KidneyCare
My condition and treatment
My condition

Kidney disease and the implications it has for me

Being aware of your condition and other factors that affect your health is an important step for you to take control of your health.

This section explains what the kidneys do and gives details about kidney disease and the treatments for it, and why it’s necessary to have the treatment.

How healthy kidneys work

Where in my body are my kidneys and what do they look like?

The kidneys are a pair of bean-shaped organs that are found at the back of the body about the level of the waist. Each kidney measures 10 to 15cm in length and weighs about 160 grams. Each kidney holds thousands of small filtering units called nephrons and each nephron holds a sieve-like structure called a glomerulus.

“Healthy kidneys remove waste products from the blood”

What they do and how they do it

Healthy kidneys remove waste products from the blood

These waste products are made normally by the body as it uses nutrients from food to make energy, repair damage and maintain healthy tissues.

As blood moves through the glomerulus, it is filtered so that waste products and extra water are removed, but normal cells and proteins are left behind. Once it has filtered through the glomerulus, the waste water passes through a series of tubes where further waste is added to it; however salts and water that the body needs to keep, are taken up again.

After passing through the tubes the waste water drains into the bladder from where it is passed out as urine.

Your kidneys do not only get rid of waste, they also make hormones that are necessary for a healthy body. These include:

- Erythropoietin, which stimulates the making of red blood cells that carry oxygen around the body.
- Calcitriol, changed from vitamin D, keeps calcium levels normal for healthy bones.
- Renin, which helps to control blood pressure.
Blood tests are regularly done. These tests check your levels of electrolytes and other elements in your blood to see how effective your dialysis treatment is. Here are some of the kinds of tests you will have done:

### Kinds of test I will have done

- **Albumin:** to see if your body is absorbing (taking in) protein well
- **Calcium:** to see if your calcium levels are as good as possible for healthy bone development
- **Chloride:** affects the sodium level in your body and should be kept at a steady level
- **Creatinine:** to see how much creatinine, a waste product, is in your body
- **Ferritin:** to see how much iron is present in your body
- **Heamatocrit:** to see the percentage of red blood cells compared to the total blood amount
- **Magnesium:** there is a high level of magnesium in patients with kidney disease
- **Phosphorus:** to ensure your treatment is removing phosphorus from your body well
- **Potassium:** to ensure your treatment is removing potassium from your body well
- **Serum CO2 /Bicarb:** the kidneys control the levels of bicarbonate in your body
- **Sodium:** too much sodium in the body can lead to excessive thirst and therefore drinking more, which leads to fluid retention and higher blood pressure
- **Urea:** to see how much ammonia, a waste product, is left in the body.

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**Common reasons for kidney failure**

Kidney (renal) failure happens when the kidneys stop working or the level of efficiency is less than 10%.

When the small filtering units, or nephrons, are damaged the kidneys can’t filter waste from the blood. This is when waste products and extra fluid start to build up and cause damage to the body. These waste products and fluids are poisonous in large quantities.

When the body can’t get rid of these poisons you start to feel nauseous and have headaches and dizziness. You might not want to eat or will not eat properly. Other symptoms include loss of concentration and difficulty to focus, fatigue (extreme tiredness), itchy skin and yellowing of the skin. You will retain fluid, which results in oedema (large build up of fluid in the body’s tissues) leading to a higher body weight. You will also develop high blood pressure and find it difficult to breathe.

Kidney failure leads to weak bones and you become anaemic (when you have too few red blood cells) with low iron levels.

Because there are so many nephrons in each kidney, you do not see kidney damage until a large portion of them (more than half) is damaged. This may make mild kidney failure difficult to see without specific diagnostic tests.

As kidney damage gets worse, the kidneys may stop filtering the blood altogether, resulting in a condition called uraemia. They also stop making erythropoietin, calcitriol and renin. This stage of kidney failure is called stage 5 or end-stage kidney disease.

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**Some of the factors leading to kidney failure:**

- High blood pressure (hypertension)
- Diabetes
- Inflammation of the kidney (glomerulonephritis)
- Drugs, poisons and radiation
- Infection
- Abnormalities of the immune system (autoimmune disease)
- Obstruction (blockage)
- Hereditary factors
- Accidents and injury caused by medicine
- Sodium: too much sodium in the body can lead to excessive thirst and therefore drinking more, which leads to fluid retention and higher blood pressure
- Urea: to see how much ammonia, a waste product, is left in the body.

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“The kidneys are very important organs and add to a healthy body in a number of ways.”
Blood tests and my levels

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<thead>
<tr>
<th>Normal ranges</th>
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<tbody>
<tr>
<td>Albumin</td>
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<td>Chloride</td>
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3.2 - 5g/dl
8.8 - 10.3mg/dL
95 - 107mEq/L
0.5 - 1.4mg/dl
13 - 300mg/ml
% Male: 41 - 50, Female: 36 - 44
1.6 - 2.4mEq/L
2.4 - 4.1mg/dL
3.5 - 5.2mEq/L
22 - 30mmol/L
135 - 147mEq/L
7 - 21mg/dL

The kidney is a very important organ and adds to a healthy body in a number of different ways. Kidney failure is therefore linked to many health worries that need to be treated.

