

# **Kidney Failure Treatment Options**

Making the Right Choice

#### **Foreword**

You have been given this introductory booklet because you have been diagnosed with kidney failure and will need dialysis or a kidney transplant at some time in the future. For most people, this is a difficult time and there are many emotional and practical issues to deal with. You are probably very worried about the future. However, many thousands of people all over the world, live very active and fulfilling lives in spite of their kidney failure. Dialysis and kidney transplantation are exceptionally successful treatments and can keep you very well. In Australia, there are currently about 8,600 people receiving dialysis treatment and about 6,500 people living with kidney transplants. In 2005, 2,210 new patients commenced treatment in Australia.

Your doctor will want you to learn as much as you can about all the treatments available. Read this booklet carefully and talk about it with your family. We hope it helps you to understand how each treatment works and to decide which treatment is most appropriate for you. Some of you may decide against treatment, particularly if other medical problems may reduce the benefits of dialysis or transplantation.

Use the booklet to help you remember the discussions and education you will have with your kidney specialist and the staff of your renal unit. You may wish to first read the whole booklet for an overview and then re-read the chapters that most interest you right now. Approach what lies ahead step by step. It doesn't all happen at once. It's usual to talk and read about all the possibilities many times before making your decision. The staff will help you make the best treatment choice for you and your family.

To assist non-English speaking patients, this booklet has been translated from English into Arabic, Chinese, Greek, Italian and Vietnamese. Interpreters are also available in hospitals for discussions with medical and other staff.

Further information, education and counselling about kidney disease, dialysis, transplantation, personal and lifestyle issues are available from the staff of your renal unit and the Renal Resource Centre. Learn about your disease and treatment. Your knowledge and active involvement in your treatment will help you to live a healthy, happy and active life.

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#### **Normal Kidney Function**

The kidneys are two vital organs. Each one has about one million filters (glomeruli). These remove waste products and excess fluid from the blood as urine. Urine is stored in the bladder and passes from the body via the urethra (see Figure 1). The kidneys also produce and regulate hormones, which help to control blood pressure, produce red blood cells and help form healthy bones.

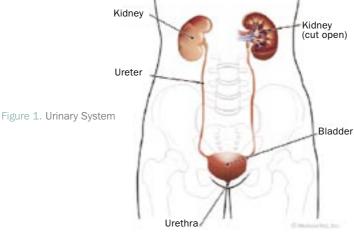
#### **Chronic Kidney Disease**

Chronic kidney disease is a process during which kidney tissue is destroyed over a long period of time. Many people are unaware of their kidney disease until over 70% of their kidney function has been lost. When both kidneys are severely damaged, the only treatments available to replace the function of the kidneys are dialysis or kidney transplantation. The most common causes of kidney failure in Australia are diabetes mellitus, glomerulonephritis (inflammation of the kidneys' filters) and hypertension (high blood pressure).

#### **Symptoms of Chronic Kidney Disease**

Some or all of these symptoms can develop once kidney function (measured using blood and urine tests) is below 30%:

- > Fluid retention causing breathlessness and swelling of ankles and feet
- Tiredness
- > Headaches
- > Poor memory and concentration
- > Irritability
- > Sleep disturbances
- > Restless legs
- > Itchiness
- > Loss of appetite and nausea
- > Weight loss
- > Reduced libido and altered sexual function



Your kidney specialist (also called "renal physician" or "nephrologist") will recommend dialysis when medication and dietary changes can no longer control these symptoms. Dialysis is a safe and effective replacement for lost kidney function. It will not stabilise or improve the function of your kidneys. However, once you start dialysis, you will notice a marked improvement in your health and wellbeing, as many of these symptoms will be minimised or completely resolved.

For many people, transplantation is another treatment option. In some cases, this may "pre-empt" dialysis, if a living donor is available (see Chapter 4 Kidney Transplantation). However, it is most usual to commence dialysis prior to transplantation. Dialysis is necessary until a suitable donor is available. This can sometimes take several years. There are some people for whom transplantation is medically inappropriate. These people can have long term dialysis. Because dialysis may be long term, it is important to choose the form of dialysis that will best suit your lifestyle.

In some circumstances, the burdens and disadvantages of dialysis and transplantation can outweigh the benefits. Good quality of life and comparable outomes can be achieved, particularly for some elderly people, by using other therapies. This is discussed in more detail in Chapter 5, Medical Management of Kidney Failure. Talk with your doctor if you are uncertain about the appropriateness of commencing dialysis.

