

Understanding Kidney Failure

2017 Edition



An Information booklet designed for patients and their families

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CHAPTER 1- THE KIDNEYS

The kidneys sit in the lower part of your back, one on either side of the backbone (see figure 1.). The 12th rib bone protects the upper part of the kidney. Between your kidneys and skin there is a layer of fat, some muscle and a capsule that surrounds the kidney. These layers ensure that the kidney is well protected when injury occurs.

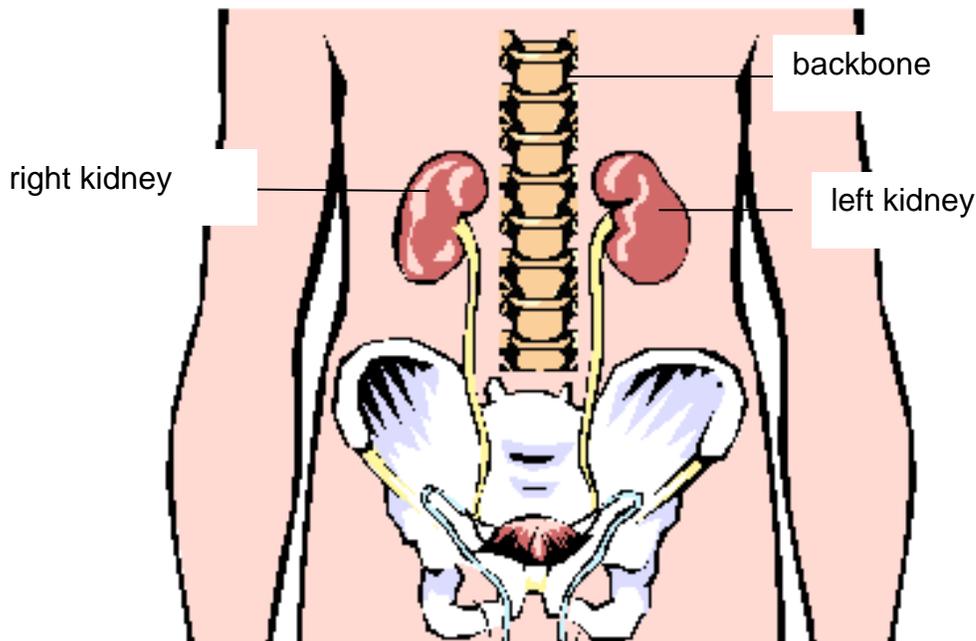


Figure 1. Shows the position of the kidneys on either side of the backbone.

Each kidney receives blood from an artery called the renal artery. The renal arteries branch off the major blood vessel in the body, the aorta. When the blood is cleaned (filtered) by the kidneys it is returned to the circulation by other blood vessels called the renal veins. These renal veins join the general circulation in a big vein called the inferior vena cava.

Each kidney is broadly divided into two areas. The outer part of the kidney is called the cortex and this is where most of the action takes place. It is within the cortex that the "nephrons" are found and the nephrons are the parts of the kidney which are responsible for filtering the blood.

The second major part of the kidney is the inner part, the medulla. The medulla is necessary for releasing certain hormones and for enabling us to concentrate the urine. Without a properly functioning medulla we would be passing urine all the time. (Figure 2.)

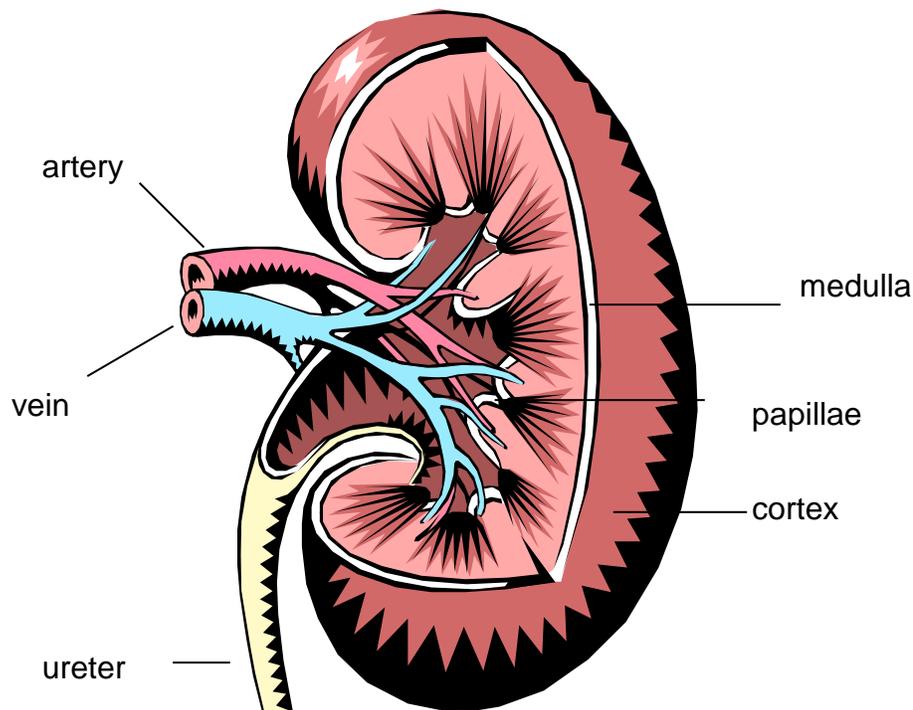


Figure 2. Shows the two main areas of the kidney

Once the blood has been filtered in the nephrons in the cortex, this filtrate goes through the medulla and any that needs to be reabsorbed back into the circulation is kept at that stage. What we no longer need passes out from parts of the medulla called papillae. These papillae are sometimes damaged in conditions like analgesic nephropathy and diabetes (see later).

By now urine has been formed and this passes down a tube called the ureter, which joins each kidney to the bladder. The urine remains in the bladder until it stretches sufficiently to signal our nervous system that it has to be emptied. Urine is then passed from the bladder to the outside world via the urethra. The urethra is quite short in the female and much longer in the male as it runs the distance from the base of the bladder through the prostate and then through the penis.

Functions of normal kidneys

The kidney has six major functions: -

- 1. To excrete the products of protein breakdown.** Everyday our bodies break down some protein (protein is the main building block of muscles). These breakdown products are usually not a worry provided the kidneys can excrete them. The major product you may know of is called urea. When the kidneys do not filter very well we tend to retain urea.

2. The kidneys need **to regulate the balance between acid and base in the body**. The main base is bicarbonate, similar to baking powder. Any of you who have a swimming pool know that you have to keep the pH correct at all times. The pH is a reflection of your acid base balance and our blood system is like a giant swimming pool where we need to keep the pH constant at all times. The kidneys perform this function by excreting acid when they should and by generating more base when it is required.

