

# Being Evaluated for Kidney or Kidney/Pancreas Transplant

A Guide for Patients and Their Families



# Vanderbilt Transplant Center

Vanderbilt Transplant Center in Nashville, Tennessee, is one of the South's main providers of solid organ and stem cell transplantation. We offer programs in heart, kidney, liver, lung, pancreas, and bone marrow transplantation, and our outcomes are among the best in the country. Our specialists strive to return every patient to a full and active life. Our mission is to provide end-stage organ failure patients an opportunity to lead an extraordinary life. We thank you for trusting us with your care.

## *As we treat you, we promise to:*

- include you as the most important member of your health care team
- personalize your care with a focus on your values and needs
- work with you to coordinate your care
- respect your right to privacy
- communicate clearly and regularly
- serve you and your family with kindness and respect.

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# Overview of the Transplant Process

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Your doctor has recommended that you be evaluated for a kidney transplant, a simultaneous (combined) kidney and pancreas transplant, or a pancreas-after-kidney transplant.

- A kidney transplant is when a person receives a kidney from an organ donor.
- A combined kidney and pancreas transplant is when a person receives a kidney and pancreas from an organ donor.
- A pancreas-after-kidney transplant is when someone has a kidney transplant first, then has a pancreas transplant later on.

For you to decide if you want to consent to this evaluation, you need to know and understand the risks and benefits of both transplant evaluation and transplant surgery. Learning about what you are agreeing to is a process called “**informed consent.**”

This booklet will help you learn what happens when a person gets a kidney or pancreas transplant. This process includes:

- the evaluation to see if you are a suitable transplant candidate
- learning about your transplant options
- what you can expect before and after surgery.

## Kidney transplants

A kidney transplant is a type of treatment for kidney failure. A successful transplant means a person will no longer need dialysis. Most patients live longer with a transplant than with dialysis; they also have more normal lifestyles. Your diet will be less restricted and you may have more energy. However, transplant is best thought of as a treatment and not a cure for kidney failure.

Donor kidneys come from 2 sources:

- a person who is alive
- a person who has recently died.

## Am I eligible for a kidney transplant?

You are eligible for a transplant if you have kidney failure and you:

- are on dialysis
- have a creatinine clearance of 20 or less.

## ***What causes kidney failure?***

The most common reasons for kidney failure include:

- diabetes
- high blood pressure (hypertension)
- immune-mediated kidney disease (glomerulonephritis)
- kidney disease or urinary tract defects that a person was born with.

## **Pancreas transplants**

### ***Will everyone who needs a new kidney also need a new pancreas?***

No. Not everyone who needs a new kidney will need a new pancreas. The pancreas transplant is an option for some diabetics with kidney disease who have to take insulin.

### ***Why would a person need a new pancreas?***

The most common reason a person needs a new pancreas is insulin-dependent diabetes, or type 1 diabetes.

### ***Three options for a pancreas transplant***

- You can be listed on the deceased donor waiting list for both a kidney and pancreas transplant. This means your kidney and pancreas transplants would happen at the same time.
- You can get a living donor kidney transplant first, and then be listed on the deceased donor list for a pancreas transplant.
- If you have had a kidney transplant in the past, you are a potential candidate for a pancreas-only transplant.

## What are the steps of a transplant?

A transplant has 4 major steps:

1. Evaluation and education
2. Waiting for an organ
3. Surgery
4. Lifelong, post-transplant care

### **Step 1: Evaluation and education**

This first step includes the many tests that will be done to see if you meet the requirements and are healthy enough to have a transplant. Having all these tests does not guarantee that you will get a new kidney or pancreas.

During the evaluation and education stage, you will also have the opportunity to learn a lot about the transplant process to help you decide whether transplant is the right thing for you. Topics you will learn about include:

- national and current Vanderbilt-specific outcomes for transplant
- risks and benefits of transplant, and alternative treatments
- evaluation and required testing
- how the transplant waitlist works
- living kidney donation
- results of tests done
- patient selection criteria
- any psychosocial or financial issues that may affect your ability to have a transplant

- the importance of following a strict medical plan after transplant
- organ donor risk factors
- your right to refuse transplant at any time.

### **Step 2: Waiting for an organ**

If all your tests show that you are healthy enough to get a new kidney or pancreas, you will be put on the donor waitlist. Your transplant coordinator will explain to you in detail how this waitlist works and how it is decided who gets a new kidney or pancreas. If you have a living donor as an option, you may not have to wait long for a transplant.

### **Step 3: Surgery**

When an organ from a living or deceased donor becomes available, you will have surgery. Before surgery:

- your surgeon will talk to you about your surgery and its risks
- you will be asked to sign a consent form for the surgery.

### **Step 4: Lifelong care and follow-up**

Having a transplant is just the first step in a lifelong process. For the rest of your life after transplant, you will be required to follow a strict medical plan, which includes follow-up appointments and medicines you will have to take every day.

## **Do I have any treatment options besides a transplant?**

Alternative treatments to kidney transplant included dialysis, ongoing medical management, and palliative care.

Alternative treatments to pancreas transplant include ongoing medical management and palliative care.

## **Do I need support during the transplant process?**

Yes. A successful transplant requires that you have someone in your life who is able to give you the support and help you will need. You need a caregiver. You cannot go through this process alone.

### ***Before transplant, your support person will:***

- go to the psychosocial evaluation with you
- learn everything they'll need to do for you after surgery, including at the hospital and long-term.

### ***After transplant at the hospital, your support person will:***

- be with you when we give you your medicines and learn about their uses and side effects.
- learn to check your blood sugars and give you insulin injections if you need them
- learn how to care for your transplant incision as you heal.

### ***By the time you leave the hospital, your support person will:***

- know all about the medicines you will take and the side effects associated with them
- be able to help you take your medicines exactly how you are supposed to
- be able to help you keep track of the medicines you take by writing down in a daily medicine log the times you take your medicines and the doses you take
- be ready to go with you to your lab and clinic appointments and your other medical visits to discuss your condition with the doctor and report any issues you are having
- have learned about (and be able to help you watch for) signs and symptoms of organ rejection, medicine side effects, or any other medical issues after you have left the hospital
- be ready to help you with your personal care activities, such as bathing or shaving
- continue helping you with your insulin injections and checking your blood sugar.

A reliable, committed support person is necessary for you to successfully go through the transplant process.

## Can I change my mind about having a transplant?

Yes. At any time during the evaluation process, while you are on the waitlist, or even just before surgery, you can change your mind about having a transplant.



## What happens if I change my mind about my transplant?

Treatment for your kidney or pancreatic disease will continue. Understand that your health is likely to get worse. Dialysis for kidney disease will continue or may need to be started. How long you live will likely be shorter than it would be if you had a transplant.

## Where do Kidney transplants come from?

There are 2 types of kidney transplant procedures that the transplant team will review with you:

- Live donor kidney transplant: This is when a patient gets a kidney from another living person. Live donation has the best results, but it is not always an option.
- Deceased donor kidney transplants: This is when a patient gets a kidney from a person who has already died.

## Where do Pancreas transplants come from?

Pancreas transplants always come from a donor who has died. A patient who has a living kidney donor will often get a kidney transplant first and then be put on the waitlist for a pancreas after.

## What happens if a transplant fails?

If a transplant fails for any reason, a patient may be eligible to have another transplant in the future. This eligibility will depend on:

- the reason the organ failure happened
- the patient's state of health.

# Financial Considerations and Medicare

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## If I have Medicare, can I have my transplant at Vanderbilt?

Vanderbilt Transplant Center is currently Medicare-approved. However, the center is audited every 3 to 5 years for continued approval. If Vanderbilt loses Medicare approval, Medicare will no longer pay for transplants at this center. We will keep you informed about our status, and let you know if we become deficient in any Medicare requirements at any time.

## Am I eligible for medicare?

In addition to having end-stage kidney disease, **one** of the following things must also be true about you for you to get Medicare support:

- You meet the required work credits under Social Security, Railroad Retirement, or as a government employee.
- You currently get Social Security or Railroad Retirement benefits.
- You are married to someone who has met the required work credits or gets Social Security or Railroad Retirement benefits.
- You are the dependent child of someone who has met the required work credits or gets Social Security or Railroad Retirement benefits.

## When does Medicare go into effect?

When your Medicare coverage for end-stage kidney disease treatment goes into effect will depend on the type of treatment you receive.

### *If you have hemodialysis*

Medicare is effective the fourth month of your treatment. For example, if your hemodialysis begins in May, your Medicare coverage would become effective in August.

