly, giving its strongest effects within 1 hour. The effects last for up to 6 hours.

Precautions

Occasionally people get rashes or ringing in the ears.

Other information

- You may take this drug with or without food.
- It is best to take bumetanide in the morning so that you don’t need to get up in the night to go to the toilet.
- Please stay on your usual diet unless you are asked to alter it.
- Sometimes the body loses a salt called potassium. If necessary, your doctor will ask you to eat more potassium containing foods such as bananas or chocolate or give you potassium tablets.

Calcium acetate (Phosex®)

(for renal patients)

What it does

Phosex® is a phosphate binder. It reduces the absorption of phosphate from food, so it treats high levels of phosphate in the blood (hyperphosphataemia). Too much phosphate in the blood can cause itching, red, sore eyes and may make your bones weak.

Precautions

Most people taking Phosex® feel very well. Some people get constipation or stomach upsets.

Other information

Phosex® tablets must be swallowed whole with meals. Phosphate binders **only** need to be taken at mealtimes.

Calcium carbonate (Calcichew®) (for renal patients)

What it does

Calcichew® is a phosphate binder. It reduces the absorption of phosphate from food, so it treats high levels of phosphate in the blood (hyperphosphataemia). Too much phosphate in the blood can cause itching, red, sore eyes and may make your bones weak.

Calcichew® can also be used as a calcium supplement for people that have low calcium levels in the blood.

Precautions

Most people taking Calcichew® feel very well. Some people get constipation or stomach upsets.

Other information

Ask your doctor why you need to take Calcichew® tablets so you know when it is best to take them.

When used as a phosphate binder, Calcichew® tablets must be sucked or chewed 5 to 10 minutes **before** meals. Phosphate binders **only** need to be taken at mealtimes.

If you are taking Calcichew® tablets for a low calcium, it is best to take them **in**

between meals.

Calcium-channel blocker

The proper name of your drug is:

What it does

This drug improves the circulation of blood and reduces the amount of work for the heart. It is used to prevent attacks of angina or to reduce high blood pressure.

Precautions

This drug is very safe. It can cause ankle swelling, headaches, stomach upsets or a rash. Very rarely, fast or slow heart beat may occur with the calcium-channel blocker. Check with your doctor or pharmacist if you are worried.

Other information

You may take this drug with or without food.

Calcium Resonium

(for renal patients)

What it does

Calcium resonium is used to lower high amounts of potassium in your blood. High amounts of potassium can disturb the rhythm of your heartbeat.

Precautions

Most people taking calcium resonium feel very well. Some people get constipation or stomach upsets.

Other information

- Calcium resonium is mixed with water and taken with food
- You may also be told to follow a low potassium diet because your kidneys are unable to remove potassium from the body

Ciclosporin (for renal patients)

Your brand of ciclosporin is called:

Please make sure that your brand of ciclosporin is always the same.

What it does

Ciclosporin is an immunosuppressant drug. By blocking your body’s immune system, ciclosporin reduces the risk of your kidney transplant rejecting.

Ciclosporin is also used to treat some people who have inflammatory kidney problems.

Precautions

Ciclosporin can cause stomach upset, a burning or tingling sensation in the hands and feet, an increase in body hair, swelling of the gums, a rise in blood pressure, a rise in blood sugar, increased cholesterol levels and may make you feel shaky. You are also at increased risk of picking up infections.

Some people are very sensitive to ciclosporin. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs like ciclosporin cause an increased risk of developing certain forms of cancer when taken for a long period of time, for example skin cancer. To reduce the chances of having these skin problems you must always apply sun protection cream with a high SPF (at least 30). You should also tell your doctor if you have any new moles or if you notice any changes in their appearance.

Other information

- Your dose of ciclosporin will change depending on how much ciclosporin is in your blood. Do not take your ciclosporin on the morning your blood is taken to check your ciclosporin level. Take your capsules to clinic with you and take them **after** your blood has been taken.
- The effects of ciclosporin may be increased or decreased by a number of drugs. Do not take any new drug without checking that it is safe to do so with your doctor or pharmacist.
- Do not drink grapefruit juice while you are taking ciclosporin.
- Take your ciclosporin at regular times each day. Do not stop unless your doctor tells you to.

Cinacalcet

(for renal patients)

What it does

Cinacalcet is used to maintain your bones strong and healthy. If your kidneys are not working, you may have high levels of parathyroid hormone (PTH) in your body. Too high levels of PTH can weaken your bones. Cinacalcet lowers your PTH levels and keeps your bones healthy.

Precautions

Most people taking cinacalcet feel very well. Some people get stomach upset.

Cinacalcet can lower your calcium levels. Sometimes this causes pins and needles or muscle aching. Tell your doctor if you experience these symptoms.

Other information

Cinacalcet should be taken with food.

Ciprofloxacin

What it does

Ciprofloxacin is an antibiotic. It is used to treat infections. It is sometimes used to prevent infections occurring.

Precautions

People taking this drug do not often get side effects. Some people can get an upset stomach and diarrhoea. A few people may feel dizzy, get headaches or a skin rash and itching. Tell your doctor if you get any of these side-effects.

Very rarely people taking Ciprofloxacin may get confused or hallucinate.

Other information

- Take this drug at regular intervals throughout the day until it is finished. If you forget a dose take it as soon as you remember.
- Other drugs may affect Ciprofloxacin - ask your pharmacist or doctor for advice if you take antacids or anti-inflammatory pain-killers such as those used for arthritis (NSAID's).
- Do not drink alcohol while taking this drug, and be careful if you are driving as it may make you less alert.
- You can take Ciprofloxacin with or without food.

Clonazepam (for renal patients)

What it does

Clonazepam is normally used in the treatment of epilepsy. In kidney patients the drug is more commonly used to relieve restless legs syndrome. This condition occurs when toxins build up in the blood making your legs feel twitchy and uncomfortable. By relaxing muscles, clonazepam can treat restless legs syndrome.

Precautions

Clonazepam can cause dizziness and drowsiness- so is best taken at night.

Other information

Alcohol enhances the drowsiness caused by clonazepam.

Clopidogrel (for renal patients)

What it does

Clopidogrel reduces the chances of clotting in narrowed blood vessels in the heart (causing angina) or brain (causing a stroke). Clopidogrel helps to prevent these problems getting any worse. Clopidogrel is also given to some people who have heart surgery.

Clopidogrel can also reduce the chances of clotting in the fistulas or lines of haemodialysis patients.

Precautions

Clopidogrel may cause stomach upsets, but this is very unusual.

Colchicine

What it does

Colchicine is used to relieve pain and inflammation in joints caused by an attack of gout.

Precautions

Colchicine causes nausea, vomiting, stomach pains and diarrhoea. Tell your doctor if you are sick or get diarrhoea while you are taking the drug.

Occasionally, colchicine causes rashes and muscular aches, pains, tenderness and weakness. These side effects should be reported to your doctor.

Other information

Most people only need to take a short course of colchicine to treat an attack of gout.

Co-trimoxazole (for renal patients)

What it does

Co-trimoxazole is an antibiotic used to prevent infections. This is important if you are on immunosuppressant drugs because you are more at risk of getting infections.

Co-trimoxazole is also used to treat infections.

Precautions

This drug can cause nausea, stomach upsets and diarrhoea. It is less likely to cause some of these problems if taken with food. A few people may be allergic to co-trimoxazole. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Other information

- Keep taking the drug until your doctor tells you to stop or until the course of treatment is finished.

Cyclophosphamide

(for renal patients)

What it does

Cyclophosphamide is an immunosuppressant drug. It can be used in a variety of conditions to block the body's immune system to prevent your kidneys being damaged.