3. A very important function of the kidneys is **to regulate the balance of salt and water in the body**. Normal kidneys can respond extremely quickly to the need for keeping salt in the circulation. An example of this occurs during hot weather when we sweat a lot or after a particularly stressful exercise such as running. Without normal kidneys we would rapidly become dehydrated and would collapse.

Conversely, the kidneys need to be able to excrete salt when the body does not need it. If you dine out at a Chinese restaurant then it is quite likely that you will ingest a lot of salt and under ordinary circumstances you will not need this. Your kidneys will excrete this salt and hence you will not get high blood pressure.

4. Regulation of electrolytes. There are certain substances in our bodies which regulate important functions such as contraction of muscles, the working of nerves and the contraction of the heart. The most important amongst these is potassium, for without a proper balance of potassium in the body, muscles will not work properly and with a build up of potassium the heart may stop! Calcium and phosphate are also important to ensure that our bones, muscles and heart all function as they should. The kidneys regulate the balance of these substances, and many more.

5. It is often not appreciated that the kidney is like one big "gland". **It produces a number of hormones and it activates a number of other hormones**, which are produced in other parts of the body such as the liver. Without the kidneys we would not have good function from hormones such as Vitamin D which is necessary to absorb calcium into the system and prevent bone diseases like osteoporosis. Another major hormone is called erythropoietin. This hormone sends a signal from the kidney to the bone marrow to tell our body to make more red blood cells, which carry oxygen and give us energy.

6. Finally, the kidney has an important function **to ensure that we remove medications that we take**. Medications are generally broken down by either the liver or kidneys and in either case the waste products from these medications often have to be excreted by the kidneys.

FUNCTIONS OF THE KIDNEY

1. Excrete products of protein breakdown.
2. Regulate acid-base balance.
3. Regulate the balance of salt and water in the body.
4. Regulates electrolyte balance.
5. Production of hormones.
6. Excretes medications to prevent their build up in the body.

CHAPTER 2 - KIDNEY FAILURE

Major causes of kidney failure in Australia

Glomerulonephritis ("nephritis") is a common cause of kidney failure. There is a range of types of nephritis but these can generally be thought of as an immune reaction against your own kidneys. In turn the kidneys leak blood and/or protein into the urine and gradually the nephrons get scarred. Once they get scarred they cannot do their filtering job properly and the kidneys begin to fail. Some types of nephritis are readily treatable with powerful medications. Others types remain untreatable and slowly progress towards kidney failure, usually over a 10-20 year period or more quickly in rare cases.

The most common cause of kidney failure is **Diabetes**. About one third of patients who have insulin requiring diabetes will develop kidney failure. This is more likely in patients with high blood pressure or where blood sugars are poorly controlled. This is commonly accompanied by eye problems as well. Recent studies have shown that very good control of blood sugar may prevent or delay the onset of kidney failure from diabetes. Some blood pressure medications are now known to also delay this process - therefore the news is not always bad for diabetics who start to develop kidney problems. The first sign of kidney problems in diabetes is the appearance of protein in the urine. This is easily tested for by a simple urine test.

Reflux nephropathy is a disorder that people are born with. In essence, the ureters did not develop properly and where they join into the bladder is faulty. When urine is passed some of it goes backwards up towards the kidneys as well as forwards into the outside world. This "reflux" back up into the kidneys gradually damages the kidneys, particularly if there is also urine infection or high blood pressure. Provided this condition is recognised in the first couple of years of life then surgery and/or antibiotics may prevent long term problems.

Analgesic nephropathy is kidney failure (kidney scarring) caused by the old analgesic powders which you may know as Bex or Vincent's. It is possible to develop a similar condition if you take a lot of medications used for the treatment of arthritis, or a lot of aspirin. This condition is becoming much less common since the powders were made illegal in the 1970s.

Polycystic kidney disease is responsible for about 10% of patients with kidney failure in Australia. This is a genetic (inherited) disorder which affects about 1 out of 2 family members. The inherited tendency is for very large cysts to fill the kidneys, resulting in kidney failure because there is not enough room for the nephrons to do their filtering. This condition is readily diagnosed by an ultrasound to see if the kidneys have been affected and generally if there are no cysts by age 30 then it is very unlikely that the condition will ever appear in that person. There is not specific treatment for polycystic kidney disease as yet, though certain blood pressure medications may be quite useful in this condition to slow the rate of decline towards kidney failure.

Ischemic nephrosclerosis is the name given to scarring of the kidneys which occurs because the blood flow to these kidneys is reduced. This is very similar to coronary artery disease or "hardening of the arteries" at any site in the body. This process arises due to a combination of factors such as a family history of hardening of the arteries, diabetes, high blood pressure, high cholesterol and smoking. It tends to affect older people and can be prevented by good lifestyle! This is becoming one of the most common causes of kidney failure in Australia and reflects our limited attention to healthy eating, exercise and blood pressure control.

There are a large number of other causes of kidney failure but these are fairly rare.

The problems with failing kidneys

A quick check of the functions of the normal kidneys will suggest what goes wrong when the kidneys start to fail.

1. The products of protein breakdown get retained leading to nausea and lack of appetite and some weight loss.
2. There tends to be a build up of acid which can result in rapid breathing and disturb other functions in the body, including the reduction of bone strength.
3. As the kidneys decline they generally retain too much salt and water leading to high blood pressure and sometimes difficulty in breathing.
4. As the filtering ability of the kidney ceases potassium tends to get retained in the body and this can cause fatal heart rhythms if left unchecked. Phosphate is also retained and calcium falls and this leads to weakening of the bones and muscle aches.
5. The kidneys fail to produce a hormone called erythropoietin (EPO). This hormone tells the bone marrow to produce red blood cells and hence a deficiency of this hormone leads to anaemia. This in turn makes you tired and may cause palpitations, loss of libido and a general feeling of lethargy.
6. Failure to activate Vitamin D can result in bone disease and changes in other hormones can raise the blood pressure. Because the kidneys break down insulin, diabetics sometimes need to use less insulin than they did before the kidneys failed.
7. Finally, certain drugs may build up in the blood stream as the kidneys deteriorate and it is always worth checking your medications with your doctor. This particularly applies to the use of some blood pressure and heart medications which can build up if the kidneys fail or may even accelerate the problems of kidney failure.

Kidney failure can potentially affect the whole body. On the following page is a list of potential complications that can occur with kidney failure. As you can see many parts of the body may be affected. This list is not exhaustive but it is worth pointing out that individual patients will get different arrays of these symptoms. It should also be noted that the major aim of treatment is to prevent these complications from occurring as much as possible.

