



**YOUR KIDNEY
TRANSPLANT JOURNEY:
FREQUENTLY ASKED QUESTIONS (FAQS)**

Your Care. Our Commitment.

FAQS

You recently had a kidney transplant and learned a lot of information along the way. You may still have questions for us. This booklet has the most frequently asked questions (FAQs) from our kidney transplant patients. It is meant to help to quickly answer some of your questions. There is extra space at the end of this booklet for you to write down any other questions you may have for us.

SYMPTOMS

1. I have had BK virus in my blood and urine. What should I do?

- BK infection is a common infection, and you may not notice the symptoms. However, if the virus is in your blood, it can damage your kidney.
- This infection can be treated by reducing your current immunosuppressive medicines. Please call and talk with your transplant coordinator or transplant doctor.

2. My blood pressure is high. What should I do?

- If your blood pressure is very high, and if you have a headache or problems with your vision, please go to the Emergency Department.
- If your blood pressure is a little high for more than a few days, please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

3. My blood pressure is low. What should I do?

- Your blood pressure may be low because you are taking more than your prescribed dose of medicine, or you are dehydrated.
- Please record your blood pressure and talk with your transplant coordinator, primary care or kidney doctor, or transplant doctor.

4. My blood sugar readings are high. What should I do?

- If your blood sugar is very high, please go to the Emergency Department.
- Please call and talk with your transplant coordinator, primary care doctor, or diabetes doctor.

5. I have had skin cancer many times. What should I do?

- Skin cancer is common in transplant patients. You should be seen and followed by a dermatologist (skin doctor).
- You may need a biopsy and removal of the problem by your dermatologist.
- Avoiding sun exposure and using sunscreen is very important.
- Please talk with your transplant coordinator, transplant doctor, or dermatologist about various options.

6. I am having chest pains/shortness of breath. What should I do?

- Chest pain can mean you have life-threatening heart or lung disease.
- It can also mean you have rib, muscle, or stomach problems.
- If you have chest pain, you should call 911 and be seen right away in the Emergency Department.

7. I had a CMV infection after my transplant. Will I get it again? Is this contagious?

- A CMV infection can happen again after you have already been treated. It usually happens within 1 to 6 months after the first infection. You may have no symptoms, or you may have flu-like symptoms.
- A second CMV infection can be treated again, and drug-resistant infection is rare.
- Please call and talk with your transplant coordinator, transplant doctor, or your infectious disease doctor.

SYMPTOMS *CONTINUED*

8. My creatinine is elevated. What should I do?

- Elevated serum creatinine (a blood measurement) may be because you are dehydrated, your body is rejecting medicines, or the medicines are toxic to your body.
- If it is mildly elevated from your baseline, talk with your transplant coordinator, kidney doctor, or transplant doctor.
- You may need to check your labs again within a few days. If your serum creatinine is very clearly elevated, please call the transplant coordinator/doctor on call, or go to the Emergency Department.

9. I have diarrhea. What should I do?

- Diarrhea can be a side effect of infection, immunosuppressive medicines, or recent use of antibiotics.
- If you have diarrhea after you were in the hospital, if your diarrhea is bloody, or if it happens when you have a fever, please call your doctor immediately.
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

10. I have a fever. What should I do?

- A fever usually means you have an infection.
- If you currently have a fever — and are experiencing any of the following — please call and talk with your transplant coordinator, primary care doctor or nephrology (kidney) doctor, or transplant doctor. You may need to be seen by a doctor as soon as possible.
 - > Your transplant was in the last few months.
 - > You were recently hospitalized.
 - > You had a procedure (such as a colonoscopy, dental work, biopsy, joint aspiration, etc).
 - > You have symptoms of urinary tract infection.
 - > You are short of breath.
 - > Your temperature is higher than 101 F (38.3 C).
 - > Your fever is persistent for more than a few days.

11. I'm having an acute attack of gout. What should I do?

- Gout is common in kidney transplant recipients. Alcohol or a rich diet with high uric acid content can make acute gout happen more quickly.
- Gout can be treated with steroids or colchicine. Avoid ibuprofen and other non-steroidal anti-inflammatory drugs as they may worsen your kidney function.
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor or transplant doctor.

12. How do I prevent frequent attacks of gout?

- Frequent attacks of gout can be decreased by changing your diet, lowering/stopping how much alcohol you drink, avoiding some medicines (such as water pills), and taking medicines such as allopurinol or colchicine.
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

13. I have a headache. What should I do?

- Your headache may be related to high or low blood pressure. It also could be because of eye, ear, throat, or sinus problems .
- You can take two regular acetaminophen (such as Tylenol®) tablets (650mg) or one extra-strength tablet (500mg).
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

14. I have joint pain. What should I do?

- Joint pain may happen because you have gout or other forms of arthritis.
- Please call and talk with your transplant coordinator or transplant doctor. It may help you if you go to a rheumatologist (arthritis specialist).