Precautions

Cyclophosphamide may cause nausea, vomiting and hair loss (which is reversible). You are also at increased risk of picking up infections.

Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs such as cyclophosphamide cause an increased risk of cancer when taken for a long period of time.

Other information

Take your cyclophosphamide at regular times each day. Do not stop unless your doctor tells you to

Cyclosporin (for renal patients)

Your brand of cyclosporin is called:

What it does

Cyclosporin is an immunosuppressant drug. By blocking your body’s immune system, cyclosporin reduces the risk of your kidney transplant rejecting.

Precautions

The drug can cause stomach upset, a burning sensation in the hands and feet (particularly during the first week of use), an increase in body hair, swelling of the gums, a rise in blood pressure and may make you feel shaky. You are also at increased risk of picking up infections.

Immunosuppressant drugs like cyclosporin cause an increased risk of developing certain forms of cancer when taken for a long period of time.

Other information

- The effects of cyclosporin may be increased or decreased by a number of drugs. Do not take any new drug without checking that it is safe to do so with your doctor or pharmacist.
- Do not drink grapefruit juice while you are taking cyclosporin.
- Take your cyclosporin at regular times each day. Do not stop unless your doctor tells you to.

Digoxin

What it does

Digoxin strengthens the heart's pumping action, so it is used to treat a weak heart. It is also used to control certain fast or irregular heartbeats.

Precautions

Most people taking this drug feel very well but loss of appetite, nausea, vomiting or blurred vision may occur if the dose of digoxin is too high for you.

If you get any of these problems, do not stop taking these tablets but do tell your doctor so he can change your dose.

Other information

- You may take digoxin with or without food.

Lactulose (for renal patients)

What it does

Lactulose is a laxative drug. It is used to relieve constipation.

Precautions

Most people using lactulose feel very well. Some people get wind or stomach cramps and may feel sick. This usually settles down within a few days. If you get diarrhoea, the dose of lactulose may be too high for you.

Other information

- Take lactulose regularly to prevent constipation. It may take up to 48 hours to work.

Ketovite (for renal patients)

What it does

Ketovite tablets are a multivitamin supplement containing, for example, vitamin B and vitamin C. These vitamins form part of a normal, healthy diet. You may need extra vitamin B and vitamin C because:

- You are on a low potassium diet. This is because many of the foods which need to be avoided as part of your diet are rich in vitamins B and C
- You are on dialysis. This is because dialysis removes vitamins B and C from your blood

Precautions

This drug is very safe

Other information

Ketovite tablets must be kept in a fridge

Iron (for renal patients)

What it does

Iron is used to increase the amount of haemoglobin in your blood. This will help to stop you becoming anaemic.

Precautions

Iron tablets (for example, ferrous sulphate) can cause stomach upset, stomach pain, diarrhoea or constipation. They are less likely to do so if you take them with or after food.

You may notice that your stools become darker in colour when taking iron tablets.

Iron can also be given as an injection by the nurses. Most people having these injections feel very well. Iron injections can rarely cause flushing, itching, low blood pressure and metallic taste.

Glyceryl trinitrate sublingual tablets (GTN)

What they do

GTN is used to treat an attack of angina and it works very quickly when placed under the tongue. GTN relaxes the coronary arteries that supply blood to the heart. The tablets reduce the work of the heart and relieve angina.

Precautions

- If an attack of angina continues for **20 minutes or more** and is **not relieved** by GTN and resting, you should seek medical attention **immediately**.

You may get a throbbing headache, nausea and/or dizziness when you first start taking these tablets. These side effects normally wear off after a few weeks.

Other information

- Once the angina pain has eased you may remove the tablet from your mouth and throw it away. This may reduce the chance of headaches. The tablet dissolves more easily if you moisten your mouth.
- You must renew the tablets after 8 weeks once the bottle has been opened because the tablets gradually lose their effects.
- It is useful to place a tablet under your tongue before doing anything that you know brings on an attack of angina.
- The benefits of using the tablets continue even in patients who need GTN every day.
- You may take GTN for each attack of angina, even if you have several attacks in one day.

Glyceryl trinitrate spray (GTN)

What it does

GTN spray is used to treat an attack of angina and it works very quickly when sprayed onto or under the tongue. GTN relaxes the coronary arteries that supply blood to the heart. The spray reduces the work of the heart and relieves angina.

Precautions

- If an attack of angina continues for **20 minutes or more** and is **not relieved** by GTN and resting, you should seek medical attention **immediately.**

You may get a throbbing headache, nausea and/or dizziness when you first start using the spray. These side effects normally wear off after a few weeks.

Other information

- It is useful to use the spray before doing anything that you know brings on an attack of angina.
- Remember to close your mouth quickly after using the spray.
- You may use GTN spray for each attack of angina, even if you have several attacks in one day. The benefits of using the spray continue even in patients who need GTN every day.

Glyceryl trinitrate patch (GTN)

What it does

The GTN patch is used to prevent an attack of angina by releasing a continuous supply of drug. It relaxes the coronary arteries that supply blood to the heart. The patch reduces the work of the heart and relieves angina.

Precautions

Some people get headaches when they start using patches, but this effect normally wears off after a few weeks.

Other information

You should remove the old patch each evening and replace it with a new patch on a different piece of skin the next morning. Place the patch anywhere on your chest, shoulders or stomach. Make sure it makes good contact with the skin. The patch may not work so well if the skin is moist or hairy.

Furosemide (for renal patients)

What it does

Furosemide is a water tablet (diuretic). Furosemide removes salt and water from the body. It is used to treat a build-up of fluid.

It works rapidly, giving its strongest effects within 1 hour. The effects last for up to 6 hours.

Precautions

Occasionally people get rashes or ringing in the ears.

Other information

- You may take this drug with or without food.
- It is best to take furosemide in the morning so that you don't need to get up in the night to go to the toilet.
- Please stay on your usual diet unless you are asked to alter it.
- Sometimes the body loses a salt called potassium. If necessary, your doctor will ask you to eat more potassium containing foods such as bananas or chocolate or give you potassium tablets.

Fludrocortisone (for renal patients)

What it does

Fludrocortisone is a steroid which controls the salt and water content of your body. It can be used to reduce high amounts of potassium in your blood. You may be given fludrocortisone to replace or increase the steroid normally produced by the adrenal glands. The drug may also be used to treat dizziness caused by a sudden fall in blood pressure when you sit up or stand up (postural hypotension).

Precautions

Most people taking fludrocortisone feel very well. Occasionally, it can cause water retention (causing puffiness of the hands and feet) and weak muscles. Tell your doctor if these are a problem. Your doctor will also monitor your blood pressure regularly.

Other information

- Do not stop taking this drug unless your doctor tells you to. If you forget a dose, take it as soon as you remember.

Eprex®

(Erythropoetin = EPO)

(for renal patients)

What it does

EPO is a hormone made by the kidneys. It helps the body to make healthy red blood cells. If your kidneys are not working you may become anaemic (measured by low haemoglobin level in the blood) because there is less EPO in your body.

Anaemia has many consequences, such as tiredness, shortness of breath and may cause heart problems, such as angina.

Your EPO injection is called Eprex®.

Precautions

Most people on Eprex® feel very well. Some people get ‘flu-like symptoms at the start of treatment. Others may get a rise in blood pressure.

Other information

- Eprex® is usually injected into the dialysis machine. It can also be injected under the skin but this is rare.
- The drug will not work straight away. It may take a few weeks for you to feel better.

- Eprex® must be kept in a fridge.