Table 1 - Potential affect on the whole body

Nervous System	Confusion; "vagueness"; reduced concentrating ability Drowsiness; forgetfulness; headaches Subtle personality changes Coma (very rare these days) Peripheral neuropathy - tingling or loss of feeling in hands and feet.
Muscles and Bones	General weakness; muscle aches Bone pain Easy fractures of bone
Blood System	Anaemia - tiredness; loss of energy; heart palpitations, shortness of breath Reduced ability to fight infection Easy bruising Blood vessels harden more easily, i.e. "hardening of the arteries".
Heart	High blood pressure - usually causes <u>no</u> symptoms but may cause the heart to pump less effectively Angina - chest pains due to "coronary disease" Heart failure
Lungs	Rapid breathing and/or shortness of breath.
Gastrointestinal System	Nausea; vomiting; loss of appetite Diarrhea Stomach ulcers (peptic or duodenal ulcers) - usually cause no symptoms but later on may cause stomach pains or may bleed.
Skin	Dry skin Itching Easy bruising Cuts do not heal so quickly
Sexual Dysfunction	Impotence - sometimes due to drugs used in treatment Loss of libido Infertility - most men do not produce normal number of sperm and most women do not ovulate (however some do and contraception is still advised).

The progressive nature of kidney failure

Once mild to moderate kidney failure has progressed, it is usual for the decline in kidney function to continue. However, the rate of decline is quite variable i.e. some kidney disorders will progress more rapidly than others and within different patients even the same disorder might progress at a different rate. The end result is that some disorders will progress so slowly that they will ultimately not affect the patient's life span whilst others will progress very rapidly and dialysis and transplantation will be required fairly quickly.

The two aims of treatment in the early stages of kidney failure are:

1. To slow the rate of decline of kidney failure; and
2. To prevent as many complications of kidney failure as possible.

Treatments to slow the decline in kidney function

Quite a lot of attention is paid to **changing your diet** once kidney failure becomes established. The main thrust is to ensure you are eating for a healthy lifestyle. Some studies have shown that a reduced protein intake may slow the rate of decline of kidney function but this should always be done in conjunction with an experienced dietitian as it is important not to reduce the protein intake too much thereby causing malnutrition.

Perhaps the most important way of slowing the rate of decline of kidney function is **meticulous control of blood pressure**. High blood pressure rarely causes symptoms but your doctor will still pay a lot of attention to your blood pressure and blood pressure lowering medications will constantly be altered.

Recent studies have suggested that **controlling cholesterol and other body fats** might also slow the decline in kidney function. Therefore you may be placed on a low cholesterol diet or even cholesterol lowering or other fat lowering medications.

It is very **important to avoid factors which might accelerate the decline in kidney function**. These include some drugs so it is always important to check any new medications with your doctor. This also applies to the use of "natural" remedies, some of which have been associated with rapid kidney failure. Becoming dehydrated at any time is not good for the kidneys and urinary tract and other infections should always be treated fairly early so you should see your doctor at the first sign of infection

Assessment of kidney function

The simplest way of assessing your kidney's ability to filter the blood is by measuring the products of protein breakdown in the blood. These are called urea and creatinine (creatinine comes from muscle). The higher the result in the blood, the worse your kidneys filtering ability.

The estimated filtration rate or the eGFR is also a calculation reported on your blood tests which can help indicate the percentage of kidney function you have.

There are more sophisticated ways of assessing kidney function and on occasions these will be necessary e.g. nuclear medicine blood tests, 24-hour urine collection etc.

As well as assessing the kidneys' functions your doctor will wish to assess your kidneys' structure. This will mean x-rays and ultrasounds but on occasion more specialised testing such a kidney biopsy will be needed. If these specialised tests are required your doctor will discuss the details of these with you.

By periodically reviewing blood tests (your doctor will determine how often this is necessary in your case) the rate of decline of kidney function can be assessed. Changes in the blood tests can often pre-date the development of symptoms of end-stage renal failure. Therefore these tests are very important and it will often be possible for your doctor to predict that dialysis is necessary before any major symptoms develop. In some cases, even with careful attention to the blood tests, the kidney function may decline rapidly towards the end and the most common symptoms at this stage will be nausea, vomiting and weakness.

CHAPTER 3 - TREATMENT OPTIONS FOR END-STAGE KIDNEY FAILURE

When your doctor decides that dialysis is about to become necessary or alternatively, you have begun to develop symptoms and/or signs of end-stage kidney failure, then several new options become available. The "medical" treatments (e.g. diets, medications etc) may still be required in conjunction with these new treatments and you will be advised about this.

The treatment options fall into four groups: -

1. Haemodialysis
2. Peritoneal dialysis
3. Transplantation
4. Conservative treatment

The principle of any form of dialysis is that the blood is artificially filtered. In essence the blood runs on one side of a membrane (like a thin sheet of paper) and dialysate fluid (a man-made solution) runs on the other side of this membrane.

In haemodialysis this membrane is an artificial kidney manufactured by companies. In peritoneal dialysis the membrane is the peritoneum which is the natural lining of the inside of your abdomen.

If dialysis is chosen as the most suitable option, dialysis at home is strongly encouraged. Patients who learn to perform their own dialysis at home generally have better health and a more independent lifestyle.

Choosing the type of treatment

This is an individual decision and on some occasions your doctor will strongly advise one form of dialysis because of other existing problems. However, where there is not any particular indication that one form would be better than another, the choice of home therapy is left to the patient.

Juggling medications, perhaps dietary restrictions and certainly a healthy lifestyle are all important no matter what option you choose. Sometimes the decisions regarding what option is best for you are difficult especially for people who have little understanding of kidney treatments. Your healthcare team including your kidney doctor, nurse consultant, social worker, dietician, GP and others are available to assist you in your decision making.

At the end of the day it is important to bear in mind that dialysis will keep you well but that, like every treatment in medicine, there may still be complications.

All patients with kidney failure should consider planning for the situation where they may not be able to make their own decisions about the medical treatments they would like in the future. More information regarding this process can be found at the dialysis unit, through clinics or ask the Renal Social Worker for assistance.

Option - peritoneal dialysis

The peritoneum is a large membrane which is the natural lining of the inside of the abdomen. The peritoneum covers the abdominal organs and receives a large blood supply. This makes the peritoneum an ideal dialysis membrane.

To perform peritoneal dialysis it is necessary to gain access to the peritoneal membrane. A surgeon inserts a plastic tube called a peritoneal catheter. This catheter remains in place permanently and is covered by a dressing which is attended by the patient (figure 4).