Treatments that may be necessary
- Healthy lifestyle changes, including a healthy diet and regular exercise and managing fluid intake
- Medicine to control blood pressure and improve anaemia and bone health
- Dialysis
- Kidney transplant

Without treatment, kidney failure will ultimately result in death.

Some of the effects of kidney failure
- Build up of waste products in the blood (uraemia)
- Lower production of red blood cells (anaemia)
- High blood pressure (hypertension)
- High cholesterol (hyperlipidaemia)
- Insufficient making and keeping of bone mass
- Itching (due to uraemia)
- Difficulty in sleeping.
Treatments

Diet, fluid intake and lifestyle changes I must make

Why it is important to follow a Renal Way of Life

Good nutrition principles, limiting of fluid, regular physical activity and taking your medicine as prescribed are the base for greater wellbeing in patients with kidney conditions.

Which foods should I avoid?

When you are in kidney failure, you have to make changes to your diet to prevent health problems. Foods that have high levels of certain nutrients like protein, phosphorus and potassium must be limited or taken out of your diet. A dietitian can help you determine what foods are best to eat.

- **High potassium foods:** High potassium levels in the blood can cause heart and muscle problems. If you have kidney failure you have to be careful of eating large amounts of foods with high potassium levels. Many foods like oranges and potatoes have high amounts of potassium.

- **High protein foods:** The kidney clears the waste products from protein out of your body. Foods that have high levels of protein can make more waste than your kidneys can clear and can lead to faster kidney deterioration.

- **High phosphorus foods:** High phosphorus levels in your blood lower the amount of calcium in your bones. Since the kidney manages the levels of phosphorus in the blood, people in kidney failure often have high levels of the mineral.

- **High sodium foods:** Sodium can cause your body to hold on to extra fluid which can lead to high blood pressure and can put more strain on your heart and kidneys.

- **Unhealthy fats:** It is important that you eat less saturated and trans fats (bad fats) to avoid high cholesterol levels. You need fat in your diet because it can be used for energy and to create very important hormones in the body. Including healthy fats can make sure that you get the necessary fats and extra calories you need. Examples of healthy fats are olive oil, corn oil and peanut oil.

“Regular physical activity and taking your medicine as prescribed are the base for greater wellbeing in patients with kidney conditions.”

Place to store my test results
To replace (put back) your natural erythropoietin, your doctor may prescribe erythropoietin injections. Depending on the type of medicine, these may be given a few times a week, once a week, every two weeks or even only once a month. Because you need iron to make red blood cells, you may also have to take extra iron which is usually given intravenously (through the vein).

There are a variety of medicines with different active ingredients that can be used to treat the same condition. Ask your doctor or clinic sister to explain to you what each of your medicines is for, how it works and most importantly, how you should take them.

**Medicine for bone disease**

**Calcium and phosphorus** are necessary for healthy bones. Your parathyroid gland together with a healthy kidney is important to control the amount of calcium and phosphorus in your body and to control their activity. In kidney disease, this controlling activity is lost:

- The kidney normally turns vitamin D into a hormone called calcitriol. In kidney disease, not enough calcitriol is made. This makes the actions of calcium, phosphorus and the parathyroid gland become abnormal.
- Calcium is lost from bone, causing weakening of the bones, which gives you a higher risk of breaking a bone.
- Because the kidneys cannot take out phosphorus, phosphorus starts to build up in the body.
- Calcium and phosphorus join to make deposits that collect in blood vessels and damage the blood supply to organs like the heart and intestines. Medicine that can help to avoid these effects include:
  - **Phosphate binders** – these tablets are taken with meals to stop the body from taking up phosphorus so that it does not build up in the body.
  - **Calcitriol** – to give you higher levels of calcitriol as it is not being made by the kidneys.
  - **Cinacalcet** – helps control the working of the parathyroid gland.

**Medicine to help reduce itching,** for example antihistamines

**Medicine to control cholesterol levels,** for example statins

**Medicine to reduce blood pressure,** for example calcium channel blockers and ACE inhibitors

**Anti-diabetic medicines to control blood sugar,** for example oral tablets or insulin injections.

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**Why I have to limit my fluid intake**

When you are experiencing kidney failure, you are unable to pass adequate volumes of urine and when you drink fluids, these fluids store in the body. The extra fluid in the body puts pressure on especially your lungs and your heart.

**Medicine I might have to take**

Because the kidneys have a number of functions that contribute to a healthy body, dialysis is only one of a number of treatments that help to replace kidney function. Your doctor may put you on dialysis as well as prescribe medicine to keep you in the best possible health. Here are some of these medicines:

**Medicine to treat anaemia**

In kidney failure, the kidneys no longer make erythropoietin, a hormone that stimulates red blood cell formation. When the body doesn’t make enough red blood cells, it results in a condition called anaemia. Anaemia causes a lack of energy and tiredness and may damage your heart.

**Why I should exercise**

There are many benefits of physical exercise. In short it makes you healthier, as it:

- Improves fitness
- Lowers blood pressure
- Helps to prevent diabetes and cardiovascular disease (problems with your heart and blood vessels)
- Improves muscle strength
- Helps to strengthen bones and lessen joint stiffness
- Helps you to lose weight (only if you stick to your diet as well!)
- Helps to improve your mood and makes you feel better.

You must try to exercise 30 to 60 minutes on most days of the week. It is very important to talk to your doctor before you start an exercise programme.

