

# **A HANDBOOK FOR KIDNEY PATIENTS**

## **INTRODUCTION**

This booklet is intended to give you, the patient with kidney problems (and your family), an overall picture of how kidney failure may affect you physically and emotionally. It will also explain how kidney failure can be treated and enable a rehabilitation process to improve your quality of life. It will help to answer some questions. Other queries which may arise, either as a result of reading this booklet or those which have not been covered by it, may be discussed at any time with your doctor or nurse. Kidney failure is a chronic illness or a long-term problem which will affect your life. However, it is hoped that the problems which lie ahead may be overcome with the support of family, friends and the renal team. With a positive determined attitude, whilst adjusting to the new situation, you may lead a fulfilling and enjoyable life. Many patients are able to work full-time and maintain their independence. There will be some sections of the following material which may not apply to you, but it may be advisable to familiarise yourself with some of the terms.



## **THE KIDNEYS**

To understand what happens when the kidneys stop functioning, it is helpful to know what the kidneys do normally.

There are two kidneys which are situated beneath the ribs and at the back of the abdomen. In the healthy human body the kidneys act as a filter. The body needs fuel to keep going. This is supplied by eating. The food is converted into chemical substances which are carried in the blood to various parts of the body where they are needed. Some substances will be used immediately, some will be stored, others will be useless or even harmful and are removed by the kidneys and passed in the urine. When filtering the blood, the kidneys also get rid of excess salt and water from the body including salts such as potassium and phosphate.

The kidneys also produce many hormones. These hormones help to maintain normal bone formation, blood pressure and production of red blood cells. All these will be explained by this booklet briefly and will be explained in more detail by the renal team.



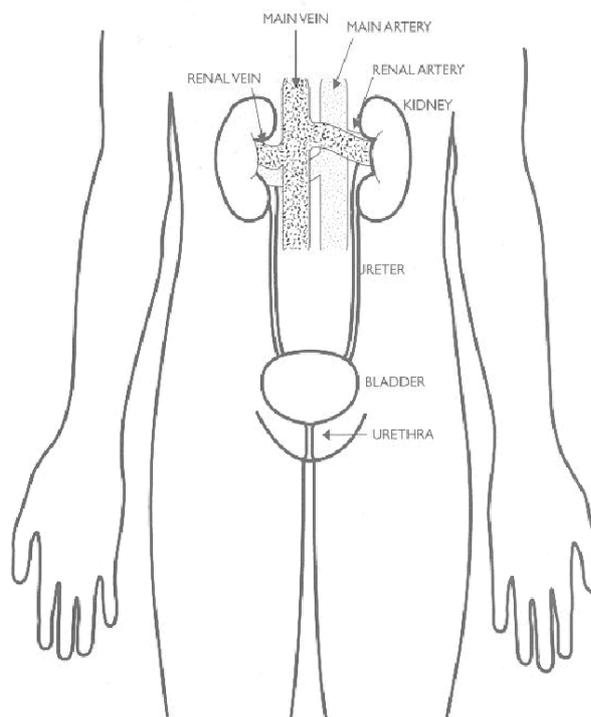
## **KIDNEY FAILURE**

If the kidneys cease to work the condition is known as kidney failure.

There are five stages of kidney failure depending on the kidney function (see below). The kidney function is measured by checking a blood creatinine level. Creatinine is a muscle breakdown product and, when the kidney function is impaired, the blood creatinine will rise. From this is

derived the estimated glomerular filtration rate (eGFR) which gives a guide to the severity of the kidney failure.

In the early stages of kidney failure, patients are completely without symptoms. Kidney failure may progress from stage 1 to stage 5 over time. The rate of progression is very variable and differs from person to person. In general, patients only develop symptoms of being unwell when they reach stage 4/5 kidney failure (i.e. after they have lost more than 75% of kidney function). When stage 5 kidney failure occurs, most patients will need to start considering specific kidney failure treatment. The treatment options will be discussed later.



eGFR	ml/min	Details
Stage 1	> 90	Kidney damage with normal renal function (structural abnormalities, or protein +/- blood in urine)
Stage 2	60-90	Mild kidney damage with other evidence of kidney damage
Stage 3	30-59	Moderate kidney damage
Stage 4	15-29	Severe kidney damage
Stage 5	< 15	End-stage renal disease/ dialysis

## **SYMPTOMS OF KIDNEY FAILURE**

The kidneys become unable to continue this important work of filtering the blood, removing waste products and making normal hormones. It is possible to survive with only one kidney, but if neither kidney is able to function adequately, the impurities (waste products) in the blood will build up and make the person feel unwell.

When someone is told that he/she has kidney failure, the question often asked is: "How can this be? I still pass a lot of urine." The simplest answer is that the kidneys may make urine, but the quality of that urine is poor. An inadequate amount of waste products are removed and so there is a build up of these in the blood.

In fact, it is only in the very late stages of kidney failure that the quantity of urine produced is reduced. Most commonly the kidney cannot concentrate the urine at night, so it may be necessary to get up two or three times each night to pass urine.

Some of the symptoms of kidney disease only occur when over 75% of the kidneys have been damaged.

The symptoms include:

1. Nausea and vomiting
2. Loss of appetite
3. Tiredness
4. Weight loss
5. Weakness
6. Itching
7. Leg cramps
8. Fluid retention, leading to ankle swelling and shortness of breath
9. Constipation
10. Unusual odour to the breath/taste alteration

In addition, members of the family may notice that the person with kidney failure becomes more sleepy.

There are a number of medical problems associated with kidney failure. The commonest are high blood pressure (hypertension), heart disease, high cholesterol, anaemia, nerve damage and loss of sexual desire or performance.