#### How Do I Decide Which Form of Dialysis is Best for Me?

If dialysis has been recommended by your kidney specialist and you wish to learn about it, there are two forms of dialysis: **haemodialysis** and **peritoneal** dialysis. These are discussed in Chapters 2 and 3.

Providing there is no medical reason why one form of dialysis is more suitable than another for you, your **choice of dialysis will be influenced by your personal circumstances.** These can include your family situation, where you live, whether you are in the workforce, your lifestyle, whether you like to swim regularly, your capacity to undertake the treatment yourself or your ability to travel to a centre for treatment. Your kidney specialist and the staff in your renal unit can assist you in choosing the form of dialysis that suits you best.

#### **Adjusting to Dialysis**

After being diagnosed with kidney failure, it is normal to wonder why this happened and to feel a range of emotions such as shock, anger and depression. Eventually, these feelings are less overwhelming, especially as you learn that an active life is possible despite your kidney failure. Learn as much as you can about treatment and use the support of your friends and family at this time. They want to help you, so don't withdraw or isolate yourself from them.

In time, you will find it easier to accept that dialysis is part of your life. You should expect to feel healthier and more positive after you start dialysis. Returning to your studies, work, leisure and social activities will help your adjustment. Some changes in your lifestyle are inevitable but manageable. Current dialysis technology makes leading a full and satisfying life entirely possible.

Remember that your kidney specialist, the staff of your renal unit and the Renal Resource Centre are available to help you and your family to find the best way of managing your life with dialysis.

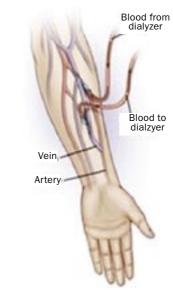


Figure 2. Arterio-Venous Fistula

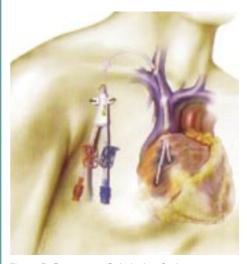


Figure 3. Permanent Subclavian Catheter

#### **How Does Haemodialysis Work?**

Haemodialysis is a treatment that is started when less than 10% of kidney function remains. It is designed to **filter the blood** of waste products and **remove any excess fluid** from the blood. The blood is cleansed outside the body using a haemodialysis machine and artificial kidney (**dialysis membrane**). Each treatment generally lasts between four to six hours and is usually performed three times per week but sometimes more often and for longer hours.

Haemodialysis can be performed at home, a hospital dialysis unit or a satellite dialysis unit (see next page). Many people will be encouraged and supported to manage dialysis at home. If this is not possible, then attendance at a hospital or satellite centre will be arranged. However, in rural and remote areas, this may not be practicable because there is no renal unit nearby. Home dialysis (haemodialysis or peritoneal dialysis) or relocation may be the only options available.

Access to the blood or circulation is necessary for haemodialysis. This is made possible by the surgical creation of vascular access.

#### Vascular Access for Haemodialysis

Your surgeon will recommend the type of access most suitable for you. Access for dialysis needs two needles (cannulas) to be put into a vein: one sends your blood to the artificial kidney machine and the second, returns it to your body. As this process occurs at least three times per week, it is necessary to have a reliable access point.

This is created by minor surgery to join an artery to a vein in your forearm and sometimes in your upper arm. This is called a **fistula** (see Figure 2). If the vessels in your forearm are too small, a vein **graft**, using a vein from your leg or a graft using artificial material (gortex), is used to create your haemodialysis access, usually in your forearm and sometimes in your thigh. It is preferable to arrange access surgery some months before dialysis is necessary. This will mean your fistula is ready to be used when dialysis starts and you can avoid the inconvenience of a temporary access.

If dialysis is immediately necessary and the fistula or graft has not been created, then a temporary form of access, using a soft catheter placed into the veins in the neck or upper chest can be used (jugular or sub-clavian catheter, known as vascath or permacath) (see Figure 3). Most people would prefer to avoid these, as they have a high risk of infection.

## Home, Satellite or Hospital: Which Location is Most Suitable for Me?

#### **Home Haemodialysis**

Successful home haemodialysis very much depends upon your motivation to remain independent with direct control of your treatment. It also helps to have a commonsense approach and a stable and supportive family or network of friends. Many people dialyse with the assistance of a partner and others are able to dialyse alone. The popularity of overnight home (6-8 hours) and more frequent haemodialysis is increasing, particularly as it frees daytime hours and results in very good health.

