

PRE-OP KIDNEY TRANSPLANT PATIENT GUIDE





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INTRODUCTION

Welcome to the UK Transplant Center. We understand the challenges of undergoing a kidney transplant and will do our best to help you return to good health.

This booklet explains the kidney transplant process and what you can expect leading up to your surgery. We hope it makes your time with us more comfortable.

If you still have questions, please ask. Our doctors, nurses and other staff members are happy to help.



TREATMENT OPTIONS FOR KIDNEY DISEASE

Kidney transplant

Kidney transplant is a surgical procedure where you receive a healthy kidney from a living or deceased donor. This new kidney takes over the work of your failing kidneys. A living donor who is a blood relative is the best option because patients often have better long-term success and a lower risk of rejection.

Living donors choose to have one of their two kidneys removed for transplant. A living donor is often a loved one of a patient who needs a kidney. A person interested in being a donor should call our living donor coordinator at 859-323-2467.

Eligible donors must:

- Be a match for the patient or be interested in paired donation (ask your nurse coordinator for more information about this).
- Be healthy enough to live with one kidney.

Deceased donors are donors who have been declared brain-dead. This is an irreversible condition. People can become a deceased donor in two ways:

- They sign up on the organ donor registry while they are alive.
- Families can decide their loved ones would want to be donors.

While on the transplant waiting list, you will be matched with a deceased donor. This is based on blood and tissue type match and the length of time you've been on the waiting list.

Dialysis

Dialysis is a mechanical intervention that cleans your blood when your kidneys are unable to function. It may be the best and safest treatment for some patients. When considering dialysis treatment or transplantation, we will assess your health history, risk factors and ability to care for a transplant. The transplant team will work with you and your nephrologist (kidney specialist) to find the best option.

How kidneys work

A healthy kidney is shaped like a bean and is about the size of your fist. The kidneys are near the middle of your back, just below the rib cage. Most people have two kidneys, but you can live a normal life with one healthy kidney. Your kidneys do several jobs to keep you healthy.

- They make urine. This removes waste and extra fluid from your body.
- They balance certain chemicals in your blood. These include sodium, calcium, phosphorus and potassium. If these chemicals are out of balance, other organs can be damaged.
- They make hormones. These help control your blood pressure and tell your bone marrow to make red blood cells. When kidneys do not make enough hormones, it can cause high blood pressure and anemia.



ROLES OF THE TRANSPLANT TEAM

Surgeons

The surgeons will perform your transplant. They work with the rest of the team to decide if transplant is the best option for you. A surgeon will meet with you before transplant and will update your family after surgery. Surgeons will manage your care as you heal in the hospital.

Transplant nephrologists

The nephrologists also will help decide if transplant is your best option. They will help care for you in the hospital. After transplant, they will manage your care. A transplant nephrologist will see you at your clinic visits.

Advanced practice providers

These include nurse practitioners and physician assistants. One of them may assess you at your first clinic visit. Before transplant, an advanced practice provider may also see you at your yearly clinic visit. They play an active role in deciding if you are a transplant candidate. During your hospital stay, they will be part of your care team.

Transplant coordinator

The coordinator is a registered nurse who works with the transplant team and is your main contact. Before transplant, your coordinator will teach you and your family about the process. The coordinator will schedule your evaluation. If you are a transplant candidate, the coordinator will:

- Place you on the United Network for Organ Sharing (UNOS) waiting list.
- Work with the living donor coordinator if people are interested in donating a kidney to you.

After transplant, you will receive a new coordinator. This person will be your new main contact. The coordinator will continue to teach you about transplant care.

Social worker

A social worker will help you throughout the transplant process. You will meet the social worker during your evaluation. The social worker will see what social, mental and financial needs you may have.



Your mental health plays a big role in the transplant process. If you feel stressed or afraid, the social worker may be able to help. Transplant patients may need psychiatric counseling. After transplant, the social worker will help you find resources and support.

Financial coordinator

After referral, the financial coordinator will check your insurance benefits and will let you know if there are steps you need to take before your procedure. The coordinator will tell you what you should expect to pay in out-of-pocket medical expenses.