### **HYPERTENSION**

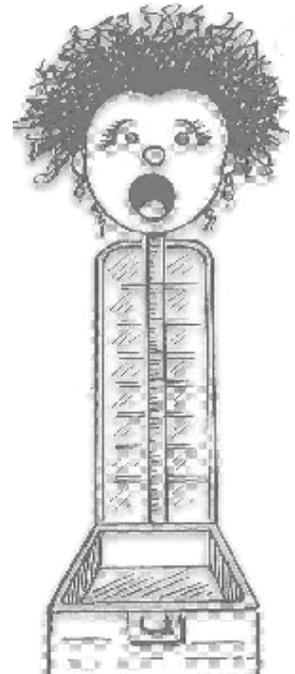
The majority of patients with kidney failure have increased blood pressure and many will require drugs to reduce it. There are a variety of drugs which may lower blood pressure and if you experience side effects with one drug, another may be found which is more suitable for you. It is, however, important for you to take your tablets on a regular basis and to have regular checks to see if the drugs are adequately controlling your blood pressure. It may well be necessary to reduce your salt intake, reduce body weight (if overweight), reduce excess alcohol, if applicable, and take adequate exercise, to help control your blood pressure. Your doctor will advise you.

Uncontrolled high blood pressure may cause damage to the heart such that it does not pump blood around the body as well as it should. When this occurs, fluid may build up in the chest causing shortness of breath. Fluid may also accumulate in the legs and cause swelling of the ankles and legs.

### **HIGH CHOLESTEROL**

One of the major factors contributing to hardening of the arteries (arteriosclerosis) is the presence of excess fats (cholesterol and triglycerides) in the blood. A modest change in your diet may be advised by a dietician. The addition of drugs, statins, may be recommended.

Keeping your weight under control and your body as active as possible, as well as avoiding cigarettes and having good blood pressure control, are just as important in avoiding hardening of the arteries.



## **HEART DISEASE**

When the kidneys are not able to filter the blood properly, excess waste products accumulate. At the same time excess salt and water also starts to build up. When there is too much salt and water retained in the body, blood pressure will go up and the heart finds it difficult to cope with the excess work load. In this situation the body will appear swollen, particularly around the ankles and legs. Water also stays stagnant in the lungs because the heart fails to pump the water out of the lungs. This will cause breathing difficulty, wheezing and coughing.

## **ANAEMIA**

Anaemia (low blood count) is common in patients with kidney disease and causes fatigue and tiredness. Anaemia may be caused by many factors, but the major cause is decreased production by the kidneys of a hormone called epoetin (erythropoietin, often shortened to 'Epo') which stimulates the bone marrow to make red blood cells.

The normal blood count, haemoglobin, is usually around 13g/dl. for females and 15g/dl. for males. The red blood cell normally survives for approximately 120 days but this is much less in patients with kidney failure.

Many patients with advanced kidney failure require injections of epoetin to treat the anaemia. These injections are given one to three times per week depending on the need of the individual. Patients can be taught to give these injections themselves (as indeed diabetics do for their insulin injections) or alternatively the injections may be given by the practice nurse or dialysis nurse. In addition, iron (either tablets or injections) may help the bone marrow to produce more red blood cells.

## **NERVE DAMAGE**

Neuropathy is a medical term meaning disease of the nerves. It usually occurs in the arms and legs. The main symptom of neuropathy is a numb feeling of the finger tips or tips of the toes. People usually say that it feels like their hands or feet are asleep. It usually involves both legs or both arms and the neuropathy may be severe enough to cause weakness of the legs. Happily, this symptom is rarely severe and does not usually occur until the later stages of kidney failure or in patients on dialysis.



## **SEXUAL FUNCTION**

People with kidney failure may have sexual difficulties, including a decreased desire for sex (libido). In men with kidney failure impotence (erectile dysfunction) may occur. There may be several reasons for these changes. The first is related to the changes in the body's hormonal balance. For women the result of this hormonal imbalance is that menstrual periods may stop or become irregular and ovulation (the production of eggs) may not occur. For men the change in hormone levels results in a decrease in the number and function of the sperm.

A second problem contributing to a decreased

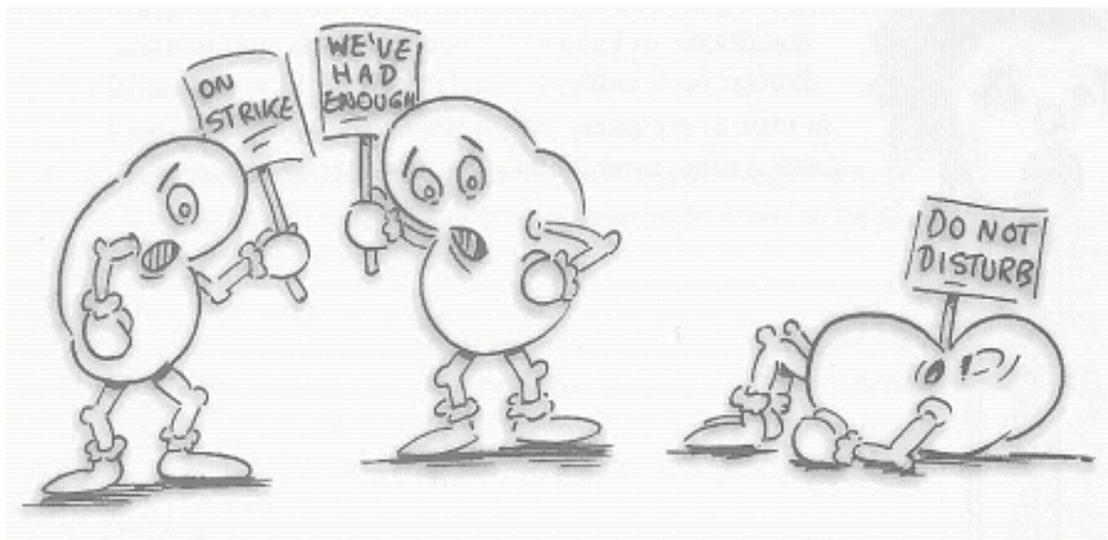
sex drive is anaemia. This causes tiredness and thus decreases the desire for a normal sex life. A third problem relates to some of the drugs which are used to control high blood pressure. A change in the drugs might improve matters. Finally, sexual function is frequently related to the overall psychological adjustment. This will be reflected in either satisfaction or dissatisfaction with various aspects of life or health. Thus dissatisfaction in work, school or at home may result in a decreased desire to have sex.

