

After your kidney transplant

East Coast Renal Services

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1 Introduction

Congratulations on receiving your new kidney!

This booklet will help you care for your new kidney and your health after your transplant. Your new kidney is a treatment like dialysis. It is not a cure. You will need to look after it and your health. This is crucial.

Our transplant team will also help you. Our team includes doctors, nurses, clinic staff, dietitians, social workers, psychologists, occupational therapists, physiotherapists. When you are first discharged you will need to visit the Renal Transplant clinic daily then weekly so we can see how your new kidney is going. We will check your blood, weight and blood pressure. We explain more about these visits in the Appendix. The visits slowly decrease in number to every 2-4 months

With a healthy new kidney you will be able to lead a more “normal” life without regular dialysis treatments. You will have more free time and you won’t need to restrict your diet and fluid intake. You may also find improvements in anaemia, bone disease and sexual function. You can do more activities such as non-contact sports, swim, go on a fun run, and have children and return to work. You need to avoid contact sports because the new kidney is under the skin in your lower abdomen and does not have the protection your old kidney had. You need to avoid infection and take your new medications as prescribed to prevent your body rejecting your new kidney.

This booklet will help you understand the issues related to your new kidney and how you can look after it and your health. Your transplant team are here to help you understand what you need to do, so ask as many questions as you like.

2 What to look out for after your operation

Immediately after the transplant you may feel very tired. This could be because of your medicines, losing blood during the operation and disruptions to your rest on our busy hospital ward.

We will monitor you to look out for these problems that might occur because of the operation:

Thrombosis

This is a rare complication. A blood clot can form in blood vessels of your new kidney. This means that blood supply to the kidney will stop. If this happens you will have to go back to the operating theatre. In most cases we need to remove the kidney.

Bleeding

With all operations there is a small risk of internal bleeding. You may need a blood transfusion in the first few days after transplant.

Urine Leak

Sometimes there can be a leak where the ureter (tubes that drain the urine) joins the bladder. You may require another operation.

Deep vein thrombosis

After all operations there is a risk of blood clots forming in the blood vessels of your legs. This problem is rarely seen in patients with renal disease.

3 Possible Complications

Sometimes, complications can occur after your kidney transplant.

Delay in your new kidney working

In most people the new kidney will start producing urine straight away. For 1 in 5 transplant recipients, their new kidney will take longer to work. While we wait for the new kidney to work you may need dialysis. Do not become disheartened sometimes it takes a little time.

There are two main causes to a delay in your kidney working:

1. Temporary damage to the kidney cells when it is removed from the donor, cooled down and then warmed up again once transplanted.
2. The blood supply to the kidney is stopped when the kidney is removed and needs time to recover once transplanted.

Sometimes the kidney may function and then stop again which may also be due to this temporary damage. We may need to test some of the cells of your new kidney by doing a kidney biopsy. We are unable to predict exactly how long the kidney will take to repair itself and how soon it will start working.

Rejection

This is when your body's immune system attacks the new kidney. You will be given medicines to reduce the chance of rejection but sometimes it can still occur. It is most common in the first 6 months after your transplant when your body's response is the strongest.

There are 3 main kinds of rejection:

Acute Rejection

This is most common within the first few weeks after your transplant. We will give you some medicines to prevent rejection, these are called immunosuppressants. You must take these at the correct time and dose to prevent rejection. We identify this type of rejection when we see an increase in creatinine levels in your blood or when we find protein in your urine. We can treat this type of rejection successfully if

we identify it early on. This is why it is important to attend your appointments at the Renal Transplant clinic.

Other signs and symptoms of rejection can include:

- Sudden gain in weight
- Swollen ankles
- Decreased urine
- Increased blood pressure
- Tenderness where your new kidney is
- Increased body temperature.

If you notice any of these symptoms alert the renal team.

Antibody Mediated Rejection

This type of rejection is seen when your body produces antibodies against the transplanted kidney. It requires a different form of treatment to the acute rejection described above. You may require plasma exchange and IVIg.

Similar to dialysis this removes antibodies that your body has produced in response to the transplanted kidney from your blood and then replaces the liquid part of your blood (called plasma). This may involve a few treatments.

Chronic Transplant Failure

This can occur months or years after your transplant. It has many causes including:

- long term rejection
- recurrence of the initial disease in the new kidney
- toxicity due to the immunosuppressant medicines
- Infection with a virus.