If you have problems with your insurance or with hospital billing, the coordinator will help. If you have a change in your insurance during the process, you must let the coordinator know.

Pharmacist

The transplant pharmacist will make sure you are on the correct medicines and that they work well together. Your pharmacist will teach you about your medicines and will meet with you before and after transplant.

Dietitian

Eating right will help you have a successful transplant. Your dietitian will make sure the foods you eat have the vitamins and minerals you will need during the transplant process.

During your evaluation, the dietitian will check your weight, lab results and eating habits. The dietitian can create an eating plan just for you. This will help you get the most out of your transplant.

In the hospital after transplant, the dietitian will check your lab results and make sure you get the nutrition you need. Your dietitian will also teach you how to eat healthy before you go home. After you go home, you can still meet with the dietitian in the clinic.

THE TRANSPLANT PROCESS

Kidney transplant is more than surgery. It is a process that includes these phases:

- Referral.
- Evaluation.
- Waiting phase (either on the deceased donor waiting list or for a living donor evaluation).
- Hospital stay for transplant.
- Care after transplant.

We want you and your family to be as informed as possible. Here is information you need to know about each phase of the process.

Referral

The process starts with a referral. Before transplant is needed, a doctor can manage your kidney failure with medicine. When that no longer works, the doctor will refer you for a kidney transplant.

Evaluation

After referral, we will schedule a visit to the transplant clinic. There you will meet members of the team, such as a surgeon, an advanced practice provider and your transplant coordinator. After this visit, the team will decide if you should continue with the transplant process.

Sometimes, dialysis is a better, safer treatment than transplant. This is often the case when patients have other health problems or if they cannot care for themselves at home. If the team thinks transplant may be an option, you will have a thorough evaluation.

This evaluation will tell us if you are a transplant candidate. You will have many tests that may require several visits to the clinic. We will check the health of all your vital organs. We have to be sure that:

- Kidney transplant is the best treatment for you.
- Your other health problems will not keep you from having a successful transplant.

You will meet with many members of our team. The transplant team includes doctors, nurses, dietitians, social workers, a pharmacist, psychologists (if needed) and a financial coordinator. They will ask you for information and tell you about kidney transplants.

Here are some of the tests you will likely have during the evaluation. Depending on your health problems, you may need other tests. Your coordinator will also give you a list of tests you will need from your other doctors.

Lung tests

- Chest X-ray.
- Breathing tests (lung function studies).

Heart tests

- Cardiology consult.
- Echocardiogram.
- Stress test.

Blood flow tests

- Ultrasound of legs.
- Ultrasound of neck arteries.
- Pelvic CT scan.

Kidney and liver tests

- Complete blood count.
- Metabolic panel.
- Liver function panel.
- Lipid profile.
- Blood coagulation profile.
- Abdominal CT scan.
- Bladder test.



Immune system tests

- Blood type.
- Antigen/antibody reactions.
- Tissue typing.
- HIV test.
- Virus tests (hepatitis, cytomegalovirus, varicella, Epstein Barr).

Consults

- Dietitian.
- Pharmacist.
- Social worker.
- Psychiatrist (as needed).
- Financial coordinator (as needed).

Tests to have done by your other doctors

- Mammogram (women age 40 and older).
- Pap smear (women age 18 and older).
- Colonoscopy (age 45 and older).
- Dental clearance.
- Pneumonia vaccine (Pneumovax 13 and Pneumovax).

Transplant candidacy

Our team meets each week to discuss our patients. During this meeting, we will discuss your need for a kidney transplant. We will go over your evaluation and talk about whether there are any reasons why transplant would be too risky.

Sometimes, patients need more tests to help us decide on the best option. If more tests are needed, we will call you to schedule them.

After we decide on a plan of care, the transplant coordinator will discuss the plan with you. Here are the possible results:

- You are a candidate. The transplant coordinator will then explain the listing process.
- You are not a candidate at this time. The coordinator will then explain why and tell you your options.
- You need more tests. The coordinator will order those tests. Based on the results, the team will make a decision.

THE LISTING PROCESS

We place transplant candidates on a national waiting list. The United Network for Organ Sharing, or UNOS, keeps this list. It is a fair and organized process for transplant patients. Each organ has its own listing process. For more information, visit www.unos.org.