Some men do not have enough active sperm to easily permit impregnation. Since women rarely ovulate, there is less chance that they would become pregnant while on dialysis. However, it remains possible and contraception should be used, although a viable pregnancy is most unlikely. Fertility improves after a successful kidney transplant.

The best form of therapy is a positive attitude toward life, the partner and towards sex itself. Love does not rely on sexual satisfaction alone. A dialysis patient and his/her partner may experience and express love by companionship. Intimacy is a second aspect and a sexual relationship still another.

If there is dissatisfaction with sexual function, additional help may be available from specialists. Please do not be embarrassed to bring up concerns at your clinic visit.

## **CAUSES OF KIDNEY FAILURE**



Kidney failure is most frequently caused predominantly by four different diseases. These are diabetes, glomerulonephritis, high blood pressure, vascular disease and polycystic kidneys. There are a number of other diseases but they are not very common. For many patients no cause will be found for the kidney disease.

## **GLOMERULONEPHRITIS**

*[Glomerulo = a filter unit in the kidney + nephritis = inflammation of the kidney!]*

This disease involves inflammation (not infection) of the small filters of both kidneys. It may be associated with protein and blood appearing in the urine (which may only be detected by the doctor or nurse testing your urine). It may take anything from a few weeks to many years for glomerulonephritis to cause kidney failure, depending of the nature and severity of the nephritis.

## **POLYCYSTIC KIDNEY DISEASE**

This is a hereditary disease which causes large cysts in the kidney. Patients, however, usually do not develop kidney failure until late middle age and sometimes even later.

## **HYPERTENSION (HIGH BLOOD PRESSURE) & VASCULAR DISEASE**

This causes narrowing of the blood vessels (arteries) in the kidneys. With prolonged high blood pressure, kidney failure can occur.

## **DIABETES MELLITUS**

This is the commonest single cause of renal failure in the UK. Diabetes for more than 15 years, particularly if there has been poor control of blood glucose and blood pressure, may result in progressive renal failure.

In some patients the diagnosis of diabetes and renal failure may occur at the same time, with previously undiagnosed diabetes causing slow progressive damage to the kidney with initially few or no symptoms.

## **OTHER CAUSES**

Kidney damage may result from the following conditions:

- a. Kidney stones may block or damage both kidneys (nephrolithiasis).
- b. Enlargement of the prostate gland in men (obstructive uropathy).
- c. Prolonged use of some drugs (drug-induced nephropathy).
- d. Back flow of infected urine from the bladder up to the kidneys in childhood (reflux nephropathy).
- e. Auto-immune disease such as Wegener's granulomatosis.

## **HOW DO WE TREAT KIDNEY FAILURE?**

Your doctor will endeavour, with your help, to keep your kidneys functioning to their best of their ability for as long as possible. As end stage renal failure occurs, treatment will include regular medication, daily salt and water restriction, dialysis and, in some, renal transplantation, as well as providing ongoing support for you and your family.

Patients with kidney failure should be able to choose the treatment which they feel is suitable for them and their circumstances. Kidney failure and its treatment can affect family members as well as the individual. It is therefore essential that all aspects relating to the types of treatment are explored.

For some, treatment in their own homes rather than in hospital enables the individual to maintain their independence despite having to have treatment. For others, this option means less time travelling for treatment and less impact on their everyday life.

Some patients, however, may not be able to carry out treatment at home for various reasons and therefore their treatment will take place at the hospital. There are occasions where the choice the patient comes to is not always feasible or successful and changing the treatment option will need to be considered. Some flexibility exists.

In some patients after learning about the treatment options, they and their family may decide that neither treatment is suitable for them nor it would not improve their quality or length of life. Usually patients in this situation are suffering from a number of medical problems. The patient, with the support of the family, may therefore choose not to start active dialysis treatment (or discontinue it) and opt for conservative palliative therapy. The Renal and Palliative services will continue to support the patient till the end of life occurs.

## **METHODS OF TREATMENT DIALYSIS**

### **Dialysis**

Dialysis is a cleansing procedure which removes waste products and excess water from the blood. This is necessary when the kidneys are no longer able to filter these waste products and remove the extra fluid which accumulates. As these waste products rise, the patients become ill. This is called uraemia. The dialysis process improves blood biochemistry and body function (homeostasis).

There are two methods of dialysis. Haemodialysis is performed by using an artificial kidney machine resulting in filtering of the blood. Peritoneal dialysis, on the other hand, cleanses the blood by using your body's own filter in the abdomen and the blood never leaves the body.

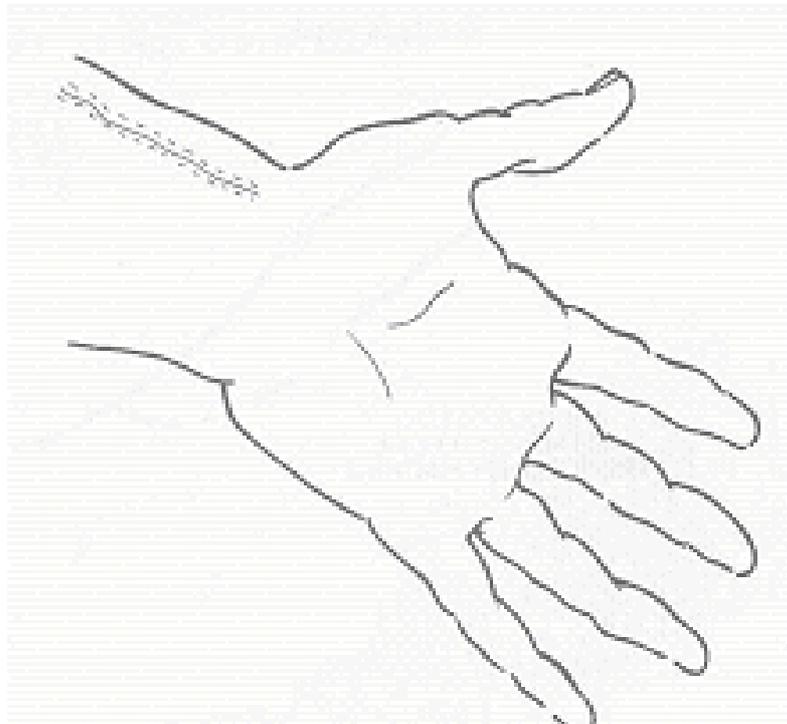
### **HAEMODIALYSIS**



Haemodialysis works by taking the blood out of the body and passing it through a filter (the artificial kidney). The blood is returned to the body after the waste products, excess salt and water have been removed. During this process improved blood biochemistry (electrolytes) is achieved.