Please see pages 59 – 66 for detailed information on food, fluid limitations, recipes, exercise tips, travelling tips and tips on looking after your bones.
What dialysis is and how it works

What dialysis is

Your condition is treated by a kidney specialist called a nephrologist or a doctor with a special interest in kidney disease. Your doctor will suggest treatment options to you, which will most likely include dialysis.

Dialysis is a medical treatment to filter waste and water from the blood when the kidneys are no longer working.

There are two different methods of dialysis, haemodialysis and peritoneal dialysis.

- **Haemodialysis** uses an external filter to clean the blood. Blood is removed from the body, passed through the filter and then returned to the body.
- **Peritoneal dialysis** uses the body’s own abdominal cavity (open space in the belly) to clean the blood.

**Haemodialysis**

Before starting haemodialysis, a tube will be inserted into a specially created blood vessel in your forearm known as an AV fistula (or arterio-venous fistula). The tube is then linked to a haemodialysis machine (also known as an artificial kidney), which pumps blood out of your body, cleans it and returns it, usually through a second tube.

How the haemodialysis machine works

Connected to the haemodialysis machine is a filter called a dialyser. The dialyser is divided into two sections, separated by a membrane. The membrane is a film covered with many microscopic holes.

Blood is pumped through one section of the dialyser and the other section is filled with a special dialysis fluid, which draws waste products out of the blood through the membrane. This membrane is semi permeable (some things can move through it) and in this way the dialysis fluid cleans the blood, but the fluid and blood cannot mix.

The haemodialysis machine also has different monitors, so that it makes sure that blood is pumped out and back into your body at the correct speed and that your blood pressure stays at a healthy level.

**“The time it takes for your dialysis treatment is the best possible time it takes to clear all the waste products, poisons and extra fluid from your body.”**

Where haemodialysis is done and how long the treatment lasts

Haemodialysis is usually done at a special dialysis clinic and most patients will need to go to the clinic for dialysis three times a week.

Each dialysis session lasts for three to five hours.

Haemodialysis can also be done at home with a home dialysis machine. In this case it can be done more often (five or six times a week) for two to three hours each session, or at night.

Why does haemodialysis happen so often and take so long?

Healthy kidneys work 24 hours a day, 7 days a week to remove the waste products from the body. Remember that dialysis replaces only a small amount of your kidney function and if you’re not getting enough dialysis, you will start to have symptoms of kidney failure, such as a metallic taste in your mouth, itching, loss of appetite and fatigue.

If dialysis were to take the place of healthy kidneys completely, you’d need to be linked up to a dialysis machine all the time.

The time it takes for your dialysis treatment is the best possible time it takes to clear all the waste products, poisons and extra fluid from your body. It can be longer or shorter, depending on your urea and creatinine blood test results. The amount of time on dialysis is worked out on an individual basis by your attending doctor but should usually not be less than three sessions of four hours a week.

Peritoneal dialysis

Peritoneal dialysis uses the body’s own abdominal cavity (open space in your belly) to clean the blood. Dialysis solution (a mixture of sugar, salt, and other minerals dissolved in water) is introduced into the peritoneal (abdominal) cavity through a catheter (tube). A peritoneal dialysis procedure is called an exchange because the used solution is removed and replaced with fresh solution. This can be done at home four times a day or continuously at night.

There are significant benefits to having peritoneal dialysis

Because it can be done at home, peritoneal dialysis may offer more freedom than haemodialysis. For some people, performing dialysis at night is sufficient, leaving the day free for other activities.
When I am on haemodialysis, how will they get access to my blood vessels every time?

When you need dialysis urgently, they will create temporary access, but for continuous dialysis the doctor will create an arterio-venous fistula.

What temporary access is and how they create it

Temporary access can be created in cases where urgent dialysis is needed and one cannot wait two to three months for the fistula to mature.

Temporary access is established using a subclavian catheter or internal jugular catheter. The subclavian catheter is a set of tubing put into the subclavian vein near the neck. The internal jugular catheter is placed into the veins on the side of the neck.

Although temporary catheters can be used for a period of time they are more likely to get an infection and blockage and are more uncomfortable than a fistula.

What an arterio-venous (or AV) fistula is

An AV fistula is the access point for haemodialysis. The AV fistula is created internally and used for a long time. To create it, the surgeon joins the artery and vein under the skin. The ideal site is the forearm (radiocephalic fistula) but it can also be done on your wrist or elbow.

During your treatment, two needles are placed in your arm to allow the blood that has built up with toxins to flow through a tube to the dialyser. The dialyser cleans the blood and it is returned to your body through the other needle. A fistula takes about six to eight weeks to mature.

What an arterio-venous graft is

This is similar to an AV fistula except that an artificial (man-made) blood vessel is used to join an artery (a blood vessel that delivers blood from the heart to the tissues and organs of the body) and a vein (a blood vessel which carries blood back to the heart). This is done when your own blood vessels are too small for fistula construction.

The graft may be straight or looped and is close to the surface of the skin. The graft is made of artificial material, or the doctor can take it from your own body tissues, for example a vein in your thigh.

How do I take care of the fistula or graft?

It is important to always keep the area clean and dry.

To make sure that the fistula is working, you can feel if blood is flowing through it (called a feeling for a thrill) by putting your finger on the area.