Once you are on the list, the coordinator will send a letter to your home within 10 days of your listing date. It may be a good idea to be on the list at more than one transplant center. Each center makes its own decisions about who is a candidate.

When a donor kidney or kidney becomes available, local transplant centers are usually the first option. Kentucky Organ Donor Affiliates, or KODA, is a local group that assigns organs. KODA makes a list of local patients who need the organ. This list is automated. All transplant centers follow the same rules for listing patients in order. Here are some factors used to decide the order:

- How long you have been on the waiting list.
- How well you and the potential donor match.
- It can be harder to find a match if the recipient has significant transplant-specific antibodies. If you have this condition, that will be considered.

WAITING LIST STATUS

Active waiting list. If you are on this list, your transplant team can receive a call with a new organ for you at any time. Your coordinator will tell you what the average wait time is. However, since we cannot say when an organ will be offered, you could get a call at any time.

Inactive waiting list

This means you are still listed and your waiting time is getting longer. However, the transplant team will not receive organ offers for you. The most common reasons for this are when the patient:

- Is traveling and is too far from the transplant center.
 - Is too sick for a transplant. This includes having infections, hospital stays and surgeries. It also applies if more tests are needed.
 - Uses nicotine (cigarettes, e-cigarettes, chewing tobacco) or non-prescribed drugs.
 - Is working to reach a safer weight for surgery.
- If your status changes, your coordinator will call you and send you a letter.

WAITING FOR YOUR NEW KIDNEY

Being on the waiting list may be the toughest part of the process. The wait may seem to go on forever. We are here to help. Here are some tips to help you deal with your stress:

Stay healthy and educate others

- Talk about your feelings with family and friends.
- Eat healthy meals.
- Exercise as much as you can.
- Take all medicines as directed.
- Encourage others to be organ donors.
- Have a living donor champion (your coordinator will explain this).
- Start or take part in activities that encourage organ donation.

Keep in touch with the transplant team

- Talk with the transplant team about your health. Tell the team about new medicines, hospital stays, infections or planned surgeries. Contact your coordinator with these updates as soon as possible.
- Always be near a phone.



- Tell your coordinator if you will be traveling more than five hours from the transplant clinic. You may need to go on the inactive waiting list until you return.
- Go to all transplant clinic appointments.
- Remind your dialysis center or doctor to send blood samples to UK HealthCare every month. When you are listed, we will send instructions to your dialysis center or doctor.
- The transplant coordinator, social worker and other team members are here to help. Call us at any time during the waiting period.
- Meet with the transplant psychiatrist or another psychiatrist. Discuss ways to manage anxiety or depression as you wait for a transplant.

Prepare financially

- Create fundraisers to help pay for the transplant.
- If you can, save money for expenses after transplant.

Plan for the day we call you to come to the hospital for the transplant. Keep a packed suitcase ready for the day of your surgery. Think about what clothes and items you would like to have in the hospital. You may want to pack books, magazines or a music player. Plan the route you will use when you come to the hospital. Know where your family plans to stay when they visit the hospital. The more prepared you are, the less stress you will have.

THE DAY OF THE TRANSPLANT

As soon as there is a kidney for you, the transplant coordinator will call you. After you get this call, come to the hospital as soon as you can. We plan for your travel time, so do not drive over the speed limit. After we call you, do not eat or drink anything. When you get to the hospital, go straight to the registration desk. A person at the desk will tell us you are here.

If you get a kidney from a living donor, you will know the transplant date in advance. You and the living donor will both have a clinic visit about a week before surgery. At this time, you will meet with the surgeon, coordinator and anesthesia team. You also will have labs, a chest X-ray and an EKG.

Getting ready for surgery

Before surgery, the anesthesiologist will discuss the procedure with you and ask questions. For your safety, we will do many tests and procedures before surgery, including:

- Doing a chest X-ray, EKG (electrocardiogram) and urinalysis.
- Taking blood samples from a vein and artery in your arm.
- Placing an IV in your arm or hand.
- Recording your vital signs: blood pressure, heart rate, respiration rate, temperature and oxygenation saturation.