The blood is removed from the body via an 'access' device. Generally, access is achieved by constructing what is called a fistula. Two blood vessels (one an artery and the other a vein) are connected underneath the skin. As a result of this connection, there is increased blood flow through the vein which enlarges and becomes thicker, until it is 'strong' enough to be used, usually 4-8 weeks after construction. This can vary from patient to patient. The procedure is usually undertaken under local anaesthetic.

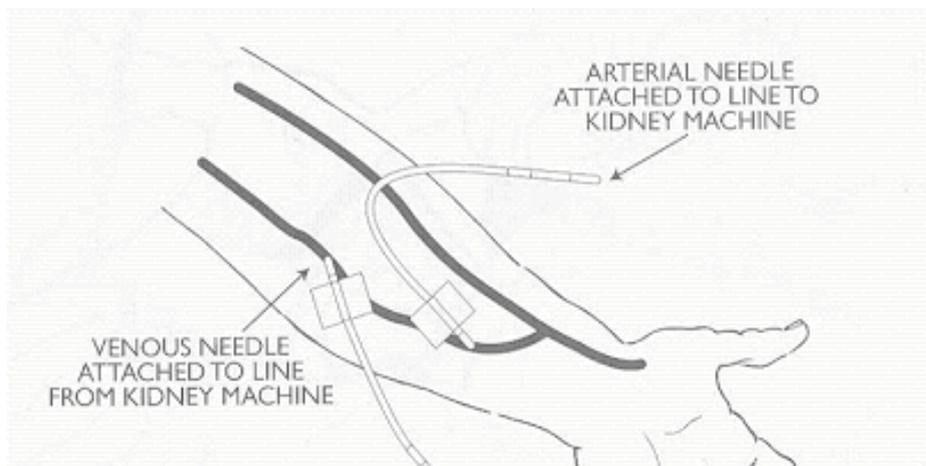
The fistula is used for haemodialysis by inserting two needles. Needling the fistula may sound painful, but to lessen the discomfort various forms of local anaesthetic can be used to numb the area. Once in place the needles have special tubing attached. Blood flows through one needle and tubing (arterial line) out of the body to the artificial kidney and back to the body through the other tubing (venous line) and needle.



There are four things which should never be allowed to happen to the fistula arm:

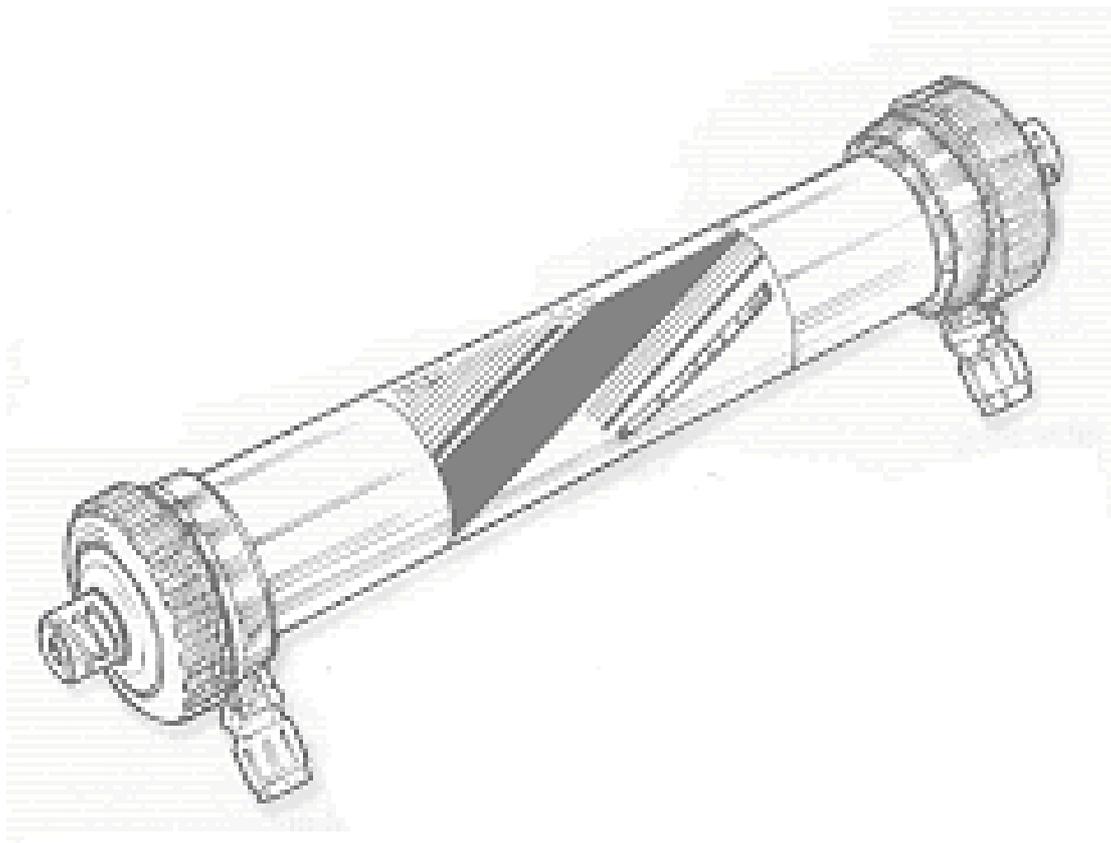
- a. Do not allow blood pressure to be measured on that arm.
- b. Do not allow blood to be taken or intravenous 'drips' to be started on that arm.
- c. Do not wear a watch or tight clothing with elastic or restrictive bands.
- d. Do not sleep on top of the fistula arm.