Avoid constriction of the area by not wearing tight clothing and jewellery and not having your blood pressure taken or intravenous administration (fluids or medicine given directly into the vein) done on the fistula arm. Avoid too much pressure on puncture sites (where the needles went through the skin) and make sure the clinic nurses rotate needling to prevent aneurysm (a localised, blood-filled balloon-like bulge in the wall of a blood vessel).

Cost of the treatment.

Circumstances at home that might help or get in the way of dialysis

Your level of motivation to stick to your treatment

How easy it will be for you to store and maintain dialysis equipment at home and keep it clean

Your job and activity levels

Transport and your ability to get to your clinic

Things I need to think about when deciding on the type of dialysis that is appropriate for me

Your doctor will discuss dialysis options with you and together you will decide what type of dialysis is right for you at this time.

In time, many patients may need both types of dialysis. When deciding what type of dialysis is right for you, various factors need to be considered.
Living donors

Most people are born with two kidneys, but some are born with only one, and they live healthy, normal lives. That is why it is possible for living donors to donate one kidney. There are two types of living donors:

- Related donors – family members are more likely to have a good tissue match to you, with a smaller chance of rejection. The donor can be anyone older than 18 years and who is part of your family, like a parent, sister or brother (sibling), child, aunt or uncle, nephew or cousin.

- Non-related donors – if you cannot find a family member who is able to donate, it is possible to get a kidney from someone who is not directly related, such as a husband or wife or a close friend.

The number of transplants from living donors is getting more. In 2012, there were 244 adult, eight adolescent (teenager) and four paediatric (child) living donor transplantations done in South Africa.
Why I might wait a long time to get a kidney

Because the number of people who need a kidney transplant is far more than the available donors, the waiting list for a kidney transplant is long. Some people may have to wait for many years before a kidney is available for them. According to the National Kidney Foundation of South Africa, the average waiting time for a kidney transplant in South Africa is four years.

Discuss the possibility of a kidney transplant with your doctor. Unless you have a family member who is willing and able to donate a kidney, the earlier your name is put on the waiting list, the more likely you are to get a kidney transplant.

Immunosuppressants, like any medicine, do have side effects

- Depending on the type of medicine, some of these side effects include:
  - A higher risk of getting an infection
  - A change in appearance – fullness around the face, acne and weight gain
  - Diabetes
  - Osteoporosis (thinning of the bones)
  - Hirsutism (abnormal growth of hair)

Factors in choosing a recipient include:

- Tissue matching – blood type, tissue type, antibodies
- The patient’s medical condition
- How long the patient has been waiting

Why I need to take medicine for the rest of my life after the transplantation

Because your immune system (white blood cells) sees that the new kidney is foreign and does not belong in your body, it will attack the kidney after it has been transplanted, causing it to fail. This is called organ rejection and is your body’s natural reaction.

You’ll need to take medicine before and after the transplant operation to suppress the immune response and reduce the chance of organ rejection. These medicines are called immunosuppressants.

Medical tests I will have before my transplantation

- Blood tests
- Tests to establish the condition of your heart and lungs
- Dental check-up and x-ray of your teeth
- Gynaecological (female parts) evaluation, including a Pap smear test, pelvic (lower belly) examination and a mammogram (x-ray of the breast) (for patients older than 40 years)
- A session with a psychologist or social worker

“Kidney donation is a gift of life from one person to another.”
**Setting up my transplantation**

If you have a living donor and your full evaluation is complete, your surgery will be set up for a time that suits you, your donor and the transplant team.

If you are waiting for a kidney from a deceased donor, you will be placed on the waiting list.

Let us know where you are and how we can reach you!

A donor can be found at any time – day or night, weekdays, weekends, holidays. This means we will need to contact you quickly when a donor is found. We must always know how to reach you and you must give an up-to-date cellphone number to your doctor and to the transplant unit. If you are leaving your town or city for any length of time, tell the transplant office when you are leaving, when you will get back home and how you can be reached. Please keep your cellphone on and with you in case that special call comes through that you have been called up for a possible transplant.

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**Getting ready for my transplant**

Your transplant could happen at any time, so it is best for you to be ready. There are a lot of practical things you can plan to make you ready and things to run as smoothly as possible when the time comes for your operation:

- Read everything your transplant team gives you and ask questions when you’re not sure of something
- Have a plan for how you will get to the hospital (it is best not to drive yourself, if nobody can take you, plan to take a taxi).
- Make plans for how you get home from the hospital.
- Make plans for someone to take care of your children or others in your care for the time you will be in hospital.
- If you live far from the transplant hospital, you will need to arrange a place to stay during the first few weeks after your operation so that you can make the frequent check-up visits to the hospital necessary after the transplant.
- Arrange for someone to drive you to the hospital for clinic visits once or twice a week during the first month before you are allowed to drive yourself.
- You may need laboratory tests once or twice a week for the first few weeks.
- If you have problems organising your medicines by yourself, have someone who can come to the hospital to be shown what to do.

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**I must stay healthy**

- Follow your dialysis routine correctly
- Take your medicines as prescribed
- Watch your weight and if you are overweight, try to lose weight
- If you smoke – stop now
- Exercise is a very important part of the programme to get ready for the transplant, if your health allows it. You must please consult your doctor, a physiotherapist or a biokineticist who is experienced in exercise training to help you and make sure you are exercising correctly.