15. I have leg swelling. What should I do?

- Increased leg swelling may be related to heart disease, kidney problems, blood clots, or be a side effect of medicines.
- Please call your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor. You may need to be seen in the Emergency Department if you also have shortness of breath or if you are producing less urine.

SYMPTOMS *CONTINUED*

16. I am having physical pain around where my kidney is. Should I worry?

- It is unusual for pain alone to be a symptom of kidney rejection. Many patients experience occasional mild, brief feelings of discomfort around where their kidney is.
- If your pain continues or becomes worse, is associated with bloody, painful, or bad-smelling urination, fevers, or swelling, you should call your transplant coordinator, kidney doctor, or transplant doctor.

17. I have shingles. What should I do?

- Shingles can happen if you are immunosuppressed.
- Shingles can be painful and most patients need short-term pain medicine. Some people may need pain medicine for up to several months.
- Shingles can be treated with medicine that can attack the virus. This medicine works best when started early (within 1 to 2 days) after the start of an attack.
- It is important to call your transplant coordinator, primary care doctor, kidney doctor or transplant doctor as soon as you notice symptoms.

18. I was near a person who had an infection (pneumonia, shingles, chicken pox). What should I do?

- You should watch for symptoms (fever, cough, skin rash, etc).
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.
- If you are near someone with chicken pox, your care team can give you medicine that can prevent you from getting chicken pox.

19. I have a stomach virus. What should I do?

- You may have a stomach virus because you have an infection. It should go away in 1 to 2 days.
- If you are unable to take your immunosuppressive medicines, tolerate food or liquids, produce less urine than usual, or have a fever, please go to the Emergency Department.
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

20. My urine amount has decreased. What should I do?

- If you are producing less urine, please call your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor right away.
- Less urine means that your kidney isn't working as well as it should. This may be a sign of urinary obstruction, that your body is rejecting medicines, or that the medicines are toxic to your body.
- If you don't make any urine, go to the Emergency Department right away.

21. I have protein in my urine. What should I do?

- Protein in your urine can mean you have kidney disease.
- The amount of protein in your urine should be measured.
- Please call and talk with your transplant coordinator, kidney doctor, or transplant doctor.

22. It hurts when I urinate/It burns when I urinate/I urinate a lot. What should I do?

- This may be related to a urinary tract infection or recent urine catheterization.
- If you have a fever, you should go to the Emergency Department.
- If you don't have a fever, you should test your urine with a urine culture and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

23. I have a urinary tract infection. What should I do?

- Urinary tract infections are common in kidney transplant patients.
- If you also have a fever, you should either go to the Emergency Department or an urgent care facility, or see your primary care doctor, kidney doctor, or transplant doctor.
- You can call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

24. I have been getting urinary tract infections often. What should I do?

- When you get urinary tract infections often, they can be treated with antibiotics.
- You may need bladder, kidney, and urine testing.
- You may call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor. You may be referred to see a urologist.

MEDICINES

1. Can I take generic medicines (cyclosporine, for example)?

- It is safe to take generic medicines. Generic medicines are tested against brand name medicines by the U.S. government.
- Generic medicines are less expensive for you (and your insurance company) compared to brand name medicines.
- You should let your transplant coordinator know if you are changing the brand of your medicine. They may ask you to monitor your labs more often when you change brands.

2. I forgot to take my medicines. What should I do?

- Please wait until your next dose. You must take your medicine on time and on a regular basis. Missing your medicines can lead to rejection of your transplanted organ.
- You may need to check your labs sooner. Please call and talk with your transplant coordinator, kidney doctor, or transplant doctor.

3. I vomited my medicines. What should I do?

- Wait an hour or two and try taking your medicines again.
- If you are not able to take your medicines and you continue vomiting, please call your doctor and go to the Emergency Department.

4. Can I take over-the-counter medicines (for cough, cold, fever, etc.)?

- Yes, you may take medicines such as Tylenol®, plain Robitussin®, Dimetapp®, and colace.
- Do not take ibuprofen, Aleve®, or other non-steroidal, anti-inflammatory medicines.

5. What medicine should I take before a dental exam?

- You will need to take amoxicillin. If you are allergic to penicillin, you can take clindamycin before you have dental work.
- Please call your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor for this prescription.

6. Can I take Viagra® or Cialis®?

- Yes, IF you are not taking nitrates for your heart or blood pressure.
- Please talk with your primary care doctor, heart doctor, kidney doctor, or transplant doctor before taking these medicines. Both drugs can cause problems if you have heart disease and may result in a sudden drop in your blood pressure.