### *If you have home- or self-dialysis*

Medicare is effective the first month of treatment if:

- you take part in a training program through a Medicare certified training facility; and
- your home- and self-training starts within the first 3 months of your treatment; and
- it is expected that you will finish your home training and your self-dialysis at home.

## ***If you're having a transplant***

Your Medicare coverage will go into effect:

- the month you are admitted to a Medicare-certified hospital for a kidney transplant or for health care you need before your transplant, if the transplant takes place that same month or within the following 2 months
- 2 months before your transplant, if your transplant is delayed more than 2 months after you are admitted to the hospital in anticipation of transplant or transplanted-related health services.

## ***If your end-stage kidney disease treatment is continuing***

Medicare is effective the month your dialysis resumes following a previously terminated period of Medicare coverage for end-stage kidney disease. There is no waiting period.

## ***Will I get Medicare if I have employer-based insurance?***

If you have medical coverage through an employer group health plan, that plan is the primary payer during the 30-month coordination-of-benefits period. Medicare is the secondary payer during this time. At the end of the coordination-of-benefits period this will reverse; Medicare would then become your primary payer, and your employer-based plan would become your secondary payer. The coordination-of-benefits period begins the first month you are eligible for Medicare.

## ***Can I defer Medicare enrollment?***

If you have insurance through your employer, you can defer your enrollment in Medicare A and Medicare B to a later date. However it is important to fully understand the benefits and limitations of your employer-based insurance before you make that decision.

What you need to consider when making your decision:

- Does your employer-based plan have yearly deductible or coinsurance costs?
- Does your employer-based plan have a yearly kidney (renal) services limit? Some policies may have a limit (called a capitation) on the amount they will pay each year for renal services. This is typically \$30,000.
- Does your employer-based plan have a lifetime limit? If so, what is the lifetime limit of your plan, and are you nearing this limit?

If you have limitations in your employer-based plan, it would benefit you to enroll in Medicare. If your employer-based plan does not have any limits and will pay all health costs during the coordination-of-benefits period, than you may want to postpone your Medicare enrollment until the coordination-of-benefits period is over.

## ***Your Medicare Part B options if you defer your Medicare enrollment***

If you defer your Medicare enrollment, these are your options for Part B coverage:

- the earliest possible month of entitlement (no more than 12 months retroactively), if you are willing and able to pay all back premiums; or
- the month in which your application is filed; or
- the month in which your enrollment is processed.

## **What happens if I defer my Medicare enrollment?**

You can enroll in Medicare for end-stage kidney disease treatment at any time from the point treatment begins through the coordination-of-benefits period. There is no penalty for deferring your Medicare enrollment. However, enrollment must be for Medicare Parts A and B. If Part B is not signed up for at the same time, you must wait for the General Enrollment period (January through March) to apply.

Under the General Enrollment period, Part B is not effective until July of the year in which you apply, and the premium rate will be higher. There are no provisions for a special Medicare enrollment period specific to end-stage kidney disease.

If you have Medicare on the basis of your age or a disability and you are paying higher premiums for Part B because you

did not sign up for Part B when you were first eligible, your premiums can be reduced by applying for Medicare Parts A and B for end-stage kidney disease.

## **Medicare coverage for immunosuppressive drugs**

To get Medicare immunosuppressive drug coverage, you must have Medicare coverage that goes into effect the month of your transplant. Medicare will cover 80 percent of your drug costs under this benefit. Your immunosuppressive drug benefit will continue for:

- 36 months, if your Medicare entitlement is based only on end-stage kidney disease
- indefinitely, if:
  - your Medicare entitlement is based on you being 65 or older
  - your Medicare entitlement is based on you getting Social Security Disability benefits for at least 2 years for a non-kidney related condition.

## **How long will my Medicare coverage last?**

Medicare coverage that is based on end-stage kidney disease ends on:

- the last day of the 36th month after the month you receive a kidney transplant; or
- the last day of the 12th month after the month in which you stop dialysis, most generally for return of kidney function.

## Learn more

If you have specific questions about your benefits or eligibility for Medicare, contact the Social Security representative in your area. Many of the offices have identified representatives who have a strong knowledge and understanding of Medicare guidelines for end-stage kidney disease.

### ***Additional resources include:***

- Medicare: [www.medicare.gov](http://www.medicare.gov)
- Centers for Medicare and Medicaid Services (CMS): [www.cms.gov](http://www.cms.gov)
- Social Security Administration: [www.ssa.gov](http://www.ssa.gov)
- Life Options: [www.lifeoptions.org](http://www.lifeoptions.org)
- Your local end-stage renal disease (ESRD) network
- Forum of end-stage renal disease networks: [www.esrdnetworks.org](http://www.esrdnetworks.org)
- Medicare Rights Center: [www.medicarerights.org](http://www.medicarerights.org)
- The CMS publication “Medicare Coverage of Kidney Dialysis and Transplant Services”: [www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf](http://www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf)

## Paying for your medicines

Without the right medicines, your body will reject your new organ. You will need to be able to pay for your medicines or have enough drug coverage at the time of your transplant. Without adequate drug coverage, your estimated costs for your medicines is about \$5,000 a month (\$60,000 a year) for the rest of your life. Because these high costs are so high, it is important that you inform us of any changes in your drug coverage. It is also important that you always have pharmacy coverage.

We also strongly encourage you to call your pharmacy carrier and ask them what your estimated co-pays will be for the following post-transplant medicines:

- Cellcept: 500mg tablets, take 2 tablets twice daily (generic available)
- Prograf: 1mg tablets, take 4mg twice daily (generic available)
- Valcyte: 450mg dose, once daily (generic available).

## Fundraising

If you anticipate that you will have any major costs that may not be covered by your insurance (including prescription co-pays, travel, and lodging), we encourage you to consider doing some fundraising. Call the numbers below and to begin the process of fundraising as soon as possible.

These organizations have been able to make quite a difference in the lives of many of our patients. They are often able to help patients before, during, and even years after their transplants:

### *Fundraising companies*

These are two organizations that help kidney patients raise money:

- NFT (National Foundation for Transplants): (800) 489-3863  
www.transplants.org
- Help Hope Live (Formerly National Transplant Assistance Fund):  
(800) 642-8399  
www.helphopelive.org

### *Getting medicines through Medicare*

If Vanderbilt Transplant Center ever loses Medicare-approved status, your ability to have your immunosuppressive drugs paid for may be affected. Our financial counselor will talk with you about these details so you can make the best decision for you.

## Your financial coordinators

We are here to keep everyone at Vanderbilt informed about your current insurance coverage, to obtain all the necessary authorizations and approvals required from your insurance throughout the process, and to help you in any way possible with your insurance questions and concerns. We know this can be a lot of information to process all at one time. Please don't hesitate to call us.

### *Notify us immediately if:*

- you begin or end the coverage you have through COBRA
- you obtain any new insurance
- any of your current insurance policies change or end
- If there are any changes in your Medicare Part D coverage.

### *Remember:*

- If you ever find yourself with Medicare Part A/B and D only, you must keep your Part D to remain active on the list.
- If your Medicare coverage is based on your end-stage kidney disease, your coverage will end 3 years after your transplant.
- If you are getting assistance through AKF (the American Kidney Foundation) to help with the cost of your dialysis, this assistance will end when you get a transplant.

# About Transplant Evaluation

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A kidney or kidney / pancreas transplant is serious and risky surgery. You will have many tests to find out if you are healthy enough to have a transplant. These tests will find out if you are medically, surgically, emotionally, and mentally able to go through a transplant. How much social support you have and your financial situation will also be considered.

During evaluation, you will meet with members of the transplant team, including your:

- transplant coordinator
- social worker
- transplant doctor
- financial coordinator
- living donor representative.

Other people you may need to meet with at his stage include a transplant surgeon, nurse practitioner, dentist, dietitian, nutritionist, and a pharmacist

## ***Your transplant coordinator***

Your transplant coordinator will be your partner through the entire transplant process. This person will be available starting from the evaluation stage. You may contact your coordinator any time you have questions or concerns. Everything you talk about is confidential. It will only be shared with the other transplant team members as needed.

## ***Routine discussions***

- We will talk with you about the risks and benefits of a transplant.
- We will identify all the tests you'll need to have done to screen you for potential medical problems.
- We will talk with you about the option of a having a live kidney donor transplant versus a deceased kidney donor transplant.

## **What kinds of medical tests will I need?**

Not every person will need all of the tests described in this section, or even the same tests. The tests you have are based on your own situation. After you have completed the tests, we will talk with you about the results.