We can identify chronic transplant failure by monitoring your kidney function, checking your urine and your blood pressure. We might take some cells from your new kidney to monitor this also. This is called a biopsy usually done at 3 & 12 months. The signs & symptoms of chronic transplant failure are similar to acute rejection. (See signs & symptoms of rejection).

Chronic transplant failure is difficult to treat. You may have to start dialysis again and your new kidney may fail after some years. You may need to go back on the transplant list. It is very important you attend your appointments over the long term so we can monitor you. If we identify the causes of chronic transplant failure early then we can reduce the impact on your kidney.

Infection

The medicines we give you to prevent rejection are called immunosuppressant's. They can suppress or weaken your immune system which means it is easier for you to have an infection. The highest risk is straight after your transplant. This is when you have the highest doses of these medicines.

Contact the transplant unit if you think you have any of these signs of infection:

- Increased temperature above 37.5
- Temperature below 35.5
- Shivers and shakes
- Night sweats
- Burning or pain when passing urine
- Red, painful or discharging wound
- Yellow or green sputum when coughing

To prevent infection you should:

- Avoid crowded places for the first few weeks after your operation i.e. movie theatres, restaurants etc.
- Avoid people with colds and viruses (especially young children).
- Contact your Doctor immediately if you come into contact with someone with chicken pox. Chicken pox is particularly contagious and dangerous after transplant. Your Doctor can give you some medicine to prevent infection.
- Take the medicines we give you to help prevent common infections. These are explained in the Medication Information Booklet we gave you.

Diabetes (Raised Blood Sugar Level)

During the first 6 weeks after transplant the sugar levels in your blood may fluctuate. This is a side effect of high doses of immunosuppressant medicines we give you to prevent rejection. You may need insulin to help control your sugar levels during this early period.

3 in 10 people who have a kidney transplant may develop diabetes. You may be more likely to develop diabetes if you have the following risk factors:

- obesity
- inactivity
- age over 45 years
- family history of diabetes
- history of gestational diabetes
- Ethnic background
- Immunosuppressant medicines.

We reviewed these risks before you had your transplant. After your transplant we regularly check the levels of sugar in your blood. Some people can control their diabetes by losing weight, increasing exercise, dietary changes & changes in immunosuppressant medication. But, some people will need to take medicines long term including insulin injections.

High Blood Pressure

This is very common before and after a kidney transplant. It may be related to a condition you already had. If it is new, it may be related to the immunosuppressant medicines. It is important to keep your blood pressure at the right level. High blood pressure can cause damage to small blood vessels in your heart and kidneys. Lifestyle factors including level of activity, diet and weight can affect your blood pressure. Many people require blood pressure medicines for the long-term.

4 Looking after yourself after hospital

Take your immunosuppressant medicines

These medicines prevent your body from rejecting your new kidney. You will be on a combination of immunosuppressants, usually prednisone, mycophenolate, and tacrolimus. It is very important to take these as prescribed to keep your kidney functioning. The renal pharmacist will give you detailed instructions.

Do these checks at home

By checking these things at home, you will notice any early signs of dehydration, rejection, or infection.

Weigh yourself

Weigh yourself on a set of scales when you first get up in the morning.

If you lose one kilogram or more in weight overnight it shows you have not drunk enough fluid the previous day. It is important to drink enough when you have had a kidney transplant so increase the amount you drink.

If you gain one kilogram or more in weight overnight this could mean you are retaining fluid, it could be an early sign of rejection. If this happens, alert the team at the Acute Transplant clinic using the numbers in the book.

Take your temperature

Buy a thermometer. If you are feeling unwell, take your temperature and call the Hospital. If your temperature is above 37.5 or below 35.5 you probably have an infection.

Diarrhoea or vomiting

This kind of illness can be serious after transplantation. If you are vomiting and cannot keep fluids down or have very frequent watery diarrhoea, we cannot be sure that your body is absorbing your immunosuppressant medicines. Diarrhoea and vomiting causes dehydration which can damage your kidneys. You should go to the Hospital Emergency Department or call the transplant clinic on the numbers listed at the back of this booklet.

5 Your follow up appointments with your renal transplant clinic

Following discharge from hospital you will need to visit your renal transplant clinic on a regular basis. For the first six weeks you cannot drive so arrange other transport to your appointments. Bring a bottle of water with you to your appointment to keep hydrated.

At each clinic visit you will see a renal Doctor and we will check your weight and blood pressure and collect urine and blood samples. This is to monitor you for infection and to make sure your body is not rejecting the kidney.

