

# **Kidney Transplant**

# Patient Information







# NEED A KIDNEY TRANSPLANT?

At the Aga Khan University Hospital, our kidney transplant team is available to guide you at every stage of your treatment. We have a multidisciplinary team that consists of the nephrologist, the transplant surgeon, trained nurses, nutritionists, technicians, coordinators and pharmacists. They all work together to ensure a comprehensive approach and your treatment plan is delivered to provide the best results for you.

#### What is a kidney?

We are born with two kidneys, which are bean-shaped organs located in the back, just under the ribs, one on each side of the spine. The left kidney is slightly higher in position as compared to the right kidney.

The function of a kidney is to filter and remove waste products from the blood. When the kidney becomes diseased, it cannot perform this function in the way it should and the waste and toxins can build up to dangerous levels in the body.

# What causes the kidney to fail?

Kidney failure means that the kidney is not working properly. The most common causes include:

- Poorly controlled diabetes
- Poorly controlled high blood pressure also known as hypertension
- Kidney stones
- Recurrent urinary tract infections
- Long term kidney inflammation also known as chronic glomerulonephritis
- Cysts that develop in the kidney due to a genetic disorder also known as polycystic kidney disease
- Excess or long term use of some medicines, e.g. pain killers like ibuprofen and naproxen
- Damage caused to the kidney when urine goes back up from the bladder to kidney also known as reflux nephropathy.

# How do I feel when my kidney is failing?

The common symptoms of kidney failure include:

- A generalized weakness and tiredness.
- A generalized swelling e.g. in the feet, legs and around the eyes.
- Have trouble sleeping.
- Feeling of nausea, vomiting and a loss of appetite
- Decreased amount of urine
- Shortness of breath that you cannot explain.

#### What is the treatment for kidney failure?

If you have been diagnosed with kidney failure, you and your doctors will jointly decide which treatment is best for you. Treatment options will depend on your medical history, health status and personal situation. Options for patients with kidney failure include:





**Dialysis:** is a procedure by which a machine is connected to you several times or more a week for a number of hours and it filters your blood. The dialysis machine actually mimics the actions of your kidneys. Your doctor based on your condition and treatment plan decides how often you require dialysis.

**Kidney Transplant:** is also known as renal transplant. It is a surgery during which your diseased kidney is removed from your body and replaced by a healthy kidney that is taken from a healthy person known as your donor. Donors are usually your family members.

A kidney transplant is usually the treatment of choice for most patients with kidney failure, because when successful kidney transplant improves your quality of life and increases your lifespan. However, in order to have a successful transplant, you and your donor will have to undergo a series of laboratory tests and radiology scans to determine if you are suitable. In addition, tests are also conducted to measure if the donor's healthy kidney matches your tissues and if your body will be able to accept it. Unfortunately many kidney failure patients have no option but to continue with dialysis until a suitable donor is found.

# When is a patient not suitable for a kidney transplant?

You may not be suitable for a kidney transplant because you:

- Have cancer or have recently received treatment for cancer
- Suffer from multiple diseases
- Have an active infection e.g. tuberculosis (TB), viral etc.
- Suffer from neurological or psychological disorders
- Are significantly overweight.

## What are the different types of kidney transplants?

There are two types of kidney transplants; living donor transplant and deceased donor transplant:

**Living donor transplant:** As the name suggests, in this form of transplant, the kidney donor is healthy and living. The Sindh Human Organ Transplant Act (SHOTA) has rules that governs and defines, who can be a kidney donor for a transplant operation. SHOTA has legal conditions that must be met for all transplants performed and has divided the category of living donors into two segments:

- a) **Living-Related (Blood Relative):** a spouse, either husband or wife, or a blood relative, including a parent, sister, brother, children, half-sister, half-brother, uncle, aunt, first cousin, nephew, niece, wet mother or her children (with court evidence) can agree to donate a kidney.
- b) Living-Non-Related (Non-Blood Relative): a person, who is not related through blood to the patient, includes friend or acquaintance. An interview and evaluation of the donor is performed by the Nephrologist to confirm the willingness of the individual to donate their kidney as well as a full review of the relevant investigations.