We will ask you to sign a consent form. It explains the possible risks involved. When you sign it, you give the medical team permission to do the kidney or kidney/pancreas transplant. Your family can stay with you for most of the time before surgery. After you go to the operating room, or OR, we will take your family to a waiting room and give them a pager. During surgery, the OR nurse will provide updates to your family in the waiting room.

In the OR

In the OR, doctors and nurses will prepare you for surgery. The anesthesiologist will give you medicines to help you relax and sleep. After you are asleep, we will place a breathing tube in your mouth and airway. The breathing tube is hooked up to a ventilator. The ventilator breathes for you while you are in surgery.

The start time of your transplant will depend on the donor's surgery. This is done by the donor team. The donor team keeps your team at UK informed about the progress. Once the donor team decides that the new kidney or kidney/pancreas is right for you, they will tell us. If the organ(s) will not work for you, the donor team will tell us. In that case, we will have to cancel your transplant, and you will remain on the waiting list.

Right after surgery

You will recover in the post-anesthesia care unit, or PACU. If you received a kidney and pancreas or if you have heart problems, we may take you to the surgical intensive care unit, or SICU. After that, we will move you to the transplant unit. The nurses in these units are trained to care for transplant patients.



WHAT TO EXPECT DURING THE HOSPITAL STAY

As you heal, you will be in a private room. Most patients stay in the hospital for three to five days after a kidney transplant or about a week after a kidney/pancreas transplant. The length of stay will depend on your needs. It may take up to two hours to get you settled in your room. After that, your family can visit.

We may need to limit the number of visitors you have. Please try to limit visitors to close family and friends. This will help protect you from infection. More visitors mean more risk of infection. If your loved ones are sick, they should not visit you. Instead, they may talk with you by phone. Children age 10 or under are not allowed to visit you in the hospital unless the transplant team says it's OK.

After surgery, you'll notice many bandages, lines and tubes. These help you heal and keep you safe. Here is what you can expect.

- An IV line may be placed in the side of your neck. It will have a bandage over it. It will let us give you fluids and medicines. You also will have at least one IV in your arm or hand.
- You will have a wound across one half of your lower belly. It will be closed with staples. It is normal to have drainage for a few days after surgery. If so, we will cover the wound with a bandage and change it often. We will remove the staples in the clinic about three weeks after surgery.
- You will have a small rubber tube in your bladder. This will empty your bladder during surgery. It

also will help us see how well your new kidney works. It usually comes out the day you go home. In some cases, patients need it for up to a week.

- The surgeon will place a stent between your bladder and new kidney. The stent is a small hollow, flexible tube. Although you won't feel that it is there, it will let urine flow while you heal. About one month after surgery, we will use a narrow catheter to remove it. This will take about five minutes in the urology clinic.

You will do deep breathing exercises. These expand your lungs to their fullest. This will help prevent pneumonia. Deep breathing strengthens your breathing muscles. You will use an incentive spirometer to help exercise your lungs.

We will keep a close watch on your health. You will notice a lot of equipment in your room. These machines help us keep an eye on important vital signs, such as blood pressure, heart rate, breathing and oxygen levels. As you heal, you will not need all of this equipment.

You will be able to get out of bed, sit in a chair and walk the hallways. The day after transplant, the goal for most patients is to walk the hall with help. We will still check your vital signs each hour. When we do, we will do our best not to disturb you, especially when you are resting. Each day, the transplant team will check your progress and update you on the plan of care. This is the best time to ask the team questions.

LEARNING TO CARE FOR YOURSELF AT HOME

As soon as you are ready, we will start to teach you how to care for yourself at home. Tell your nurse when your main support person is at the hospital. The nurse and your nurse coordinator will teach both of you at the same time.

The coordinator will bring you your Post-op Kidney Transplant guide. You will go over important information, such as:

- Things you can and cannot do.
- Diet instructions.
- Symptoms to be aware of.
- Follow-up visits with the doctor.

The pharmacist will give you a binder with a diary. In it, you will record the medicines you take and your vital signs each day. It is your job to use the diary to learn how to take your medicines. If needed, your nurse will teach you about diabetes.

The things you learn will help extend the life of your new kidney. You will need to make some big changes and our team will help you prepare. We are also here as you need help along the way.