Erythropoietin (EPO)

(for renal patients)

What it does

EPO is made by healthy kidneys and stimulates the bone marrow to make red blood cells. If your kidneys do not make enough, you may need extra EPO to stop you becoming anaemic.

Precautions

Most people on EPO feel very well. Some people get ‘flu-like symptoms at the start of treatment. Others may get a rash or a rise in blood pressure.

Other information

- EPO is injected, usually underneath the skin on the thigh or in the tummy.
- The drug will not work straight away. It may take a few weeks for you to feel better
- EPO must be kept in a fridge

Doxazosin

What it does

Doxazosin is used to reduce high blood pressure

Precautions

Most people taking doxazosin feel very well. Some people get a headache, feel dizzy, feel tired or get swollen ankles.

Other information

- The first dose of doxazosin may cause a big drop in blood pressure. Take your first tablet in bed to reduce the risk of fainting.

Domperidone

What it does

Domperidone is used to relieve nausea and vomiting. It is sometimes used when the gut is not working normally to speed up the movement of food along the gut.

Precautions

Most people taking domperidone feel very well.

Metolazone (for renal patients)

What it does

Metolazone is a diuretic drug (sometimes known as water tablets). The drug removes salt and water from the body. It is used to treat a build up of fluid.

Metolazone is commonly used in combination with another water tablet (for example frusemide or bumetanide) for a short course of treatment to remove a large build up of fluid.

The drug may occasionally be used to reduce high blood pressure.

Precautions

Most people taking metolazone feel very well. Some people get stomach upsets, muscle cramps, headaches or feel dizzy.

Other information

- Metolazone is best taken in the morning
- Please stay on your usual daily diet and daily intake of fluids unless your doctor advises you to alter them.

- Sometimes, metolazone causes the body to lose a salt called potassium. If necessary, your doctor will ask you to eat more potassium containing foods such as bananas or chocolate or give you a course of potassium tablets to take.

Lansoprazole

What it does

Lansoprazole reduces the amount of acid produced in the stomach. This can help stomach ulcers to heal and reduce the chances of other ulcers forming. It can also be used for other conditions where too much stomach acid is a problem.

Precautions

Most people taking this drug feel very well. Some people get stomach upsets, headaches or rashes.

Other information

You can take lansoprazole with or without food.

Do not take indigestion remedies at the same time of day as lansoprazole.

Minoxidil

What it does

Minoxidil is used to reduce high blood pressure

Precautions

Minoxidil causes water retention and a fast heartbeat. Tell your doctor if you get either of these problems when taking minoxidil because you may need extra drugs to treat these side effects.

Some people get an increase in body hair growth, dizziness or an upset stomach while they are taking minoxidil.

Methylprednisolone

(for renal patients)

What it does

Methylprednisolone is a steroid used to stop your body rejecting your kidney transplant. The drug can be given as a short course of injections when there are signs that the kidney is being rejected.

Precautions

Short term use of methylprednisolone may cause an increase in blood sugar levels and fluid retention

Metoclopramide

What it does

Metoclopramide is used to relieve nausea and vomiting. It is sometimes used when the gut is not working normally to speed up the movement of food along the gut.

Precautions

Most people taking metoclopramide feel very well. Tell your doctor if you get muscle spasms in the face, eyes or body. Metoclopramide may also make you feel tired, dizzy or restless.

Moxonidine

What it does

Moxonidine is used to reduce high blood pressure

Precautions

When taking moxonidine you may get a headache, feel tired, dizzy or sick or experience difficulty sleeping or flushing of the skin. These symptoms usually ease as treatment continues.

Mycophenolate mofetil (Cellcept®)

(for renal patients)

What it does

Mycophenolate mofetil is an immunosuppressant drug. By blocking your body's immune system, mycophenolate mofetil reduces the risk of your kidney transplant rejecting.

Mycophenolate mofetil is also used to treat some people who have inflammatory kidney problems.

Precautions

This medicine can cause stomach upset, stomach pain and diarrhoea. These effects may improve with time. You are also at increased risk of picking up infections.

Some people are very sensitive to mycophenolate mofetil. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs like mycophenolate mofetil cause an increased risk of developing certain forms of cancer when taken for a long period of time, for example skin cancer. To reduce the chances of having these skin problems you must always apply sun protection cream with a high SPF (at least 30). You should also tell your doctor if you have any new moles or if you notice any changes in their appearance.

Other information

- Mycophenolate mofetil can be taken with or without food but always stick to the same routine in relation to your meals. For example: always take you mycophenolate mofetil with food **or** always take your mycophenolate mofetil without food.
- Take your mycophenolate mofetil at regular times each day. Do not stop unless your doctor tells you to.

NeoRecormon® (Erythropoetin = EPO)

(for renal patients)

What it does

EPO is a hormone made by the kidneys. It helps the body to make healthy red blood cells. If your kidneys are not working you may become anaemic (measured by low haemoglobin level in the blood) because there is less EPO in your body.

Anaemia has many consequences, such as tiredness, shortness of breath and may cause heart problems, such as angina.

Your EPO injection is called NeoRecormon®.

Precautions

Most people on NeoRecormon® feel very well. Some people get ‘flu-like symptoms at the start of treatment. Others may get a rise in blood pressure.

Other information

- NeoRecormon® is injected, usually underneath the skin on the thigh or in the tummy. For those people who have haemodialysis, NeoRecormon® can be injected into the dialysis machine.
- The drug will not work straight away. It may take a few weeks for you to feel better.

- NeoRecormon® must be kept in a fridge.

Nifedipine (for renal patients)

What it does

Nifedipine improves the circulation of blood and reduces the amount of work for the heart. It is used to treat angina or to reduce high blood pressure.

If you have had a kidney transplant you may be taking nifedipine to help protect your new kidney from damage by cyclosporin or tacrolimus.

Precautions

Most people taking nifedipine feel very well. Some people get headaches, skin flushing, swollen ankles, stomach upset or feel tired or dizzy.

Other information

- Nifedipine is less likely to cause stomach upset if taken with food
- Do not drink grapefruit juice while you are taking nifedipine

Nitrate

The proper name of your drug is:

What it does

This drug is taken regularly to treat angina or to relieve the strain on a weak heart, or both.

It works by relaxing the blood vessels, reducing the work of the heart and improving the blood supply to the heart.

Precautions

Some people get headaches when they start taking this drug but these effects normally wear off after a few weeks.

Other information

- You may take this drug with or without food.

OKT3 (for renal patients)

What it does

OKT3 is used to stop or prevent your kidney transplant from being rejected. It will be given to you as a short course of injections, usually for 7 – 14 days.

Precautions

OKT3 can give you a fever, chills, stomach upset, diarrhoea or a headache. It can also make you feel breathless, nauseous and shaky. These effects may only occur in the first few days of treatment.

Omeprazole

What it does

Omeprazole reduces the amount of acid produced in the stomach. This can help stomach ulcers to heal and reduce the chances of other ulcers forming.

It can be used for other conditions where too much stomach acid is a problem.

Precautions

Most people taking this drug feel very well. Sometimes people get stomach upsets or headache.

Other information

- Up to four capsules can be taken together as a single dose. If your doctor tells you to take more than four capsules a day, take half in the morning and half in the evening.
- You can take this drug with or without food.

Penicillin

The proper name of your drug is:

What it does

This drug is an antibiotic. It is used to treat infections. It is also sometimes used to prevent infections occurring.

Precautions

Some people get mild diarrhoea while taking this antibiotic. This is nothing to worry about but tell your doctor if it gets very bad. If you get a rash, start to itch badly or feel short of breath tell your doctor straight away.