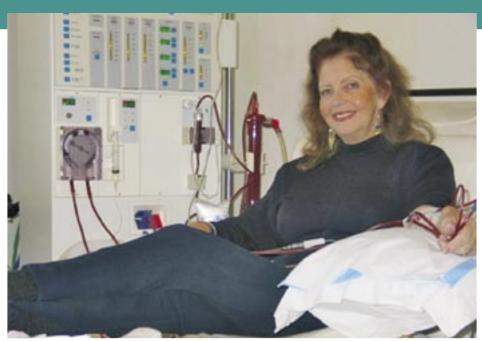
The dialysis equipment and disposable items and training necessary to perform haemodialysis at home are provided by the government at no cost. Patients provide plumbing for the machine, recliner chair and weighing scales. It is possible that financial assistance for these items can be arranged.

Your doctor will refer you to a specialist home haemodialysis training unit. The average time to learn how to manage your own haemodialysis treatment is **6-8 weeks**. If you are employed, you will need to arrange leave for the duration of your training. Your kidney specialist, social worker and nursing staff will help you to decide whether treatment at home is possible.

#### Satellite and Hospital Haemodialysis

If, for medical or social reasons, home haemodialysis is unsuitable, dialysis treatment is available in satellite or self-care dialysis centres usually 5 hours, 3 times per week. However, the location of these special centres is not always convenient to your home, especially in rural and remote areas. In most cases, you will be responsible for arranging your transport to the dialysis centre. Ambulance transport is generally unavailable.

In a satellite centre, you can manage your own dialysis treatment, under the supervision of nursing staff. In the case of complex medical problems, hospital haemodialysis with full nursing care is available for the duration of any acute illness and sometimes as a long-term option. Your kidney specialist, social worker and nursing staff can give you more information about which dialysis location is most suitable for you.



> Home Haemodialysis



> Satellite or Hospital Haemodialysis

#### What Can I Do During Haemodialysis Treatment?

If you dialyse during the day, you will probably dialyse in a recliner chair. Unfortunately, it is not possible to walk around during dialysis but it is certainly possible to read, watch TV, listen to music, chat or snooze. There is no discomfort during dialysis. The hardest part is finding something to do to pass the time. Dialysing at home offers maximum flexibility. Many people, especially those who work full time now dialyse overnight in the comfort of their home.

> Medications, Fluids, Diet and Exercise Haemodialysis alone is not enough to keep you well. Medications, fluid restrictions and dietary control are also usually necessary. Haemodialysis treatment is intermittent and so waste products and excess fluid can accumulate between treatments.

There are less restrictions with more frequent dialysis. Taking all the medications (at the appropriate time) prescribed by your doctor, following your fluid limits and diet are all very important in ensuring you maintain good health. Regular exercise is also beneficial in building strength, energy, stamina and a healthy heart.

- > Pregnancy and Contraception Women who dialyse and are of childbearing age can conceive but are strongly advised against becoming pregnant. The chances of the pregnancy reaching full term with a normal sized baby are very small. Pregnancy should be postponed until after successful kidney transplantation.
- > Employment Haemodialysis allows you to maintain an active life. It is certainly possible, especially if you do home haemodialysis, to continue to work full time, even if your work is quite physical. Combining work with dialysis shifts at a satellite unit can be difficult. Treatment at home offers greater flexibility.
- > Holidays Holidays are an important way of providing a break from the routine of dialysis. Unfortunately, it is not possible to have a holiday from dialysis. However, a change of environment and having someone else do the treatment for you (if you dialyse at home) is very beneficial for you and your family. For those on a budget, some Australian states have holiday homes, owned by kidney patient associations. These are available at very reasonable rates. Sometimes, a dialysis machine can be installed in the home or dialysis can be arranged at a dialysis centre nearby. Dialysis centres are located in most major cities and towns throughout Australia. Air travel is safe for you. Booking holiday dialysis well in advance is essential.

Obtaining haemodialysis overseas is possible but can be expensive. Australians eligible for Medicare can be dialysed in public hospitals (subject to availability) at no charge in certain countries. These are New Zealand, the United Kingdom, the Republic of Ireland, the Netherlands, Norway and Sweden. Holders of passports for countries that are members of the European Union have access to dialysis in all EU countries. In other countries, you must pay for haemodialysis. Sometimes, private health funds will pay part of the fee.