POTENTIAL COMPLICATIONS AFTER TRANSPLANT

Rejection

This means your immune system is attacking your new kidney or pancreas. Most transplant patients have at least one episode of rejection. This often happens during the first six months after transplant. Rejection is less likely as your body gets used to the new kidney or kidney/pancreas as long as you continue to take your medications as prescribed.

Preventing rejection. We will do a blood test with the potential donor. To do this, we take samples of your blood and the donor’s blood. If your blood cells destroy the donor’s blood cells, the result is “positive.” This means it is more likely you will reject the new kidney. In that case, we would probably cancel the transplant.

You will also take medicines that keep your body from rejecting your new organ. We call these immunosuppressants. Without these medicines, most transplanted organs would be rejected.

Symptoms of rejection. In most cases, rejection does not cause any symptoms. However, potential symptoms can include:

- New pain over the transplant site.
- Less urine output.
- Swelling of the arms or legs.
- New or unusual tiredness.
- Low-grade fever.

If you have any of these symptoms, call your transplant coordinator or transplant doctor right away. Because most patients with rejection do not have symptoms, it is extremely important to keep all your scheduled clinic visits.

Diagnosing rejection. Your lab results or symptoms can cause us to suspect rejection. To make sure, we may take a biopsy of your new organ. First, the

doctor gives you a shot to numb the site. Then, a large needle goes into the kidney. This lets us take a small sample to test. If you are not admitted to the hospital, you will still need to stay for six to eight hours after the biopsy so we can make sure the biopsy did not cause bleeding. Bring a driver with you, as you may need medicine that will make you sleepy.

Treating rejection. Immunosuppressant medicines both prevent and treat rejection. To prevent rejection, you will take a combination of drugs. If we detect rejection, we may need to add other treatments. We will run tests to help us decide the right treatment for you. We will try to avoid having you stay in the hospital. If possible, it is better for you to have treatments at home.

Infection

You will take many immunosuppressants after surgery. Because these medicines weaken your immune system, it’s easy to get an infection, especially during the first six months after your transplant. You should be able to return to most regular work and activities, but you should use common sense every day.

Preventing infection

- Wash your hands and use good hygiene.
- If people with signs of a cold or infection want to visit you, ask them to wait. They can visit once they are healthy.
- Stay away from crowded places. It’s easy to pick up germs in crowds.
- Six months after transplant, you may get shots for flu, pneumonia and hepatitis.
- Do not get a “live virus” shot. Avoid people who have had these shots in the past one to two weeks. Examples are shots for chickenpox, measles,

mumps, or rubella (MMR), and the flu mist (the flu shot is OK). These may give you an infection after transplant.

- Wash fresh fruits and vegetables well before eating.
- Do not eat raw seafood. Eggs, chicken and pork should be cooked well done.

Symptoms of infection

- Fever, usually higher than 100.5 degrees Fahrenheit.
- Chills.
- Excessive sweating or night sweats.
- Cough.
- Nausea, vomiting or diarrhea that lasts more than three days.
- Unexplained pain in chest, throat, belly or back.
- Redness, swelling or drainage at a wound site.

Tumors and cancers

When you take immunosuppressants, you have a greater risk of developing tumors and cancer. Your body’s immune system naturally fights tumor and cancer cells, but the medicines you take after transplant may keep your body from doing so.

Skin cancer. This is the biggest risk for transplant patients. To prevent skin cancer, you should:

- Stay inside or in the shade from 10 a.m. to 4 p.m. This is when the sun is most harmful to your skin.
- Use a sunblock of SPF 30 or higher on all skin exposed to the sun.
- Use sunblock even on cloudy days.
- Put more sunblock on every two hours.
- Don’t forget to put sunblock on your feet, ears and the back of your neck.

- Wear clothes that cover most of your skin. This includes pants, long-sleeve shirts, wide-brimmed hats and sunglasses.
- Don’t let your skin burn. This means no sunbathing and no tanning beds.

After transplant, you should check your skin at least monthly and see a dermatologist at least once a year. You will need to check your moles often to look for signs of cancer. If you notice any of these signs, tell your doctor right away.