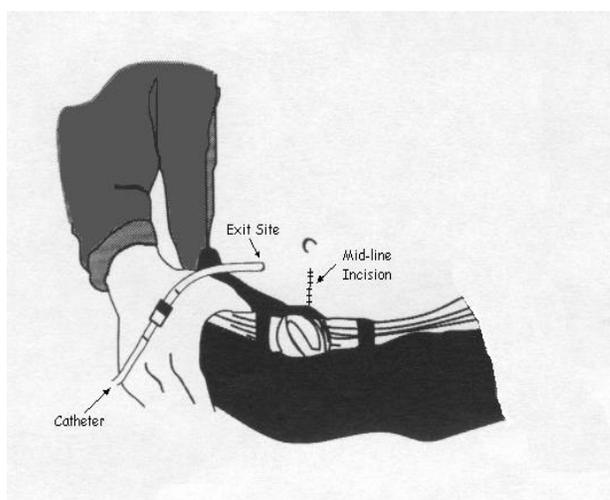


Figure 3. Shows the position of the peritoneal dialysis catheter

There are two ways to perform peritoneal dialysis continuous ambulatory peritoneal dialysis (C.A.P.D), and automated peritoneal dialysis (APD).

- In **C.A.P.D** special fluid is run into the abdomen via the peritoneal dialysis catheter. The catheter is then capped and the fluid is left inside. The patient is free to do whatever they wish and the dialysis process will be going on continuously. The blood flowing on one side of the peritoneum gets cleaned and the waste products go from the blood across the peritoneum into the fluid on the other side (see figure.5). After about 6 hours the fluid containing the waste products is drained and a fresh bag is instilled and the process begins again Each C.A.P.D bag exchange takes about 1/2 an hour and must be done with extreme care to prevent infections.

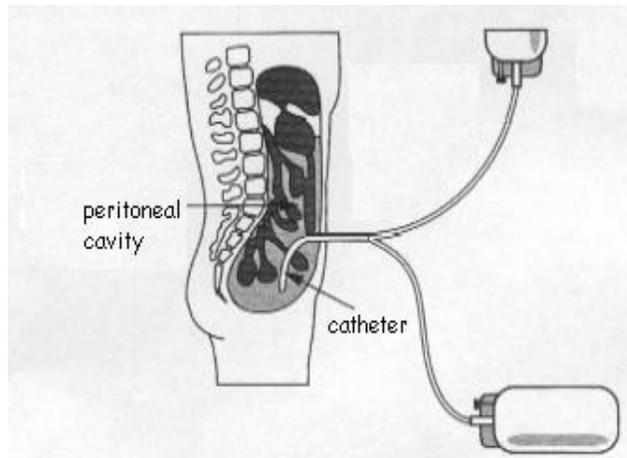


Figure 4. The CAPD exchange

- **APD** involves a machine which can be programmed to deliver peritoneal dialysis fluid into the abdomen over an 8 -12 hour period at night. This is often an advantage for people who work or have a busy lifestyle.



Figure 5. APD machine set up next to the bed

Option - haemodialysis

Haemodialysis involves the filtering of blood through an artificial membrane using a machine. Blood is withdrawn and circulates through the artificial kidney or dialyser and is then returned to the patient.

Before haemodialysis can be commenced it is necessary to gain access to the patient's blood stream. This will require an operation to create an AV fistula. During an AV Fistula operation the surgeon makes an opening in the wrist or elbow and connects one of your veins to your artery. The wound is then closed with internal sutures.

After the operation your vessel begins to enlarge under the skin and when you place your fingers over the area a buzzing (thrill) can be felt after 6-8 weeks these veins become suitable for the placement of needles required to withdraw and return the blood to your body during haemodialysis. (See figure 5.)

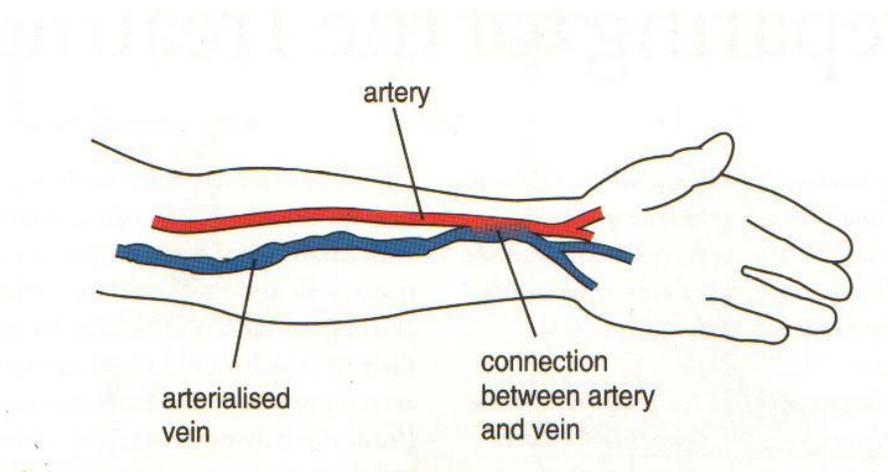


Figure 5. An AV fistula created in the arm. The artery and vein are stitched together and the blood from the artery flows directly into the vein making the vein stronger.

The Vascular Access Nurse (VAN) will arrange you to have ultrasounds of your vessels before you see the surgeon. The VAN will also follow you up post operatively to ensure your fistula is developing well. Although it sounds somewhat frightening at first, most patients learn to put their own needles in and become extremely good at this. The process of haemodialysis usually takes 5 hours and is done at least 3 times per week.

What are the benefits of Home Haemodialysis?

- Home haemodialysis makes it possible for you to remain independent of hospital care, rigid routines, a “sick” environment and the risk of cross infection.
- Home haemodialysis permits flexibility with days or hours for dialysis treatments and can be done while asleep, leaving the days free for work, school and play.
- Our data from quality of life surveys repeatedly identifies home haemodialysis as the dialysis option which promotes the best quality of life.
- Home haemodialysis provides the opportunity for successful rehabilitation and continued employment.

- Time, money and difficulties in arranging transport are saved by not having to travel to dialysis units three times every week.
- Home haemodialysis comes with good follow up support in the home by trained staff.
- You should experience fewer problems with your fistula because the same person puts the needles in each time.
- Good for patients who are remote from hospital as home haemodialysis requires people to only come to hospital for clinic visits.
- You can perform home haemodialysis if you live alone.