7. When should I request refills of my medicines?

- Please request your refills and get your medicines at least 1 to 2 weeks in advance.
- Do not call for your routine refills as an emergency.
- Please keep track of your medicine refills.

8. One of my non-transplant doctors would like to start me on a new medicine or change the dose of one of my medicines. Do I need to let my transplant coordinator know?

- Yes. Many medicines can interact with your transplant immunosuppressive medicines.
- Your transplant coordinator can review any medicines with our transplant pharmacist for safety and update the medicine list we have on record for you.
- You may be asked to have more frequent lab monitoring for a short time after making any changes to your medicines.

VACCINATION

1. Can I take the flu vaccine?

- Yes, you may take the flu vaccine shot, but NOT the inhaled flu vaccine (mist).
- You should avoid taking the flu vaccine for the first few months after your transplant or after an episode of rejection.

2. Should I take any precautions when my children, grandchildren, or pets receive vaccinations?

- For inactive vaccines, no special precautions are required.
- For live vaccines, you should avoid close contact (especially from respiratory and gastrointestinal secretions), if possible, for at least 6 weeks.

3. What kind of vaccination is safe for me?

- Killed or inactive vaccines are acceptable. Live vaccines are NOT recommended.
- Please call and talk with your transplant coordinator, primary care doctor, kidney doctor, or transplant doctor.

4. Can I get the shingles vaccine?

- No, the shingles vaccine is a live vaccine and should not be taken.

FINANCE

1. I have insurance problems. Who can help me? What should I do?

- Please talk to your transplant coordinator, who will connect you with the transplant social worker.
- It is very important that you do not stop your transplant medicines because that will lead to kidney failure.

2. I don't have money for medicines, lab work, or clinic visits. What should I do?

- Please talk to your transplant coordinator, who will connect you with the transplant social worker.

AT HOME

1. When can I start driving after my transplant?

- Most patients can start driving approximately 4 to 8 weeks after transplant.
- You should NOT drive if:
 - > You are still taking pain medicines.
 - > Your blood sugars are not controlled.
 - > Your surgical incision/wound is not yet completely healed.
 - > You are feeling weak.

2. Should I wear a seat belt? Will that hurt my transplant kidney?

- Please wear a seat belt at all times.

3. Can I do gardening?

- You should avoid gardening for a few months after your transplant or immediately after a treatment for acute rejection.
- When you are gardening you should use gloves and wash your hands well when you are done.

4. Can I paint?

- Yes, but use gloves and make sure to wash your hands well when you are done.

5. Can I travel outside of the United States?

- Yes, but follow Center for Disease Control (CDC) guidelines for travel outside of the United States.
- Your medicines should be packed in your carry-on luggage.
- Please make sure you eat well-cooked, healthy, and clean food, and drink bottled water when outside of the United States.

6. Can I travel to Mexico?

- Yes, but follow CDC guidelines for travel outside of the United States.
- Your medicines should be packed in your carry-on luggage.
- Please make sure you eat well-cooked, healthy, and clean food, and drink bottled water when outside of the United States.

PREGNANCY AND NURSING

- 1. What precautions should I take to make sure I don't become pregnant?**
- You need to use two different types of birth control.
 - Condoms, low-dose oral birth control, and intrauterine (inside your uterus) devices (IUD) are acceptable forms of birth control.
 - Please talk with your transplant coordinator, primary care doctor, kidney doctor, transplant doctor, or gynecologist.

- 2. Is pregnancy safe if I have had a transplant?**
- Pregnancy is possible after a transplant. Pregnancy should be planned and discussed with your doctors in advance and is NOT recommended until after the first year after your transplant.
 - It is important to know that certain transplant immunosuppressive medicines are not safe during pregnancy. Certain drugs may result in serious birth defects. They need to be stopped several months BEFORE you attempt to conceive to allow the drug to “wash out” of your body.
 - Please talk with your transplant coordinator, primary care doctor, kidney doctor, transplant doctor, or gynecologist about pregnancy.

- 3. Can I breast feed my child?**
- The major transplant medical societies recommend AGAINST breast feeding while on transplant immunosuppressive medicines. Many of the drugs can be transferred to the baby through breast milk.

- 4. What else should I know about pregnancy and transplant?**
- It is possible to have a normal vaginal delivery with a working transplant kidney.
 - There is a higher chance of delivering early or prematurely.
 - After pregnancy, there is a higher chance of developing acute rejection of the transplant kidney. This means you will need to be monitored closely after delivery.

- 5. Are there any restrictions for sexual activity?**
- There are no restrictions for sexual activity.

OTHER QUESTIONS

Please use this space to write down any other questions you may have for your transplant care team.



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