There are other types of access to the circulation (blood), but these are usually temporary. The commonest is a central line (often known as a Permcath catheter), which can be used immediately after it has been placed. It is usually placed in a large vein in the neck and may be used for several weeks or months until the fistula is ready. However, there are problems associated with such access, especially the risk of infection and hence all patients are encouraged to have a fistula.



Treatment on haemodialysis varies for each individual. You may start on twice a week but should expect to require dialysis three times a week in due course usually for three to four hours on each occasion.

## **THE ARTIFICIAL KIDNEY**



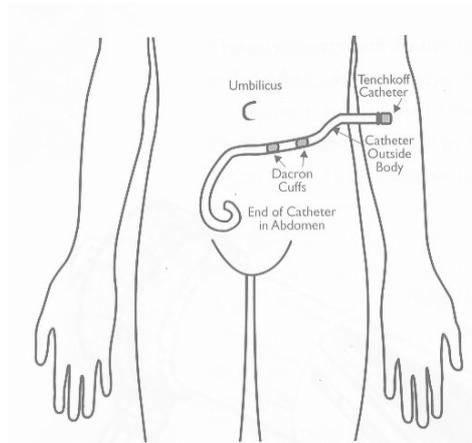
This consists of thin strands of hollow fibres through which the blood is passed. The blood enters the artificial kidney at the red (arterial) end and leaves at the blue (venous) end. The specialised fluid made by the kidney machine is known as the dialysis solution. It enters the artificial kidney and flows around the outside of the fibres in the opposite direction to the blood. Waste products move from the blood through tiny holes in the fibre wall and into the dialysis solution which is then pumped to a drain.

## **HOME HAEMODIALYSIS**

Many find that travelling for dialysis to the hospital is both inconvenient and time consuming. Studies show that patients who manage independently at home do better. Haemodialysis at home is often possible, after a suitable period of training for both the patient and helper (partner, relative or friend). It therefore provides an opportunity for full employment with dialysis in the evenings and/or weekends. The patient is therefore in more control of his/her illness and has more independence to choose the time for dialysis.

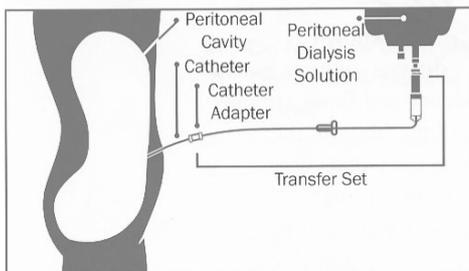
## **PERITONEAL DIALYSIS**

Peritoneal dialysis is a procedure in which 2-3 litres of fluid flow into the abdominal cavity through a tube. It can be performed in two ways: Continuous Ambulatory Peritoneal Dialysis (CAPD) or Automated Peritoneal Dialysis (APD).

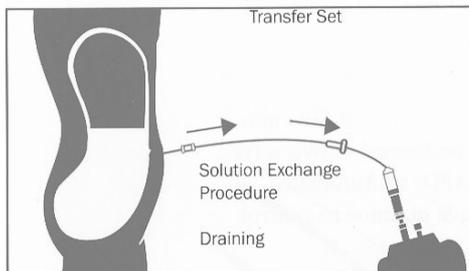


A soft plastic tube, known as a Tenckhoff catheter, is placed under local or general anaesthetic into the abdominal cavity on one side of the navel (belly button), usually on the right side of the abdomen if the patient is right-handed or vice versa.

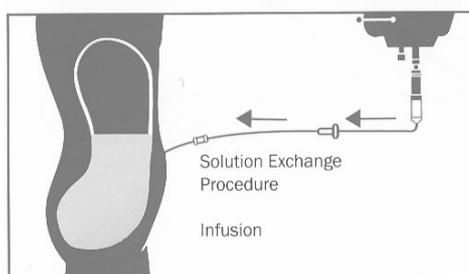
Once the catheter has been inserted, the patient will have a period of approximately 2-4 weeks before starting peritoneal dialysis to allow the wound to heal. Thereafter training for CAPD starts, during which the patient will be taught to manage his/her dialysis. The process is simple and very quickly learned but appropriate supervision and support from the CAPD nurses will be available.



A bag of peritoneal dialysis fluid (initially usually 2 litres) is drained into the peritoneal cavity through the catheter. The patient then clamps off the catheter line before disconnecting himself/herself from the system and securing the catheter in place. The fluid is left in the abdomen for 4-8 hours.



At the end of this time the patient reconnects himself/herself to a new sterile system and drains the fluid out before allowing fresh fluid to fill the abdomen. This process is known as an exchange and takes approximately 30 minutes from beginning to end.