But most of all home haemodialysis offers flexibility and improved quality of life

Because you are at home you are not restricted to the usual three times a week dialysis for a set number of hours. Many home haemodialysis patients now dialyse every second day or overnight. Longer hours of dialysis means better clearance of waste and fluids from your body. Kidneys normally work 24 hours a day therefore longer and/or more frequent dialysis will make you feel better, stronger and reduce the restrictions and medications you may otherwise have.

What are the benefits of more frequent & longer dialysis?

- Dialysis related symptoms e.g. lethargy, post dialysis headaches, cramps etc are rare
- Better fluid control with reduced restriction on fluid intake
- Better nutritional status with reduced restriction on foods that contain potassium and phosphate
- Less sleep disturbances
- Less medication required e.g. blood pressure and phosphate binders
- Sexual desire and activity is improved
- General physical, mental and long term health outcomes are improved.

St George home haemodialysis training is a satellite of Sydney Dialysis Centre (SDC) based at Royal North Shore Hospital. People are required to go to SDC for an interview and the final part of training but the majority of the training can be done at St George. Usually training will take an average of 6-8 weeks. The duration of the training is very individual, so the time frame is tailored to each patient. When you are reaching the end of the training you will be transferred to SDC where you will have dialysis in the graduation room. This simulates the home environment to ensure you are confident and safe to start dialysis at home. You will meet the SDC nurses who will provide the 24 hour on call service to you and will visit you at home to monitor your progress and ensure your dialysis is trouble free.

We have around 50 patients who perform haemodialysis treatment at home. In total SDC cares for approximately 150 patients on home dialysis. Most patients do 5-6 hours every second day. About 25% of the patients perform nocturnal (at night) dialysis for 8-10 hours. Approximately 35% of the patients perform dialyse solo (without any support from family or friends).

Who is suitable to do home haemodialysis?

People who have:

- Motivation to succeed and are self reliant at home
- Good eyesight
- Good hand dexterity
- The ability to understand the concepts of home haemodialysis
- Good vascular access (fistula or graft)
- Space at home for equipment
- Good general health, memory, alertness and mobility.

Option - kidney transplantation

A kidney transplant is one of the alternatives for treatment of kidney failure. Recipients of successful transplants generally feel significantly better, and their lifestyle is usually more reminiscent of that before they developed kidney problems. The results for kidney transplantation within Australia are comparable to the best in the rest of the world. According to the most recent figures, approximately 90% of the transplants performed in this country still function at the end of one year, and 95% of the recipients are still alive. The corresponding figures after five years are around 75% and 85% respectively. Nevertheless, there are some risks involved in kidney transplantation, and recipients face a lifetime of taking powerful drugs that suppress the function of the immune system. The following brief description is designed to answer a number of the common questions about transplantation.

Who can have a kidney transplant?

Not everyone is a suitable candidate for a kidney transplant. The presence of conditions such as chronic infection, cancer or serious heart or lung disease makes some people unsuitable candidates for renal transplantation. This is because these conditions substantially increase the risk of postoperative complications or prevent the use of transplant medications which work by suppressing the immune system. While age is not the primary consideration in whether a person is suitable for a transplant, the increased risk of conditions such as heart disease as patients get older means that in practical terms many patients older than the age of 60 are not suitable candidates for a renal transplant. However, the decision about whether a patient is suitable for a transplant is made on an individual basis after assessment by the patient's renal physician in consultation with the transplant physician.

What are the benefits and risks of kidney transplant?

The most obvious short-term benefit of a kidney transplant is the freedom from dialysis and a dramatic increase in spare time. Following recovery from the operation, most recipients also feel much better, and many are able to return to full-time work. Usually the only restriction on activities is to avoid contact sports, rather than run the risk of injuring the transplanted kidney. In most cases recipients also experience improved sexual function and interest, and most women of childbearing age will regain their fertility. There have been many examples of successful pregnancies following transplantation, so contraceptive precautions are required once again.

These benefits do not come completely free of risk. The initial risk is of the operation itself, and surgical complications are not uncommon, but are usually minor or easily fixed. The major long-term risks are secondary to the immunosuppressant drugs that are necessary to prevent the body from rejecting the transplant. There is an increased chance of infections, some of which can be life threatening. Hence, we advise all recipients to take precautions to avoid exposure to people with infections, especially in the first few months following the transplant, and during this time they are seen very frequently and assessed carefully by the transplant doctors. This is also the time when rejection of the transplant is most likely.

Treatment of rejection requires bigger doses of the drugs or more powerful medications and so is a particular time when infections can occur. Treatment with immunosuppressant medications also puts the recipients at increased risk of certain forms of cancer, particularly skin cancer.

We advise precautions against excessive sun exposure, and arrange regular review by a dermatologist. Women are also at increased risk of gynaecological cancers (e.g. cervical) and need to have a formal gynaecological examination at least annually.

There is a further long list of potential side effects of the immunosuppressant medications which will not be described here. It is important to be aware that every effort is made to minimize these problems particularly by reducing the doses of the drugs to the lowest level required to prevent rejection of the transplant.

Where do the kidneys come from?

Most kidneys transplanted in Australia come from cadaveric donors i.e. victims of motor vehicle accidents or other catastrophic events that have been declared brain dead. This is also the source of other transplanted organs, such as livers, hearts, lungs, and pancreas. The Red Cross coordinates kidney allocation. When a donor is identified the body is maintained on a mechanical ventilator until the transplant surgeon removes the kidneys, which are then transported to the recipient's hospital packed in ice. Kidneys stored this way are useable for up to 36 hours, although sometimes recovery of kidney function may be delayed for several days or weeks after surgery. During this time the recipient is kept on dialysis until the new kidney takes over.

Approximately one third of kidney transplants in Australia now come from living donors, most of whom are close blood relatives of the recipient (e.g. parent, sibling). This is particularly common in children with renal failure, where one parent is the donor. Occasionally donation by a non-related person is considered, but only if that individual has very strong emotional ties to the recipient e.g. spouse, stepparent. There must be no question of inducement to donate a kidney. The risks to the donor include that of the operation, and probably a slight long-term increased risk of high blood pressure. However, one normal kidney is ample for good health and the donors generally consider that these small risks are comfortably outweighed by the potential benefits to the recipient. The long-term survival of well-matched living donor kidneys is excellent. Potential living donors undergo a careful screening procedure including a medical history, physical examination, blood and urine tests and X-rays to ensure their suitability for kidney donation.

How are the kidneys allocated?

At the time of entry on the transplant waiting list all patients have their blood type and tissue type determined by the Red Cross. When a cadaveric kidney becomes available, it is allocated to the person on the waiting list with the best matching of both blood and tissue type, provided that they do not have a positive cross-match. If there is more than one suitable recipient, the kidney goes to whoever has been waiting the longest.