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**I must tell the transplant team about any change in my health, no matter how small**

Report any of these changes to your doctor immediately. Any illness or infection or any other medical condition could put you at risk of complications and your doctors may decide not to do your transplant surgery at that time. Your doctor will tell the transplant unit if you have any of the following issues if they have an impact on your transplantation:

- Any illness
- Any changes in medicine or any new medicine
- Any hospitalisation
- Any changes in the days you have dialysis
- Any changes in doctors
- Any blood transfusions you get.

**I will have regular blood tests done**

While you are waiting for a kidney, your transplant team will need regular new blood samples from you, to allow them to look for new antibodies and match you with possible donors. Make sure you have these tests done whenever asked to do so. If you don’t have these done when asked to do so and you are waiting for a donor organ transplant, your name may be taken off the waiting list.

"Remember to always tell your transplant team if there is any change in your address and telephone numbers so they can always contact you."

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**Before I go to the hospital**

If your kidney is going to be from a living donor, your operation will be planned for a specific date.

As the date gets closer, you must tell your doctor and the transplant team immediately if:

- You have any illness, including a cold, a problem with a tooth, or an infection
- You are taking any new medicines, including over-the-counter or herbal medicines, or food supplements
- You are planning any trips away from home
- There are any changes in your contact information.
About the donor’s operation

Transplantation operations are now highly successful procedures and it is seen as routine surgical practice for treating kidney failure.

Traditionally, the donor operation has been through a single cut of about 10 – 18cm, but live donation is more and more done by laparoscopic surgery (a modern method in which operations in the belly are performed through small cuts (usually 0.5 – 1.5cm long).

This new method gives less pain and scarring, and speeds up the donor’s healing process. As more donor operations are done by laparoscopy, making the operation far less large-scale than before, more people have become live donors.

The donor stays in hospital for about as long as the recipient does. However, with laparoscopic surgery or other new methods that use smaller cuts, it may be possible for the donor to leave the hospital in two to three days.
Looking after my incision (operation site/cut)

The incision will most likely be covered with a plaster right after surgery, and you may have a drainage tube in place. The incision itself will be sore and the area around it will be numb for several months until the nerves heal. The nurses will show you how to care for your incision.

Doctors will take out any stitches or staples when your incision has healed. Follow your doctor’s orders about caring for the healed wound and don’t try to take off any plasters unless your doctor has told you to do so.

Other medicines I will need after surgery

Immediately after your surgery, you will begin to take anti-rejection and other medicines like antibiotics. Some of these will be given through your drip and others will be given by mouth.

By the first evening, the nurses may begin to teach you about your medicines, especially those you will take when you go home. It is important to start taking note and learning early on what medicines you are taking and why you are taking them.

Measuring and monitoring

The nurses will continue to measure your blood pressure and other vital signs (pulse, temperature and oxygen saturation levels) frequently as well as measure your urine output every hour.

Getting moving

You must do the deep-breathing exercises your physiotherapist has shown you. Don’t forget to cough. When in bed, turn every one to two hours. You may be given an oxygen mask for the first day. With each day you will become more active, and you should walk the halls of the transplant unit at least three times a day once you are allowed to get out of bed.

Getting up and about after your operation

It is important for your health and recovery to get up and move around as soon as you can.

Exercise will help prevent pneumonia (lung infection) and blood clots and will help your bowel to work. A physiotherapist will visit you after your operation to start a programme that is focused on preventing:

- Lung collapse
- Muscle atrophy (wasting away of your muscles), joint stiffness and lower blood circulation that could form clots in the blood vessels
- Swelling, slow wound healing and other major complications.

Controlling my pain

You will be able to give yourself pain medicine directly into your drip (IV) through a device called a patient-controlled analgesia (PCA) pump. If you feel pain, simply push the button. Do not worry about taking too much pain medicine; it is important that you are not in pain so that you can begin to move comfortably as soon as possible. As soon as you can eat food, you will be given pain-relieving medicine my mouth.

My visitors

Once you are settled in your room, the nurses will allow you to get visitors when you are fully awake and your condition is stable.

Some patients may need to stay in the intensive care unit (ICU) for a time so that the medical team can monitor their heart and lung functions more closely. Visiting hours in the ICU are limited.

For many patients and their family members, the filling of the urine bag is a welcome sign.
Going home

If there are no complications, most patients go home about eight to ten days after their operation. You are ready to go home if:

- You have no fever
- You have had a bowel movement
- You are able to eat, drink and take your medicines
- Your creatinine is dropping, which means your transplanted kidney is working well
- Your incision looks good or is getting better on antibiotics.

By the time you are ready to go home, you should be able to set up your own medicines and know why, how and when to take them.

If my transplanted kidney does not work

The most common cause of delayed graft function (where the transplanted kidney doesn’t work immediately after being transplanted) is acute tubular necrosis or ATN – where the tubule cells of the kidney are damaged.

There is no specific treatment for ATN other than avoiding fluid overload and controlling potassium, calcium and phosphate levels. Some immunosuppressant medicines are harmful to the kidney and may be replaced by other, less damaging medicines during this period. It may also be necessary in severe cases where the transplanted kidney does not work, to put you on dialysis for a time until the transplanted kidney starts functioning well enough.

Delayed graft function can, in most cases, be healed.