## How Does Peritoneal Dialysis Work?

Just as with haemodialysis, peritoneal dialysis is a treatment commenced when less than 10% of kidney function remains. It filters the blood of waste products and removes any excess fluid from the blood in daily treatments. In contrast to haemodialysis, peritoneal dialysis, filters the blood inside the body. It uses the peritoneum or peritoneal membrane as the filter for dialysis. The peritoneum is a membrane that lines the wall of the abdomen and covers the abdominal organs.

Special fluid called dialysis solution drains into the abdominal cavity through a special tube called a peritoneal catheter (Tenckhoff catheter) (see Figure 4). Wastes and excess fluid pass from the tiny blood vessels in the peritoneal membrane into the dialysis solution, which is then drained from the abdominal cavity through the peritoneal catheter. Peritoneal dialysis is a daily treatment performed by you at home. Peritoneal dialysis works using a series of periodic exchanges. An exchange is when dialysis solution is drained from the abdominal cavity (carrying away waste products and excess water from your blood) and is exchanged for fresh dialysis solution, which is instilled into the peritoneal cavity.

There are two forms of peritoneal dialysis: CAPD and APD.

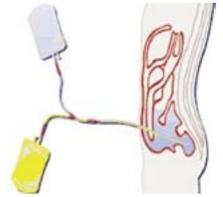


Figure 4. Peritoneal Dialysis Solution & Catheter



> Continuous Ambulatory Peritoneal Dialysis (CAPD)



> Automated Peritoneal Dialysis (APD)

#### **Continuous Ambulatory Peritoneal Dialysis (CAPD)**

When the exchanges are performed manually during the day, this is called CAPD (Continuous Ambulatory Peritoneal Dialysis). Each exchange of 2-3 litres of dialysis solution takes about 45 minutes to complete. However, you can read or watch television, etc., while the fluid is being instilled or draining out. These exchanges are done at intervals of 4-6 hours during the day. After the used solution is drained from your abdomen into an empty bag and fresh solution is instilled into the abdominal cavity, the drain bag is disconnected from the catheter and discarded. You never have to wear a bag. In the case of CAPD, there is always a volume of 2-3 litres of fluid in your abdominal cavity. It is possible to comfortably hold that volume of solution in your abdominal cavity.

In between exchanges, you can carry on with all your usual activities. You just need to plan your dialysis exchanges around your daily routine. Exchanges are typically at breakfast, lunch, late afternoon and evening.

#### **Automated Peritoneal Dialysis (APD)**

It is also possible for these exchanges to be performed for 8-10 hours overnight, using an **automated cycler machine**. This machine allows the dialysis solution to **automatically** fill and drain from the abdominal cavity while you are asleep. You will usually carry a volume of fluid in your abdominal cavity during the day. Sometimes, you may be required to perform an exchange during the day.

For people who are working or leading very busy lives, a cycler machine can make peritoneal dialysis much more convenient and manageable. However, it is not always suitable.

#### **Access for Peritoneal Dialysis**

The dialysis solution is run into and drains from the peritoneal cavity using a special soft tube called a **peritoneal catheter**. During **surgery**, this catheter is placed into the peritoneal cavity and exits your abdomen. It is a permanent access for dialysis. Caring for your catheter and the point at which it exits your abdomen or **exit site** is very important.

Care must be taken not to introduce any infection into the abdominal cavity. Such infection of the peritoneum is called **peritonitis**. It is essential that antibiotic treatment be commenced immediately symptoms of infection occur.



#### Peritoneal Dialysis at Home

Peritoneal dialysis is managed at home. Nursing staff will teach you how to safely perform a dialysis exchange. You will attend the training centre **daily** until you are safe and confident in your technique. If you plan to do peritoneal dialysis overnight, then you will also learn how to use the cycler machine. The training for peritoneal dialysis will usually take **1-2 weeks**.

You should be able to carry out all your usual activities and resume work, especially if you are dialysing overnight. The only consideration is whether any of these activities put you at risk of infection of your exit site or peritonitis via the peritoneal catheter. Certain situations should be avoided. For instance, exposure to "dirty" work conditions or swimming in unclean water, such as crowded, public pools or polluted beaches, should be avoided. Speak to your kidney specialist about any concerns you may have.

> Medications, Fluids, Diet and Exercise Peritoneal dialysis alone is not enough to keep you well. Taking all the medications (at the appropriate time) prescribed by your doctor, following the fluid limits and diet are all very important in ensuring you maintain good health. Regular exercise is also beneficial in building strength, energy, stamina and a healthy heart.