The current average waiting time for a kidney transplant in NSW is over three years, and the waiting list continues to grow. The major problem is the low rate of organ donation in this country compared to the rate in other countries, particularly in Europe.

Option – Conservative management – choosing not to have dialysis

For people with chronic kidney disease there is no specific pill or operation. In other words there is no cure. For some the disease will progress to a stage where treatments such as dialysis and or transplantation are recommended; for most the condition will still progress but at a slower rate.

Providing you with information about treatment options early in the course of kidney disease allows you the time for it all to sink in. There will be time to gain information about the dialysis options and about what it might be like if you decide not to take up dialysis. You can decide not to take up dialysis. You have the right to refuse treatment you do not want. It is preferred that this decision is informed which means you have an understanding of the other treatments and what they entail. Making decisions is a way that patients exercise their right to be involved in their health care.

There is information your kidney doctor can use to assist you in your decision. As you can imagine your other significant diseases and your age will impact on your future health no matter whether you choose to proceed with dialysis or not.

It is a good idea to involve family, friends and carers in your decisions as it will also affect them and the healthcare team encourages that to happen. Occasionally, patients and family members have unrealistic expectations about what dialysis can achieve. Dialysis is not a 'cure' for kidney disease. Ultimately it is your decision as to what you want to do about treatment for your kidney disease.

What symptoms might I experience and how can they be managed?

Everyone is an individual and they respond to kidney disease in different ways. Most patients will report an increase in tiredness and inability to do the physical activities they once could manage. You may also experience emotional changes, appetite changes, itchiness, and changes in breathing and fluid accumulation.

Support at St George Hospital

Some patients think that if they choose the 'no dialysis' option they will be abandoned by their kidney doctor and healthcare team. Sometimes patients have been visiting their kidney doctor regularly for a number of years and if you choose not to have dialysis you will continue with these visits.

At St George Hospital we pride ourselves on the support we provide for people who choose not to have dialysis. Our focus has always been on the quality of life and the journey of our patients. Arising from our endeavours are a number of initiatives but the most exciting is the Renal Supportive Care Clinic.

The strong partnerships we have forged with the palliative care service at the hospital have allowed us to use the expertise of these doctors and nurses to help in kidney failure management. The service is crucial in controlling and supporting patients with symptoms and when the time comes - end of life care. Your kidney doctor may refer you to this clinic to help you with your decision regarding whether or not to have dialysis or to assist in controlling your symptoms if you choose not to have dialysis. Remember you will still continue to see you kidney doctor regularly.

CHAPTER 4 - NUTRITIONAL MANAGEMENT

Nutrition is an important part of your treatment program. Together with medication, exercise and a healthy lifestyle your health will be better maintained. If you need to make changes to your diet, your doctor will refer you to a renal dietitian.

Role of the Renal Dietitian

- * To provide you with dietary counseling, education and an individual nutrition care plan.
- * To provide ongoing assessment and support to ensure your nutrition needs are met.

Nutrition and your Kidneys

Food and drinks provide you with the energy and nutrients to keep your body working well. Once your body has used the nourishment, the waste products e.g. urea, excess fluid and minerals (e.g. salt, potassium and phosphorus etc) build up in the blood. The kidneys work to **keep** what your body needs and **filter** out the unwanted substances and pass them into the urine.

The kidneys also play an important role in regulating some of the hormonal systems in your body e.g. red blood cell formation and the control of calcium, phosphorus and vitamin D balance to keep your bones strong.

When you have kidney problems, your kidneys are not working well enough to maintain good control of these systems and dietary changes may be required to restore the balance.

Following a diet is of vital importance to your health.

The aims of the diet are: -

1. To keep your body well nourished.
2. To help you feel better by eating the right foods.
3. To keep the blood levels of nutrients, waste products and fluids at a good level to avoid any complications - both short-term and long-term.

The diet you need depends on the **type** and **stage** of your kidney condition. Your diet may change a few times even before you need dialysis. It will also change again after starting on dialysis and also after a kidney transplant. However, everybody is different and you have your own individual dietary needs.

Good nutrition is important in maintaining good health, especially when you may also need to follow a special diet. Some of the important components in food and drinks are:

Protein, fat, carbohydrate – starches and sugars, vitamins, minerals, fibre and water

You need a balanced diet which provides your body with enough **energy** and the right amount of essential **nutrients** to suit your treatment. Your dietitian will help you to choose the right types and amounts of food from the table of food groups each day.

Food Groups

Bread and cereals



For energy, carbohydrate, vitamins, Minerals and fibre. Bread, cereals, Breakfast cereals, rice, macaroni, spaghetti, pastas, noodles and biscuits.

Fruit and vegetables



For carbohydrate, vitamins, minerals, and fibre – green and root vegetables, potatoes and fruit.

Meat and other protein foods



For protein, vitamins, iron, zinc and other minerals – lean beef, veal, lamb, pork, poultry, fish, seafood, eggs, cheese, baked beans and lentils.

Milk and milk products



For protein, calcium and vitamins – milk, yogurt, milk products, ice cream and custard.

Fats



For energy, essential fatty acids, vitamins – margarine, oils.

A. Pre-dialysis dietary management

Protein – Your body needs protein e.g. meat, fish, chicken eggs and milk for many important functions. This includes making muscles and tissues and helping your immune system prevent and fight infection depending on the **type** and **extent** of your kidney problems, your doctor may advise you to follow a protein restricted diet. This may be to relieve the symptoms, such as tiredness caused by the build up of protein waste. Hopefully it will help to ease the workload of the kidneys and slow down the loss of kidney function.

How much protein you need depends on how well your kidneys work and your body size. Additional calories (energy) from fats and sugars will be used to make up your energy needs, so that your body can use the ‘recommended’ amount of protein more efficiently and help prevent muscle loss. If you need a protein-restricted diet, your doctor and dietitian will see you regularly to monitor your progress.

Sodium (Salt = Sodium chloride). Your body needs small amounts of sodium/salt everyday. At some stage, your doctor may advise you to eat less salt to help blood pressure control. Remember in some kidney conditions, the kidneys cannot conserve enough salt, so the restriction of salt could be harmful.

Potassium is a mineral and is found in most foods including fruit, vegetables, meat, milk and legumes. It is essential for keeping your body muscles and nerves working properly. Too much or too little potassium in the blood is dangerous. High blood potassium can cause paralysis of the heart muscle and lead to a heart attack, while low blood potassium can cause symptoms such as muscle weakness.

