

Life After Transplant Surgery

After a kidney/pancreas transplant

This chapter explains what to expect in the months after your transplant surgery.

In time, you will start to receive your ongoing care from the nephrologist who referred you for your transplant. This usually happens after 3 months.

Even after this change occurs, you will still visit the Transplant Clinic during the first year after your transplant. But, these visits will be less often than before. After the first year, you will be seen once a year in the Long-Term Follow-up Clinic.

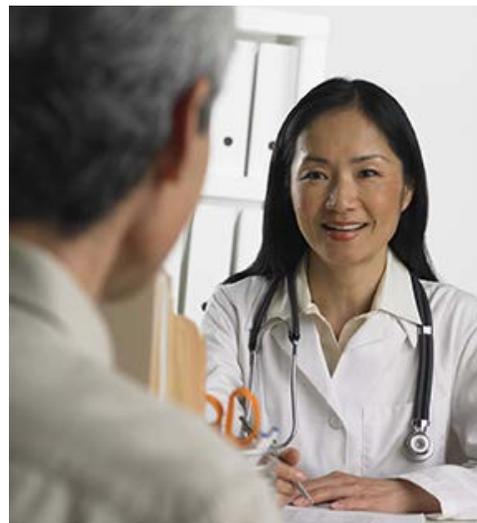
Long-term Self-care and Follow-up

The goals of a kidney or pancreas transplant are a better quality of life and a more normal lifestyle. But, a transplant is only a treatment for renal failure or diabetes, not a cure. This means that you will have some new lifelong responsibilities in caring for your new kidney or pancreas. After a while, your new routines and lifestyle will start to feel normal.

Here are some things you will be responsible for after transplant:

Take Charge of Your Ongoing Healthcare

- Report a fever or illnesses to your nephrologist **right away**. If your doctor is out of town, ask to talk with the doctor who is covering for your doctor. You must talk with your regular doctor or the doctor who is on call before you call the transplant center.
- See your nephrologist as instructed to check how your new kidney or pancreas is working.
- Report any health problems to your nephrologist. Be open and honest with your nephrologist when talking about your health issues.



After about 3 months, we will transfer your care to the nephrologist who referred you for transplant.

- As instructed, have blood draws to check how your kidney and pancreas are working and to check your anti-rejection medicine levels.
- Keep your vaccinations up to date. This includes getting a yearly flu shot and a tetanus booster every 10 years.
- **Never** get live virus vaccine, such as a measles, mumps, rubella vaccine, nasal flu vaccine, or shingles vaccine.
- Have your body systems checked as instructed. This includes eye exams and dental exams. Ask for tests to check your bone density, heart health, and skin (for skin cancer).
- Visit your dentist for a checkup twice a year.
- Women: Have screening tests for breast cancer (*mammogram*) and cervical cancer (*Pap smear*).
- Have screening tests for colon cancer (*colonoscopy*).
- If you plan to travel outside the country, go to a travel medicine clinic before your trip. Tell clinic staff that you have had a transplant.

Take Your Medicines

You will take anti-rejection drugs on a strict schedule for the rest of your life. Missing a dose can lead to rejection.

- Take all your medicines as prescribed.
- Plan ahead to get refills of your medicines so you do not run out.
- If any of your medicines make you ill, **keep taking them as prescribed**, but call your doctor right away.
- Do **not** take any medicines prescribed for other family members or friends, or any medicines you were taking before transplant.
- Check with your doctor **before** taking herbal products or other medicines.

Rejection

Rejection of the *graft* (organ) is a natural response of your body. Your immune system tries to destroy the new organ because it does not see it as being a part of you. Anti-rejection medicines interfere with your body's rejection process. They block *lymphocytes*, the white blood cells that "fight" your graft. The immune system is so strong that rejection can still occur even when you are taking strong anti-rejection medicines.

Types of Rejection

Most rejections occur in the first 6 months after transplant. These are called *acute rejections*. Acute rejections can often be reversed by taking *intravenous* (IV) medicines.

Late rejections are called *chronic rejections*. They may be caused by infections, not taking medicines as prescribed, or a change in drug levels for some other reason. This type of rejection:

- Occurs 1 or more years after transplant
- Happens more slowly than acute rejections
- Can cause damage that cannot be repaired, leading to graft loss

Signs of chronic rejection are usually subtle, such as a slow rise in *creatinine*. Late rejections are hard to treat.

Rejection does not mean for sure that you have lost your kidney or pancreas graft, but it is an emergency that needs treatment right away. A treated and reversed rejection is known as a *rejection episode*.

When a rejection episode starts, you may feel fine or you may have symptoms such as fever, muscle aches, fluid retention, or pain or swelling over your kidney or pancreas. Your serum creatinine or other lab results may or may not change. Regular doctor visits and lab tests are important to help watch for signs of rejection.

Preventing Rejection

The best defense against rejection is prevention. To prevent rejection:

- Take your anti-rejection medicines as prescribed by your nephrologist, in the right amounts and at the right times.
- Tell your nephrologist or the transplant team if you run out of your medicines or if you cannot buy them for any reason.
- Have your lab tests done on schedule.
- Tell your nephrologist right away if you notice a change in how you are feeling or there is a change in your lab results.
- Keep all of your routine nephrology visits, even if you feel fine.