Other reasons why your transplanted kidney will not work properly soon after your transplant include:

- Low blood pressure
- A blood clot in the kidney’s artery, vein or ureter
- Certain anti-rejection medicines
- Rejection.

Each of these problems can, in most cases, be treated.

Getting food in

You will begin eating on the second or third day after your transplant, depending on your recovery. This will mostly be in a semi-liquid form and then they will bring in more solid food as your bowels begin to function normally. Your nurses will ask you about your stomach and whether you have had a bowel movement. If you don’t have a bowel movement by the second or third day, the nurses may give you medicine to help you have a bowel movement (laxative).

My catheter will be removed

The nurses will take out the catheter from two to seven days after the transplant. Once it is taken out, you must empty your bladder regularly, whether you feel like going or not. This is very important to help the bladder heal properly.

I may need to stay in hospital longer

Some patients may have to stay in hospital longer if complications come up after the transplant. These include:

- The new kidney has acute tubular necrosis (ATN) (where the tubule cells of the kidney are damaged) or there is delayed graft function (DGF) where the transplanted kidney doesn’t function immediately after being transplanted
- They require added anti-rejection medicines
- They have a fever
- They are having trouble emptying their bladder completely
- They have complications or other medical problems that may or may not be related to the transplant.

It is very important to stick to all treatment as not taking your medicines properly may cause chronic kidney rejection (when your body’s immune system rejects your new kidney, which destroys the transplanted tissue) and failure and result in your transplant being unsuccessful.
Care after my transplantation

Taking care to reduce my risk of rejection

Once you have had a transplant, the goal of your treatment is to prevent your body rejecting your new kidney. Rejection is the body’s natural process to protect itself from anything foreign.

When rejection is picked up and treated early, it can be controlled. However, all anti-rejection treatments available today work by suppressing (holding back) the body’s immune system, making your body less able to fight off diseases caused by intruders such as bacteria, viruses and fungi. The immune system can no longer effectively see and destroy abnormal cells that can lead to tumours or cancer.

You can lower your risk of rejection. It is important to find the right balance between protecting the transplanted organ and protecting the health of the rest of the body. To lower your risk, you can:

- Take your anti-rejection medicines as prescribed
- Learn what the early warning signs of rejection are
- Attend all clinic and doctor visits that is set up for you.

Self-monitoring is very important to be aware of warning signs of rejection. Keep a personal health diary, perform self-tests to monitor whether any of the above signs are present and write down the results.

Also make sure you never miss a set up blood test or clinic visit, where a range of tests may be done to monitor the working of your new kidney.

In some cases, even with the most aggressive treatment, it is not possible to turn around the rejection process, and the patient goes back on dialysis treatment. Another transplant is usually possible. Unless the transplanted kidney is causing health problems, it will not be removed.

Warning signs of rejection

If you get any of these symptoms, call your doctor or the transplant team immediately:

- Flu-like symptoms
- Drop in the amount of urine output
- Fever of over 37.8 °C
- Pain or burning during urination
- Fluid retention, seen in fast weight gain
- Dark, bloody or bad-smelling urine or swelling of your ankles
- Dark or bloody stools
- Higher blood pressure
- Pain or redness in the area of your surgery

Keeping infections at bay

Transplant patients are at greater risk of infections caused by viruses, bacteria and fungi. You can take steps to lessen your risk of getting infections, but if necessary, the right medicines will be prescribed to fight any infections you do get.

Because of your high risk of infections, you should try to avoid fast foods after your transplant because they are full of bacteria, which can cause serious food poisoning.

I may get diabetes after my transplant

New onset diabetes mellitus (NODAT) can happen as a side effect of some of the immunosuppressive medicines given to transplant patients. Your doctor may change your medicines and doses to lower your risk while on immunosuppressants.

You may get counselling about the importance of lifestyle changes including weight control, the right diet and following a sensible exercise programme.

Your glucose levels will be monitored on an ongoing basis after transplantation. If you do develop new onset diabetes mellitus (NODAT), your condition will be managed with oral anti-diabetic medicines. But about 40% of patients may in the end need to change to insulin therapy.
The role of my family members or friends

Family members or friends can first choose to be a donor if you need a transplant operation. They can also help you in different ways before and after the operation. When you get the call to come to the hospital for the transplantation, you can make sure you have one or a few family members or friends on standby to drive you or go with you to the hospital. After you have been admitted, they can bring you any items you may need during your stay in hospital and visit you once it is allowed after your operation, to give very necessary emotional support.

Once you can go home from hospital, they can drive you home again because you will not be allowed to drive until the doctor says it is okay to do so.

In the early stages after surgery, they can possibly help you at home in any way necessary, like helping you get used to your medicine and exercise schedule and take you for follow-up tests and clinic visits.

Family members and friends can continue to give emotional support and to get you help if necessary for depression if you have complications after the transplant, or if your body rejects your new kidney and you have to go back to dialysis.

How I can promote organ donation

To become an organ donor, a person has to register as a donor. Registering is free and there will be no cost to their family after their death. Visit the Organ Donor Foundation’s website at www.odf.org.za to register.

Becoming a living donor means you have to be committed and willing to donate, well-matched with the patient and in good health.