Other information

- If your drug is called **ampicillin, penicillin V or flucloxacillin** it is best taken half an hour before food (on an empty stomach).
- Take each dose at regular times, evenly spaced throughout the day.
- If you forget a dose take it as soon as you remember.
- Keep taking the drug until it is finished.

Phenytoin

What it does

Phenytoin is used to prevent fits.

Precautions

Before taking this drug tell your doctor if you have ever had kidney or liver disease, are diabetic or may be pregnant.

Some people taking this drug get an upset stomach or are sick. A few may get headaches, feel shaky or have trouble sleeping.

Tell your doctor if any of these are a problem or if:

- you become unsteady on your feet
- your speech becomes slurred or you get blurred vision
- you get a sore throat or fever
- you get sore, bleeding or thickened gums
- you get mouth ulcers
- you get a rash
- you get persistent "pins and needles"

Other Information

- Do not stop taking this drug unless your doctor tells you to.
- Phenytoin can affect other drugs you may be taking, including oral contraceptives. Tell your doctor if you are on the pill or taking any other drugs including those you have bought yourself.

Potassium supplement

(for renal patients)

The proper name of your drug is:

What it does

Potassium is a kind of salt. If the blood level of potassium falls then you may get muscle weakness. This can be due to a poor diet, water tablets or diarrhoea and vomiting. The drug is used to help replace lost potassium.

Precautions

Patients with kidney failure are much more likely to get a high blood potassium. This drug must only be taken if prescribed by your doctor. If you are asked to stop taking these tablets, you must do so immediately.

It can cause stomach upsets. This is less likely if you take the drug with a meal.

Other information

- If you are short of potassium you may be asked to eat more potassium containing foods such as bananas, chocolate or citrous fruits

Prednisolone (for renal patients)

What it does

Prednisolone is a steroid drug. It is used to reduce the risk of your kidney transplant rejecting. It works by blocking your body’s immune system. Prednisolone can also be used to reduce inflammation in conditions such as rheumatoid arthritis, asthma and vasculitis.

Precautions

Long term use of prednisolone can cause water retention, high blood pressure, fragile bones and diabetes. It may also increase the risk of picking up infections, increase your appetite, cause stretch marks, a round face and acne. Tell your doctor if you get a fever, are sick, get diarrhoea or are exposed to infectious diseases, particularly chickenpox or shingles.

Other information

- Unless you have been taking this drug for only a short time, you must reduce the dose gradually before stopping. This allows your body to build up its own supply of steroid. Do not stop taking this drug unless your doctor tells you to. If you forget a dose, take it as soon as you remember.
- Unless told otherwise, take this drug in the morning with food or milk
- Carry your steroid card with you

Quinine (for renal patients)

What it does

Quinine is used to treat leg muscle cramp. Kidney patients often suffer from cramp, especially if they are on regular haemodialysis.

Precautions

Most people taking quinine feel very well. Some people are very sensitive to the drug and may experience abdominal pains, nausea, headache, skin flushing, ringing in the ears, visual disturbances (for example blurred vision), rashes or confusion.

Other information

Quinine is best taken at night when leg cramp usually develops.

The full benefits of quinine may take a few weeks to develop.

Ranitidine

What it does

This drug reduces the amount of acid produced in the stomach. This can help stomach ulcers to heal and reduce the chances of other ulcers forming. It can be used for other conditions where too much stomach acid is a problem.

Precautions

Most people taking this drug feel very well. Sometimes people get stomach upsets, headache, dizziness or rash.

Do not stop taking this drug without contacting your Doctor.

Other information

- You may take this drug with or without food.
- Smoking reduces the effectiveness of this drug.

Senna (for renal patients)

What it does

Senna is a laxative drug. It is used to relieve constipation.

Precautions

Most people taking senna feel very well. Some people get stomach cramps and your urine may turn a red/brown colour. If you get diarrhoea, the dose of senna may be too high for you.

Other information

- Senna is usually taken at night. It normally works within 6-12 hours

Sevelamer (Renagel®)

(for renal patients)

What it does

Renagel ® is a phosphate binder. It reduces the absorption of phosphate from food, so it treats high levels of phosphate in the blood (hyperphosphataemia). Too much phosphate in the blood can cause itching, red, sore eyes and may make your bones weak.

Precautions

Most people taking Renagel ® feel very well. Some people get constipation or stomach upsets.

Other information

Renagel ® tablets must be swallowed whole with meals. Phosphate binders **only** need to be taken at mealtimes.

Statins

The name of your statin is

What it does

These drugs are used to lower high amounts of cholesterol and triglycerides (lipids) in the blood. High amounts of these fats in the blood does not make people feel ill, but can lead to problems such as heart disease when they clog blood vessels.

Precautions

Some people may get stomach upsets (such as heartburn, sickness and diarrhoea, or constipation) and headache. Statins can rarely cause muscular aches and pains, tenderness and weakness. These effects should be reported to your doctor.

Tell your doctor if any of these continue for more than a few days.

Do not take a statin drug called simvastatin if you are also taking warfarin without checking that it is safe to do so with your doctor or pharmacist.

Other Information

- Statins are best taken with food. If you take the drug once a day, take it with your evening meal.
- High cholesterol and other blood fats need long term treatment, so do not stop taking this drug unless your doctor tells you to.
- Follow advice about diet and exercise, and give up smoking. This will help your drug work.

Sirolimus (Rapamune®)

(for renal patients)

What it does

Sirolimus is an immunosuppressant drug. By blocking your body’s immune system, sirolimus reduces the risk of your kidney transplant rejecting.

Precautions

Sirolimus can cause stomach upset, mouth ulcers and a rise in your blood cholesterol level. Taking sirolimus makes you more likely to pick up infections, especially water infections.

Some people are very sensitive to sirolimus. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs like sirolimus cause an increased risk of developing certain forms of cancer when taken for a long period of time, for example skin cancer. To reduce the chances of having these skin problems you must always apply sun protection cream with a high SPF (at least 30). You should also tell your doctor if you have any new moles or if you notice any changes in their appearance.

Other information

- Your dose of sirolimus will change depending on how much sirolimus is in your blood. Do not take your sirolimus on the morning your blood is taken to check your sirolimus level. Take your tablets to clinic with you and take them **after** your blood has been taken.
- The effects of sirolimus may be increased or decreased by a number of

drugs. Do not take any new drugs without checking with your doctor or pharmacist that it is safe to do so.

- Do not drink grapefruit juice while you are taking sirolimus.
- Sirolimus can be taken with or without food but always stick to the same routine in relation to your meals. For example: always take you sirolimus with food **or** always take your sirolimus without food.
- Take your sirolimus at regular times each day. Do not stop unless your doctor tells you to.

Sodium Bicarbonate

(for renal patients)

What it does

Sodium bicarbonate reduces acidity of the blood. Acids are waste products of your body’s metabolism and are removed by the kidney in the urine. If your kidneys are damaged, these acids may build up in the blood. Sodium bicarbonate helps to neutralise them.

Precautions

This drug is very safe

Sulphonylurea

The proper name of your drug is:

What it does

This drug is used in diabetes. It helps to control the amount of glucose (sugar) in your blood by helping the body to produce more insulin.

Precautions

Most people taking this drug feel very well, but sometimes it causes mild stomach upsets or skin rashes.

Very rarely it can overdo its useful effects and make the blood glucose level fall too low and cause a hypoglycaemic reaction ("hypo"). This is more likely to happen when alcohol is taken on an empty stomach or when strenuous exercise is taken after missing a meal. The symptoms which occur may be sweating, dizziness and fainting. Glucose, in the form of a tablet or sweet drink, should be taken.