At most of your clinic visits, we will also measure the levels of medicines in your body. For patients taking Tacrolimus, Sirolimus or Everolimus medicines, **do not take your morning dose of these medicines** until after your blood test at the clinic. Bring your medicine to the appointment so you can take it immediately after your blood test. Do not miss a dose of your medicines.

See below for a guide to the schedule for each Hospital's clinic appointments. Clinic visits will become less frequent as your kidney function stabilises and your general health improves.

Prince of Wales Hospital

Follow this appointment schedule to visit our Renal Transplant Clinic at the Kidney Care Centre:

Time after your transplant	How often to visit
Discharge to 30 days	Each day Monday – Friday visit the Clinic. On Saturday, we can arrange a home collection or visit our dialysis unit. You may be given Sundays off if you are well
4 - 6 weeks	3 times per week - Monday, Wednesday and Friday
6 weeks – 3 months	2 times per week
3 – 6 months	Once a week You will need a biopsy at 3 months
6 – 12 months	Every fortnight (once every two weeks)
12 months – 2 years	Once a month
After 2 years	Once every 2 - 4 months

Wollongong Hospital

If you live a long distance from Wollongong Hospital you may stay at the Hospital accommodation Alkira Lodge for a few weeks after leaving Prince of Wales Hospital. The clinic nurse will book this for you.

Follow this appointment schedule to visit our Renal Transplant Clinic:

Time after your transplant	How often to visit
Discharge to 30 days	Each day Monday – Friday visit the Clinic. The renal clinic is closed over the weekend however your renal doctor will give instructions about blood collection and review.
1 – 3 months	3 times per week
3 – 6 months	Once a week
6 – 12 months	Every fortnight (once every two weeks)
12 months – 2 years	Once a month
After 2 years	Once every 2 - 4 months

St George Hospital

Follow this appointment schedule:

Time after your transplant	How often to visit
Discharge to 30 days	Each day Visit the Renal Clinic at the Kidney Care Centre at Prince of Wales Hospital.
1 – 3 months After 1 month you can return to St George Hospital.	3 times per week – Monday, Wednesday and Friday At 7.30 am visit the St George Hospital Pathology Centre with a pink priority sticker. At 8.30am visit the Acute Transplant Clinic, Ward 4 West at St George Hospital.
3 months	You will need a biopsy at 3 months and a review by our kidney specialist doctor
3 – 6 months	Once a week - Day and time depends upon when your kidney specialist has their clinic.
6 – 12 months	Every fortnight (once every two weeks)
12 months	You will need a biopsy at 12 months and a review by our kidney specialist doctor.
12 months – 2 years	Once a month or once every two months
After 2 years	Once every 2 - 4 months

6 Long term care after your transplant

Diet

Your appetite might increase after your transplant and you may gain weight easily. This is due to your medicines and also feeling better and increasing your activity.

Our dietician will visit you before you leave the Hospital and provide you information about your diet after your transplant. You should follow these guidelines:

- Eat a low fat and low cholesterol diet.
- Limit salt to help control your blood pressure.
- Eat more calcium rich foods like low fat milk, yoghurt or cheese to strengthen your bones. Make sure they are pasteurised.
- Avoid soft and blue veined cheese such as brie, camembert, roquefort, stilton, gorgonzola or other unpasteurised cheese.
- Wash fruit and vegetables before eating.
- Avoid takeaway and pre-cooked foods.
- Avoid raw or rare meat or fish cook meat until it is well done.
- Thoroughly cook eggs. Avoid runny yolks and foods containing raw eggs such as cookie or cake dough & homemade mayonnaise.
- Avoid salad bars and buffets.
- Avoid deli meats & pates
- Do not drink from a well or water that has not been filtered or boiled.
- On hot days drink more fluids to prevent dehydration.

The dietician will also be available in the renal outpatient clinic to help you with weight control or any other nutrition related problem.

Exercise

You need to do regular exercise for your rehabilitation and to manage your weight and cholesterol. Exercise is also important for your mental wellbeing.

Low impact exercises you can do are:

- Walk every day
- Swim
- Bicycle.

Avoid contact sports such as rugby, as any injuries to the transplant area could damage your kidney.

Drink more fluids while you are exercising to prevent you from getting dehydrated. For every 20 minutes of exercise, you should try to drink 200 mls of fluid.

Cholesterol

Cholesterol is important for some body functions, however too much cholesterol can cause heart disease. You need to eat a low cholesterol diet (avoid processed foods, choose lean protein, low fat dairy products and high fibre foods) and exercise. You will have your cholesterol levels measured in the clinic.