- Every test will be explained to you in detail in advance.
- If the test has any risks, they will be explained to you in advance. We will ask you to sign a consent form which outlines the risks in detail and shows that we have explained the risks to you.

## ***Medical tests and consultations (round 1)***

Your first tests and office visits will tell us about your overall physical health. These tests and visits include:

- a review of your health history
- a consultation with one of the doctors
- an EKG (electrocardiogram), a test that measures the electrical activity of your heart
- a chest x-ray
- blood tests
  - to identify your blood type so you can be matched with an organ
  - to check your blood to see if you are immune to or have certain viruses, including Hepatitis and HIV (human immunodeficiency virus).
- evaluation by a social worker.



## ***Additional medical tests and consultations (round 2)***

These tests will look at your health in more detail and include kidney, liver, and lung evaluations, and may also include, but are not limited to:

- heart testing (such as echocardiogram, stress test, or cardiac catheterization)
- imaging scans (such as ultrasound or CT scan)
- vascular studies to evaluate circulation
- bladder study
- dental evaluation
- cancer screening.
  - A pap smear is required for all women who have not had a hysterectomy.
  - A mammogram is required for all women older than 40.
  - A colonoscopy is required for everyone older than 50.
  - A PSA (prostate specific antigen) is required for all men older than 55.

## ***Risk evaluation***

There are many risks that come with getting a new kidney or pancreas. We'll talk about this with you. Along with medical risks, getting a new organ has risks that are psychological, emotional, social, and financial.

## ***Psychosocial evaluation***

A social worker will meet with you for a psychosocial evaluation. Your support person will need to go to this meeting with you.

Your social worker will:

- decide if you are able to understand and agree to the risks, benefits, and expected results of a kidney or pancreas transplant
- discuss the reasons you have decided to pursue a kidney or pancreas transplant
- decide if you and your family seem able to hold up under the emotional, financial, and physical stress of a kidney or pancreas transplant
- determine if you will have the amount of social support you'll need through the entire transplant process.

Remember: Every person who sees a social worker has a different set of needs. Do not be embarrassed or afraid to bring up any topic with your social worker, transplant doctor, or nurse. They are there to help, and, with their wealth of experience and access to resources, can do a lot to make life easier for you, your family, and your loved ones.

## **Will I see a lot of doctors during my evaluation?**

During the evaluation stage, you might need to see some doctors in addition to the doctors on the transplant team if you have other medical problems. For example, some patients need to be seen by a lung doctor (pulmonologist) if they have lung problems, and a heart doctor (cardiologist) if they have heart problem.

## ***How long does evaluation take?***

The time needed for a kidney or pancreas transplant evaluation is different for each patient and depends on the medical tests or problems you have.

## ***Do I need to come to Vanderbilt for my evaluation tests?***

Yes. Your evaluation and your evaluation tests must be done at Vanderbilt with the exception of preventive cancer screenings, including pap smears, mammograms, and colonoscopies.

# Finding a Donor

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## How long will it take to get a new kidney or pancreas?

There is no way of knowing how long you will have to wait before an organ becomes available for you.

- If you find a live kidney donor, your wait time for a kidney may be greatly reduced.
- The wait time for a deceased kidney donation can take a very long time and is highly unpredictable.
- It is also impossible to say how long it will be before you are matched with a pancreas.
- It is possible for a patient to die while waiting for a new organ.

## Living kidney donors

One source of kidneys for transplant is the living donor. A living donor must be healthy and is a person who does NOT have:

- high blood pressure
- infections, such as HIV or hepatitis
- diabetes
- heart disease
- cancer
- kidney problems, such as frequent kidney stones or urinary tract infections.

If you want to get a kidney from a live kidney donor, you should begin looking for a live donor during your transplant evaluation.

## What happens if I have someone who is interested in donating a kidney to me?

If someone is interested in donating a kidney to you, they can learn more, submit their information, and find out if they are a potential donor by:

- going to the Vanderbilt Kidney Transplant website, where they can submit their health information confidentially and apply online at [www.VanderbiltTransplantCenter.com](http://www.VanderbiltTransplantCenter.com)
- contacting the living donor coordinator at (615) 936-0695 or (866) 748-1491.



## How does finding a live kidney donor work?

If the live donor's health history meets donor requirements, a blood test will then be done to find out if you and your donor are blood type compatible. This test shows how well you and your potential donor match. Results of the test will be given in confidence to the potential donor.

### ***If you and your potential donor are a match***

If your blood types are an acceptable match, your donor will then have a medical evaluation done at our transplant center.

### ***If you and your potential donor are not a match***

If the person tested is not compatible with you, there may still be other options for donating. You can learn more about these options on page 17 of this booklet.

## What determines if I am compatible with a donor?

### ***Blood type compatibility***

To receive an organ from a donor, your blood type must be compatible with your donor's blood type.

### ***If you have antibodies in your blood***

Antibodies are a protein substance that can cause your body to react against a donor's cells. The presence of antibodies in your blood would cause your body to reject your donor's organ. To see if you are compatible with your donor, we will do a test called a crossmatch to see if antibodies are present in your blood.

- A negative crossmatch is a normal result and means you do not have antibodies in your blood.
- A positive crossmatch is an abnormal result and means you do have antibodies in your blood.

If you and your potential donor have a positive crossmatch but you have no other living donor options or swap potentials, you may be a candidate for a treatment, such as IVIG. Treatments like IVIG lower the level of antibodies in your body. Lowering your antibodies allows you to receive your donor's organ while helping prevent organ rejection.

## Types of living donors

Every year more than 6,000 living people donate organs to their relatives, spouses, or friends. This kind of donation has been done for more than 30 years. All living donors must be healthy and have excellent kidney function. Good physical health is not the only important consideration when making the decision to donate a kidney. Emotional health and general well-being are also important.

There are two types of living donors:

- those who are “blood related” (parents, children, siblings, cousins)
- those who are “not blood related” (spouses, friends).



## Living-related donors

All family members can be considered, including aunts, uncles, cousins, adult children, parents, and grandparents. A living-related donor offers 2 important advantages over deceased kidneys:

- The rejection rate is lower because the kidney of one of your relatives is more likely to match your own tissue and may last longer.
- A living-related transplant can be planned and scheduled in advance when the surgery is convenient, preventing a long wait. In some cases, because the wait is not as long, dialysis can be avoided altogether.

## Living-unrelated donors

If a blood-related family member cannot donate a kidney to you, someone else in your life—such as a friend, spouse, or coworker—may be able to donate. Even though living-unrelated donor matches are typically less of a match compared with living-related donors, these donations still have a high degree of success.

A transplant from any type of living donor, related or unrelated, allows you to schedule your transplant surgery for a specific time instead of waiting for an unknown period for time. Living donor transplants also have a better success rate when compared with deceased donor transplants.

## More living donor options

### *Paired donation (paired exchange):*

This is when recipients have donors who are medically able to donate, but are not compatible with the intended recipient. In a paired exchange, 2 or more recipients basically “swap” donors.

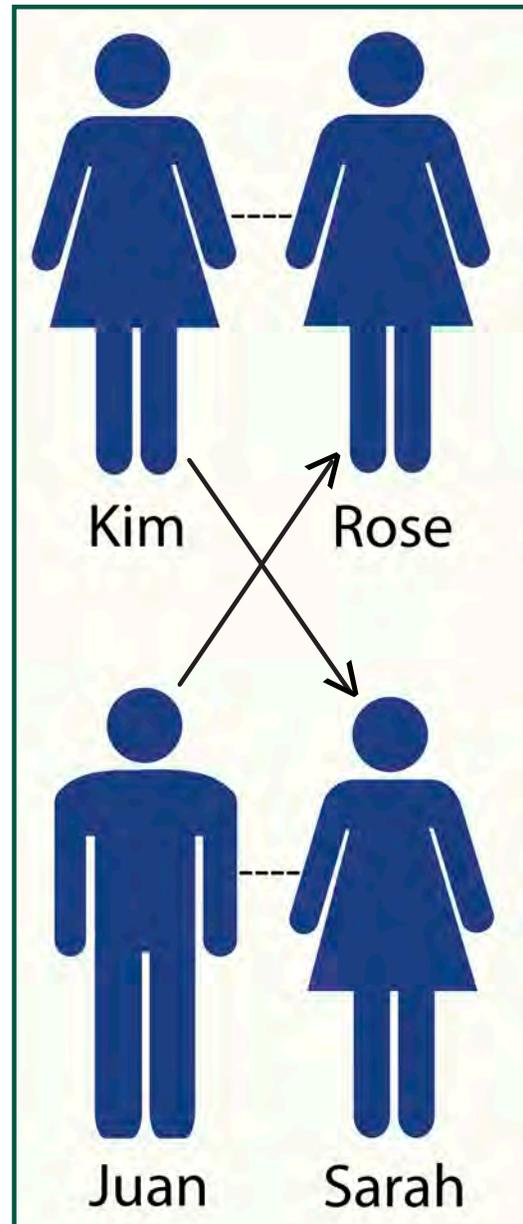
For example, in the diagram to the right, Kim wants to donate to her sister Rose, but they do not have matching blood types. Juan wants to donate to his wife Sarah, but they are also not compatible. But, it turns out that Kim IS a match for Sarah, and Juan IS a match for Rose. By “swapping” donors, two transplants are made possible.