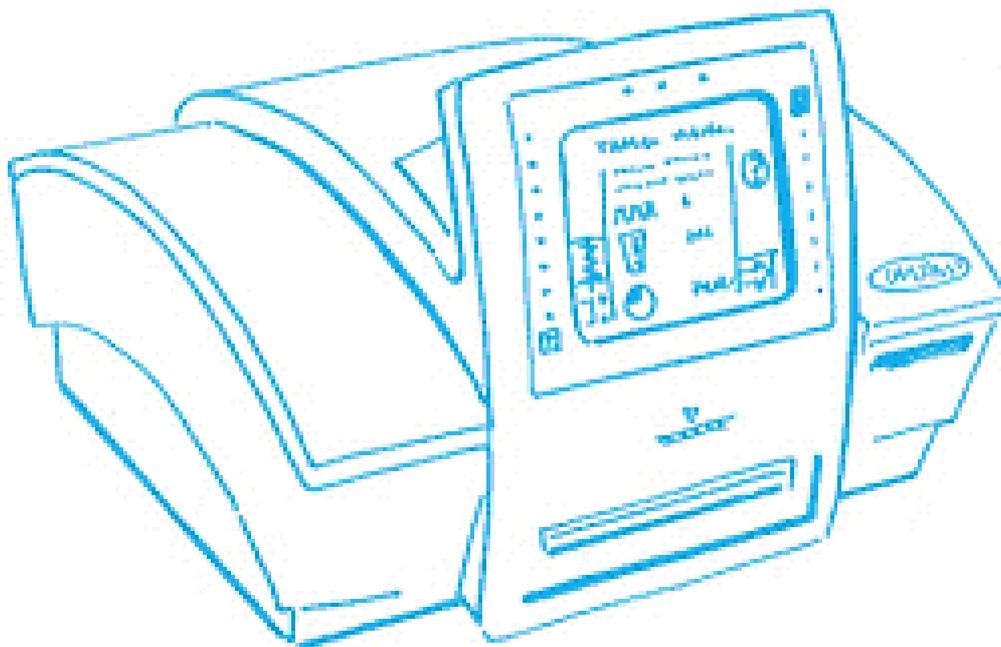
Usually, four exchanges a day are performed, in the morning, lunchtime, teatime and at bedtime. The last exchange at night stays in the abdomen for eight to ten hours, thus allowing the patient a night's sleep.

The patient has to perform these exchanges seven days a week and in so doing the treatment performs some of the functions of the failed kidney. Ongoing support is provided by the PD nurses with back up out-of-hours services from the Renal Ward (Langley) at the Norfolk & Norwich University Hospital.

## **APD (AUTOMATED PERITONEAL DIALYSIS)**

Automated peritoneal dialysis (APD) is a peritoneal dialysis treatment which uses a machine at home to perform dialysis exchanges at night. The patient attaches himself/herself to the machine when they go to bed and, as with CAPD, fluid is drained in, left in the abdominal cavity and drained out. This occurs automatically whilst the patient is sleeping. In the morning the patient disconnects themselves from the machine, thus allowing freedom from performing CAPD exchanges during the day. In some cases, however, one daytime exchange may need to be performed. The APD programme can be arranged to suit the individual's requirements and, after

some additional training, is simple to perform.



APD can be used as the initial treatment for patients who wish to opt for peritoneal dialysis, but it is also used as an alternative treatment for those patients on CAPD who are experiencing problems and who otherwise would have to transfer to haemodialysis. You need to discuss this option further with your doctors and renal nurses. Some patients combine CAPD and APD to extend their time of peritoneal dialysis.

## **Haemodialysis**

Advantages:

- ◆ Treatment three times a week for three to four hours on each occasion.
- ◆ No treatment on days between sessions therefore freedom from dialysis.

Disadvantages:

- ◆ More rigid diet and fluid restriction.
- ◆ Minor symptoms around periods of dialysis.
- ◆ Needle phobia.
- ◆ Body image - fistula can become large.
- ◆ Holiday - availability of haemodialysis in other centres limited.
- ◆ Access problems associated with small blood vessels or clotting.
- ◆ Infection.

## **CAPD**

Advantages:

- ◆ Less restricted diet.
- ◆ Less rigid fluid restriction.
- ◆ Independence.
- ◆ Easy to learn.
- ◆ Home based.
- ◆ Travel/holidays.

Disadvantages:

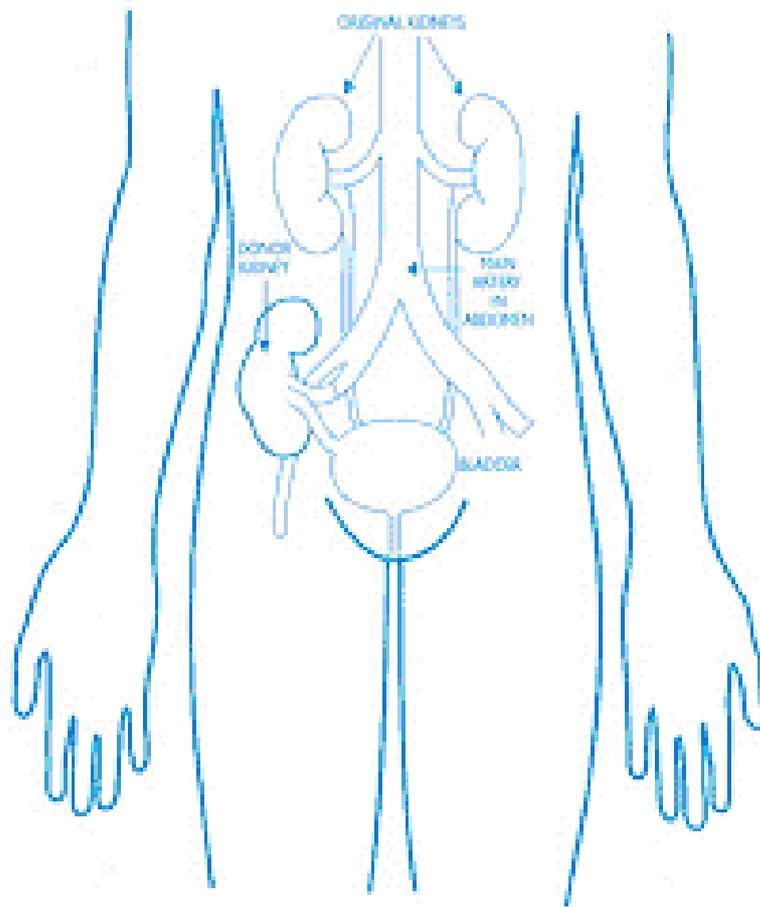
- ◆ Treatment required daily.
- ◆ Body image - catheter appearance.
- ◆ Infection.
- ◆ Hernias.

## **TRANSPLANTATION**

Kidney transplantation is a very good treatment for some patients. Kidney transplantation is an operation which provides a healthy functioning kidney. The new kidney performs all the functions which the damaged kidneys are unable to do.