Dietary control and fluid intake may be less restrictive for people treated with peritoneal dialysis than for those treated with haemodialysis. This is because peritoneal dialysis is continuously removing waste products and excess fluid from your body.

- > Pregnancy and Contraception Women who dialyse and are of childbearing age can conceive but are strongly advised against becoming pregnant. The chances of the pregnancy reaching full term with a normal sized baby are very small. Pregnancy should be postponed until after successful kidney transplantation.
- > **Employment** Peritoneal dialysis allows you to maintain an active life. It is certainly possible to continue to work full time, even if your work is quite physical. Peritoneal dialysis is possible in a variety of work environments. However, if this is difficult in your work environment, overnight peritoneal dialysis may be more manageable.
- > Holidays Holidays are an important way of providing a break from the routine of dialysis. Unfortunately, it is not possible to have a holiday from dialysis. However, a change of environment is very beneficial for you and your family. For those on a budget, some Australian States have holiday homes, owned by Kidney Patient Associations. These are available at very reasonable rates.

Fortunately, your travel plans should not be restricted by peritoneal dialysis. You can either take your dialysis supplies with you or in most cases, the dialysis company can deliver your stock to your holiday destination. These arrangements also apply to overseas holidays.

#### What is a Kidney Transplant?

A kidney transplant involves taking a kidney from the body of one person and implanting it surgically into the body of someone with kidney failure. One transplanted kidney provides enough kidney function to keep the recipient well.

Compared to dialysis, a kidney transplant provides you with a much improved quality of life and life expectancy. You will not need to spend several hours each week having dialysis. You will not have to follow special dialysis diets and fluid limits. Overall, you will feel better and have greater freedom.

After a kidney transplant, it will still be necessary to regularly see your kidney specialist. It is also essential that you take special medications every day to prevent the transplant being rejected by your body's immune system. Medical supervision and medications are required for the life of the transplant.

The aim in any transplant is to reduce the possibility that the kidney will be rejected. First, the donor and recipient must have **compatible bloods groups**. Second, the donor's **tissue type** (see below) will be matched as closely as possible to the recipient's tissue type.

You will be assessed for suitability for transplantation. If a kidney transplant is recommended, you will be placed on the kidney transplant waiting list after you start dialysis. If you have a living donor, the transplant may be possible before dialysis is commenced. This is called a "pre-emptive" transplant.

#### Where Do Kidneys for Transplantation Come From?

There are two types of kidney donors:

#### **Deceased Donors**

Kidneys from deceased donors are allocated to the person on the transplant waiting list whose **tissue type** most closely matches the deceased person's tissue type. Potential deceased donors are screened for cancer and viruses to make sure these are not transmitted to the recipient.

Unfortunately there are not enough deceased donors for the number of patients awaiting kidney transplants. This means you may have to wait several years before a kidney from a deceased person becomes available. Fortunately, dialysis can keep you well while you wait for a kidney donor.

There are **no guarantees** that the kidney will work or for how long it will work. However, the chances of a good outcome are high (see Kidney Transplant Success Rates below).

Please note: If you are NOT a permanent Australian resident eligible for Medicare, then you cannot be allocated a kidney from the transplant waiting list. If you have a living donor, then transplant surgery can be performed in Australia, at your own cost.

#### **Living Donors**

For many years, close **relatives**, such as parents, siblings and adult children of the recipient were the main sources of living donors (**living related donors**). It is now common for **unrelated** people, such as those with close emotional or family ties to the recipient to be kidney donors (**living unrelated donors**). This means that spouses, in-laws and friends can also be living kidney donors. Occasionally, anonymous donors donate kidneys but this is much less common (**altruistic living unrelated donors**).

About 40% of all kidney transplants now performed in Australia use living donors. There are **no guarantees** that the donated kidney will work or for how long it will work. However, the chances of a good outcome are very high (see Transplant Success Rates below).

#### The benefits of living donor surgery are:

- > waiting a lengthy period for a kidney from the pool of deceased donors is avoided
- > transplant surgery can be conveniently planned for the donor and recipient. Sometimes it is possible to have the transplant before starting dialysis
- > living donors from your own family and ethnic group are more likely to be a good tissue match
- > kidneys from living donors usually function immediately (kidneys from deceased donors may sometimes take a little longer to start functioning)

#### **Kidney Transplant Success Rates**

The success rate for a functioning transplanted kidney **one year** after surgery for living donor transplants is approximately 97% and 92% for deceased donor transplants (ANZDATA Registry, 2006). The success rate for a functioning kidney after **five years** for living donor transplants is approximately 86% and 80% for deceased donor transplants (ANDATA Registry, 2006).