This type of exchange often involves multiple living kidney donor/transplant candidate pairs.

### *An example of paired donation*

In the example below:

- Kim gives a kidney to Juan's wife, Sarah
- Juan gives a kidney to Kim's sister, Rose.



## Support for living donors

All potential donors will be assigned to a Living Kidney Donor Coordinator. The coordinator will help them through the entire process. It is important for you and your potential donor to remember that learning about kidney donation does not mean they must donate.

Remember: The health information of your potential donor(s) is completely confidential. We will not share this information with you. Likewise, we will not share your information with them.

## Deceased donors

Deceased donor organs come from people who have already died. The organs are chosen if they are healthy and work well. Donor organs are not matched by sex, color, race or culture.

Unfortunately, the number of organs that are suitable for donation is less than the number of organs needed.

- Currently, the average overall wait time at Vanderbilt is 5 to 8 years. This can change based on different factors, including your blood type and your immune system activity.
- In some states, such as Tennessee, the wait time is sometimes shorter because there is a high rate of organ donation.
- In other states, the wait time is longer than 5 years because there is a low rate of organ donation in that state.

## How does the kidney transplant waitlist work?

The policy that determines how donor kidneys are given to recipients considers the circumstances of both the donor and the transplant candidate. The policy ensures that kidneys are given out fairly, efficiently, and effectively. A combination of factors determines who receives which organ. Factors include:

- how long a donor has been on the waitlist
- if the transplant candidate is a child
- if there is a tissue match between the donor and the candidate
- the blood type and blood antibody levels of the donor and the candidate.



## Changes to the kidney matching system

In late 2014, some changes were made to the way donor organs are assigned. Patients on the waitlist will have the option of getting less traditional organ donations.

- The changes are an effort to reduce the number of people on the national waitlist (currently about 100,000).
- The changes will address the fact that many donated kidneys go unused, which means people who need these kidneys are not able to get them.

### *Things that changed with the new matching system:*

- Those who are likely to need a kidney for the longest amount of time after transplant will be matched more often with kidneys that are expected to last for the longest amount of time.
- Those who are hard to match with donor kidneys because of blood type or immune sensitivity will get extra priority.
- The way donor kidneys are classified will change. Instead of “standard” or “expanded criteria,” kidneys will be classified according to a new score called a Kidney Donor Profile Index (KDPI).

### *Things that stayed the same in the new matching system:*

- The time you spend waiting for a kidney is still a major factor in matching you with a donor kidney.
- You will not lose credit for time already spent on the waitlist.
- If you were on dialysis before getting on the waitlist for a transplant, your transplant waiting time will be backdated to your first dialysis date.

### *The Kidney Donor Profile Index*

Donor kidneys will now be classified according to a new score called a Kidney Donor Profile Index (KDPI) score. This score ranges from zero to 100 percent. The score rates how long a donor kidney is expected to function compared with other donor kidneys available. The lower the score, the longer a kidney is expected to function. For example:

- a KDPI score of 20 percent means the donor kidney is likely to function longer than 80 percent of the other kidneys available
- a KDPI score of 60 percent means that the donor kidney is likely to function longer than 40 percent of other available kidneys.

### ***How a KDPI score is calculated***

A KDPI score is based on facts about the donor that affect how long the kidney is likely to function after transplant. These factors include:

- age, height, weight, and ethnicity of the donor
- if the death of the donor was caused by loss of heart function, loss of brain function, or stroke
- if the donor had a history of high blood pressure or diabetes
- if the donor was ever exposed to the hepatitis C virus
- the levels of serum creatinine in the donor kidney.

### ***How transplant candidates are classified***

Each kidney candidate will get an individual Estimated Post-transplant Survival (EPTS) score. Your transplant team will figure out your score. The score ranges from zero to 100 percent and rates how long you will need a functioning kidney when compared with other candidates on the waitlist. For example:

- If you have an EPTS score of 20 percent, you will likely need a kidney longer than 80 percent of other people on the waitlist.
- if you have an EPTS score of 60 percent, you will likely need a kidney longer than 40 percent of other people on the waitlist.

## ***How your EPTS score is calculated***

The EPTS score is calculated based on facts about that affect how long you are likely to need a kidney.

These factors include:

- your age
- how much time you have spent on dialysis
- if you have received a previous transplant of any organ
- if you have diabetes.



## ***How KDPI and EPTS scores are used to decide who gets a kidney***

Kidneys with a KDPI score of 20 or less (those kidneys expected to last longer than 80 percent of donor kidneys) will first be offered to patients whose EPTS scores show they will likely need their transplants for the longest amount of time after transplant.

- If a kidney with a KDPI of 20 percent or less is not accepted by any of these patients, it will then be offered to any other person who would match, regardless of their EPTS score.
- Kidneys with higher KDPI scores (those that are expected to last for a shorter amount of time after transplant than other donor kidneys) may be used to help candidates who are less able to stay on dialysis for a long time and simply need a kidney right away.
- The 15 percent of donated kidneys that are likely to function for the shortest time after transplant (those with a KDPI score of 85 to 100) will first be offered to a larger area of the country than other kidneys. The goal is to use these kidneys by finding suitable patients as quickly as possible. The potential benefit to accepting one of these kidneys is a shorter wait time on the list. The decision to accept a kidney with a KDPI score higher than 85 percent is always entirely up to you.

Your transplant team can discuss with you the best options for matching based on your EPTS score and the types of kidneys that would best meet your need.

## ***What has changed for patients who are hard to match***

Some patients are hard to match with most kidney offers because they have uncommon blood types. Other patients are hard to match because they have immune system sensitivities that increase the chance that their bodies will reject most kidneys. The new system will seek to boost these patients' chances of getting a matching offer.

### **For patients with uncommon blood types**

Because type B blood is uncommon, patients with type B blood have often waited longer for kidneys than patients with more common blood types. Under the new system, more patients with type B blood will begin to get more offers for kidneys. This is why:

- Donors with blood type A generally can't donate to a person with blood type B, but some A donors have a "subtype" that allows them to match a type B candidate. The new system will give first priority to type B patients for these donor kidneys.
- Since blood type A donors are more common than blood type B donors, more offers now should be available for type B candidates.

### **For patients with immune sensitivities**

In other cases, people have immune system responses that make it very hard to find a kidney their bodies won't reject. This can be caused by having a previous transplant, a previous blood transfusion, or even from being pregnant. Currently, people who are "highly sensitized" often have to wait for 5 years or more before getting even one kidney offer. The new allocation system will change this.

- Under the new system, people who are immune sensitized will get more priority for kidneys they aren't likely to reject. How much priority you get is based on the extent of the sensitivity.
  - If you have slightly higher sensitivity, you will get slightly more priority
  - If you are very highly sensitized (98 percent or above), you will get much more priority.
- Kidneys that are first offered to highly sensitized candidates, but not accepted for them, will then be offered to other patients on the waitlist.

If you are highly sensitized, we will talk with you in greater detail about the new system and your additional priority.

## How does the pancreas transplant waitlist work?

Your blood type and how long you have been waiting are the first things considered for the pancreas waiting list. The more you match a particular organ and the longer you have been waiting, the more likely it is that you will receive an offer for an organ. This is different from the kidney-only waitlist.

When a patient has a living donor, they will often get a living donor kidney transplant first and then be listed later for a pancreas-after-kidney transplant.

## What can I do to support my health while on the waitlist?

Do everything your health team says you should do. This includes everything from taking your medicines and going to dialysis to eating a healthy diet.

### *While you are waiting for an organ*

- If you smoke: **Quit!**
- See both your primary care doctor and your transplant team exactly as instructed.
- Take your medicines exactly as directed.
- Exercise to the best of your ability.
- Follow your prescribed diet.
- Consider joining a support group of pre-and post-transplant recipients.

Also, while you wait for an organ, let us know immediately if:

- your medical condition changes or if you have to be hospitalized
- you have any changes of address, phone numbers, or insurance coverage. We need to be able to reach you quickly if a kidney becomes available at any time during the day or night.