Diagnosing Rejection

If your doctor suspects a rejection, a *biopsy* may be the only way to diagnose the problem. Biopsy results will tell:

- The type of rejection (acute or chronic)
- The grade of rejection (mild, moderate, or severe)

To do the biopsy, the doctor will inject a local anesthetic into your skin above your graft. A needle is quickly passed in and out of your transplanted organ to take a small tissue sample. This is done 2 to 4 times.

The tissue taken during the biopsy is sent to the pathology lab. It will be checked under a microscope for signs of rejection or other problems. Your doctor will receive your biopsy test results in 1 to 5 days.

Based on the type of rejection and how severe it is, your doctor will plan your treatment. You may need a hospital stay or a series of outpatient visits. After your treatment is done, you may have a follow-up biopsy to check on your progress.

Read the chapter “Transplant Renal Biopsy” to learn more about biopsies.

Graft Loss

Sometimes, a transplanted organ cannot be saved from rejection, infection, or recurrent disease. Graft loss is hard emotionally, and it is normal to feel angry if it happens.

The transplant team will help you. It may be possible to get another transplant. This will take some time and planning. In the meantime, you will return to dialysis for kidney loss and to insulin for pancreas loss.

Kidney Retransplant

If you lose your new kidney, you may be able to have another transplant. This is called *retransplantation*. But, you will need to meet the eligibility requirements to be listed for retransplant.

If you request retransplant, the transplant team will review your actions after your first transplant. We will check to see if you have taken your medicines as prescribed, had the required lab tests, gone to healthcare visits, and done dialysis as needed.

If the transplant team decides you have not followed your care plan or if you are actively smoking, you will be denied retransplant at our center.

Insurance Coverage

Keep your insurance coverage for medicines up to date. Anti-rejection drugs usually cost over \$1,000 a month and must be taken regularly. If paying for them is an issue, the transplant social worker can help you.

The medicines your insurance covers can change often. Check your plan every year for changes.

Medicare coverage for medicines ends at 3 years after transplant if you do not qualify for Medicare, either because of your age or because of other health problems besides kidney failure.

Call a member of your transplant team if you cannot find insurance coverage for your medicines.

Your New Lifestyle

Stay Healthy and Active

- When your doctor says it is OK, return to your usual activities. This will help your recovery and improve your mental and physical health.

- Take good care of yourself. Stay active, get regular exercise, eat a healthy diet, and limit how much alcohol you drink.
- Remember, smoking or using tobacco in any form means you are not eligible for a retransplant. Tobacco raises your risk for heart attack, infection, and cancer.
- Get yearly flu shots and keep other vaccinations up to date.

Rethink Your Self Image

Start thinking of yourself as a healthy person again, not as a “patient.” Although you will always need doctor visits and medicines, you can lead a normal life that includes work, school, volunteer work, family, and friends.

Get Support

You will still need the support of your family and loved ones. As you get healthier after your transplant, your lifestyle and your relationships with others may change. Keep the people who care about you involved and use their support when you need it.

Talking with others who have had a transplant can be very helpful. Your transplant social worker has a list of patients you can talk with for support.

For Women

Menstrual Periods

It is common not to have your periods or to have them off and on during a chronic illness such as renal failure. After transplant, menstruation often returns. Your periods may be irregular, light or heavy, and short or long. Tell your doctor about any changes in your periods.

Pregnancy

It is possible to become pregnant at any time after transplant. You must have a plan for birth control in place before your transplant surgery. See a gynecologist to help you choose a birth control method.

- If you are planning to have a *tubal ligation*, it can be done at any time, but it is best to have it done before your transplant.
- If you are on birth control pills, tell your surgeon at the time of your transplant. You may or may not be able to keep taking them while you are in the hospital, because they may increase the risk of blood clots.
- Be aware that *intrauterine devices* (IUDs) may increase your risk of infection.

Please tell your transplant team if you plan to become pregnant, because some anti-rejection medicines can cause birth defects. We will change your medicines *before* you become pregnant.

We advise waiting at least 1 year after transplant surgery before getting pregnant. Waiting to get pregnant will lower your risk of kidney rejection. It also allows time to ensure that your new kidney is stable and that your ongoing immunosuppressive drugs are working well.

Pregnancy makes your new kidney work harder, and it also increases your risk of losing your graft. Pregnancies are “high risk” for transplant patients. This means it is common for the baby to be premature and need a hospital stay. See an obstetrician who specializes in high-risk pregnancies if you are planning to have children, or if you find out you are pregnant.

Sexually Transmitted Infections and Diseases (STIs and STDs)

Casual sexual activity – whether homosexual, heterosexual, or bisexual – can increase your risk of getting an infectious disease such as HIV/AIDS, hepatitis, genital herpes, gonorrhea, and others. Even if you are *monogamous* (have only 1 sexual partner), your partner may not be monogamous.