If the transplant works well in the first year, the chances are good that it will function for many years. However, there is no guarantee it will function forever. If the transplant fails, a second transplant is usually still possible. Many people, who received kidney transplants 25-30 years ago, remain very well with those original transplanted kidneys.

#### **Living Donor Kidney Transplant**

Transplantation from living donors is very successful. Donor surgery can be performed as either an **open procedure**, involving a large incision under the ribs or as **keyhole surgery**, involving much smaller incisions in the abdomen and the use of a camera to guide the removal of the kidney.

**Keyhole surgery** is becoming more common and makes the removal of a kidney from the donor a much less traumatic procedure. Recovery from surgery is faster. Donors can be discharged from hospital 2-4 days after keyhole surgery and can usually return to work within a month after surgery. Heavy lifting must be avoided for about 4 weeks.

Traditional, open procedure surgery requires a hospital stay of about 1 week. In this case, heavy lifting must be avoided for about 3 months.

If someone is thinking about being a **living related** or **living unrelated** donor, he or she should speak with a kidney specialist. Simple blood tests are all that are necessary at first. If these tests show the potential donor is compatible with you and the potential donor wishes to proceed with further testing, then chest x-rays, kidney function test, an electro cardiogram, CT scans and a general health check will be necessary. **The donor's health will not be put at risk for the sake of obtaining a kidney**.

It is illegal to accept any kind of payment from the recipient for kidney donation. All donors are assessed to ensure they are not motivated by any kind of financial or personal gain. They are counselled to ensure they are fully informed of all risks and the potential effects of their donation on their relationship with the recipient. Any concerns about medical and other expenses or medical insurance can be discussed with the renal unit social worker.

#### Long-Term Effects for Living Related or Unrelated Donors

Living with one kidney does not change the life expectancy of the kidney donor. In general, donors find the opportunity to help a loved one to be a very rewarding and fulfilling experience. Spouses and parents may also directly benefit from the improved quality of life a kidney transplant can bring to the recipient and his or her family.

In a few cases, some donors have negative or mixed feelings about the donation and this can sometimes lead to family upheaval or disharmony. It is also possible that the kidney transplant may fail. It is not possible to return the kidney to the donor. A failed kidney transplant can be very devastating for all parties involved. This is why it is very important to think about and discuss all the implications of donation very thoroughly with your kidney specialist, social worker or psychologist, who are experienced in these issues.



#### **Preparing for a Kidney Transplant**

#### > Suitability for Kidney Transplantation

**Medical investigations** are necessary to ensure your fitness for transplantation. These include physical examination, blood tests, x-rays of heart, lungs and sometimes, stomach and bladder. **Pre-transplant education** sessions prepare you for the surgery and your on-going care.

People with major medical problems, such as severe heart and/or vascular disease, may encounter problems associated with transplantation. For those people, dialysis is often a more suitable treatment. Some people are so satisfied with their dialysis treatment that they prefer not to have a transplant. Your kidney specialist will discuss your medical suitability and your preferences regarding transplantation with you.

In the case of people whose kidney failure is due to the complications of Type 1 diabetes and for whom kidney transplantation is being considered, a **combined kidney and pancreas transplant** may be possible. Further information on this procedure and eligibility requirements can be obtained from your kidney specialist.

#### > Blood Groups, Tissue Typing and Cross Matching

The **blood** groups of the donor and recipient must be compatible for a kidney transplant. It is also necessary to match white blood cells. This is called "tissue typing" and "cross matching".

#### 1. Blood Group

The ordinary blood groups (A, B, AB, O) match the **red blood cells** of the donor and recipient. **They must be compatible, just as for a blood transfusion**. If a prospective living donor's blood group is not compatible with the recipient's blood group, further discussion with the kidney specialist is suggested.

Transplant Compatibility Table						
RECIPIENT Blood Type	DONOR Blood Type					
	Α	В	AB	0		
Α	Yes	No	No	Yes		
В	No	Yes	No	Yes		
AB	Yes	Yes	Yes	Yes		
0	No	No	No	Yes		

#### 2. Tissue Typing and Cross Matching

This involves matching of a type of white blood cell called "lymphocytes". These and all body cells have special markers called antigens on their surfaces. A special group of these antigens, called HLA (Human Lymphocyte Antigens) are important in transplantation. The closer the match of antigens between donor and recipient, the better the chance of a successful transplant. This applies to transplants from both living and deceased donors.