Depending on your kidney function and the medication used, you may need a **high** or **low** potassium diet to keep the blood potassium within acceptable levels. Many blood pressure tablets are known to affect potassium levels, for example diuretics such as lasix, make you lose potassium in the urine.

Some ACE inhibitors e.g. captopril retain potassium. Always check with your doctor as to whether any of your tablets might upset your body’s balance of potassium.

Phosphorus you may need to follow a low phosphorus diet and take a phosphate-binding tablet to keep your bones strong and prevent any itchiness.

Fluids you may need to limit fluid intake if oedema (or swelling) is a problem.

Fats High blood fat (cholesterol and triglycerides) is common in chronic renal failure. Too much fat can block the blood vessels of the body including the vessels in the heart and kidneys. The good control of blood fats may help slow down the loss of kidney function and prevent other blood vessel problems. Some people may need medications to help control blood fats or need to eat less saturated fat in the diet. Examples of foods that contain lots of saturated fats are meat fat, chicken skin, butter, lard, cream, full fat dairy foods and some take away foods.

Vitamins and minerals Kidney failure changes your body’s ability to use vitamins and minerals you eat in food. In some conditions you may need to take the supplements as prescribed by the doctor e.g. iron tablets to help correct anaemia. If you need to follow a low protein diet your doctor

will prescribe a low dose of vitamin B and C for you. **ONLY take the supplements as prescribed by your doctor** and eat a well balanced diet to obtain the vitamins and minerals from food.

Healthy Weight

Aim for your weight to be in a healthy range for the good control of blood pressure and blood fats. If you are overweight, you will need to lose weight. On the other hand unintentional weight loss means you will lose muscle. The declining kidney condition as well as changes in taste and appetite can cause unintentional weight loss.

B. Dietary management for dialysis

Once you have started on dialysis, either haemodialysis or CAPD, your dietary needs will be revised. Your nutrition needs depend on your body size, food habits, lifestyle and the type of dialysis that you are on. However it is important to remember that dialysis does not totally replace the work of the healthy kidneys and therefore you need to eat and drink sensibly to

1. Maintain good nutrition and body weight
2. Replace nutrients that are lost during dialysis
3. Avoid excess build up of waste products, minerals and fluid. This helps lower any side effects of the build up of these products.

The table summarises the dietary requirements for both dialysis types.

DIETARY REQUIREMENTS	HAEMODIALYSIS	CAPD
	Intermittent	Continuous
Energy	high	Moderate
Protein	Moderate	High
Salt	No added salt	No added salt
Potassium	May be restricted	Moderate
Phosphorus	Restricted plus binders	Restricted plus binders
Fats	Mono and poly unsaturated fats	Mono and poly unsaturated fats
Fluids	Restricted	Restricted
Vitamins and minerals	Individualised supplementation by your doctor	Individualised supplementation by your doctor

Malnutrition is common in people who do not eat an adequate diet. This may lead to poor health and complicate your dialysis treatment. Poor nutrition may increase your risk of getting infections this includes peritonitis for those who are on CAPD. It is important that you remain well nourished.

CHAPTER 5 - MEDICATIONS

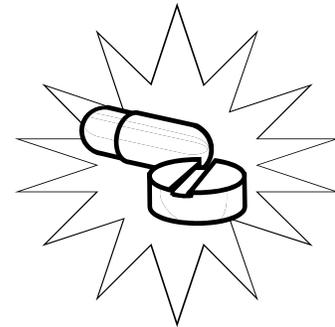
All of us need to know some basic facts about the medicines we take, whether for long-term use or short-term use, e.g. a course of antibiotics.

Prescribed medicines should be properly labeled with: -

- Name and strength of the medicine
- The amount to be taken.
- How often to take it.
- Any special instructions e.g. with or before food, avoid alcohol etc.
- Quantity in container.
- Patient's name.

Side Effects

- All medicines have possible side effects.
- Not everyone experiences side effects.
- Different people can experience different side effects.
- If you experience any unwanted effects tell your doctor.



Storage

- Store medicines in a cool, dry place, safe from children.
- Some medicines have to be refrigerated.
- Check expiry dates.
- Do not remove from original packaging.

DON'TS

- Don't take more than your prescribed dose.
- Don't take someone else's medicines.
- Don't leave the doctors' surgery without fully understanding the instructions.
- Don't stop taking a prescribed medicine because you feel better.
- Don't stop taking your medicine because of a minor side effect - talk to your doctor or pharmacist.
- Don't stop taking your medicine because you feel it is not doing any good - talk to your doctor.
- Don't take leftover medicines without talking to your doctor.
- Don't be afraid to ask for more information or help in managing your medications.

CHAPTER 6 - THE RENAL DEPARTMENT

The St George and Sutherland Hospitals are part of the South Eastern Sydney Local Health District. Since its inception in the 1970s, the St George Hospital Renal Department has rapidly developed into a service with dialysis and transplant outcomes as good as other major Teaching Hospitals in Australia.

The Department offers a wide range of services for people with kidney problems. These include:

- Peritoneal dialysis training
- Haemodialysis home training
- Haemodialysis incentre and satellite
- Renal transplantation preparation and follow up
- Blood pressure monitoring
- Clinics
- Laboratory and research facilities

4 SOUTH - Situated on the 4th floor of the Ward Tower Block, 4 south is the dedicated ward for patients requiring admission for kidney failure and related disorders. Visiting hours on 4 South are restricted to allow patients adequate rest.

4 WEST - 4 west houses the haemodialysis services which comprises 34 machines. Patients who are in hospital have haemodialysis treatments on 4 west. Some patients who require haemodialysis are elderly or have medical reasons why they cannot perform dialysis at home. This group of patients also attend 4 west. The unit promotes self-care and education to ensure that the patients are as independent as possible. Haemodialysis is required 3 times a week for 4-5 hours. Patients are allocated a treatment time, which is subject to change. The unit operates 6 days per week and delays are lengthy due to the large workload.

HOME HAEMODIALYSIS - 4 west is also the place where people train to perform haemodialysis at home. There are around 40 St George patients who are performing home haemodialysis.

THE PERITONEAL DIALYSIS-TRAINING UNIT is located in a house in South Street Kogarah between the public and private hospitals. Specialist nurses are available for the training and follow up of patients on peritoneal dialysis. It usually takes about two weeks to be able to do your dialysis well. Following training the nurses visit on a regular basis, and then less frequently as time progresses. Peritoneal dialysis patients are required to attend the centre for review by their doctor at special clinics.

SUTHERLAND SATELLITE UNIT -This service is located within the grounds of The Sutherland Hospital. Patients who are unable to perform home haemodialysis attend this unit if there is a position. There is minimal nursing supervision and patients are expected to perform self-care where able.