Cardiovascular disease (heart disease)

Cardiovascular disease is the leading cause of death and illness after transplantation. You are at a lower risk than those patients who remain on dialysis however are at a higher risk than those in the general population. It is essential for you to have:

- good blood pressure control
- see your cardiologist regularly
- stop smoking, and
- Control your weight.

We will continue to monitor you for heart disease and conditions that may increase your chance of developing heart disease after your transplant. Your doctor will check your blood for your lipid levels. You might need regular Cardiac Echo's and a Stress tests. Your Doctor will let you know when these are needed.

Bone disease

You may have an increased risk of developing osteoporosis following your transplant due to your new medicines. Osteoporosis is where your bones become thin, weak and fragile. To help prevent this you should follow the advice of our Dieticians and do daily exercises where your body is supporting your weight such as walking, stair climbing, low impact aerobics etc. You might need a bone density test to check how your bones are going.

Kidney disease

The disease which originally caused your kidney failure may continue with your new transplant. Diseases which can recur after your renal transplant are:

- Diabetes mellitus – High glucose& insulin resistance.
- Systemic lupus erythematosus – Chronic autoimmune disease.
- IgA Nephropathy –Deposits of immunoglobulin causing inflammation.
- Focal segmental glomerulosclerosis – Development of scar tissue.
- Membranous glomerulonephritis –Protein in the urine causing inflammation.
- Membranoproliferative glomerulonephritis – Infection or autoimmune disease.
- Amyloidosis –Protein build up (fibrils) deposit in organs or tissues.
- Cystinosis. Build-up of cysteine (amino acid) in different organs or tissues.

In most cases, transplantation is worthwhile since usually the disease comes back very slowly and may take many years to damage the new kidney.

Skin cancer

Your new medicines will make your skin very sensitive to the sun. The incidence of skin cancer is higher in people who have had a transplant. You need to wear protective clothing, sunglasses, high factor sun screen (SPF 50+) & seek shade when you are out in the sun. Avoid outdoor activities between the hours of 10am to 2pm when the sun's rays are strongest. You should check your skin every three months for any changes.

Changes to look out for when checking your skin:

- new moles
- moles that increase in size
- an outline of a mole that becomes notched
- a spot that changes colour from brown to black or is varied
- a spot that becomes raised or develops a lump within it
- the surface of a mole becoming rough, scaly or ulcerated
- moles that itch or tingle
- moles that bleed or weep
- spots that look different from the others.

You should see a dermatologist each year for a thorough skin examination.

Gynaecological issues

Women should have a gynaecological examination every three years as there is an increased risk of infections and some cancers following transplantation. Women over the age of 40 should have a mammogram every two years. If you have a family history or previous history of breast cancer you should have mammograms every year.

Prostate gland

When men are over the age of 50 their prostate gland becomes larger. The prostate gland is located at the base of the bladder and is around the urethra (the tube leading from the bladder). As this gland becomes larger it can lead to an increasing amount of difficulty in passing urine.

If you notice any of the following symptoms you should notify your doctor:

- Difficulty in starting the stream
- Passing small volumes of urine frequently

- Dribbling urine
- A feeling that your bladder isn't completely empty
- A reduction in the force of the stream of urine.

Dental Care

Brush your teeth and gums twice a day and floss your teeth daily. You may be more susceptible to infections. Some medicines can cause an increase in gum tissue as well as tenderness of the gums.

Visit your Dentist every year. Tell your renal team if your Dentist says you need a procedure. You may need antibiotics before the procedure.

7 Resuming normal activity

Return to work

After your transplant your aim is to return to an independent lifestyle. Many transplant patients return to work 3 months following the transplant operation. This depends on the individual patient and the type of work you perform.

Driving

The Transport for NSW (formally known as RTA) restricts driving after major surgery. It is recommended you do not drive for six weeks after your transplant. Check with your insurance company to ensure you are covered when driving after your transplant.

Don't forget to make arrangements to be able to get to your regular transplant clinic appointments after your operation and when you are not driving yourself.

Alcohol

You can occasionally drink alcohol after your operation. Do not drink alcohol regularly or excessively as it can cause dehydration and interfere with the absorption of some of your new medicines.

Return of dialysis equipment

Contact the home training unit to return your home dialysis equipment after your transplant.