When blood from the donor is mixed with blood from the recipient, and there is no reaction, this is called a **negative cross match**. There must be a negative cross match for the transplant to proceed.

#### The Transplant Waiting List

Everyone waiting for a deceased donor kidney transplant has his/her tissue recorded on a national computer list. Each month, a blood sample is taken to check if any antibodies against an HLA antigen have formed (e.g. due to a blood transfusion) and to cross match cells if a donor kidney becomes available. When a donor kidney becomes available, the donor's tissue typing is matched against the tissue typing of everyone on the list. The kidney is then allocated to the recipient whose tissue type best matches the tissue type of the donor. If several recipients match the donor's tissue type, then the kidney is allocated to the recipient who has been waiting the longest time.

#### Staying Healthy Prior to Kidney Transplantation

It is very important to keep yourself healthy while you are waiting for a transplant. If your general health is poor, you are less likely to be considered a good candidate for a transplant. You must:

- > maintain your dialysis schedule to stay healthy
- > **not smoke** to reduce the risks of heart disease and lung infections after the transplant
- > control your weight to reduce the risk of heart disease
- > control your blood pressure to reduce the risk of heart disease
- exercise to improve fitness, strength and stamina and reduce the risk of heart disease
- > visit your dentist to prevent infection of teeth and gums after the transplant
- > protect your skin against sunburn to reduce the risk of skin cancer after the transplant

#### **The Transplant Operation**

The operation takes approximately **3-5** hours. Your own kidneys are not removed. The new kidney is placed on the left or right side of the abdomen, below the navel (see Figure 5). The new kidney's artery and vein are joined to an artery and vein in your pelvis. The ureter (urine tube) from the kidney is attached to your bladder.

#### After the Operation

There is usually some pain around the operation site. The pain can be successfully controlled with strong medication. A bladder catheter (tube to empty the urine) and drainage tubes from the wound in your abdomen are needed for about a week to help healing. Recovery is usually very fast. Most people are out of bed the day after the operation and can walk around within a few days.

Sometimes, a deceased donor kidney may take a few days to weeks (or sometimes even longer) to start working properly. If this happens, it doesn't mean the kidney will not eventually function well. While the kidney is recovering, you may need to continue to have dialysis to keep your body in good chemical balance.

The time you stay in hospital will depend on how well the kidney works and if there were any complications. The average length of stay in hospital is 1-2 weeks.

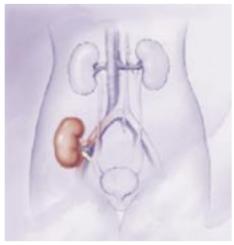


Figure 5. Kidney Transplantation

#### **Care After the Transplant**

After the transplant there are a number of precautions you must take to care for the transplanted kidney and your general health.

You will need to take a combination of special **anti-rejection medications every day** for the life of the transplanted kidney. The chance of the kidney being rejected if you stop the medication is very high.

Because your immune system will be lowered by the anti-rejection medications, you will need to take special care to avoid sources of infection. You will also need to take special care of your skin to protect it from sun exposure as you will be more susceptible to skin cancer. This is another side effect of anti-rejection medications.

Some anti-rejection medication can increase your appetite and make it easy to become overweight. A **healthy diet and regular exercise** can also help you to reduce the risk of heart disease.

#### Life with a New Kidney

A kidney transplant can mean freedom from dialysis and a healthy life. You should be able to return to all normal activities and full time employment, **3-6 months** after the kidney transplant.

It is normal to have a period of adjustment. Initially, there are frequent visits to your kidney specialist. This usually means daily visits for several weeks after the transplant. For country residents, this may mean staying near the transplant unit for 2-4 weeks after the transplant. This can be disruptive to your routine, family life and maybe your work. You may also need to adjust to the uncertainty of not knowing how long the transplant will function and the disappointment of returning to dialysis. Time with a functioning kidney is the best reassurance. Clinic visits become less frequent as your kidney function stabilises.

If you are planning to become pregnant, you must discuss the advisability and safety of pregnancy with your renal physician as early as possible. Women who have received a new kidney are not advised to become pregnant until after 1-2 years of good kidney function. Some of the newer anti-rejection medications are not safe in pregnancy. There are increased risks of complications, so careful monitoring of the pregnancy is needed. Some tests and x-rays may be necessary and need to be performed before you become pregnant.

Dialysis treatment can prolong but does not always provide good quality of life, especially when general health and wellbeing are already affected by ageing and other medical illnesses.