## Can I get on the waitlist at other transplant hospitals?

Yes; you have a right to do this. Your transplant coordinator will talk with you about how to get on the waitlist at more than one transplant hospital. To improve your chances of getting an organ, remember that:

- getting on the waitlist in multiple places outside of your local area may improve your chances of getting a kidney offer; but
- you probably will not improve your chances by listing yourself at multiple centers within the same local area.

We'll explain all this to you.

## What happens when an organ becomes available?

- You will get a phone call from the transplant team telling you an organ is available and that you need to come to the hospital.
- Do not eat or drink anything from the time you are called until you arrive at the hospital.
- Ask us if there are any medicines you should take before you come to the hospital.
- Remember that you could possibly be sent home again if the transplant team discovers a problem with the new organ or finds that you have a condition that could affect your health or transplant success.

Occasionally a kidney transplant may be cancelled after a patient has arrived at the hospital. Possible reasons include damage to the donor kidney or a reaction between your blood and the blood of your donor (positive cross-match). If this happens to you, remember that your safety is our primary concern.

### ***We have program coverage at all times***

A transplant surgeon, transplant doctor, and transplant coordinator are available 24 hours a day, 365 days a year to assist with patient management. Back-up coverage is available for each of these people as well. If you ever need help or assistance at any time, a surgeon or

doctor can always be on site at Vanderbilt within 60 minutes.

## Information sharing

As you go through the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If you do end up getting a new kidney or pancreas, information about you, which will include your identity, will be shared with the United Network for Organ Sharing (UNOS). This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information sharing is an important part of overall transplant program success, both nationally and locally.

## What if Vanderbilt is unable to do my transplant?

If Vanderbilt is unable to do transplants for any reason, such as a natural disaster, we will let you know as soon as possible. If necessary, we will also refer you to another center for transplant care.

# At the Hospital

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## What happens when I get to the hospital?

You will meet with your transplant surgeon and the surgical resident and sign a consent form for the surgery.

## Pre-transplant tests and procedures

- We will take your blood and send it to the lab for necessary tests, including kidney and liver function tests and red and white blood cell counts.
- We will do a final cross-match test with the donor.
- We may do a chest X-ray and EKG if you have not recently had one.
- You will also meet a member of the transplant nephrology team to determine if you need dialysis before surgery.

Other tests may also be done depending on your current health status. If there are problems with any of these test results, the transplant may have to be cancelled.



## Preparing you for surgery

- We will take you to the anesthesia holding area or directly to the operating room. Your caregiver can stay with you until that time.
- Someone from the anesthesia department will visit you to ask questions and decide which type of anesthetic is best for you.
- Your operation will be appropriately timed for the arrival of your organ.
  - After removing a kidney from a deceased donor, the team has about 24 to 36 hours in which to safely perform your transplant.
  - After removing a pancreas from a deceased donor, the team has about 12 to 24 hours in which to safely perform your transplant.

## What happens in surgery?

When it is time for your surgery, we will give you medicine to make you sleepy. It will also make you feel light-headed, and your mouth may feel dry. If you are not already in the operating room, you will be taken there on a stretcher. There will be a lot of activity around you.

- An IV line will be put in a vein in your arm to allow our staff to give you any necessary medicines and to keep you from getting dehydrated. This line and other lines will still be in place when you wake up after your surgery.
- The anesthesiologist will give you medicine that will put you to sleep during surgery. This will be given to you through an IV. The anesthesia team monitors your blood pressure, heart rate, breathing, and blood chemistries very closely during the entire surgery.

## After you are asleep

- A breathing tube (endotracheal or ET) will be placed in your throat and connected to a machine (respirator) that will breathe for you while you are asleep. This tube may still be in place when you wake up after surgery.
- One or more IVs will be placed in your body. IVs allow us to give you fluids, medicines, and to take blood we may need to do lab work. The IVs are removed before you leave the hospital.
  - Some patients may have 1 IV placed in a vein on one side of the neck (called a central line).
  - Other patients will have 2 IVs placed in the veins of their arms.
- A soft, small tube called a Foley catheter will be put into your bladder to drain your urine. This tube will still be in place when you wake up after surgery.
- For pancreas transplant patients, a soft tube may be put through your nose or mouth that will go into your stomach. This is called a naso-gastric (NG) tube, and is used to keep your stomach empty to prevent vomiting and choking. This tube may still be in place when you wake up after surgery.

## Kidney transplant surgery

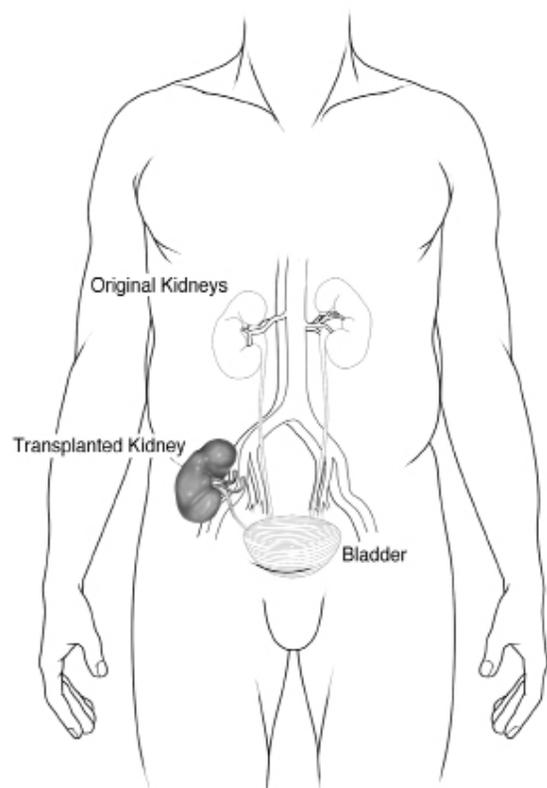
Your surgeon will make a cut in the groin area that is 8 to 10 inches long. The cut is curved and goes from your pubic bone to your hipbone. If you still have one or both original kidneys, they will be left in your body.

Next, the artery and vein of your new kidney are attached to an artery and a vein in the groin area. Then the new kidney's ureter—the tube that carries urine to the bladder—is attached to your bladder. A tube called a "stent" will be placed in the ureter to hold it open and protect it until it has healed. There is no discomfort associated with a stent. The stent will be removed by a urologist during an office visit about 3 to 4 weeks after surgery.

Your cut will be closed with staples, covered with a gauze dressing, and you will go directly to the post anesthesia care unit (PACU) after the operation. From there, you will go to the transplant unit.

### ***Will my new kidney begin working right away?***

Often the kidney begins making urine immediately, particularly when the kidney comes from a living donor. Living donor kidneys are placed within minutes of being taken out of the person's body, whereas a deceased donor kidney may be out of the donor up to 36 hours.



Some kidney transplants, especially from deceased donors, do not begin functioning right away. During this time of waiting for function to begin, it may be necessary for you to be on dialysis for a while.

### ***How long does the surgery take?***

Transplanting a kidney generally takes 2 to 4 hours, depending on whether you are receiving a kidney only or a kidney and a pancreas at the same time.

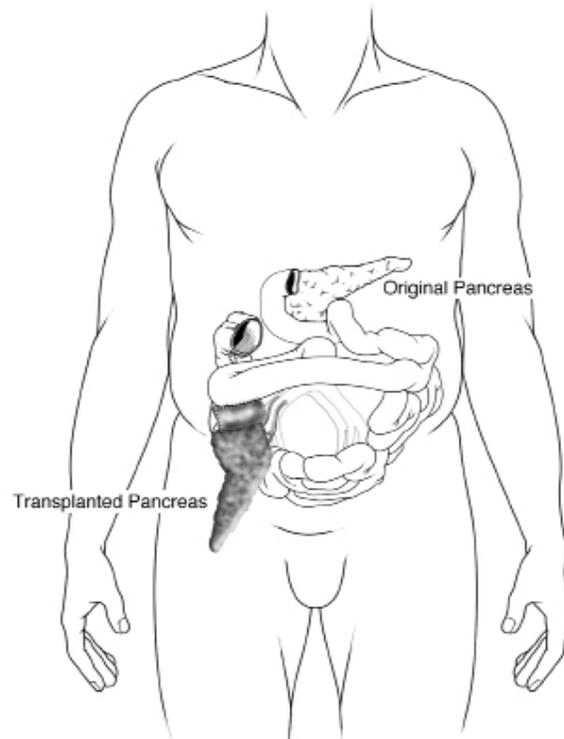
## Pancreas transplant surgery

Your surgeon will make a cut in the center of your belly that is 8 to 10 inches long. The donor pancreas is usually placed on the right side of the pelvis. The pancreatic secretions are drained into the small intestine. The old pancreas is left in place; it will not harm the new organ.