SYDNEY DIALYSIS CENTRE – Located on the grounds of Royal North Shore Hospital, SDC oversees the home haemodialysis training conducted at St George.

CHAPTER 7 - THE IMPACT ON YOUR LIFE

The diagnosis

The diagnosis of kidney failure can be a frightening and difficult experience for you and those close to you. The implications of kidney disease and its treatment may seem overwhelming.

Each person reacts differently to a diagnosis of kidney failure however it is likely that you will experience a range of feelings. Some of these may include:

- Shock and denial
“This cannot be happening to me”
“There must be some mistake”
- Anger, resentment and frustration
“Why me?”
“I’m too young”
- Numbness and fear
“What’s going to happen to me?”
“Am I going to die?”
- Distress and depression
“I can’t cope”
“What’s the point anyway?”

All of these reactions are normal. You need time to work through your feelings. It is often helpful to talk with family, friends or a social worker. You do not need to go through this alone.

Life style changes

Although kidney failure will affect different people in different ways, it is likely that most people will have to make some adjustments or changes to their lifestyle to manage kidney disease and its treatment. Some of these may include:

- Less time for usual activities due to the treatment routine.
- Dietary and fluid restrictions, which may make socialising seem difficult.
- Increased dependence on family and/or friends
- Role changes within the family
- Reduction in the ability to participate in sport or other strenuous activities.
- Need to change or cease employment and possible financial stress that may follow.
- Decreased interest in sex.
- Change in body image.

These adjustments or changes are stressful for you and for your family. You may feel quite depressed in response. It is extremely important that you are able to share how you are feeling and seek support as needed. Once again, this is a normal response to a very difficult situation.

Impact on the family

Kidney disease affects your partner, family or significant others as well as you. As such, it is likely they too will experience a range of feelings following your diagnosis.

Each family member will deal with their feelings differently. Some may not want to talk at all while others may have strong outbursts of emotion. This can create significant tension within the home. Although it is difficult it is important for family members to be sensitive to each other’s needs as far as possible. Facing kidney disease together will make things easier.

Where open, honest communication can be achieved it allows for the expression of fears, anxieties etc. It also provides the opportunity for mutual support, which is much needed when

facing a disease such as kidney failure. This is not always possible however as not all families are able to be sharing and supportive, particularly at such a difficult time.

It may be helpful to seek additional support from extended family, friends or from the team in the Renal Unit, particularly the social worker.

The social worker

The social worker can provide you, your family and friends with both practical and emotional support. This may be on issues such as:

- Physical and emotional implications of your illness
- Body image and sexuality
- Adjustment to illness or loss
- Managing at home
- Relationship problems
- Financial matters
- Accommodation/housing
- Social security
- Transport
- Arranging community support services
- Providing information on services/referrals and any other personal, relationship or family matters you wish to discuss

Resources for the renal patient and family

The Renal Association of NSW was founded in 1970 by a group of patients and friends to assist people with renal failure and their families. Membership is open to patients, family and friends from all Renal Units and application forms are available from the Renal Unit Staff. The Association holds regular meetings, as well as a number of social and fundraising events during the year. Major activities include: -

- Provision of holiday facilities
- Publication of a newsletter to keep members informed about association activities
- Financial assistance to those with difficulties in meeting costs resulting from their treatment.
- Patient information.
- Personal assistance - particularly to those people new to dialysis. Meetings can be arranged between people in a similar situation who understand and can give advice.

The Renal Association is a registered charity and has no paid staff. They are therefore reliant on membership fees, donations and fund raising to continue their activities.

Renal Resource Centre is based at the Sydney Dialysis Centre, the Renal Resource Centre provides renal patients with information and educational material to assist them in coping with the effects of renal disease on lifestyle.

Kidney Health Australia is a non-profit organisation dedicated to the eventual eradication of kidney disease. The aims of KHA are:

- Medical and scientific research
- Education
- Public information

CHAPTER 8 - USEFUL CONTACTS

St George Hospital Gray St Kogarah 2217	9113 1111
4 West Haemodialysis 4 th floor, Ward Block	9113 1151 9113 2078
Peritoneal Dialysis Unit	9113 3775
4 West clinics	9113 3885
The Sutherland Hospital Satellite Unit	9540 8660
Your doctor's Number	_____
Renal Nurse Consultant (Predialysis education and assessment)	9113 1111 page 843 or 91133634
Dietitian Nutrition and Dietetics 2 nd floor, Pritchard Wing	9113 2752 or 9113 1111 page 009
Social Worker Social Work Department 4 th Floor, Pritchard Wing	9113 2494 or 9113 1111 page 742
Kidney Health Australia	1800005881 www.kidney.org.au

CHAPTER 9 - GLOSSARY OF TERMS

AV fistula	A surgical connection between an artery and vein in the wrist. Required for haemodialysis treatments.
Cortex	Outer part of the kidney where most kidney function takes place
Creatinine	Breakdown product of muscle which becomes a waste product in the blood.
Dialysis	Filtering of the blood across a semi permeable membrane i.e. haemodialysis, peritoneal dialysis.
End stage renal failure	Kidney failure where dialysis or transplantation is necessary to maintain life.
Erythropoietin	Hormone stimulated by the kidneys .Responsible for the production of red blood cells.
Haemodialysis	Filtering of blood through an artificial membrane using a machine.
Dry weight	You are said to be at your dry weight when your blood pressure is within normal limits and you have no signs of fluid overload.
immunosuppression	Medications taken to prevent a recipient from rejecting a kidney transplant.
Medulla	The inner part of the kidney which is responsible for concentrating the urine.
Nephron	Filtering component of the kidney.
Peritoneal dialysis	Dialysis utilising the peritoneum as the dialysis membrane.
Renal	Medical term meaning “to do with the kidneys” E.g. renal failure.
Urea	Breakdown product of protein. Urea retention occurs in kidney failure
Vascath	A catheter inserted into the major neck or shoulder vessel which is used for haemodialysis. Used when there is no functioning AV fistula or vein graft.
Vitamin D	A hormone which is activated by the kidney. Necessary to absorb calcium into the system and prevent bone disease

SPECIAL NOTE FOR YOUR GENERAL PRACTITIONER

Kidney Health Australia provides accredited education for health professionals through the Kidney Check Australia (KCAT) program.

Please download a copy of the booklet:

Chronic Kidney Disease (CKD)
Management in General Practice 3rd Edition 2015
From www.kidney.org.au

This booklet provides guidance and clinical tips to help identify, manage and refer CKD in your practice.

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