Other information

- Follow the advice you have been given about diet and take your tablets as instructed. This will reduce the long term risks of diabetes.
- If you buy any medicines remember to tell your chemist that you are a diabetic.
- This drug is best taken half an hour before food (breakfast if you take it only once a day).

Thyroxine

What it does

Thyroxine is used to replace or increase a hormone normally produced by the thyroid gland in your body.

Precautions

People taking the right dose of Thyroxine feel very well. Below are listed some signs that your dose may need changing. Tell your doctor if:

- you gain or lose weight without explanation
- you are often too hot or too cold
- you cannot stay awake, or have trouble going to sleep

Other information

- You will be told what dose to take by your doctor.
- You should take this dose each morning. If you forget a dose take it as soon as you remember, but do not take more than one dose per day.
- Do not stop taking this drug unless your doctor tells you to.
- You can take thyroxine with or without food.
- The dose will be adjusted from time to time

according to the results of blood tests

Tacrolimus (Prograf®)

(for renal patients)

What it does

Tacrolimus is an immunosuppressant drug. By blocking your body’s immune system, tacrolimus reduces the risk of your kidney transplant rejecting.

Precautions

Tacrolimus can cause stomach upset, a burning or tingling sensation in the hands and feet, a rise in blood pressure, a rise in your blood sugar level, increased cholesterol levels and may make you feel shaky. You are also at increased risk of picking up infections.

Some people are very sensitive to tacrolimus. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Immunosuppressant drugs like tacrolimus cause an increased risk of developing certain forms of cancer when taken for a long period of time, for example skin cancer. To reduce the chances of having these skin problems you must always apply sun protection cream with a high SPF (at least 30). You should also tell your doctor if you have any new moles or if you notice any changes in their appearance.

Other information

- Your dose of tacrolimus will change depending on how much tacrolimus is in your blood. Do not take your tacrolimus on the morning your blood is taken to check your tacrolimus level. Take your capsules to clinic with you and take them **after** your blood has been taken.

- The effects of tacrolimus may be increased or decreased by a number of drugs. Do not take any new drugs without checking with your doctor or pharmacist that it is safe to do so.
- Do not drink grapefruit juice while you are taking tacrolimus.
- Tacrolimus can be taken with or without food but always stick to the same routine in relation to your meals. For example: always take you tacrolimus with food **or** always take your tacrolimus without food.
- Take your tacrolimus at regular times each day. Do not stop unless your doctor tells you to.

Trimethoprim

What it does

Trimethoprim is an antibiotic used to treat or prevent infections, especially infections in the urine.

Precautions

The drug may cause nausea and stomach upset. A few people may be allergic to trimethoprim. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising.

Other information

Keep taking the drug until the course of treatment is finished or until your doctor tells you to stop.

Valganciclovir (for renal patients)

What it does

Valganciclovir is used to treat or prevent a viral infection called cytomegalovirus (CMV). There is a risk of getting this infection if you have had a transplant and are taking immunosuppressant drugs.

Precautions

Some people are very sensitive to valganciclovir. Tell your doctor if you get a fever, sore throat, skin rash, mouth ulcers or unexplained bleeding or bruising. Valganciclovir may also cause nausea and stomach upset.

Other information

To **prevent** CMV infection, you will be given a course of valganciclovir tablets, usually for 3 months after your transplant. These tablets must be taken with meals and must not be crushed.

To **treat** CMV infection, you will be given a higher dose of valganciclovir for a short course, usually 14 to 21 days.

The dose of valganciclovir can change over time depending on your kidney function.

Vancomycin (for renal patients)

What it does

Vancomycin is an antibiotic used to treat infections. It is usually given as an injection. If you are on peritoneal dialysis and get an infection called peritonitis you may be given vancomycin in your peritoneal dialysis bags.

Some people may need vancomycin capsules to treat infection in the gut.

Precautions

The drug may make you feel nauseous and feverish and can cause a rash

Verapamil

What it does

Verapamil is used to control certain fast or irregular heart rhythms. Depending on the dose, this drug may also be used to treat angina or to reduce high blood pressure.

Verapamil helps to stabilise the electrical activity of the heart. It also relaxes blood vessels to improve the circulation of blood, and reduces the amount of work for the heart.

Precautions

This drug occasionally causes constipation, headaches or skin flushes. Slow heart beat may occur in some people. If you are worried, check with your doctor.

Other information

- You can take this drug with or without food.

Warfarin (for renal patients)

What it does

Warfarin makes your blood less likely to clot. This is particularly important for people with artificial or damaged heart valves, in conditions where the risks of clotting are increased and for people on haemodialysis if there is a risk that their fistula or line may become blocked.

Precautions

The dose of this drug must be adjusted to the needs of your body. These needs can change and, for this reason, your blood needs to be tested regularly.

If you get bruising or nosebleeds, do not stop taking warfarin but be sure to tell your doctor. Cuts take longer to stop bleeding in patients taking warfarin.

Do not take pain killers containing aspirin while taking warfarin. Certain other tablets, especially those used to treat arthritis, can effect the dose you need.

Do not take any new medicines without checking if it is safe to do so with your doctor or pharmacist.

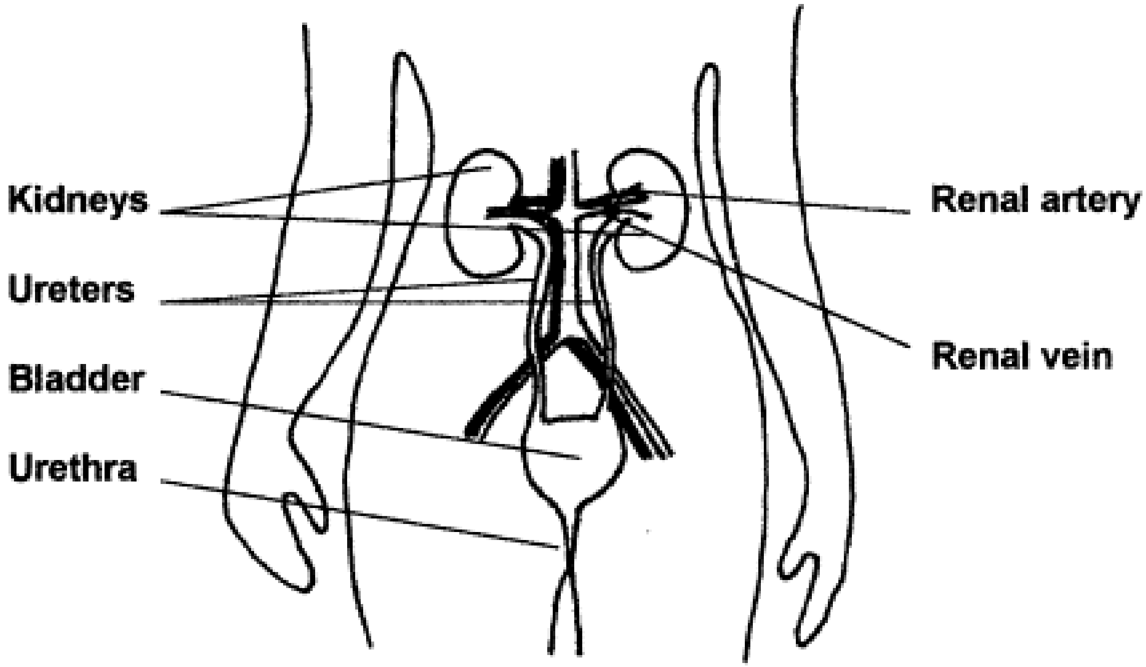
Other information

- Try to avoid drinking alcohol, especially in large amounts, as it may seriously upset the effects of the drug.
- Take your warfarin at a regular time each day. Do not stop unless your doctor tells you to.
- Carry your anticoagulant card with you at all times.