If you are also getting a kidney transplant, your new kidney will be placed on the left side of the lower abdomen and connected to the arteries and veins in the pelvis.

### *How long does the surgery take?*

The surgery takes about 3 to 6 hours, depending on whether you are getting a pancreas only or both a kidney and a pancreas at the same time.



## What happens after surgery?

After surgery, you will first be taken to the post anesthesia care unit (PACU) so the doctors and nurses can watch you very closely. Kidney and pancreas transplant patients will sometimes be transferred to a room in the Critical Care Tower after recovery in the PACU.

We will watch over you as you wake up and begin to recover. You will have several machines connected to you after surgery:

- Drainage tubes. These tubes are placed in your belly through your skin. They are used to help drain blood and fluid from the site of your surgery as you heal. These tubes are usually removed before patients leave the hospital. But sometimes patients keep them until they return to the clinic for their follow-up appointment after surgery.
- IV tubes. These tubes go under the skin into your veins. They are used to give you medicine. These may be in your hands, arms, or neck.
- Urinary catheter. This tube carries urine from your bladder into a container.

During your hospital stay, you will see many members of the professional staff. The transplant nurse coordinator acts as a link between you and the rest of the hospital staff and transplant team. She or he is there to answer questions for you and your family, to provide education and support, and to talk with you about any problems or concerns you may have.

Your primary nurse on the transplant floor will also teach you about your care in the hospital and at home.

### *When you first wake up*

- You will hear sounds that may not be familiar to you such as the machines that are monitoring your heartbeat, blood pressure, and breathing.
- You may feel sick to your stomach. This is caused by the anesthesia you were given. We will give you medicine for relief.

## How will I feel after surgery?

### *Pain*

After surgery you can expect to feel pain and discomfort. This may include:

- gas pains
- sore throat
- soreness
- backaches
- incision pain.

We'll give you medicine to help relieve it.

- For the first 24 hours you will most likely have some pain medicines through your IV, and then be switched to pills once you are able to take fluids by mouth.
- Previous transplant recipients have described the incision pain as very controllable.

Most kidney/pancreas transplant patients are free of pain about 2 weeks after surgery. However, some people continue to have pain for a longer period of time.

### **Your incision**

The dressing on your incision will be checked frequently and may be changed. It is not unusual for fluids to drain from your incision for some time after surgery.

### **Tests and measurements**

- Doctors and nurses will continuously monitor how well your new organ is functioning by taking various tests:
  - blood tests
  - measurements and tests of the fluids your body produces
  - other tests, such as X-rays, when necessary and appropriate.
- Blood is taken every morning to follow your progress and adjust your daily medicines. The most important blood tests to measure your kidney function are CREATININE and B.U.N. Serum glucose, amylase, and lipase are important tests with pancreas transplants.
- An ultrasound of your transplanted kidney may be done if the kidney does not make urine right away. This does not hurt. It is done to make sure there aren't any problems with the blood vessels or ureter of the kidney.

- Vital signs (temperature, pulse, respirations and blood pressure) will be taken regularly while you are in the hospital. You may be woken up at night to have these checked because they are important measures of how your body is responding to the kidney. You will be encouraged to take your own vital signs as soon as you are able, thus allowing you to be involved in your own care.

### **Foley catheter**

For 3 days after surgery, you'll have a Foley catheter tube in your bladder. This helps us know how much urine you're making. Don't worry if you see clots and blood-tinged urine in the tube. This is normal after surgery.

We'll measure your urine every hour. Occasionally your catheter will need to be irrigated or changed to remove clots that could stop up the catheter. You may feel some bladder spasms as long as the catheter is in place. We'll give you medicine to help with the pain and discomfort of these spasms if you have them.

Once your Foley catheter is removed, we'll continue to measure how much urine your body makes. At first, the nurses on the floor will measure this for you. When you're able, we'll teach you how to do this for yourself. You may find yourself up several times during the night to pass your urine until your bladder stretches to hold larger amounts.

## **Weight**

We will weigh you every day before breakfast. It is important that you are weighed at the same time each day on the same scales with the same clothes on. This is a habit you need to continue after you leave the hospital. Weight gain can be one of the signs of rejection of your new kidney, especially if you also have less urine output.

## **Exercising your lungs**

One possible problem after any surgery is pneumonia. Exercising your lungs can help keep this from happening to you. We will teach you coughing and deep breathing exercises you will need to do. You will begin doing these lung exercises in the recovery room. This may cause some discomfort around your incision that can be lessened by holding a pillow with some pressure over the incision while you cough.

## **Walking**

On day of surgery, we'll encourage you to get out of bed and walk. This is very important. Walking increases your blood circulation, helps relieve gas pains, and helps keep your muscles toned.

Starting on the day after surgery, your goal will be to walk down the hall at least 3 times each day.

## **Sleeping**

Some people have trouble sleeping while in the hospital, and some people experience strange dreams that seem very real. Many transplant recipients also report memory problems after the surgery. These problems are temporary and should not worry you.

## **How long will I be in the hospital?**

Kidney transplant patients are usually in the hospital for 3 to 4 days. Patients who had kidney and pancreas transplants or just pancreas transplants are usually in the hospital for 5 to 7 days. However, this can change depending on how sick you were before your transplant and if you had any trouble during surgery. You will be able to leave the hospital when your doctor is confident it is safe for you to do so.

## **Can I drive myself home from the hospital?**

No. You cannot drive yourself home. Your support person will have to make sure you have a ride from the hospital. You will not be allowed to leave on your own. Remember: As long as you are taking prescription pain medicines, it is not safe for you to drive—even short distances.

# After You Leave the Hospital

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## What happens after I leave the hospital?

When you leave the hospital, you will still be recovering. During this time:

- you will need frequent follow up with the transplant center
- your support person will need to be with you.

### *Short-term care*

Your short-term care will include:

- frequent appointments with your doctor or nurse practitioners to check on your new kidney or pancreas. (at least 1 time a week for the first 6 weeks after surgery)
- blood work and other tests to see how your kidney or pancreas is doing.

If you have any complications at any time after your surgery, the transplant team may need to see you more often.

## *Long-term follow-up with the transplant team*

Patients will choose whether they want to be followed at the transplant center or alternate their visits between the transplant center and their local kidney doctor long-term. Your doctor will follow you for the rest of your life to make sure your function is good. It is important that you keep this relationship going and maintain all your follow-up care.

Follow-up typically involves:

- frequent lab work
- routine clinic visits.

You should plan to continue your regular medical care with your primary care provider for routine health maintenance.

# The Risks of Transplant

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## What are the risks of a kidney or kidney/pancreas transplant?

A kidney or kidney / pancreas transplant is complex, and the risks are high. Your doctor cannot know exactly how your body will respond to a transplant until it happens. It is never fully known how the problem that caused your original kidney or pancreas disease will affect your transplant.

The success of your transplant will also be affected by how sick you were before surgery. Sicker patients have a lower chance of having successful results. Please see the patient education sheet that shows our transplant center outcomes.

### *Risk of cancelled surgery*

Sometimes a surgery is cancelled. This can happen if:

- the donor organ does not seem healthy enough to use; or
- the surgical team decides a patient has become too much of a high risk.

### **If your surgery is cancelled because the donor organ is not healthy:**

- you will return home and remain on the transplant waiting list
- you will not lose your place on the wait list.

### **If your surgery is cancelled because you are determined to be high risk:**

- we will conduct further evaluation to decide if you will be a suitable candidate for transplant in the future
- you will be placed in an inactive status on the waitlist, but you will not lose your wait time.

### *Risk of rejection*

There is always the chance that your body will reject your new organ. The risk is highest the first year after surgery. The good news is that rejection is usually treatable. Treatment may be given at home or may need to be done at the hospital.

Your body will never develop a tolerance to your new kidney or pancreas. This means you have to take medicine to keep your immune system from attacking those organs. You will have to take these medicines for the rest of your life, or for as long as the transplanted organ is functioning.

### ***Risk of complications from your lifelong, anti-rejection medicines***

Anti-rejection medicines are critical to preventing organ rejection. You will take them for the rest of your life after transplant. However, these medicines do have potential complications, including:

- increased risk of cancer
- high blood sugar levels
- damage to other organs, including your kidneys
- high blood pressure
- increased risk of infection
- increased risk of bone disease.