Sources:
Organ Transplant Information System (OTIS) (Roche)
www.odf.org.za
A new kidney saved my life - Kutlwano (4)

“He was ill from birth, but we didn’t realise immediately that it was kidney disease,” says his mom Lorraine. Kutlwano was at first misdiagnosed and treated for bronchial pneumonia (infection of the lungs). “His urine wasn’t coming out normally, and there was water on his lungs,” she remembers. It was only when Kutlwano was one year and two months old that doctors realised he had kidney failure.

Congenital nephrotic syndrome is linked with severe loss of protein and is quite rare. The symptoms include generalised swelling, anaemia, failure to grow, bone disease – which is complicated by low calcium, poor appetite, and delayed developmental milestones. In many cases this condition can be deadly, as transplants can only be done when babies weigh more than 10kg.

Kutlwano was very small and needed long-lasting dialysis, which was very difficult. Unfortunately Lorraine was not able to donate her kidney to her son as she has high blood pressure.

He was on a transplant list for over a year before a kidney donor was found.

But in December 2009, the family was overjoyed to hear that he could have a transplant. “After the surgery Kutlwano was so much better. He was so much happier and was really well for the first time in his life,” Lorraine says. Kutlwano is looking forward to starting at crèche soon.

Swimming is the love of his life; and this transplant is the best thing that’s ever happened to him and to us.”

Stories from other people who have had transplants

Facing the possibility of a kidney transplant can be scary. It can help to calm your fears by knowing that many people and their families are enjoying happier, fuller lives after a successful transplant.

Here are a few of their stories...

Transplant is the best thing that’s ever happened to me - Tevin (13)

When Tevin was nine years old he started complaining of joint pain. “We ignored it,” says his mom Tess. “We didn’t take it seriously, thinking he was just trying to get out of school. But when the pain didn’t go away we took him to the doctor.”

The doctor found a high level of inflammation after blood tests, and prescribed some medicine. But after two rounds of medicine, hospitalisation and many tests, Tevin still wasn’t better. Eventually a urine test showed that Tevin had kidney failure.

“We had to be so careful with his diet,” says Tess. “He could only have one litre of water a day, including the fluid in his food. At one time he stopped urinating altogether.” This restriction (limitation) was especially difficult for an active young boy. And, at his age, he didn’t fully understand the strain his body was under. Sometimes he was so thirsty he would secretly drink water.

When Tevin’s kidneys failed he began dialysis. “I can honestly say dialysis was the worst time of his life,” says Tess. “It was a total change for Tevin. He went from being a normal, active child who could eat almost anything and swim whenever he wanted, to suddenly not being able to have any foods containing potassium, like bananas or chocolates. He couldn’t swim any longer because we feared infection of the catheter in his tummy. He couldn’t even bathe, and this was very difficult for a child to bear.”

Tevin’s sudden decline and peritoneal dialysis were very difficult for the whole family. Eventually an infection in his belly meant he had to change to haemodialysis. “This was even more difficult, as we had to go to the hospital three times a week. I had no control over the treatment, and even more discipline was necessary at home,” remembers Tess.

Then in 2006, doctors confirmed Tevin’s glomerulonephritis (inflammation of the membrane tissue in the kidney that serves as a filter) was not active, and the risk wasn’t as high as it was before. Tevin went onto a donor list. “Eight months later, at 4 am, we got a call to say there was a kidney for Tevin. At first I was highly irritated to be woken up in the middle of the night, then I realised what the caller was saying and I just screamed with joy – we were all in tears! We woke Tevin up at 5 am and told him there was going to be no school that day. Instead we were going to the hospital to get a new kidney. We had no doubt that the transplant was going to be a success, we were very sure. My child just cried: thank you, thank you!” says Tess.

Since his surgery five years ago, Tevin has been a different child. He can eat, swim and play just like all his friends. “Swimming is the love of his life; and this transplant is the best thing that’s ever happened to him and to us,” says Tess. “When people meet him they can’t believe he’s had a transplant, he’s so ‘normal’!”

“Swimming is the love of his life; and this transplant is the best thing that’s ever happened to him and to us.”
My mom gave me the gift of life, again - Albe (9)

Albe was diagnosed with polycystic kidneys (when cystic growths appear in the kidneys) and other complications at birth. “We kept track of his kidney function and in those first few years there were no problems,” says his mother Natasha. But his kidney function deteriorated, and by the age of seven, Albe showed signs of being very tired. “He had some blood tests, and we were notified that he needed a transplant immediately,” says Natasha. In two weeks, Albe’s kidney function had halved. “We thought we still had six months to a year before we had to think about a transplant; it was a big shock emotionally,” she says.

Right away Natasha and her husband, Albert, were tested to measure if their tissue matched as donors. “Testing was the worst day of my life,” says Natasha. “The decision about whether our child lived or died was out of our hands, and we were just waiting to hear a yes or no that would decide our futures.” In addition to the blood tests and scans that are used to check whether someone can be a donor, the test includes how the donor would cope physically with only one kidney. Luckily Natasha was a match and Albe got one of his mother’s kidneys.

“People think being a donor is very painful and very dramatic,” says Natasha, “But it’s not at all. The worst part was the needle - and the waiting.”

“We were very blessed,” she says. She describes how yellow and pale Albe’s skin was before the operation. “An hour after the operation the change was remarkable. He was flushed pink with the healthy new blood. That’s something I will never forget – he was literally a new child.”