- Shape – If you imagine dividing your mole in half, do the halves look different?
- Borders – Are the edges of the mole blurred or jagged?
- Color – Does the mole look like it has more than one color? Has the color of the mole changed over time? Is it getting lighter or darker?
- Size – Is the mole wider than a pencil eraser?
- Changes – Is the mole’s color, size or shape changing over time?

Lymphomas. This type of cancer is also more common in transplant patients. Symptoms include fever, feeling tired, weight loss, poor appetite and sweating. It may be treated by cutting back on immunosuppression medications and sometimes chemotherapy or radiation therapy. You should continue to have regular screenings such as a mammogram, Pap smear, prostate exam and colonoscopy as directed. You should see your primary care provider annually to assure these tests are scheduled when due.

TRANSPLANT MEDICINES

You will need to take medicines every day for the rest of your life. Here are some common types of medicine patients need after transplant.

Immunosuppressants: These medicines help prevent your body from rejecting the kidney or kidney/pancreas. You will need to take them for the rest of your life, as long as your organ is still working. Prograf (tacrolimus) and Cellcept (mycophenolate mofetil) are the immunosuppressants used most often.

Steroids: You will take a steroid called prednisone. If there is no rejection, you will be weaned to a low dose soon after transplant.

Anti-infection: Because you will be taking immunosuppressants, you will be at a higher risk of infection. You will need to take medicines that fight infections.

Anti-ulcer: These will help protect your stomach and bowels. Some of the other medicines you take can cause ulcers and upset stomach.

Blood pressure medicines: Many kidney transplant patients need to take these. After transplant, the team will decide if you need them. You may require more or less medication to control your blood pressure than before your transplant depending on your body's reaction to your transplant and your new medications.

Potassium supplements: Your new kidney may clear too much potassium from your body. If so, you may need a supplement. Potassium is essential for the proper functioning of the heart, kidneys, muscles, nerves and digestive system.

Magnesium supplements: Taking immunosuppressants may cause a loss of magnesium in your body. Low magnesium may lead to irritability, muscle weakness, cramps, tingling and irregular heartbeat. You should take magnesium supplements only under the supervision of your doctor.

Calcium and vitamin D supplements: These help prevent osteoporosis and bone fractures. Prednisone, cyclosporine and diuretics may all lead to calcium loss.

DIET CHANGES

Before transplant

It is important that you start eating healthy right away. It will help you heal better after transplant. Successful healing means you'll spend less time in the hospital and have a better quality of life. A registered dietitian will meet with you before transplant and will work closely with you to help you eat healthy before transplant.

After transplant

Eating healthy will be one of your biggest goals after transplant. You should do all you can to have a healthy body weight. Weighing too much is bad for your new kidney. Too much salt, cholesterol and triglycerides can also cause problems. The dietitian will work with you to design an eating plan you can follow.

Gaining too much weight after transplant is bad for your health. It can cause your cholesterol, triglycerides, blood sugar and blood pressure to be too high. To avoid weight gain, you should cut back on simple sugars and concentrated sweets. This means you should limit table sugar, brown sugar, corn syrup, honey, sodas, rich desserts and candy. You should use fresh fruit as dessert most of the time. Save heavy desserts for special occasions. The dietitian can help you learn to eat balanced meals.

Some of the medicines you will take may cause higher cholesterol, meaning you will have a greater risk of artery disease after transplant. The best way to prevent it is to eat less fat and follow a heart-healthy diet.