### ***Risk of pain, bleeding, or injury***

Transplant surgery can cause pain, bleeding, or damage to other organs in the belly.

### ***Risk of sickness or infection***

This surgery can cause sickness and infection, including:

- feeling sick to the stomach
- fevers
- pneumonia
- bladder infections
- infections to other organs in the chest.

### ***Risk of blood clots***

This surgery may cause you to have blood clots in your legs. This is dangerous since clots can travel to your lungs and make it hard for you to breathe.

To keep blood clots from forming, you may be given special devices, such as plastic boots that inflate and deflate to keep the blood in your legs flowing during and after surgery.

If you have a pancreas transplant, we will most likely prescribe a blood thinner (such as Coumadin) for you to take for the first few months after surgery. Blood thinners will help keep your pancreas from clotting.

### ***Increased cancer risk***

Your chance of getting certain types of cancer (skin and lymph) will slightly increase. This is caused by the medicines you will take for the rest of your life to keep your body from rejecting your new organ.

## ***Risk of disease or infection from the donor***

The risk of getting a disease or infection from your donor is rare. All donors are carefully tested for transmittable diseases and infections, including HIV, Hepatitis C, and Hepatitis B. However, you need to know that no transplant is completely free of this risk. If you catch a disease or infection, you could end up with a serious illness. The situation would be complicated by the fact that some of your post-transplant medicines will suppress your immune system.

### **More about elevated risk donors**

During the screening process, we may find that a potential donor has a higher than normal risk for having a transmittable disease or infection. This type of donor is often called a "PHS elevated risk donor." If we find that your donor has an elevated risk, we will discuss this with you to help you decide if you wish to accept the organ for transplant.

Please remember that all donors carry the risk of transmittable disease or infections, even though this risk is low.

## ***Risk of death***

As with any surgery, there is the risk of death. This is especially true with transplant surgery given how serious it is.

## ***Anesthesia risks***

This surgery will be done under general anesthesia that will make sure you sleep and feel no pain during surgery. There are a number of known risks any time general anesthesia is used. An anesthesiologist will explain these to you and give you a separate consent form to sign.

## ***Risks of blood transfusion***

You may need to receive blood during or after this surgery. Even though all blood is carefully checked for HIV, hepatitis, and other diseases, anytime you receive blood, there is the risk of being infected.

## ***Risk of other complications***

Other things that can happen include:

- injury to structures in your belly
- pressure sores on the skin caused by the position of your body during surgery
- burns caused by the electrical equipment used during surgery
- damage to your arteries and veins
- heart attack
- stroke
- seizures
- a scar where the incision is made
- nerve damage where the incision is made.

## ***Psychosocial risks***

Having a transplant can be very stressful emotionally and psychologically, as well as physically. After transplant, there is the risk you may develop psychosocial health problems, including:

- depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety about having to depend on others
- feelings of guilt.

There are many resources to help you if you have any of these issues. Let us know if you need any help at any time.

## ***Financial risks***

Transplants are expensive. It is natural to wonder how the cost of transplant will affect you and your family. It is important that you understand what your insurance will cover. You also need to create a plan that will allow you to manage the costs of your care. The financial coordinators and social workers will help you understand the financial details of your transplant.

# Potential Complications of a Kidney Transplant

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The most common complications after a kidney transplant are:

- rejection
- infection
- high blood pressure
- diabetes
- delayed kidney function
- ureter complications
- bleeding
- thrombosis
- recurrence of original disease
- dehydration.

## Transplant rejection

The most common complication of a transplant is organ rejection. It can happen at any time throughout the life of your new kidney or pancreas. Organ rejection happens when the body's immune system recognizes the new organ as something foreign in the body and tries to destroy it.

There are two major types of kidney transplant rejection—acute rejection and chronic rejection.

## Acute Rejection

Acute rejection is a sudden reaction of your body's defense (immune) system against the kidney transplant. As many as 1 in 5 transplant patients may experience this type of rejection at some point in time. This rejection causes kidney function to decrease. If it is not treated, the kidney will be destroyed.

- This type of rejection usually happens during the first year after transplant but can occur at any point in time.
- An acute rejection episode will require you to return to the hospital.
- If treated early, kidney function will almost always improve.
- If your body totally rejects your transplanted kidney, you will need dialysis. The kidney may or may not need to be removed.

## ***Signs of acute rejection***

- sudden increase in blood pressure
- sudden weight increase or swelling of ankles
- decrease in how much urine you make
- pain, tenderness, or swelling of the new kidney
- elevated creatinine levels
- fever or chills.

Sometimes the only sign of acute rejection is an increase in creatinine noted on your blood work. This is why it is so important to follow up at transplant clinic and have routine blood work drawn. You should have your labs drawn at least once a month for the first year.

## ***Chronic rejection***

Chronic rejection is a gradual decrease in kidney function. This type of rejection usually occurs months or years after the transplant. Because this rejection is a slow process, dialysis may not be needed for quite some time, possibly years.

## ***Treating chronic rejection***

The cause of chronic rejection is not clearly understood. Treatment with medicine is less effective than with acute rejection. If your body shows signs of a rejection, you may have a kidney biopsy and ultrasound. If a rejection episode is verified, your anti-rejection medicine(s) will be increased, or we will give you a new combination of anti-rejection medicines.

## ***Infection***

Infection is a risk after transplant because the anti-rejection medicines that you will take to keep your body from rejecting your kidney also allow your immune system to accept other things in your body that it would usually fight. In other words, these medicines put you at greater risk for getting an infection.

## ***Common infections after kidney transplant***

- infections of the lungs
- infection of the surgical incision
- bladder or urinary tract infection.

## ***Signs of infection***

- fever or chills
- tiredness
- diarrhea or throwing up
- redness or drainage around your incision
- a cough and sore throat.

## ***Treating infection***

If you get an infection, it will be treated with antibiotics, anti-viral medicines, or anti-fungal medicines. The infectious disease team at the medical center works with the transplant team if it is necessary.

## Preventing infection

To help prevent infections, you may take anti-bacterial, anti-viral, and anti-fungal medicines for a certain period of time after surgery. If you get an infection after leaving the hospital, it is usually treated with antibiotics as an outpatient. However, sometimes people need to be readmitted for treatment with IV medicines.

## High blood pressure

If you develop high blood pressure after your operation, your doctor will prescribe medicine to regulate it. If you already take blood pressure medicine, your doctor may change your dose or type of medicine.

## Delayed kidney function

Sometimes, deceased donor kidneys do not work right away. To get an idea of why this is, it helps to think of your new kidney as being “asleep” (this is called acute tubular necrosis, or ATN). This condition can last a few days or up to 2 to 3 weeks. You may still need dialysis after your surgery until your new kidney starts to function on its own.

## Ureter complications

The ureter that was connected to your bladder during surgery may leak or become blocked after surgery.

- A sudden decrease in urine output or sudden pain can be a sign that this is happening.
- An ultrasound will usually show us if you are having this problem.
- If the ureter becomes disconnected, leaks, or is blocked, you will likely need an operation to fix it. A stent is placed during surgery to help prevent this complication.

## Bleeding

Occasionally, there may be bleeding from the new kidney. This may require a blood transfusion. On rare occasions, a second surgery is required to control it.

## Thrombosis

Very rarely (about 1 percent of patients), the blood vessels to the kidney clot after transplant. This is called thrombosis. If this happens, the kidney cannot work and must be removed. You will need to return to dialysis. You may be listed for another kidney transplant.

## Recurrence of disease

Certain causes of kidney failure can end up developing in the transplanted kidney after a period of time. Examples of such diseases include MPGN, FSGS, IgA nephropathy, and diabetes. Your transplant doctor will monitor your lab work and urinalysis closely for signs of recurrence if you have any of these diseases.

## Dehydration

After your transplant, you will need to drink more fluids than you did when you were on dialysis. It is common for people with kidney transplants to sometimes become dehydrated.

Dehydration can make you:

- feel dizzy or light-headed
- develop low blood pressure
- have elevated creatinine levels.

You may have times when you have to be hospitalized briefly to get fluids put into your body through an IV.



# Potential Complications of a Pancreas Transplant

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The most common complications after a pancreas transplant are:

- rejection
- infection
- bleeding
- blood clotting in the pancreas
- enteric leak (when pancreatic digestive juices leak into the place where the pancreas is connected to the intestine)
- pancreatitis (inflamed pancreas)
- dehydration.

It is not uncommon for pancreas transplant recipients to be re-hospitalized during the first 6 months after transplant for these complications.

## Rejection

If you have rejection, it is a signal that your immune system has identified your new pancreas as foreign tissue and is trying to get rid of it. Preventing rejection with immune-suppressing medications is the first priority.

## *Signs of rejection*

Rejection can be more difficult to detect at an early stage with pancreas transplants than with kidney transplants.

- Blood sugar levels are not a useful tool for detecting rejection because blood sugar levels rise only when much of the pancreas function has been lost.
- Measuring blood amylase and lipase levels and being aware of belly or back pain and fever are better indicators of rejection.

If you have signs of possible rejection after you have left the hospital, you may need to come back to the hospital for additional tests or medicine.

## Infection

- The most common infections result from viruses that have been lying dormant in your system or in the donated pancreas.
- Other infections include:
  - urinary tract infections
  - wound infections
  - pneumonia
  - the collection of fluid or an abscess around the pancreas.

## Signs of infection

- fever
- tiredness
- diarrhea or throwing up
- redness or drainage around your incision
- a cough and sore throat.

## To check for infection

You or your caregiver may take sputum (the substance coughed up from your lungs), blood, or urine samples.

## Treating infection

If you get an infection, it will be treated with medicine that specifically targets the infection. The infectious disease team at the medical center will consult with the transplant team when necessary.

## Preventing infection

To prevent infections, you will take anti-bacterial, anti-viral, and anti-fungal medicines for several months after your surgery. If an infection develops after you have been discharged from the hospital, it usually is treated with antibiotics as an outpatient. However, sometimes people need to be readmitted so they can be treated with IV medicines.



## Bleeding

Blood thinners (e.g., Heparin, Lovenox, Coumadin, aspirin) are used after transplant to prevent clotting of the pancreas. These increase the risk of bleeding around the pancreas. This might require a blood transfusion or even repeat surgery to stop any bleeding. If this happens, it is usually within the first 2 to 3 days of surgery.

## Blood clotting

About 5 to 10 percent of pancreas transplants fail within 1 week after surgery because of blood clotting in the pancreas. This is because circulation in the pancreas is slow, which makes it easy for clotting to happen. We will probably give you a mild blood thinner to lower the chances of this happening.

## Enteric leak

Occasionally, pancreatic juices leak from where the new pancreas is connected to your intestine. This is known as an enteric leak. If this happens, you may get severe stomach pains. This may need to be treated by either a tube (drain) placed by a radiologist during a CT scan or else require repeat surgery in the operating room to repair the leak.

## Pancreatitis

Pancreatitis is an inflammation or swelling of the new pancreas. Pancreatitis may be caused by trauma to the pancreas from donor death, retrieval, storage, or implantation. Inflammation is usually seen within the first several days after surgery. It generally improves with the use of IV fluids alone.

Patients with pancreatitis often have belly or back pain and abnormal lab results.

## Dehydration

After your transplant, you will need to drink more fluids than you did when you were on dialysis. It is common for people with kidney transplants to sometimes become dehydrated.

Dehydration can make you:

- feel dizzy or light-headed
- develop low blood pressure
- have elevated creatinine levels.

You may have times when you have to be hospitalized briefly to get fluids put into your body through an IV.

# Common Medicines for Transplant Recipients

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As a transplant recipient, you will need to take various medicines for the rest of your life. You will get medicines to help your body accept your new organ. These are known as “immunosuppressive drugs” or “anti-rejection medicines.”

After transplant, patients usually go home taking 2 or 3 types of anti-rejection medicines. This is in addition to their other medicines. Anti-rejection medicines help your body accept the transplanted organ by lowering your body’s natural reaction, which is to attack foreign tissue. At first, you will take large doses of these medicines. The amount you take will gradually be lowered as your body accepts the new organ.

It is important that you ALWAYS take your medicines exactly as directed.

- You need to know the names of these drugs, how much you are taking, and what the pills look like.
- Your nurse will help you and your support person learn all about your medicines so you can take them yourself in the hospital and at home.
- Failure to take these drugs or skipping doses can cause your body to reject your new organ.
- It will be necessary for you to take all your medicines on a strict schedule.

## Common medicines

The two most common anti-rejection medicines for transplant patients are:

- Tacrolimus (Prograf)
- Mycophenolate (Cellcept)

These medicines are very effective at lowering the risk of rejection, but they also have a number of potential side effects including:

- lower ability to fight infection
- increased risk of certain cancers
- increased risk of birth defects
- nausea or diarrhea
- high blood sugars.

There are additional side effects as well. We will talk with you about them.

After transplant, you will have to take anti-rejection medicine for the rest of your life. Once you are transplanted, we will give you more detailed information about the specific medicines you will be on and instructions on how to take them.

## Prednisone

At our center, most transplant patients do not have to take prednisone long-term. But, if you were on prednisone before transplant, or if you are at a high risk of rejecting the transplanted organ, you will be sent home on a daily prednisone dose.

# Life after Transplant

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## Prevent infection

The medicines you will take for the rest of your life will make you more prone to getting infections. The good news is that with good habits, you can stay healthy.

Some of these things you will need to do for the rest of your life. Other restrictions may be lifted in time. Your transplant doctor or nurse will tell you when some of these restrictions may be lifted.

### *Tips to prevent infection:*

- Stay away from people who are obviously sick with the flu or a cold.
- Try to avoid children with chicken pox or strep throat.
- Wash your hands with soap and water before you eat and after you go to the bathroom.
- Shower or bathe regularly. Wash your incision as you would any other part of your body. Do not use lotions or powders on your incision.
- Clean cuts and scrapes right away with soap and water; then apply an antiseptic and a bandage.
- Do not, under any circumstances, change the litter in the cat box or birdcage without wearing gloves. This could cause a serious infection. Avoid cat scratches.
- Do not garden, dig in the dirt, or mow the lawn for 6 to 8 weeks after your transplant without gloves. Doing so could cause a serious infection.
- Keep your fingernails and toenails clean and trimmed. If your toenails are hard to manage or are ingrown, see a foot specialist.
- Talk to your doctor about getting the flu and pneumonia vaccines. Neither of these vaccines contain live viruses. Both vaccines are safe for you to have.
- Do not get any vaccine that contains a live virus, such as the smallpox or polio vaccine.
- Talk to your doctor if someone in your house is going to receive a live virus such as the oral polio vaccine or diphtheria vaccine if you have not already been vaccinated.
- Do not smoke. And do not expose yourself to second-hand smoke.
- Avoid community whirlpools.
- Avoid swimming in lakes or ponds.



## If you want to have a child

### Women

If you decide to become pregnant after your transplant, it is very important to discuss this with your transplant doctor or nurse in advance. Some of the medicines you will be on may not be safe for you to take during pregnancy.

Avoid pregnancy:

- for 1 to 2 years after your transplant
- at all times if you are taking the medicine mycophenolate.

### Men

Although men may father children at any time, talk to your doctor before trying to conceive to be sure the medicines you are taking, such as mycophenolate, will not affect the baby.



# Resources and Patient Tools

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## Learn more

You may get more information about transplantation from the United Network for Organ Sharing (UNOS).

- The UNOS website: [www.unos.org](http://www.unos.org).
- The UNOS toll-free patient phone line: 1-888-894-6361. This phone line:
  - is to help transplant candidates, recipients, donor, and family members understand the way organs are matched with patients who need them
  - can be used to find data, information, and statistics about transplants
  - can be used to talk about any problems you have at your transplant center or with the overall transplant system.

## When you need support

There are many national and local organizations dedicated to providing information, support, referrals to other recipients, and financial help to transplant recipients. We encourage you to get as much information as you can as you go through this difficult time in your life. The following is only a sampling of the resources available to you, and one resource will likely lead you to another.

### ***National Kidney Foundation***

(800) 622-9010 or (800) 380-3887  
[www.Kidney.org](http://www.Kidney.org)

### ***Tennessee Kidney Foundation***

(615) 383-3887  
[www.TennesseeKidneyFoundation.org](http://www.TennesseeKidneyFoundation.org)

### ***State Renal Program (TN)***

(615) 741-5259

### ***Children's Organ Transplant Association***

1-800-366-2682  
[www.COTA.org](http://www.COTA.org)

### ***American Association of Kidney Patients (AAKP)***

(800) 749-2257  
[www.AAKP.org](http://www.AAKP.org)

### ***Polycystic Kidney Research Foundation***

(800) 753-2873  
[www.PKDCare.org](http://www.PKDCare.org)

### ***Transplant Recipients International Organization, Inc.***

[www.TrioWeb.org](http://www.TrioWeb.org)

### ***American Kidney Fund***

(800) 638-8299