There are two sources of donated kidneys:

Live donor: when the kidney comes from a family member, friend or partner. Anyone wishing to donate a kidney is looked at thoroughly to ensure their long-term health will not be adversely affected.



Deceased donor: when the kidney comes from someone who has died, usually as a result of injury to the brain which has caused brain death. The family of the deceased person have given permission for the donation, or the deceased has previously carried a donor card.

Once a person is accepted for transplantation, their name is entered onto the National Kidney Transplant list. The wait for a transplant depends on the number of available kidneys of the right blood group and tissue type. Kidneys are allocated according to the best match and then by length of time on the waiting list.

Less than half of patients who have end-stage renal failure can be considered for a transplant. A series of tests are performed to make sure they are healthy and thus ensure that the operation is safe for the individual and likely to succeed. This may include patients not yet started on dialysis if it is likely that dialysis will be required within the next six or so months.

Joint assessment for patients for transplantation is undertaken by doctors at Norfolk & Norwich University Hospital and Addenbrooke's Hospital, Cambridge.

All renal transplants are performed by a specialist team at Addenbrooke's Hospital, Cambridge, and you will get the opportunity before going on the renal transplant list of meeting them to discuss any issues which you may have. Follow-up, following successful transplantation, is undertaken after three months by the renal team at Norfolk & Norwich University Hospital.

Approximately 90% of transplanted kidneys are still working after one year and 70% at five years. The major concern after transplantation is rejection, which is the body's response to tissue which is not its own. To prevent rejection there are a number of drugs which may be used including

steroids (prednisone), azathioprine, mycophenolate, ciclosporin, sirolimus and tacrolimus. These medications may make the transplant patient more susceptible to infection.

There are obvious advantages to having a kidney transplant since dialysis is no longer required. In addition, many of the associated problems of kidney failure, such as anaemia, fluid overload and dietary restrictions, disappear. However, kidney transplants do not come with guarantees and may fail after a period, in which case dialysis is once again available. It is important that there is strict adherence to the medications prescribed and regular attendance at outpatient clinics to assess progress.

## **DIET**

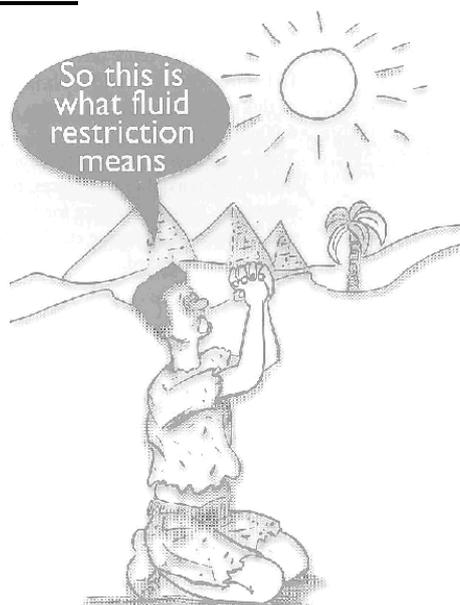
Diet is a very important part of the overall care of kidney failure. Whether haemodialysis, continuous ambulatory peritoneal dialysis or a kidney transplant is used, adaptation to diet may be required. It may be confusing, but a renal dietician will spend time explaining and planning an individual diet when dietary advice is indicated. The general well-being of a dialysis patient depends on a balance between the quantity of dialysis, diet and prescribed medications. Blood samples are taken regularly to monitor the effectiveness of your treatment.



Dialysis will help remove dietary waste products and excess fluid from the blood. However, this is not as efficient as having normal healthy kidneys. In renal failure you cannot therefore be allowed to eat and drink exactly what you like.

Accumulation of waste products and fluid between dialysis treatments can, to some extent, be controlled by diet and fluid restriction and relies greatly on patient co-operation. Failure to adhere to the diet may mean more time on dialysis which is obviously undesirable.

## **FLUID**



I know you said I would have to drink less but this is ridiculous.

With kidney failure, the kidneys can no longer get rid of large quantities of fluid or water. Excess fluid (salt and water) therefore will be retained in your body. This results in overloading of the circulation which can lead to breathlessness, a rise in blood pressure and swelling of the ankles.

Changes in fluid balance are usually reflected by changes in weight.

A target weight will be set and used as a guide for the patient in the management of their fluid balance. Because the urine volume can change, a 24-hour urine collection can be measured at intervals to re-assess fluid allowance.

## **SALT**

With kidney disease, the body is often unable to get rid of extra salt (sodium). Salt can make you thirsty, cause water retention and increase blood pressure. Dialysis patients are therefore advised not to add salt at the table, use salt sparingly and avoid salty foods. The dietician will discuss this with you in more detail. Salt substitutes must also be avoided and may be dangerous.

## **POTASSIUM**

Potassium is an important constituent of the body and is usually kept within a tight range (3.6-5.2mmol/l) by normal kidneys. Those with kidney failure have difficulty in getting rid of potassium and hence it may increase. An elevated potassium in the blood usually produces no symptoms but, if high, the heart can suddenly stop or muscles become suddenly weak. Hence, the dietician will give you advice about your diet and may instruct you to avoid those foods which are high in potassium.

## **CALCIUM & PHOSPHATE**

It is important to control the calcium and phosphate levels in the blood to maintain healthy bones as well as prevent damage to blood vessels (with consequent narrowing). Since the failing kidney cannot get rid of phosphate adequately, medication which binds phosphate in the gut may be recommended. In addition, there may be a lack of 'activated' vitamin D by the kidney and therapy may be prescribed to correct this. Dietary advice and medication will be given when appropriate.

## **IMMUNISATIONS**

Patients who are approaching the need for dialysis are recommended to have immunisation for hepatitis B. This is largely a precautionary measure and you will be advised to liaise with your G.P. when this is appropriate. In addition, immunisation against influenza is recommended every winter.