Your kidneys and what they do

Basic facts

- One in 1,000 of the population have only one kidney, but the majority have two.
- Each kidney is approximately the size of your fist.
- The kidneys are situated in the lower back, on either side of the spine.
- Normally, filtering of waste products takes place at a rate of 120mls per minute.
- When this slows down to approximately 10mls per minute, it is time to start dialysis treatment (but this does vary between individuals).



What causes renal failure?

There are a wide variety of causes, but in some people the cause is never found. The commonest causes which some of you may identify with are:

Diabetes mellitus

High blood pressure

Polycystic kidney disease

Glomerulonephritis

Repeated scarring from kidney infections

Obstruction

What do our kidneys do?

- Act as a filter system. As blood passes through the kidneys it is sieved and cleaned. The toxins (such as urea and creatinine) are passed out with any excess water in the form of urine.

- Balance the body’s fluid content. If there is too much fluid in the body (overload) the kidneys excrete more in the urine and if there is not enough (dehydration) will hold on to the water content.

- Produce hormones that control blood pressure.

- Healthy kidneys balance the chemicals in the blood such as potassium and phosphate. They also regulate the acid levels in the blood, often termed as acid-base balance.

- Activate Vitamin D, which helps to keep your bones healthy.

- Produce a hormone called Erythropoietin (EPO), which prevents you becoming anaemic. Anaemia can make you feel weak and tired.

What happens when the kidneys fail?

- If the kidneys are damaged they may carry on producing urine buy they become less efficient at removing waste products from the blood. Instead, the waste products continue to circulate and build up in the bloodstream. This may lead you to experience nausea, itching and loss of appetite, with perhaps a ‘metallic’ taste in your mouth.

- Losing your kidney function may mean that your kidneys find it difficult to remove water and salt, and consequently you may develop high blood pressure and swollen ankles/legs.

- Severe kidney damage can understandably make it progressively more difficult to concentrate on your daily activities and get motivated. This can affect your work and family commitments. In addition, it is common to experience loss of libido/sex drive.

- Coping with kidney failure is not just about managing the physical symptoms with treatment. It is a major life change that may cause a great deal of emotional reactions:

Anxiety Feeling low Frustration Anger

If you are currently experiencing any of these and wish to discuss this confidentially, then please contact your specialist nurse.

When will I need to start dialysis?

After a time, the kidneys become less and less able to cope and this leads to what we call “Established Renal Failure”. At this stage, dialysis is essential to take over some of the work that your healthy kidneys used to do. The decision to start dialysis is based upon a combination of your symptoms and blood test results. The time course varies from person to person, and is dependent on medical factors and the underlying kidney problem.

Making an informed choice

If your kidneys fail, there are a number of treatment options to choose from. However, certain medical and social factors will need to be discussed with you and your family/carer to help you decide what is best for you.

Peritoneal dialysis, haemodialysis and transplantation are effective treatments, each with their respective advantages and disadvantages. Your specialist nurse can help explore the most appropriate choice of dialysis with you. She can discuss your individual issues and worries with you, and help you to plan ahead.

Ref: H: misc/your kidneys and what they do AJ 12.9.06

CHAPTER 11 RESEARCH

This section has more than one leaflet please choose the leaflet you wish to view by clicking the blue underlined text

+ 11. Research

- **Kidney Research at the University Hospital of Wales**

Glossary of common terms in renal medicine

abdomen - the part of the body that lies below the rib cage and above the pelvis, more commomly known as the tummy or belly.

access - in order to perform dialysis on a patient, a means or way must be found to gain entry to the patient's blood vessels for haemodialysis or of the abdomen for peritoneal dialysis. This is known as 'access'. See also: vascular access; fistula; permacath; Tenckhoff

Acute Renal Failure (ARF) - sudden onset [within days or weeks] of kidney failure. May be reversible

Acute Tubular Necrosis (ATN) – the name given to the condition when either a person's own kidneys or in the case of a transplant the donor kidney appears to be 'asleep' and not working. This usually means that the kidney is still alive and may be able to rescued or awakened.

Albumin - a protein found in the blood that helps to carry other materials in the bloodstream. See the leaflet 'Understanding Your Blood Results'

Alport's Syndrome – an inherited renal disease causing kidney failure and may be associated with hearing difficulties.

anaemia - a lack of red blood cells in the bloodstream causing tiredness, breathlessness and lethargy. This is diagnosed by low haemoglobin levels.

angina – heart pain caused by partial blockages in the arteries of the heart leading to a lack of oxygen in the heart muscle.

angiogram – an investigation that allows an x-ray picture to be taken of the blood supply to an organ e.g. the kidney or heart. Also known as an arteriogram. See separate leaflet on renal angiogram.

antibody – a special protein made by the body to defend it against bacteria and viruses

anticoagulants - drugs used to delay or prevent the bloods natural clotting processes e.g. heparin, warfarin

anuria - no urine production

APD - **A**utomated **P**eritoneal **D**ialysis. This form of peritoneal dialysis uses a machine (usually overnight) to carry out exchanges over 10-12 hours

artery – a blood vessel that carries blood away from the heart to the tissues of the body

arteriogram - see angiogram

bacteria - the medical term for germs. They are found everywhere. Antibiotics are used to kill them when they cause an infection.

Bence Jones protein - a type of antibody produced by abnormal myeloma cells. It is found in the blood and urine. Its detection in the urine collected over 24 hours from a patient is used in the diagnosis of myeloma.

bicarbonate – a substance found in the blood that counteracts blood acidity. It is also used in dialysis fluids.

biopsy – the removal of a tiny piece of tissue for examination under a microscope. See separate leaflets on transplant & non-transplant kidney biopsy.

bladder - an organ in the body. Urine drains from the kidneys to the bladder where it is stored until being released when you pass water

blood pump – a pump in the dialysis machine that pumps blood from the patient to the machine

blood pressure (BP) - the pressure that blood exerts against the walls of the arteries of the body. See separate leaflet on 'Hypertension/High Blood Pressure'

brain stem death – permanent damage to the part of the brain that is responsible for control of vital functions like breathing from which a patient will not recover– see the leaflet on organ donation

cadaveric donation/transplant – organ donation/transplant from someone who has died

calcium – a chemical important with phosphate in the maintenance of healthy bones

CAPD - **C**ontinuous **A**mbulatory **P**eritoneal **D**ialysis, a form of dialysis that uses the peritoneal membrane that lines the abdomen, to dialyse the patient. The patient is taught to use gravity to administer bags of a dialysate into the abdominal cavity several times a day. This is done via a surgically installed access point. A patient may have to carry out the procedure 3 or 4 times a day.

catheter - any tube that may be introduced into the body to transport fluids or blood either into or out of the body. See Tenckhoff

CCPD - **C**ontinuous **C**yclic **P**eritoneal **D**ialysis – as for CAPD but instead of the patient administering bags of a dialysate, a machine is used to pump dialysate in and out of the abdominal cavity overnight to achieve the same result.

Chronic Renal Failure (CRF) - gradual and irreversible loss of kidney function. Typically occurs months or years after the beginning of kidney disease or injury.

creatinine - creatinine is a chemical produced by the muscles of the body.