Pregnancy

For women, after your kidney transplant your normal menstrual cycle will return in time. It is possible to have children, however, pregnancy is considered high risk. Avoid falling pregnant until after you have had one year of stable renal function and good blood pressure. You will need to see a nephrologist and high-risk obstetrician. There is a much higher incidence of premature births and hypertension (high blood pressure). Some of your new medicines may affect the foetus. Therefore careful monitoring of the pregnancy is essential.

Sexual function

You may find that your interest in sex will improve after your kidney transplant. Sexual activity will not harm your new kidney nor increase the risk of infection; however, it is advisable to wait about four weeks; this is the same for most major surgery. Start planning contraception before you resume sexual activity.

Discuss methods of contraception with your nephrologist as some of your new medicines like mycophenolate can reduce the efficacy of the contraceptive pill.

Some men who have been on haemodialysis with major problems with their blood vessels may have been impotent. This may not improve as impotence may have another cause, which is unrelated to your kidney condition, so best to seek advice.

Travel

One of the benefits of a kidney transplant is the freedom from dialysis and an ability to travel. If you are planning a holiday, the renal team will provide advice about destinations, food and water safety, vaccinations, medicines and also ensure that you are fit to travel. It is important to remember **you cannot receive any “live” vaccines.**

Pets

Handling of pets is usually safe after your transplant if they have had all the recommended vaccinations and worm medicines. Strict hand washing is recommended after handling of animals including family pets as they may carry infections.

Gardening

Avoid working around compost piles, wet leaves and rotting organic matter. These materials may contain mould which can cause respiratory infections when your

immune system is compromised. Wear gloves when gardening to prevent infections which may arise through cuts in your hands.

8 Emotional Changes

When you have a kidney transplant there are many emotional changes. It is a tense time for you and your family, as you wait and see if the kidney will work and what happens if our body rejects the kidney. Your new medicines can cause physical side effects that may be distressing as you face changes in your body image. The medicines can also cause changes in your mood such as irritability, depression and feelings of elation.

Some of these changes may be offset by an increased sense of wellbeing as your new kidney begins to work. However, with so many changes occurring so quickly you may feel overwhelmed. It is important during this time to share these feelings with someone close. The social work staff and clinical psychologist are also skilled in addressing the many issues you and your family may have.

9 Contact details

Contact your clinic if you have any questions or concerns:

Prince of Wales Hospital

Contact the Renal Clinic in the Kidney Care Centre.

Opening hours: 8.00 am – 4:00 pm Mon- Fri

Renal Clinic Reception phone: 9382 4442

Renal Clinic Nurse phone: 9382 4426

Transplant Coordinator phone: 9382 4437 or 9382 4443

Location: Level 3 of the Parkes Building at Prince of Wales Hospital, High Street, Randwick, NSW 2031.

After Hours:

If you become unwell outside the opening hours, call the Hospital switch board on 9382 2222 and ask to page the Renal Registrar.

If you develop sudden vomiting, diarrhoea or a fever (above 37.5 degrees Celsius) you should come to the Emergency Department of Prince of Wales Hospital.

Do not wait until the next time clinic is open.

Wollongong Hospital

Contact the Renal Clinic at Wollongong Hospital.

Opening hours: 8.30 am – 4.30 pm 8:30am-4:30pm weekdays only

Renal Clinic phone: 4222 5876

Location: 3-5 Dudley Street Wollongong, NSW, 2500

After Hours:

If you become unwell outside the opening hours, call the Hospital switch board on 4222 5000 and ask to be put through to the Renal Registrar.

If you develop vomiting, diarrhoea, a fever (above 37.5 degrees Celsius) or reduced urine, you should come to the Emergency Department of Wollongong Hospital or phone 000 for an ambulance.

If you live in the Southern areas of the Illawarra Shoalhaven District and you become very unwell and are unable to travel to Wollongong, go to the Emergency Department of your nearest Hospital or call 000 for an ambulance and ask them to call the Wollongong Hospital Renal Team.

Do not wait until the next time clinic is open.

St George Hospital

Contact the Renal Clinic on Level 4 West.

Opening hours: 8.00 am – 4.30 pm

4 West Renal Clinic phone: 9113 4534

Transplant Coordinator phone: 9113 4205

Renal Department phone: 9113 2622

Location:

After Hours:

If you become unwell outside the opening hours, or develop vomiting, diarrhoea, a fever (above 37.5 degrees Celsius) or reduced urine, you should come to the Emergency Department of St George Hospital or phone 000 for an ambulance.

Do not wait until the next time clinic is open.