**Deceased Donor Transplant:** In this case, the kidney donor is deceased but has provided legal consent before passing away. Presently deceased donor transplant services are not available at our hospital.

#### What is a multidisciplinary transplant team?

A Multidisciplinary Transplant Team referred to, as the Transplant Team comprises of various health care professionals from different specialties who work together to deliver every individual patient treatment plan.





They discuss the benefits of the kidney transplant, the risks of the surgery, make you aware of possible complications and ensure that these are properly addressed and you and your donor has the best opportunity for success. Our Transplant Team includes:

The **Transplant Nephrologist** is a medical doctor with expertise in nephrology and transplantation medicine. The doctor is responsible for the medical management of your kidney disease, determines if you are medically suitable for a transplant and takes care of you after the transplant.

The **Transplant Surgeon** is a doctor with special training performing surgeries and expertise in kidney transplantation. The surgeon is responsible for removing your diseased kidney and replacing it with the healthy kidney taken from the healthy donor.

The **Psychiatrist** is a doctor with expertise and special training in mental health. This doctor is responsible for conducting an in depth psychiatric evaluation and assessment for both, you the patient and your donor. Having a kidney transplant or donating a kidney may cause some fear, anxiety, inability to sleep at night and depression. It will take time to adjust to life with your new kidney and the medications that you have to take. Our psychiatrist will help prepare you deal with these issues and be available to guide you if you need additional counseling.

The **Transplant Anesthesiologist** is a doctor with special training in ensuring that you and your donor are safe and pain free during the transplant. This doctor will determine the type of anesthesia that will be used during the surgery and can explain the risks and benefits of the anesthesia. You and donor will be required to provide informed consents.

The **Transplant Coordinator** is a registered nurse with special training in kidney transplantation. Our transplant coordinators are equipped to provide you and your donor with education throughout your transplant process, from the time of evaluation, during transplantation and for years afterwards. A coordinator will be assigned to meet with you to evaluate your ability to cope with the stress of transplantation, and your ability to follow a rigorous treatment plan, both before and after transplantation. Your coordinator will also help you coping strategies and identify your support network. Your coordinator is your facilitator throughout the transplant process and is available to answer any questions. You are encouraged to bring family members to these meetings.

The **Financial Counselor** has special training in the financial aspects associated with the transplant. He or she will discuss the costs with you including the financial impact longer term that comes from the need to have regular medical tests and follow-up, and daily medication. If the ability to pay becomes an issue, the financial counselor can help determine if you are eligible for the patient welfare and/or Zagaat programmes.

The **Transplant Dietitian** has special expertise in the nutritional requirements of kidney disease patients. The dietitian will perform a detailed nutritional assessment and can provide you and your donor with nutrition education throughout the transplant process.

The **Transplant Pharmacist** has special training and knowledge on the multiple medication requirements of transplant patients. The pharmacist will review all your medications throughout the transplant process. Our pharmacists can help you understand your medications, prepare you for and help minimize any side effects, check for medication interactions and suggest changes to maximize the overall results.

Other **Specialty Doctors** are available on the hospital campus should you require any other consultations and if a complexity should arise. These specialists include but are not limited to, urologists, infectious diseases,





hematologists, vascular surgeons, pulmonologists, cardiologists, dentists and dermatologists. At the Aga Khan University Hospital, we have all services, all under one roof including detailed diagnostics and laboratory testing. In cases where some patients may need to be referred to another doctor, they can be conveniently seen here in our hospital or clinics and the medical records are easily accessible which ensures continuity of care.

#### THE KIDNEY TRANSPLANT PROCESS

When a healthy kidney is available for your transplant, your medical team will begin the process of taking care of you before, during and after your transplant.

#### Step 1: To assess your eligibility for kidney transplant

Before you can have a kidney transplant, the transplant team; the nephrologist, transplant surgeon and transplant coordinator will talk to you and your donor about the procedure, examine you both and run a series of evaluation tests that may include but not limited to:

- A general health assessment: involves a full medical history and physical examination.
- **Psychosocial evaluation:** to make sure you are emotionally prepared for the surgery, care after the transplant and living with a new kidney.
- Compatibility tests: involves knowing the blood typing, tissue typing and crossmatching for you and your donor to ensure that the healthy kidney from your donor will match your body and have a high probability of acceptance.
- **Blood tests:** to check the function of your heart, kidneys, liver, thyroid and immune system. This will include blood sugar control and electrolyte balance as well as tests for certain viruses e.g. hepatitis B, C, HIV/AIDS and IGRA (Interferon Gamma Release Assay) to test for TB (tuberculosis).
- Chest X-ray: to check the size of your heart and your lungs for infection, disease or any other abnormalities.
- **Echocardiogram:** an ultrasound to check for any problems with the chambers, valves and pumping function of your heart.
- **Electrocardiogram:** to test the rhythm of your heart and make sure there are no abnormalities.
- Cardiac stress test: to ensure that your heart is strong enough for the transplant surgery.
- Cancer screening tests: to make sure that you do not have cancer or if you have had cancer in the past, that it has not returned. These tests include; colonoscopy (over age 50), mammography (women over age 40), pelvic exam and pap smear (for women) and prostate exam (men over age 50).
- **Dental examination:** to check for and treat infections, cavities or gum disease before the transplant because if not corrected, they can cause problems after the transplant.

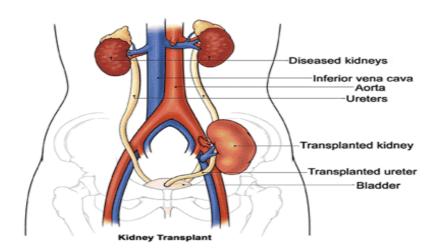
The transplant team will meet to discuss your results, any concerns and decide if you are suitable for the kidney transplant. You will be informed and a treatment plan for you specifically will be developed.

#### **Step 2: Kidney transplant surgery**

During the transplant surgery, the donated healthy kidney will be placed at the right or left side of the lower abdomen, just above and in front of your hipbone. This operation usually takes 3-5 hours.







After the surgery, you will be taken to a recovery room. Once you are stable, you will be shifted to a single room with special care and monitoring. You will stay in the hospital until your doctor feels that you are ready to go home. This could be a week to ten days. The length of your hospital stay depends on your health and how well the new kidney is functioning.

#### **Medicines**

After your surgery, you will be given medicines that prevent your body from rejecting the new kidney. It will take some time for your body to accept the new kidney. You will be given immunosuppressive medicines also known as anti-rejection medicines. These drugs suppress the immune system enough to keep your transplanted kidney healthy. The life of your kidney depends on these medicines. You must take your medicines exactly as prescribed. Altering your schedule may result in an episode of rejection and damage to your new kidney. If you stop taking your medicines, even after years of successful transplant, your body will reject your kidney. Do not take any medicines other than those prescribed by your transplant team. Other medicines can interfere with the absorption of your transplant medicines and cause an unwanted increased level of medicines in your blood, which may damage your kidney. Check with a member of the transplant team before taking any new medicine, including those for simple cough, cold and allergy. You must take your prescribed medicines for the rest of your life. Never allow yourself to run out of your medicines. If you have any questions about your medicines, you should speak with your doctors and or pharmacists. Our pharmacists are available 24/7 on the drug and poison hotline.

#### Diet

Diet plays an important role in maintaining your health. The optimal function of your new kidney is also influenced by what you eat. Individual needs vary; however, the main nutritional goals after transplantation are controlling blood cholesterol, uric acid levels and avoiding excessive weight gain. A regular exercise program can enhance the achievement of these goals. The transplant dietician will review with you a diet plan and guidelines on what you can eat and should avoid before you are discharged from the hospital. At the time of discharge you will receive additional materials to help you manage your diet. The dietician will also be available to assist you in the clinic as and when needed.





#### **Wound Care**

You may shower, even if your staples are in place. No dressing is needed over your incision, but some light gauze may be applied if you have staples that are irritated by your clothing. The staples will be removed in the clinic about two weeks after the surgery.

#### **Step 3: Discharge from the Hospital**

Before you are discharged from the hospital, your medical team will ensure that you and your family understand the following:

- 1. All your medications by name, appearance, purpose, dosage and when to take the medicines.
- 2. Major side effects of your medications and special precautions that you must take.
- 3. How to check and record your vital signs twice daily.
- 4. Signs and symptoms of infection.
- 5. Signs and symptoms of transplant rejection.
- 6. Diet advice and the exercise regimen you should follow.
- 7. Appointments and schedules for returning to the clinic for follow-up care.
- 8. How to contact the transplant coordinator in case of any concerns.

Once you are home and if you need any assistance please contact the team on the numbers mentioned below. Your transplant team is here to care for you.

#### Step 4: Staying healthy after the transplant surgery

Following the transplant surgery, the transplant team will assist you with rehabilitation and prepare you to care for yourself when you go home.

# Complications of kidney transplant surgery

Your transplant team will do their best to reduce any chances of complications by continually checking for signs of:

- Infection
- Rejection
- Delayed graft function is when your new kidney does not begin functioning as it should
- Diabetes
- Blood Pressure
- Anxiety and depression

It is important that you and your family fully understand the signs of complications from kidney transplant, remain alert and immediately inform the transplant team if you notice any problems:

**Infection:** Anti-rejection medications that you must take to avoid rejection, interfere with your natural immunity. This means that you are at high risk of catching infections after your transplant surgery. If you feel or notice any of the listed symptoms, inform your transplant team immediately:

• Fever above 100°F





- Burning sensation or pain during urination
- Blood in your urine
- Shortness of breath
- Sore throat
- Cough
- Pus in the wound
- Muscle or joint aches and pains
- Severe headache.

**Rejection:** Your immune system will see your new kidney as a foreign body and may not accept it. To prevent rejection, you must take anti-rejection medications for the rest of your life. The probability of rejection is low; however, it is very important that you learn to recognize the symptoms of rejection and to report these immediately, if noticed. Timely intervention by your transplant team and healthcare providers may help prevent rejection.

- Fever above 100°F
- Decreased amount of urine output to less than 50% of the amount you are drinking in a 24 hour period. For example, if your intake is about 2000cc a day and your output drops to 1000cc or less, this is cause for concern. Your urine output should be nearly equal to your intake.
- Rise in weight by 5 pounds or more within 3 days.
- Swelling or tenderness (pain on touching) at the surgical site.
- Fluid retention, moderate swelling OF face, feet, hands, ankles and/legs.
- Two blood pressure readings taken one hour apart, more than 160/90 or less than 90/60 (not always the sign of rejection)

If your body is beginning to reject your new kidney, the blood urea, nitrogen and creatinine levels become raised and must be actively monitored by your transplant team to avoid rejection.

**Delayed Graft Function:** After your transplant, your new kidney may not immediately start functioning also known as "a sleepy kidney", resulting in the need for dialysis until the kidney "wakes up". Delayed function may last from a few days to several weeks.

**Diabetes:** Some of your prescribed anti-rejection medicines are known to cause high blood sugar levels. You will be routinely monitored after the surgery to check for this condition through blood and/or urine tests.

**Blood Pressure:** High blood pressure is a very common complication following kidney transplantation, particularly during the early months while you are kept on high doses of steroids. Blood pressure will be routinely monitored during your clinic visits, and you may be advised to monitor yourself at home as well.

**Anxiety and depression:** A serious operation such as a transplant can put a lot of mental stress on you and your family. It is common for transplant patients to experience anxiety and depression during the treatment. We offer counselling services to help you adjust to your new life at home as well as return to work.

#### Activity

When you return home from the hospital, begin a daily routine of walking for exercise. Avoid lifting heavy objects over 5 lbs. including lifting children or straining your abdominal muscles for at least six weeks. Lifting and straining may result in the opening of your wound or the formation of a hernia.





Try to avoid people who are sick especially those with colds or flu. While we know this is not possible all the time, stay away from situations where you will be in small, enclosed spaces with large groups of people. Wash your hands frequently. Do not share utensils, drinking glasses or toothbrushes.

Your transplant team will inform you when your condition is stable and you are safe to return to work or school. Generally, this happens at about two to three months after the transplant.

#### GENERAL INFORMATION FOR THE LIVING KIDNEY DONOR

#### Living donation

Living donation takes place when a healthy person donates an organ for transplantation to another person. The living donor can be a family member such as parent, child, brother, sister or spouse or not related but emotionally connected to patient such as a friend. Altruistic donation is also a type of living donation, where by the donor and recipient is neither related or knows each other.

#### Who can be a kidney donor?

If you are a healthy person in good physical and mental condition, you can donate a kidney. As a general rule, the donor should be 18 years or older. There is no upper age limit to being a living donor, as long as you are in good health!

One of prerequisites for donation is to have a normal kidney function. There are some medical conditions that could prevent you from being a living donor. These include having uncontrolled high blood pressure, diabetes, cancer, HIV, hepatitis or acute infections. Having a serious mental health condition that requires treatment may also prevent you from being a donor. As well as physical and mental health criteria, a donor is selected based on the following considerations:

- Should not be under any pressure to donate by family or any other influence.
- Must fully understand all the risks to their own health and benefits to the patient recipients' life.
- Should have good family and social support.
- Should not have any alcohol or substance abuse problems.

# Advantages and outcomes of having a living donor

Kidney transplants performed from living donors have several advantages compared to transplants performed from deceased donors:

- In Pakistan, most living donor transplants are from family members who are genetically similar. A better genetic match lessens the risk of rejection and improves the overall success.
- A kidney from a living donor usually functions immediately, because the kidney is out of the body for a very short time. Delayed function of the kidney may be seen in 3-5% of transplant patients.
- Living donor kidney transplants are highly successful and success rates continue to improve. Immediate rejection of the healthy kidney is extremely rare in present days. However problems may occur during or after the transplant surgery. Surgical complications include





blood loss or urine leakage in the transplant patient can occur and be managed accordingly. Life threating complications including infections (bacterial or viral) and pulmonary embolism are uncommon but important enough to mention.

#### Functional life of a transplanted kidney from a living donor

On average, the survival of the transplanted kidney at 10 and 15 years is about 75-76% and 35-45% respectively. Most patients will require a second transplant after 15 years however some kidneys may continue to function even after 15-20 years. The survival of the transplanted kidney depends on many factors including, degree of match, sudden and long-term rejection episodes and infections.

#### Is living donation safe for the donor?

This is the most frequently asked question from a potential donor. As a matter of fact almost all individuals have two kidneys. Donating a kidney to another person generally does not harm your health. Prior to donation the transplant team conducts a full investigation to make sure that you are not at any additional risk of developing kidney disease yourself in the one remaining kidney after the donation.

Donation is not a risk free procedure. The risk of developing kidney disease requiring hemodialysis after donation is extremely rare at 0.08 per 10000, 15 years after donation. This risk also depends on your race, gender and general health condition over the years.

#### Surgery for removing the healthy kidney from the donor (harvest)

The healthy kidney that is removed from you as the donor is known as 'harvesting'. This surgery is performed under general anaesthesia. There are two main techniques

- 1. Open donor nephrectomy
- 2. Laparoscopic donor nephrectomy.

Your risk as a donor of undergoing anaesthesia is assessed before surgery. The risk of serious complications during surgery is low but not zero. Bleeding requiring blood transfusions, wound infections, deep vein thrombosis leading to pulmonary embolism, lung infections and pain are the main mentionable complications. The risk of dying during surgery is extremely rare.

After the surgery, which lasts for 3-4 hours, you are shifted to recovery and monitored for urine output and pain. After a few hours stay in the recovery, you are shifted to the ward. The pain usually settles after 48 hours. Your stay in the hospital ranges from 3-5 days.

At our hospital, we perform the surgery using the open technique, whereby a small 10cm cut is made on the abdomen.

# When can I, as the donor return to normal activities?

Although the healing time varies, most donors can resume normal activity within 3-4 weeks after the surgery. Lifting heavy items including children or climbing stairs more than two flights of stairs should be avoided for at least 12 weeks.





# What types of medical follow up do I, the donor require?

After removal of any stiches you should follow up with the doctor after about six months. The main aim of this follow up is to ensure that the health of your one remaining kidney is good. After the first year after donation, you are advised to have certain laboratory investigations and a kidney ultrasound once every year.

#### What is it like living with one kidney?

Generally it is considered safe to live with one kidney. Your transplant team will outline the possible risks, which include the most common as well as rare and those specific to you based on your health status. Several studies have indicated that donors may experience:

- Slightly elevated blood pressure
- Slight increase in the level of proteins in the urine
- Risk of long term kidney failure is slightly increased compared to the general population.

It is also important to be aware that, risks across the board are very low. Every individual is different and it is not possible to predict what may actually happen down the road.

#### What is my life expectancy after donation?

Living donation does not change your life expectancy. Survival after donation is the same as in the general population. In general, most people with a single normal kidney have few or no problems; however, you are encouraged to ask questions about your individualized risks.

#### What can I expect emotionally after donating a kidney?

Before the kidney donation a psychological assessment is performed to ensure that you have no additional psychosocial risk. After donation, very small number of donors have reported a range of mixed emotions, from joy and relief to anxiety and depression. Living donors generally rate their experience as positive. However, concerns about the transplant patients' outcome as well as your own recovery can contribute to feelings of anxiety, and you may experience a feeling of "let down" afterwards. Feelings of depression among living donors are not uncommon, even when both the donor and patient are doing well.

If you find that you are struggling with mixed emotions at any time after you donate, you should:

- Let your transplant team know how you are feeling both physically and emotionally during your follow-up visits.
- Talk to the transplant coordinator for support and guidance.
- Seek professional counselling or other outside help to manage difficult emotions.
- Talk with other living donors who can be particularly supportive if they have experienced similar feelings.

# Are there any dietary restrictions after donation?

After donation you should be able to go back to a regular, healthy lifestyle. Healthy individuals do not need to follow any dietary restrictions.





# Can I become pregnant after donation?

Pregnancy after donation is possible but is usually not recommended for at least six months after the donation surgery. Living donors should talk to their doctor and transplant team before planning for a pregnancy. Prenatal care is of utmost importance in kidney donors.

Generally, living kidney donors do well with pregnancy after their donation. However, donors may be at a slightly higher risk of gestational diabetes, pregnancy-induced hypertension (high blood pressure) and protein in the urine known as pre-eclampsia. Early identification of these conditions will help your doctors to take timely actions and manage them appropriately.

# Kidney Transplant Unit

The Aga Khan University Hospital, Karachi Mon-Fri 8:00 A.M. - 4:00 P.M.

Tel: +92-213-486590/91

Hot line number 0301-8245171

Mon-Sun After Hours Tel: 021 34865190/91

# **Emergency Department**

The Aga Khan University Hospital, Karachi 24 hours service

Tel: 021 34861090/91

# Pharmacy Department

Drug and Poison Department The Aga Khan University Hospital, Karachi 24 hours service

Tel: 021 3486 1504/1506

Always Follow The Recommendations Of Your Transplant Team.





# TRANSPLANT PATIENT GUIDE

Patient Name:	Medical Record Number:
Date of Surgery:	Date of discharge:
Weight at the time of discharge:	Date of stent removal:

Date	Weight	Blood pressure			REFLO (sugar) monitoring		Temperature	Urine output
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Labs	Date							
Tacrolimus Levels								
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DATE	TACROLIMUS DOSE	CELCEPT DOSE	PREDNISOLONE DOSE	REJECTION SIGN (YES/NO)	If yes, any treatment given