The more muscle you have, the more creatinine you produce. It is a waste product, the result of normal wear and tear of the muscles. One of the kidney's tasks is to clean the blood of creatinine. In kidney failure this does not happen as effectively. So, measuring levels of creatinine in the blood is one way to assess how well the kidneys are working. The higher the creatinine, the worse the kidneys are working. However, because the amount of muscle you have dictates how much creatinine you may have in your blood a more accurate measure of kidney function is to measure the amount of creatinine found in the urine, after the kidney has done its work. This measure is taken from a urine specimen collected over 24 hours.

creatinine clearance - creatinine clearance is the amount of blood that is "cleared" of creatinine in a given period of time, usually measured in mls per minute. The normal creatinine clearance of an adult is 120 ml/min. Commonly, an adult requires dialysis because of the appearance of symptoms of kidney failure at a clearance of less than 10 - 15 ml/min. Creatinine clearance is measured by a 24 hour urine collection and blood sample which provides a more accurate estimate of kidney function than creatinine levels measured in the blood because it does not depend on the amount of muscle one has. Lower than normal levels of creatinine in the urine indicates that the kidneys are not working properly.

cross-match - cross-matching is the final test, which takes place immediately before transplantation and involves mixing serum (a part of the blood) from the patient and cells from the donor to see if the patient has any antibodies that react to the donor and will cause rejection. Transplant only proceeds if the cross-match is negative. Patients are also always cross-matched before receiving donated blood to remove the risk of a patient reacting to a blood transfusion

cytomegalovirus (CMV) – a virus belonging to the herpes family of viruses. See separate leaflet on CMV and transplant.

diabetic kidney disease - or diabetic nephropathy, kidney disease resulting from the damage and destruction of blood vessels in the kidney leading to chronic renal failure in some diabetic patients.

dialysis - the removal, by artificial means, of excess water and waste products from the bloodstream.

Dialysis Co-ordinator – a health worker usually with a nursing background who supports patients with renal failure as they make choices about their treatment

dialysate - the fluid used in dialysis

dialyser - the machinery or apparatus used in dialysis. Also known as the artificial kidney.

dry weight - the patients body-weight that is aimed for at the end of a haemodialysis session and all the time when using peritoneal dialysis.

dwell time - the length of time fluid is kept in the peritoneum during CAPD, APD or CCPD

echocardiogram (ECHO) – an ultrasound investigation of the heart

electrocardiogram (ECG) – a test performed by attaching leads to the chest, wrists and ankles that allow a tracing of the electrical activity of the heart to be recorded.

electrolyte – any chemical with the potential to conduct an electric current when in solution because of their ability to accept a positive or negative charge. In the body, electrolytes are associated with the control of differences between fluids inside and outside cells. Important electrolytes are potassium, sodium, chloride, calcium, magnesium, bicarbonate and phosphate.

end-stage renal failure (ESRF) or end-stage renal disease (ESRD) in the USA - permanent, non-reversible kidney failure requiring dialysis and/or transplantation in order to carry on the tasks of the kidney by artificial means.

erythropoietin (EPO) - a hormone that is produced by the kidneys which causes bone marrow to make red blood cells. It is now made artificially and used to treat anaemia in many dialysis patients.

EPO Co-ordinator – a specialist nurse responsible for helping patients who are taking EPO.

exit-site infection – infection of the skin and tissue around a Tenckhoff catheter used in peritoneal dialysis

ferritin - a protein that stores iron in the body. Measurements of the amount of ferritin in the blood are used as an indication of iron loss caused by dialysis

fistula - a form of access that allows haemodialysis to take place. It is created by joining an artery to a vein directly, usually in the arm. This creates a bulging of the vessels that allows a needles to be more easily put into the vessels, allowing blood to be drawn into the dialysis machine for it to be cleaned and the cleaned blood returned back to patient again.

fluid overload - the dangerous build up of water in the body beyond the capacity of the body to cope with it. May be caused by taking in too much water between dialysis sessions

glomeruli – the microscopic filters in the kidneys. Each kidney contains about 1 million glomeruli. The first step in the formation of urine is filtering fluid from the blood through the glomeruli.

glomerulonephritis – inflammation of the kidneys not caused by bacteria. Affects the glomeruli, the microscopic blood filters, of the kidney. Affects both kidneys equally when it occurs.

graft – a transplanted organ

haematocrit – or PCV (packed cell volume) is the measure of the amount of red blood cells in the bloodstream

haematuria – blood in the urine

haemodialysis - the removal of waste products and excess water from the blood and regulation of important chemicals necessary to the body by passing the blood through an artificial kidney outside of the body.

haemofiltration – the removal of fluid and electrolytes by a process of ultrafiltration and convection.

haemoglobin (hb) - contained within the red blood cells of the bloodstream, haemoglobin is a chemical compound that allows oxygen to be carried around the body from the lungs. Haemoglobin is used as a measure of a patient's anaemia as it is contained within the red blood cells. The lower the amount of haemoglobin you have, the more anaemic you are.

hepatitis - inflammation of the liver, usually caused by viral infection. Patients are now tested under Renal Association guidelines for hepatitis viruses B & C every three or six months respectively. See separate leaflet on hepatitis.

hormone – a substance that is excreted by glands of the body directly into the bloodstream. The hormone causes a response in another part of the body, e.g. EPO is released by the kidneys and stimulates red blood cell production in the bone marrow.

hyperkalaemia - high levels of potassium in the blood

hypokalaemia - low levels of potassium in the blood

hyperparathyroidism - the term used to describe the condition that results when parathyroid glands work harder then normal producing too much parathyroid hormone. Se separate leaflet on 'Hyperparathyroidism & Renal Bone Disease'

hypertension - abnormally high blood pressure

hypotension - abnormally low blood pressure

IgA Nephropathy – a common type of glomerulonephritis which is often mild.

See leaflet on IgA Nephropathy

immunosuppressants - medications used to damp down the body's natural defence mechanisms. Used in almost all kidney transplant patients in order to prevent the rejection of the donated organ. e.g. cyclosporin (Neoral), tacrolimus as well as to treat conditions when the immune system damages ones own organs ; for eg: Lupus or vasculitis.

inflammation - a normal reaction of the body to allergy or infection by bacteria, virus and parasite. Tissues swell, become hotter and full of white blood cells.

intravenous - 'into a vein', the process of introducing medicines and materials directly into the blood stream by means of a vein.

IPD – **I**ntermittent **P**eritoneal **D**ialysis, a form of peritoneal dialysis that takes place 2-3 times a week for 12 hours as opposed to 4.

K - see potassium

link nurse – a nurse working in a ward with responsibility for creating a link between the ward and a specialist nurse in a specialist role e.g. EPO co-ordinator. The role includes acting as: a first point of contact for patients requiring the specialist service; a resource for colleagues and educating staff in the ward on developments

Living Related Donor (LRD) - a person donating a kidney who is related to the recipient of the kidney

LFTs - abbreviation for Liver Function Tests. See separate leaflet on 'Understanding Your Blood Results'

mature fistula – a fistula that is ready to be used for dialysis

mid-stream urine (MSU) – a specimen of urine collected by saving the middle part of a stream of urine achieved by starting to urinate, stopping, collecting the next burst of urine and finally passing the last part of the urine into the toilet. the specimen is sent to the laboratory to be tested for the presence of infection.

MRSA (methicillin/multiple resistant staphylococcus aureus)– a special type of bacteria identical to the ones that normally cause spots and boils but resistant to most antibiotics.

myeloma – a cancer of the white blood cells. See separate notes on myeloma.

needling - the process of introducing needles into an access point e.g. a fistula in order to obtain blood for haemodialysis

nephrectomy - the removal of a kidney through surgery.

nephritis - inflammation of the kidneys

nephrologist - a doctor specialising in the care and treatment of kidney patients.

nephrology - the study of the kidney, its function and diseases.

nephron – the filtering unit of the kidney which includes the glomerulus, the actual filter. There is one glomerulus to every nephron. The kidney is made up of millions of nephrons.

nephropathy - any kidney disease

nephrostomy - a tube inserted in the lower back under local anaesthetic to drain urine from a kidney when the normal drainage pathway is blocked for some reason.

nephrotic syndrome - a type of glomerulonephritis characterised by excessive protein loss from the blood into the urine caused by an abnormality of the glomeruli.

oedema – swelling of the tissues, often the legs and face usually caused by fluid overload or in patients with kidney failure.

oliguria – too little urine production

outflow time – the time taken for dialysate to drain out of the abdomen in peritoneal dialysis.

overload - see fluid overload

parathyroidectomy - surgical removal of the parathyroid glands. See separate leaflet on 'Parathyroidectomy'

peritoneal dialysis (PD) - the use of the peritoneal membrane for dialysis. See APD, CAPD & CCPD. A solution (dialysate) is introduced into the abdominal cavity that removes excess water and waste products from blood passing through the peritoneal membrane and regulates the amounts of important chemicals necessary to the body. At the end of each treatment, the solution is drained from the abdominal cavity. See separate leaflet ‘Introduction to peritoneal dialysis’.

Peritoneal Equilibration Test (PET) - a test used in peritoneal dialysis to measure the rate that waste products in the blood pass into the dialysis fluid in the peritoneum. It provides doctors and nurses with information on how your peritoneum is working. From this information your dialysis prescription may be changed to meet your individual needs. These changes may include increasing or decreasing bag volume, the number of bags or the use of automated peritoneal dialysis.

peritoneum - a semi-permeable membrane that lines the inside of the abdomen

peritonitis - an infection of the peritoneum that occurs in patients using peritoneal dialysis. Symptoms include pain and peritoneal dialysis fluid becoming cloudy

phosphate – a chemical important with calcium in maintaining healthy bones. See separate leaflet on phosphate binders.

platelets - these are cells in the blood that helps blood to clot

plasmapheresis – the process of filtering & removing components of blood plasma to treat certain diseases. See separate leaflet on vasculitis

polycystic kidney disease (ADPKD) – an inherited kidney disease. See separate leaflet on Autosomal Dominant Polycystic Kidney Disease

potassium (K) - a chemical element present in all living creatures. Potassium is used by the body in the transmission of signals through nerve pathways. The kidneys operate to keep potassium in the body at the right level. Both too much and too little potassium is dangerous. In kidney disease the danger usually comes from having too much potassium. Some kidney patients have to be careful not to eat foods rich in potassium.

pre-dialysis – any patient who has chronic renal failure, but does not yet require dialysis but will do so in the near future is considered to be in a pre-dialysis phase.

proteins – large molecules made up of amino acids, in turn made up of a combination of carbon, hydrogen, oxygen and nitrogen plus or minus iron, sulphur and phosphorus. There are many different types of proteins, performing a variety of functions in the body such as helping with chemical reactions, transporting substances in the blood e.g. haemoglobin or acting as chemical messengers in the form of hormones e.g. erythropoietin and defending the body against harmful agents in the form of antibodies.

pulmonary oedema - the name of the condition in which fluid builds up in the lungs. This causes breathlessness. It can occurs in people on haemodialysis who have fluid overload due to drinking too much between dialysis sessions or not having enough fluid removed during a dialysis session.

pyelonephritis – kidney infection, usually bacterial, spread from bladder

red blood cells - cells in your blood that contain haemoglobin which carries oxygen to the tissues of the body. A decrease in haemoglobin is called anaemia.

reflux nephropathy – see separate leaflet

rejection – rejection is the result of the body identifying a transplanted organ as foreign and attempting to the destroy the tissue of the organ. See separate leaflet on kidney rejection after transplantation.

renal biopsy – a special test whereby a fine needle is inserted into a kidney to remove a tiny core of tissue for examination under a microscope. See separate leaflets on transplant and non-transplant renal biopsy.

renal bone disease – a weakening of the bones also known as renal osteodystrophy resulting from kidney failure. See leaflets on hyperparathyroidism and phosphate binders.

renal calculus – an abnormal inorganic mass that occurs inside the kidney. More commonly known as a kidney stone.

run-in time – the time taken for dialysis fluid to run into the body during peritoneal dialysis

saline – saline in a medical context is sterile salt water

simple kidney cysts – see separate leaflet

sodium – the commonest form of electrolyte in the body. It is found in all body fluids including blood as well as bone. The kidneys control the normal balance of sodium in the body. Kidney failure is often accompanied by excess sodium in the body. Excess sodium causes high blood pressure and/or swelling (oedema). Sometimes a reduction of sodium in the diet is needed to help to restore a normal balance.

subcutaneous – literally ‘under the skin’ usually used to describe a form of drug delivery in which the drug is injected, shallowly, under the skin

stenosis – a narrowing or stricture of a duct or canal of the body e.g. stenosis of an artery, vein, urethra

systemic lupus erythematosus (SLE) – a disorder of the connective tissues of the body, characterised by inflammation. Often affects the skin, joints, kidneys, lungs, heart and gastrointestinal tract. See separate leaflet

Tenckhoff - a catheter/tube that allows access into the abdominal cavity for peritoneal dialysis. Named after Dr H. Tenckhoff who developed it in 1968.

tissue type – besides blood group, all tissues of the body carry special markers that are inherited from parents. The body recognises its own markers or tissue type, but will attack any different tissue type. Transplant gives the best results when the tissue types of the donor and the recipient are as close as possible. See separate leaflet on tissue typing.

Transplant co-ordinators – health workers usually with a nursing background who are responsible for the arrangement and organisation of transplants

ultrafiltration (UF) – a term used in dialysis to describe the removal of fluid from the blood using a pressure gradient.

ultrasound scan – a test whereby sound waves are sent out from a special microphone into the body and the echoes are recorded by the same microphone and then displayed on a TV screen. This test is used very commonly to help to determine kidney size, shape and the type of disease.

uraemia - describes the signs and symptoms of chronic renal failure (such as nausea, vomiting and loss of appetite) caused by the excessive levels of urea and other chemicals in the blood that occur when your kidneys are no longer functioning normally.

urea - urea is a waste product that occurs as a result of the body’s normal processes, breaking down food and converting it into energy. One of the kidney's tasks is to clean the blood of urea. In kidney failure this does not happen as effectively. So, measuring levels of urea in the blood is one way to assess how well the kidneys are working. The higher the urea, the worse the kidneys are working. Similar to creatinine.

ureter – the tube connecting the kidney to the bladder through which urine flows.

urethra – the tube leading from the bladder to the outside of the body through which urine is passed.

vascular access - access into the bloodstream of a patient for the purpose of haemodialysis.

vein – a blood vessel that returns blood to the heart from the tissues of the body.

virus - A virus is an organism that lives and reproduces itself by taking over the cells of a host. It causes the cell to make more viruses rather than doing whatever it is should do. These burst out of the host cell and proceed to infect other cells.

vitamin D – a vitamin, of which the active form is produced by the kidneys, that is important in the maintenance of strong healthy bones by helping the body to absorb calcium from the food we eat. Patients with kidney failure may need to take vitamin D capsules.

VRE (vancomycin resistant enterococcus) – a special type of bacteria resistant to many antibiotics. It tends to live in the lower bowel.

wash back – a method using saline (sterile salt water) to wash blood back from the dialysis circuit at the end of dialysis to minimise blood loss

white blood cells – White blood cells are responsible for the production of antibodies or immunoglobulins, which circulate in the blood and attack any bacteria and viruses that invade the body. See also the section on blood tests.