When people are told they will require dialysis, it is not unusual that their first reaction is to postpone or even refuse treatment. They are often distressed and depressed and are not ready to face the future. This is a normal reaction to unpleasant news. A much more positive approach to the future usually follows after learning about treatment options and dealing with all the issues and emotions such news brings. People in good health, apart from their kidney failure, can very successfully manage their lives with dialysis or a kidney transplant.

However, some people with complex medical problems and chronically poor health and particularly the elderly, may consider that dialysis will bring very little benefit. They believe it will just extend a life of chronic illness, dependence and limitations.

#### Benefits vs Burdens of Dialysis Treatment

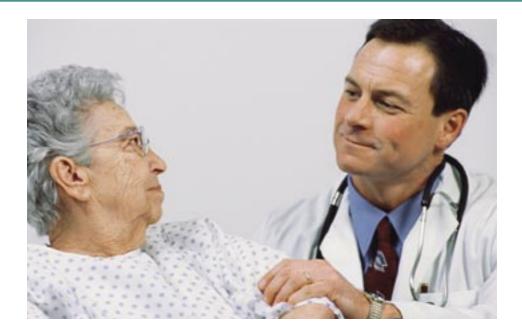
When people choose to have dialysis, they should feel confident it will extend and improve their enjoyment of life and not be so hard that it will make life miserable. If you think that dialysis will not be beneficial to you, you should discuss your reservations with your kidney specialist. He or she is the best person to discuss your case and how much dialysis is likely to benefit or burden you.

#### **Declining Dialysis Treatment**

After discussion with your kidney specialist and family, you may choose to be treated without dialysis. Medications to control anaemia (low red blood cell levels), chemical and hormone imbalances, dietary support, skin creams for itch and sedatives for sleep disturbances and restless legs can be used very effectively to reduce symptoms and optimise your wellbeing.

#### Withdrawing from Dialysis Treatment

Withdrawing from dialysis treatment is a consideration when the burden of dialysis outweighs the benefits. You may have been having dialysis treatment for some time or have other serious medical problems. Illness may be affecting your enjoyment of life and limiting your independence. Travel to and from the renal unit and being dialysed or even managing your own treatment at home, may be getting harder, tiring and very time consuming.



Under such circumstances, life can become very difficult and revolve entirely around dialysis treatment, endless visits to hospital and other medical appointments. Under such circumstances it is reasonable to consider withdrawing from dialysis.

#### **Palliative Care**

If you choose not to commence or to withdraw from dialysis treatment, specialist medical care, called palliative care, can complement the care provided by your kidney specialist. When kidney failure is very advanced or you withdraw from dialysis treatment, your kidney specialist and palliative care specialist can control your symptoms and maximise your comfort and quality of life.

#### **Your Family**

Dialysis and kidney transplantation are treatments which need your special commitment and often the commitment and involvement of your family. Choosing not to have dialysis or stopping dialysis can be a very difficult decision for you and those who love you. Your kidney specialist, social worker or spiritual mentor can help you in your discussions with your family. For many people, choosing not to have dialysis treatment is very appropriate and ultimately, can lead to peace of mind.

#### **Final Thoughts**

After a diagnosis of kidney failure, all families experience a time of crisis. It is not unusual that family members or friends will raise the possibility of living kidney donation. Kidney donation is a major decision for everyone and should be very carefully considered. Do not rush into any course of action before carefully considering all your options.

Make sure you learn as much as you can about all methods of dialysis and transplantation and how to stay healthy and active. In most cases, it is not essential to have a kidney transplant immediately.

Dialysis is a very efficient treatment and can keep you very well for many years.

You and your family will benefit from psychological, emotional and social support now and at all other stages of your treatment. Discussing all your options and how each will affect your life is very important. Social workers are members of your renal team and are trained to help you with these issues. Your kidney specialist, renal unit nursing staff and the Renal Resource Centre are also available to help you and your family learn about and successfully manage dialysis and transplantation.

Many people have gone before you with great success.

We wish you well.



#### **Useful Contacts**

#### Renal Resource Centre

#### Information Line

Freecall: 1800 257189 Tel: 02 9362 3995

renalresource@nsccahs.health.nsw.gov.au

www.renalresource.com

Kidney Health Australia

Freecall: 1800 682 531 www.kidney.org.au

Transplant Australia

www.transplant.org.au

## Kidney Failure Treatment Options: Making the Right Choice

Available in English, Arabic, Chinese, Greek, Italian, Vietnamese



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