Albe has now lived one year with his new kidney and he’s a happy and active boy. “He’d always been a lot smaller than friends of the same age, but now he’s growing about a centimetre a month, it’s incredible!” she laughs. “I think our biggest accomplishment was handling Albe as normally as possible, we never treated him as ill,” she says.

The first thing Albe wanted after his operation was a peanut butter sandwich, which he’d longer for, but had never been able to have. “Everything was new and bright and exciting. His sense of taste changed. “I live a healthy lifestyle and see my specialist once a month to ensure that we keep my very persistent and I made a strong case as I was very fit, my heart was in good shape and my health was well-controlled.”

André was approved for transplant and then began the anxious wait for a donor. “I was at the office when I got a call to say it was time, there was a match for me. My wife and I met at the Donald Gordon Transplant Centre with a mix of emotions: fear, excitement and gratitude. I thanked God for this miracle which was about to take place in my life.”

“I had only been on dialysis for six months, which is a very short compared to the many friends I made at the dialysis centre, who have waited many years. The feelings were so mixed as we knew that someone had died and in turn, was giving me a new life. We continue to pray for my donor’s family and are forever grateful,” says André.

Although there were times when André felt low, he has an incredibly positive attitude, and he feels this made all the difference through the difficult times. “I just wanted to get up and start living a fuller life again,” he says. It has been three years since the transplant, and the Murphy’s lives are forever changed. “I live a healthy lifestyle and see my specialist once a month to ensure that we keep my very precious organs healthy. No more dialysis, toxicity, diabetes, or insulin – what a blessing.”

Natasha welcomes communication from other mothers in similar situations. If you would like to contact her, please email her at: Natashag@autotec.co.za

“An hour after the operation the change was remarkable. He was flushed pink with the healthy new blood. That’s something I will never forget – he was literally a new child.”

André and Murphy’s offer their support and personal experiences if you are awaiting a transplant or have had one already. Email: marcelle.murphy@telkomsa.net

“Four-hour dialysis sessions three times a week were very tiring, but the support I received from family, friends and colleagues kept me going.”
Some conditions that are caused by diabetes include:

- Kidney disease and in the end, kidney failure
- Eye disease and blindness
- Heart attacks and strokes, and blockage of arteries in the legs and other parts of the body
- Damage to nerves, causing loss of sensation, pain and abnormal function of the blood vessels, bladder and digestive tract
- Skin damage, sores and ulcers (especially of the legs and feet)
- More likely to get infection.

What diabetes is

In people with diabetes, the pancreas does not produce enough insulin, or the body does not respond to insulin in the way that it should. Because insulin is the hormone that controls how the body uses blood sugar (glucose) for energy, the body does no longer respond correctly to glucose that is absorbed from food, it does not make glucose correctly for itself, and it does not use the glucose that is available in the bloodstream correctly.

This results in abnormal blood sugar levels – too high after eating and too low in between meals. Both high and low blood sugar levels cause illness.
**Why it’s important to keep my blood glucose levels under control**

Good glucose control can slow down the damage linked to diabetes. Using diet and medicine to control glucose, and keeping blood glucose levels as close to normal as possible, is necessary to slow down the development of these linked conditions listed on the previous page. Even if you have some of these conditions already, it is necessary to control your blood glucose as best you can to prevent them from getting worse and to help prevent other problems.

Diabetes can cause damage all over the body.

**Controlling my blood glucose levels**

Controlling blood glucose levels in end-stage renal disease and dialysis is challenging. Some of the reasons why it may be more difficult to control your blood glucose levels during dialysis are:

- Lower or no kidney function means that medicine usage may need to be more closely monitored and controlled
- Insulin may be the only medicine that can work, but because the kidneys do not excrete it properly, dosing may be complicated
- Because there are limits on the things you may eat and drink, it is difficult to control your blood glucose levels by eating right.
- Sugar concentrations in dialysis fluid may affect glucose control.

**Tips to keep me healthy**

You’ve most likely had diabetes for a while and therefore you are at greater risk for other conditions like eye problems, sores and ulcers. That is why it is important that you do everything you can to help control your diabetes and keep yourself healthy.

- **Follow your treatment plan**
  - Take all your medicine as prescribed — the correct dose at the correct time
  - Follow your dialysis plan – don’t miss sessions.
- **Follow your diet plan**
  - Monitor your blood sugar as prescribed
  - Keep track of your sugar levels with a diary — it will help your doctor.

"People with kidney disease are more likely to have other conditions linked to diabetes."

**Know as much as you can about diabetes and how to control it**

You must be able to know low blood sugar (hypoglycaemia) and know what to do when it happens

Your doctor can send you to a diabetes educator if you have not seen one already.

**Have your eyes checked regularly by an ophthalmologist**

Ask your doctor how often this must be.

**Look after your skin and feet**

- Keep your feet clean and toe nails short
- Check your feet and toe nails every day for redness, cuts and scratches
- Wear properly-fitting shoes
- Don’t walk barefoot.

**Floss and brush your teeth every day**

**Follow a physical activity plan that is right for you**

**Don’t neglect cuts, sores or ulcers on your skin**

- Get advice if you damage yourself
- Keep any sores or ulcers that you may have clean and correctly dressed
- If necessary, seek advice from your healthcare professional or podiatrist (foot doctor).

**Tell your doctor if you feel unwell**

- If you have a fever
- If you experience anything new that worries you, for example dizziness, diarrhoea or trouble passing urine.

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