## **HOLIDAYS**

It is possible for patients on dialysis to have a holiday away from home, but you need to plan in advance and discuss this with your consultant or dialysis nurse. Holidays in a number of countries for patients on continuous ambulatory peritoneal dialysis are easy to arrange, since the company which supplies the fluid will be able to deliver it to your holiday destination. Please note that it may take some time to arrange supplies so several months notice should be given when possible. For patients on haemodialysis it is more difficult to arrange as there are limited haemodialysis facilities in a number of cities and countries and this will need to be discussed with your consultant or dialysis nurse. Some assistance with funding is available. Each renal unit usually has their own patient association which can provide assistance or act as a support group for kidney patients and their families. All patients are encouraged to go on holiday if medically fit and it is just as important for families to have a break.



## **THE RENAL SOCIAL WORKER**

The Renal Social Worker provides patients and their family with support, resources and information. Our practice is client-centred and we advocate on behalf of patients to gain access to the services and resources which they may need. We support patients to make their own choices, assist patients to gain control of their own lives and to develop skills and networks to maintain or improve well-being. If you need any assistance please ask your nurse or doctor to refer you to the social worker.

## **THE RENAL COUNSELLOR**

The Renal Counsellor provides the patient and their family with the support to explore the emotional, mental and physical effects which the transition of becoming a dialysis patient can generate as well as continuing support thereafter. If you need help, please ask your doctor or nurse to arrange an appointment.

## **ON CALL**

Kidney patients can always seek advice regarding dialysis-related problems from the Renal Unit or Renal Ward and telephone numbers will be given to you. General problems of health may be dealt with by the G.P.

## **RENAL INFORMATION EVENINGS**

Meetings are held monthly in the evening to explain in more detail to patients (and their families) the nature and implications of renal replacement therapy. An opportunity will be given to meet many of staff involved in dialysis, ask questions and be shown round the unit. In addition, patients undergoing peritoneal dialysis or haemodialysis will share their experiences with you and answer any questions. It is also possible to put you in touch with other dialysis patients so that you can meet to find out more about the treatments and the effects it has on an individual's quality of life.

## **CONCLUSION**

It is hoped that this booklet has helped to explain some aspects of kidney failure. The renal team of doctors, nurses, dieticians, social worker and technicians are available to explain any further details as appropriate.

## **Glossary**

Anaemia	A deficiency in the quality of red blood cells resulting in a low blood count.
APD	Automated Peritoneal Dialysis - peritoneal dialysis performed overnight with the use of a machine.
Arterial line	Blood is taken via this connection from the patient through the artificial kidney.
Azathioprine	A drug used in transplant patients to suppress any rejection of the donor organ.
Calorie	A measure of the energy contained in food.
Calcium	A substance needed for healthy bones.
CAPD	Continuous Ambulatory Peritoneal Dialysis: method of continuous dialysis via abdominal cavity membrane (patient is mobile).
Creatinine	A protein product of muscle breakdown which is excreted in the urine.
Cyclosporin	An anti-rejection drug used in transplant patients to suppress any rejection of the donor organ. Levels are monitored in the clinic.
Dialysate	Fluid containing glucose and mineral salts which is used for dialysis purposes in both peritoneal and haemodialysis treatment.
Diffusion	The process of transfer of substances such as urea or potassium across a semi-permeable membrane.
Dual lumen catheter	A temporary catheter which can be inserted via the jugular vein in the neck to allow access for haemodialysis.
Erythropoietin (epoetin)	A hormone normally produced by the kidneys. In kidney failure, this hormone (Epo) can be given by injection to raise the haemoglobin (blood count). The drugs used are Eprex, NeoRecormon and Aranesp.

Exit Site	The place where either the haemodialysis or peritoneal catheter comes through the skin.
Fistula	An opening created surgically between an artery and a vein to enable needle insertion for haemodialysis.
Haemodialysis	A treatment used to remove impurities from the blood by passing it through an artificial kidney.
Mycophenolate mofetil	A drug used to prevent rejection after transplantation.
Osmosis	The process of transfer of water across a semi-permeable membrane. In CAPD the peritoneum is used and in haemodialysis the artificial kidney.
Peritoneum	The membrane which surrounds the abdominal cavity.
Peritoneal fluid	The fluid used to dialyse via the peritoneum.
Peritonitis	Infection of the peritoneal fluid usually caused by introduction of germs/bacteria during an exchange or via the catheter exit site.
Phosphate	A substance which is needed in combination with calcium for strong healthy bones. In renal failure it may go too high and drugs may be used to lower it.
Potassium	One of the substances excreted by the kidneys. It can be dangerous if the level of potassium goes too high.
Prednisone	A steroid drug used in transplant patients to suppress rejection of the donor organ.
Protein	An essential substance for the growth and development of the body.
Semi-permeable membrane	This is a thin lining with very small holes in it. As the holes are of a certain size only small particles are able to pass through. In haemodialysis the artificial kidney contains a semi-permeable membrane. In peritoneal dialysis, the peritoneum is the semi-permeable membrane.
Sodium	A component of salt.
Tacrolimus	A drug used to prevent rejection of the transplanted kidney. Levels are monitored in the clinic.
Tenckhoff Catheter	A permanent flexible tube inserted into the abdomen. This is used to transport fluid in and out of the peritoneal cavity in APD and CAPD.
Urea	A by-product of protein excreted by the kidney.
Urea & electrolytes (U&E)	A blood test performed to measure the amount of concentration of impurities in the blood.
Venous line	Blood which has passed through the artificial kidney is returned to the body via this connection.

## IMPORTANT CONTACTS AND TELEPHONE NUMBERS

Consultant: \_\_\_\_\_

Renal Unit: \_\_\_\_\_

Clinical Dialysis Nurse Leader: \_\_\_\_\_

CAPD Department: \_\_\_\_\_

Home Dialysis Unit: \_\_\_\_\_

Dietician: \_\_\_\_\_

Social Worker: \_\_\_\_\_

Renal Counsellor: \_\_\_\_\_

Transplant Co-ordinator: \_\_\_\_\_

Pre-dialysis Educator: \_\_\_\_\_

Anaemia Co-ordinator: \_\_\_\_\_

Renal Ward (Langley): \_\_\_\_\_

Further information: