

FOLLOW UP CARE KIDNEY TRANSPLANT DEPT OF RENAL SCIENCES MAX HOSPITAL GURUGRAM

HOW YOU MAY FEEL

1. You may feel weak or “washed out” for 6 weeks. You might want to nap often. Simple tasks may exhaust you.
2. You may have a sore throat because of a tube that was in your throat during surgery.
3. You might have trouble concentrating or difficulty sleeping. You might feel depressed.
4. You may find you have a poor appetite or that food doesn't taste the same. This is related to your new medications. It will get better in a few weeks.
5. All these feelings and reactions are normal and should go away in a short time. If they do not, tell your nephrologist.

AT HOME

1. You will need to have a blood pressure monitor, thermometer, and weighing scale in preparation for discharge
2. Weigh yourself and take your temperature and blood pressure at the same time every day. Record the results on your daily record. Meet your doctor if you have a temperature of 101 or higher, or if your weight goes up more than 1.5 kgs in 2 days
3. If you are a diabetic you will need to monitor your blood sugar frequently
4. Do not smoke. Smoking makes you more prone to getting a respiratory infection and makes it more likely for your new organ to fail in the future.
5. If you need any immunizations (for travel or for routine care), make sure you do not get any “live virus” immunizations. The doctor or nurse giving you the immunization will be able to tell you whether or not it contains live virus. Always check with your nephrologist.
6. You should not get any vaccines within 3 months' post-transplant and/or within 3 months' post treatment of a rejection episode. The annual flu vaccine injection is encouraged as long as you are 3 months beyond your transplant.
7. Never stop taking your anti-rejection medicine and never adjust the dose without first speaking to your transplant coordinator or doctor. If you vomit after taking your pills and do not see any medication in the vomit, do not repeat your doses. If you see your meds, you can try taking the pills again.
8. Do not take any over-the-counter (non-prescription) medicine – including vitamins, herbs, and supplements – without referring to your nephrologist

FOLLOW UP

1. Follow Up frequency: Twice/ week on Tuesday & Friday with prior appointment.
2. Physical visit is preferable. Alternately video consult can be done
3. PI carry your discharge summary and register and all inv reports during the visit
4. INV:
 - a. CBC, KFT, LFT, Urine RE, Bld Sugar F/PP, Urine RE.
 - b. Any additional inv reqd will be advised during follow up
 - c. Drug Level: Drug levels will be ordered as reqd for Tacrolimus, Everolimus & Cyclosporine.
 - i. C0 level: Sample has to be given 30 min before morning dose
 - ii. C2 level: Sample has to be given 2 hrs after morning dose

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MEDICATIONS

A. Tacrolimus

Side Effects: Low magnesium levels • High potassium levels • High blood pressure • High blood sugar/developing diabetes • Decreased kidney function • Tremors/shakiness • Headache • Trouble sleeping

Special Instructions: Avoid grapefruit and any drinks that contain grapefruit juice and pomegranate

B. Mycophenolate Mofetil/ Sodium

Side Effect: Stomach upset (nausea, vomiting, diarrhea) • Low white blood cell count

Special Instructions: If you take anything with calcium, magnesium, or aluminum hydroxide (Maalox, Mylanta, Tums, or Phosphate Binders) you should take them 1 hour before or 2 hours after taking your Myfortic (MMF)

FDA warning: this medication is linked to increased risk of loss of pregnancy and birth defects.

Females of child bearing age must be counseled about preventing pregnancy and planning

* If you become pregnant while taking this medication, let your doctor know immediately

* Before taking the medication, talk to your team about birth control options

C. Prednisolone

Side Effects: Trouble sleeping, mood swings, night sweats, High blood sugars, Water retention, high blood pressure, Acne, Increased appetite, heartburn, Osteoporosis

D. Valganciclovir

Side Effects: Low white blood cell count, Low red blood cell count, Low platelets

E. Clotrimazole:

This medication is used to help prevent a fungal infection in your mouth and throat called “thrush” which is from Candida. You should let one lozenge melt in your mouth three times a day after meals. You should not eat or drink anything for 15 min after taking the medication to allow the medication to absorb into your mouth and throat where it needs to work. In most cases we will instruct you to discontinue this medication 3 months after your transplant

F. Pain Medication

Sometimes patients need to take medications after transplant for pain from the surgery. . . If you need to take pain medications at home, you must discuss this with the transplant team. Crocin/ Ultracet are pain medications that you can take if needed for pain.

Some pain medications like non-steroidal anti-inflammatory drugs (NSAIDs) can be harmful to your new kidney. You should not take any medications that contain ibuprofen or naproxen unless the transplant team tells you to take them. Aspirin is also an NSAID and should only be taken to protect your heart if the transplant team tells you to take it.

G. Constipation:

After transplant you may have difficulty moving your bowels. This can be a side effect of pain medications, surgery, and laying down while recovering. If it hurts to move your bowels or if you have not moved them after transplant, you should tell the transplant team. The team may tell you to take medications to help you move your bowels. Cremaffin/ Looz/ Dulcolax/ Lacti hep are laxative medications that will help you move your bowels. If you're having diarrhea, stop taking these medications.

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DIET

1. Consume fresh cooked food.
2. No cut fruits/ veg
3. Boiled or bottled water only
4. People who have received a kidney or a pancreas transplant may be able to have an occasional alcoholic drink after three months. Always check with your doctor.
5. Do not eat grapefruits or drink grapefruit juice, as this can affect how some of the transplant medications work in your body.
6. Food should be cleaned, cooked, and stored properly. Avoid foods that are high-risk for bacterial contamination. Some of your drugs reduce your immune system. A reduced immune system increases your risk of developing food borne illness.
7. High risk foods (for infection)
 - a. All raw and undercooked meats (especially ground), poultry, fish, game
 - b. Sushi, raw oysters, and raw shellfish
 - c. Raw or undercooked eggs and foods that contain them. (i.e., cookie dough, cake batter, Caesar dressing, etc)
 - d. All fresh sprouts (bean, alfalfa, etc.)
 - e. All unpasteurized milk and dairy products, including cheeses
 - f. All unpasteurized juices and ciders
 - g. Raw or spoiled foods items
 - h. Foods contaminated with a food borne illness
8. Always practice the following:
 - a. Keep kitchen and food storage areas clean.
 - b. Remove jewelry and scrub hands with soap under warm, running water for 20 seconds before preparing food and after handling raw meat, poultry, or eggs. Use a clean towel to dry hands.
 - c. Defrost all foods in a refrigerator or microwave, not on the counter.
 - d. Use separate cutting boards for raw meat and fruits or vegetables (Replace cutting boards that have cracks or deep groves).
 - e. Wash fruits and vegetables under running water just before eating. Scrub firm produce like melons and potatoes with a clean produce brush. Cut away any damaged or bruised areas and peel before using. Bacteria can build up in damaged areas of produce. Berries are harder to wash properly, so you may want to avoid these.
 - f. Start with a new food stock. Discard any opened jars or packages (including condiments), expired foods, food with mold, dented cans, and cracked eggs.
 - g. Keep cold foods COLD and hot food HOT!!!
 - i. Cold: Check the thermometer on your refrigerator. It should be 34-40 degrees F.
 - ii. The freezer should be less than 5 degrees F.
 - iii. Hot: Food should be cooked and reheated at least 165 degrees F. Whole poultry (like Thanksgiving turkey) should be cooked to 180 degrees F.
 - iv. You should invest in a food thermometer to ensure you are keeping your refrigerator and foods at the correct temperature.

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- h. Store Food Promptly and appropriately:
 - i. Store raw meat, poultry, and eggs below ready-to-eat foods.
 - ii. Put leftovers in the refrigerator as soon as possible. For foods that are still hot, store them in a shallow dish, and throw away any food that is left out of the refrigerator for over an hour.
 - iii. Eat refrigerated leftovers within 24 hours and reheat only once (freeze any extra).
- i. Wash dishes with hot water and liquid dish detergent. Allow dishes to air dry.
- j. When eating out, avoid foods containing uncooked ingredients, such as eggs, meat, poultry, or fish.
- k. Avoid buffets, salad bars, potlucks, etc., which may contain undercooked foods or foods that have been at room temperature too long.

9. Higher Protein

*Protein is found in meat, dairy, nuts, beans, and fish.

- a. Why do I need to eat more protein?
 - i. To heal from surgery! Protein helps you heal after surgery. It builds and repairs muscles and tissues.
 - ii. *The steroids that you are on after transplant can break down muscle. Protein helps build up muscle that may be broken down.
- b. What should I do?
 - i. Eat low fat, protein-rich foods
 - ii. Lean meat, poultry, and fish
 - iii. Eggs (no runny yolks)
 - iv. Low fat milk, yogurt, and cheese
 - v. Dried or cooked beans and peas
 - vi. © Your dietitian can help you figure out how much protein you need every day.

A higher protein diet is temporary. Eventually you can return to a normal amount of protein.

10. Less Sodium:

- a. Read food labels! Aim for less than 140 mg of sodium per serving
- b. What is it?
 - i. Less than 2000 mg (2 g) of Sodium per day. Sodium is found in salt and other preservatives.
- c. Why should I follow a lower salt diet?
 - i. Some transplant medications (like steroids) can cause your body to hold fluid. A diet high in sodium can cause the body to hold more fluid, putting stress on the body, and raising blood pressure.
- d. What should I do?
 - i. Avoid foods that are commonly high in sodium. These include:
 - ii. Table salt or seasoning salt
 - iii. Cured meats like ham, bacon, sausage
 - iv. Lunch meats/cold cuts
 - v. Canned or dehydrated soup
 - vi. Commercially frozen meals

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vii. Condiments like pickles

11. Less Sugar

- a. What is it?
 - i. Sugar is found in sweets and candy, fruit juices, refined carbohydrates.
- b. Why should I eat less sugar?
 - i. Surgery and immunosuppressant medications, such as prednisone, can increase blood sugar. If not controlled, diabetes can develop.
- c. What should I do?
 - i. Eat less candy, dessert, and pastries.
 - ii. Limit fruit juice. Choose fresh fruit instead.
 - iii. Avoid sweetened drinks like juice and soda.
 - iv. Drink more water and calorie free beverages.
 - v. Choose whole grains instead of refined white grains.

12. Less Cholesterol/Saturated Fat

- a. What is it?
 - i. Foods high in cholesterol and saturated fat can raise your cholesterol levels. Saturated fat should be limited to < 2 grams per serving. Trans fat can also raise cholesterol, and should be avoided completely. Saturated fat and cholesterol are found in animal products like meat, cheese, and ice cream.
- b. Why do I need to follow a low cholesterol/saturated fat diet?
 - i. The medications you are taking can also raise your cholesterol. High cholesterol increases the risk for heart disease. By controlling the fat and cholesterol you eat, it can help decrease the risk of developing high cholesterol. Healthy cholesterol levels are below 200 mg/dL.
- c. What should I do?
 - i. Avoid fatty meats like cold cuts, sausage, bacon, and liver.
 - ii. Choose skim or 1% milk.
 - iii. Eat no more than 3-4 egg yolks per week.
 - iv. Select baked, broiled, or poached seafood, chicken.
 - v. Eat less mutton cheese.
 - vi. Avoid baked, processed foods that tend to be high in trans-fat.

13. Healthy Eating for Weight Control

- a. What is it?
 - i. Weight control is all about balance. The calories you take in should equal the calories you expend. If you need to lose weight, then you should eat fewer calories than you need.
- b. Why do I need to watch my weight?
 - i. After transplant, it is common for people to gain weight. You are feeling better! And there are fewer restrictions to your diet. Steroids can make you hungrier, making you eat more, thus gaining weight.
- c. What should I do: Follow healthy eating tips:
 - i. Eat more high fiber foods (fruits, vegetables, whole grains, cereals, and brans).

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- ii. Eat high protein, low fat foods (chicken, turkey, seafood, lean red meat, low fat dairy).
- iii. Eat balanced meals throughout the day.
- iv. Stop eating when you are full! Listen to your body.
- v. After talking with your doctor, start exercising.
- vi. Meet regularly with your dietitian. They can help make sure that you are at a healthy weight.
- vii. Engage in regular physical activity. This is one of the most powerful things you can do to stay well after your kidney transplant.

14. More Calcium

- a. What is it?
 - i. Calcium is needed for bone strength and health.
- b. Why do I need to eat more calcium?
 - i. Some of the medications you may be taking can cause bone thinning and osteoporosis.
 - ii. Transplant patients can lose as much as 10% of their bone calcium during the first 5 months after surgery!
- c. What should I do?
 - i. Eat 4 servings of calcium rich foods a day. These include:
 - ii. Low fat dairy: 1% or skim milk, low fat yogurt, and low fat cheese
 - iii. Fish
 - iv. Dark leafy green vegetables, such as beet greens, turnip greens, kale, collard greens, and spinach
 - v. Foods fortified with calcium, such as soymilk, rice milk, and some cereal
 - vi. If you don't eat these foods, talk to your dietitian and/or to see if a calcium supplement would be beneficial for your individual needs.

15. Other Things to Note:

Some of these diet needs are different from your normal diet regimen due to post-transplant medications you may now be taking.

- a. Potassium restriction is usually not necessary after transplant. However, depending on your future lab draws, you may be told to restrict potassium.
- b. Your phosphorus level may fall too low after transplant due to how well your kidney is doing its job. Include a lot of phosphorus foods in your diet, such as milk, yogurt, low fat cheese, and beans to help maintain a normal phosphorus level.
- c. Your magnesium level may fall too low after transplant due to the side effects of the medications. Include a lot of magnesium-rich foods in your diet, such as legumes, nuts, whole grains, and certain vegetables
- d. Vitamin supplements are typically not necessary after transplant if you are eating a balanced and varied diet. Before starting any supplement, including herbal supplements, discuss it with your doctor to avoid any possible interactions with your medications.
- e. Alcoholic beverages should be avoided in the early post-transplant period. Later, an occasional drink should be fine, but check with your doctor first.

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- f. Grapefruit and grapefruit juice should be avoided. Grapefruit and grapefruit juice can interact with your Prograf, which can be very dangerous

ACTIVITY

1. Do not drive until you have stopped taking pain medicine and feel you could respond in an emergency
2. You may climb stairs.
3. You may go outside. Avoid traveling long distances.
4. Don't lift more than 4-5 kgs for 6 weeks. (This is about the weight of a briefcase or a bag of groceries.) This applies to lifting children, but they may sit on your lap.
5. You may start some light exercise when you feel comfortable. Refer to the section in your binder on Activity Guidelines for further information.
6. In most cases, swimming is OK after 4 to 6 weeks, as long as the incision is completely healed. Before you swim, please check with your transplant team to make sure it is okay.
7. Heavy exercise may be started after 6 weeks, but use common sense and go slowly at first.
8. You may resume sexual activity whenever you feel ready.
9. For anyone, spending a lot of time in the sun can make you more likely to get skin cancer. The medicines you are on make you more likely to get cancer from the damaging effects of sun exposure. Avoid spending long periods of time in the sun. When you are in the sun, use sunscreen at all times. Wear a wide-brimmed hat and long sleeves

EXERCISE AND LIFTING

1. With doctor-approved exercise programs, transplant patients often see an increase in strength, stamina, and energy. Exercise helps control blood pressure, reduce sleeplessness, and control weight. Exercise has also been shown to decrease the incidence of depression, decrease anxiety, and increase the sense of wellbeing. Discuss an exercise program with your transplant team.
2. For the first 12 weeks post-transplant, exercise should be limited to aerobic activity that does not place strain on abdominal or 'core' muscles. An example of an approved exercise would be daily walking, slowly increasing speed and duration.
3. When discharged, you should not lift anything heavier than 3-4 kgs and over the course of the first six weeks, gradually work up to 7-8 kgs. From week 6 to week 12, you can slowly increase the weight you lift to 15 kgs. Avoid lifting, pushing, or pulling heavy objects and performing strenuous physical work for at least twelve weeks. These guidelines are meant to help you avoid developing a hernia in your incision.

BOWELS

1. Constipation is a common side effect of many medicine. If needed, you may take a stool softener or a gentle laxative.
2. If you have difficulty or pain moving your bowels, please inform nephrologist

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3. If you get diarrhea, don't take anti-diarrhea medicines. Drink plenty of fluids but avoid ORS/ Electral or other electrolyte supplements as these could cause serious lab abnormalities. If the diarrhea does not get better in 1-2 days, please call your nephrologist

DANGER SIGNS

1. Fever, chills, sore throat
2. Ankle swelling
3. Pain over the kidney
4. A rise in blood pressure
5. Weight gain (sudden large amount, 4 to 5 pounds in one day)
6. Generally, not feeling well, fatigue
7. A decrease in urine output

SEX

1. You may resume your normal sexual activity as soon as you feel comfortable after your discharge from the hospital. Please remember that safe sex measures including the use of a latex condom are strongly recommended, especially for those of you who are not in long-term monogamous relationships. Condoms may help to prevent sexually transmitted diseases.
2. Women should discuss their method of birth control with the transplant team. Although your menstrual cycle may not be regular during the first few months after your transplant, you may still ovulate and even become pregnant. If you or your spouse is considering having children, please discuss it with your nephrologist. We recommend that females avoid pregnancy and males avoid fathering a child for at least two years after transplant.
3. Male patients may experience some degree of sexual dysfunction early after the transplant, which resolves with time. If you continue to experience this for an extended period of time, please let us know.

Planning a family- Women

We recommend avoiding pregnancy in the first year after the transplant. If you are considering pregnancy please discuss it with the doctors in the clinic and we will arrange for pre-pregnancy counselling with the specialist team. You must withhold Mycophenolate at least 6 weeks to 3 months before conceiving the baby. The doctors will change your Mycophenolate to a safer alternative. Studies have shown that Mycophenolate can cause increased risk of miscarriage and pregnancy loss during the first trimester, structural deformities and birth defects in the baby. Hence we recommend for you to use two effective methods of contraception (for example the contraceptive pill and barrier methods such as condoms) during treatment with Mycophenolate and for 6 weeks after stopping treatment.

Planning a family –Men

Men wishing to start a family after a transplant should discuss with the transplant team, as their medication may need to be changed. Each situation needs to be considered on an individual basis, looking at potential risks/benefits of continuing or switching medications. As we do not have sufficient

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data to exclude a risk of harm to the foetus, we recommend you wait at least one year before trying for a family. We also advise male patients and their female partners to use reliable contraception during treatment and for at least 90 days after stopping your last dose of Mycophenolate.

GENERAL GUIDELINES

1. Now that you have had a transplant, you are not a sick patient but a normal, healthy recipient. This applies to your relationship with family and friends just as it does to your professional and recreational activities.
2. You can resume your previous activities, and you may even feel good enough to add some new ones. You may need extra rest the first day or two after leaving the hospital, but a daily exercise program will improve and maintain your health. You will not damage, hurt, bump, or strain your kidney as long as you follow your transplant team's recommendations. Here are some general guidelines:
 - a. Avoid lifting, pushing, or pulling heavy objects and performing strenuous physical work for at least twelve weeks. When discharged, you should not lift anything heavier than a gallon of milk (approx. 8 lbs.) and over the course of the first six weeks, gradually work up to 15 lbs. From week 6 to week 12, you can slowly increase the weight you lift to 30 lbs. These guidelines are meant to help you avoid developing a hernia in your incision.
 - b. If you intend to return to work, including heavy physical labor, get your doctor's OK first.
 - c. Avoid dark, dusty, damp areas where mold or fungus may grow (attics, wet basements, ...)
 - d. Avoid contact sports.
 - e. Students should check with the transplant team before returning to school.
 - f. If you plan to go away on vacation or for business, you **MUST** let the transplant team know ahead of time. Take all your medications with you. When traveling by plane, carry your medications with you.
 - g. Do not check them with your luggage. Also, take your physician's name and number where he or she can be reached. You should also find out the location of the Transplant Center nearest to your travel destination before you leave home.

PET SAFETY TIPS

1. Patients who have received organ transplants are more likely than most people to get diseases from animals. However, simple tips can be followed to reduce their risk of getting sick after contact with animals. These recommendations were originally made for bone marrow transplant patients, but they also may be useful for other organ transplant patients. Although this section focuses on how to protect organ transplant patients from pet related diseases, many groups support the health benefits of pets.
2. Keep Clean!

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- a. Wash your hands thoroughly with running water and soap after handling animals and their feces (stool). If possible, you should avoid direct contact with animal feces. Adults should supervise the hand washing of children.
3. Caring for Your Pet
 - a. If your pet is ill, seek veterinary care as soon as possible. Any cat or dog that has diarrhea should be checked by a veterinarian for infection with Cryptosporidium, Giardia, Salmonella, and Campylobacter.
4. Caring for Birds: Bird cage linings should be cleaned daily. Wear gloves whenever handling items contaminated with bird droppings.
5. Caring for Fish: Avoid cleaning fish tanks by yourself; ask a family member or friend for assistance. If this task cannot be avoided, you should wear disposable gloves during such activities. Wash your hands thoroughly with running water and soap afterwards.
6. Caring for Cats: If you have a cat, try to have another person clean out litter on a regular (daily) basis. Do not place litter boxes in kitchens, dining rooms, or other areas where food is prepared and eaten. Keep your cat indoors. Avoid handling stray cats. Pet cats do not need to be tested for toxoplasmosis.
7. Feeding Your Pet
 - a. Just like people, pets can get diseases from eating contaminated food. By protecting your pet from food borne diseases, you can protect your own health as well. Pets should be fed only high-quality commercial pet foods. If eggs, poultry, or meat products are given to your pet as supplements, they should be wellcooked. Any dairy products given to your pets should be pasteurized.
 - b. Additionally, pets should be prevented from drinking toilet bowl water and from having access to garbage. Do not let your pet scavenge for food, hunt, or eat other animals' feces.
8. Animals to Avoid

The following animals are considered high-risk animals for immuno-compromised people (including organ transplant patients):

 - a. Reptiles, including lizards, snakes, and turtles.
 - b. Baby chicks and ducklings, many types of birds.
 - c. Exotic pets, including monkeys. Note: All persons should avoid direct contact with wild animals.
 - d. Do not adopt wild animals as pets or bring them into your home.
 - e. Contact with these animals and their environments should be avoided by people with compromised immune systems. If you do touch these animals or their environment (their food or cage, for example), wash your hands thoroughly with running water and soap. Additionally, organ transplant patients should be extra cautious when visiting farms and when in contact with farm animals, including animals at petting zoos and fairs.

REJECTION

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The immune system's normal response to anything foreign is to attack and try to destroy the foreign object. Normally, this is a good thing, as it helps your body fight off infections caused by bacteria, viruses, or other unwelcome material. This is true after transplantation as well – the normal immune response is to recognize the transplanted organ as foreign and try to destroy (reject) it. To combat this immune response against the transplanted organ, you will need to take immunosuppressive (anti-rejection) medications. The goal is to prevent rejection without eliminating your body's ability to fight infections. The risk from too little immunosuppression is a rejection episode. Rejection is almost always easily treated, as long as it is caught early. The risk of too much immunosuppression is infection, which can be very serious. For more information on the immunosuppressive medications you will be taking, see the "Medications" section. You will never be completely taken off your immunosuppressive medications because your body will never completely stop trying to reject the transplanted organ. However, as time passes, the amount of immunosuppression that your body needs will decrease. Thus, your immunosuppressive medication doses will be decreased over time. In spite of the immunosuppressive medications, it is possible that you will experience at least one episode of rejection. This most often occurs during the first two weeks after transplantation and almost always within the first three months. It is possible for rejection to develop much later, but as long as you continue to take your medications as prescribed, it is rare to have rejection more than one year after surgery. An episode of rejection is a period of time where the kidney function is abnormal and requires intervention because the immune system is attacking it. Ninety-five percent of all rejections are cured with temporary increases in immunosuppressive medications. Usually there are no symptoms associated with a rejection episode. Your doctors will detect it via a change in the kidney function on your lab tests. An ultrasound and a biopsy may be done to confirm the diagnosis of rejection. You will be getting blood tests frequently and you will be monitored very closely, especially during the first 4 months after your transplant. In most cases, the first sign of a rejection episode is a change in your blood tests without your experiencing any symptoms.

**IN CASE OF ANY QUERIES/ DOUBTS PLEASE SEEK CLARIFICATION FROM YOUR
NEPHROLOGIST/ TRANSPLANT SURGEON**

Prof Dr D Mukherjee
Senior Director
Dept of Nephrology & Kidney Transplant