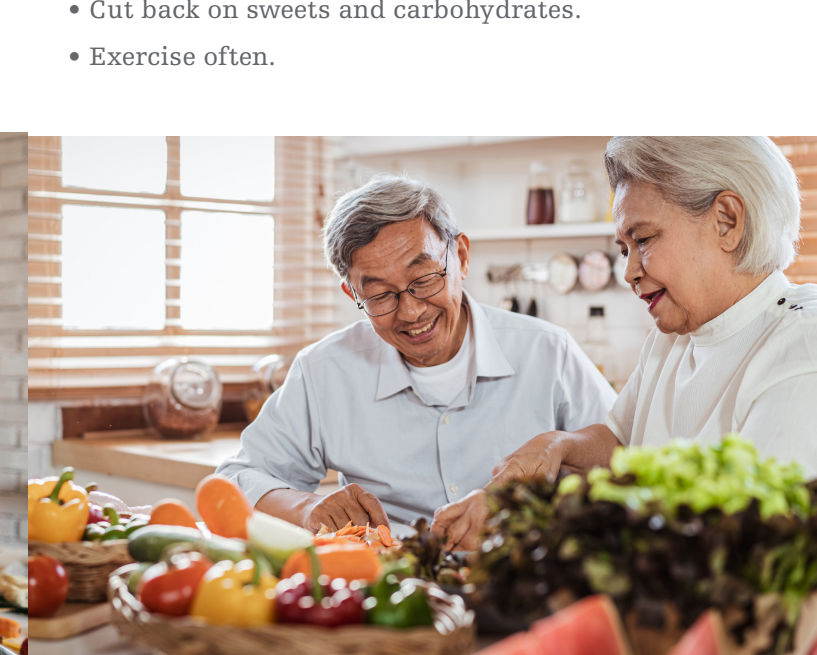
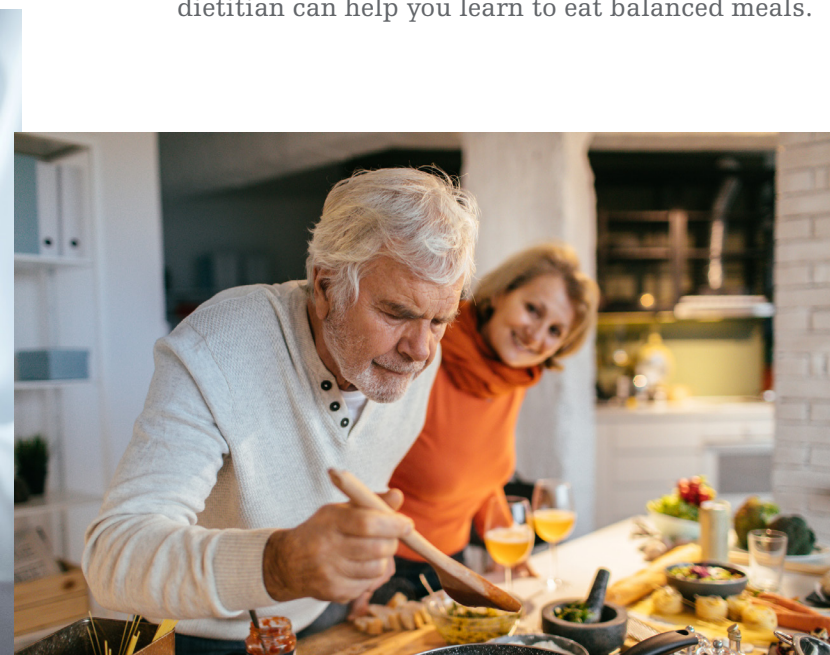
Blood sugar

Some of the medicines you will take may cause high blood sugar. If your blood sugar is not under control, it can damage your new kidney. Right after transplant, you may need insulin through an IV. After a few days, you will get insulin shots as needed. If you need insulin shots at home, a nurse will teach you how to:

- Use a glucometer.
- Draw up insulin in a syringe and give yourself a shot.
- Decide how much insulin you need.
- Care for yourself if your blood sugar is too low.

The nurse will watch you do these things before you go home to ensure that you can keep your blood sugar under control. You should also:

- Eat a heart-healthy diet.
- Cut back on sweets and carbohydrates.
- Exercise often.



NOTES

FOLLOW-UP CARE

You will visit the transplant clinic often after surgery. The kidney and pancreas transplant clinic is open Monday through Friday. You will have visits twice a week after you go home. As you heal, you will visit less often. If you have problems with your transplant, we will see you more frequently.

Expect clinic visits to last at least three hours. This will allow time for labs and a visit with the transplant nephrologist. You may want to read or take a walk while you wait for your lab results. Once we have your lab results, you will meet with your nephrologist.

Transplant requires many lifestyle changes, medicines and visits with your doctors and other members of the transplant team. Remember, our entire transplant team is here to help you with this process. We look forward to embarking on this journey with you to improve your overall quality of life.





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