The best way to prevent these infections and diseases is to practice safe sex and use condoms in addition to your usual birth control. **Only condoms protect against STIs.** If you get an infection, tell your doctor right away.

Infections

The medicines you take to prevent rejection of your new organ weaken your body’s ability to fight infections caused by viruses and bacteria. These common infections may occur during the first several months after transplant:

- Respiratory infections such as colds and flu
- Urinary tract infections
- Wound infections
- Certain viral infections

Infections can show up in your bloodstream, or anywhere in your body. They can be spread from the environment, from sexual contact, from your donor organ, and from inactive viruses already in your body that become active.

You will take many antibacterial and antiviral medicines to help prevent infections. If you develop an infection, more medicines may be prescribed. Treatment for some infections requires a hospital stay. Sometimes, severe infections can lead to loss of your transplant.

Common Infections in Transplant Patients

Infection	Cause	How to Prevent	How to Treat
Colds and flu	<ul style="list-style-type: none"> • Virus • Being in contact with others who are ill • Spread by touching objects in the environment or by touching your hands to your eyes 	<ul style="list-style-type: none"> • Good hand washing • Yearly flu shot • Keep your hands away from your face 	<ul style="list-style-type: none"> • Rest and drink plenty of fluids • Take antihistamines or decongestants if your doctor says they are OK • Call your doctor if you have vomiting or diarrhea • Take acetaminophen, but avoid ibuprofen (Advil, Motrin) and products that contain aspirin
Urinary tract infections (UTIs)	<ul style="list-style-type: none"> • Bacteria entering the bladder (which is usually free of bacteria) • Catheterization, poor hygiene, or not emptying bladder all the way when you urinate 	<ul style="list-style-type: none"> • Shower every day • Wear clean underwear • Wipe from front to back • Avoid tub baths and hot tubs • Urinate after sexual intercourse 	<ul style="list-style-type: none"> • Drink plenty of fluids • Urinate often and empty your bladder all the way each time • Take antibiotics as prescribed • Take cranberry tablets to block bacteria growth in the urinary tract
Wound infections	<ul style="list-style-type: none"> • Bacterial contamination 	<ul style="list-style-type: none"> • Keep wounds clean • Keep wounds covered when bathing • Change dressing often 	<ul style="list-style-type: none"> • Take antibiotics as prescribed • Incision may need to be opened, and dressing applied
Pneumocystis	<ul style="list-style-type: none"> • Fungal infection • Environmental exposure 	<ul style="list-style-type: none"> • Trimethoprim/sulfa (Bactrim) 	<ul style="list-style-type: none"> • Trimethoprim/sulfa (Bactrim)
Cytomegalovirus	<ul style="list-style-type: none"> • Virus 	<ul style="list-style-type: none"> • Antiviral medicines such as valganciclovir 	<ul style="list-style-type: none"> • If severe, hospital stay and IV antiviral medicines
Chicken pox and shingles	<ul style="list-style-type: none"> • Virus • Droplets from direct contact with an infected person 	<ul style="list-style-type: none"> • Vaccine before transplant • Immunity against chicken pox from having it as a child • Antiviral medicines 	<ul style="list-style-type: none"> • Antiviral medicines • Tell your doctor if you have a fever, skin pain, or a rash or itching (avoid scratching) • If you had chickenpox as a child, you are at lower risk to have it as an adult
Other viruses and bacterial infections	<ul style="list-style-type: none"> • Environmental • Infections from resistance to antibiotics, a dormant virus, or donor 	<ul style="list-style-type: none"> • Keep your body clean • Avoid being around people who are ill • Avoid cat litter, and do not let your pets bite or scratch you 	<ul style="list-style-type: none"> • Antiviral medicines • Antibacterial medicines • Experimental medicines • Take entire prescription of antibiotics as directed

How to Protect Yourself from Infections

Keep Your Body Clean

- Wash your hands often.
- Shower every day.
- Avoid tub baths and hot tubs.

In Your Home

- Reduce dust and clutter in your home. Your house does not need to be sterile, but it should be clean.
- Wash your bed linens, towels, and clothes often and when soiled.
- Clean your computer keyboard and mouse, and the mouthpieces of your phones.

Food

- Do not eat food that has been sitting at room temperature or outside.
- Wash raw fruits and vegetables well before eating or cooking.
- Avoid raw meats and fish.

Outside Activities

- Do **not** work in the garden for at least 6 months after your transplant. After that, wear thick leather garden gloves and a facemask.
- Avoid construction sites and construction dust.
- Avoid crowded places during flu season. If you can, sit apart from most of the crowd.

Skin Cancer Risks

Immunosuppressive drugs and some antibiotics may make your skin more sensitive to the sun. Over time, being out in the sun for long times or often may cause permanent skin changes. It also raises your risk for skin and lip cancer.

Transplant recipients are more than 10 times more likely to have *non-melanoma* skin cancers, such as *squamous cell carcinoma* and *basal cell carcinoma*. This risk increases with time after transplant. Transplant recipients are about 3 times more likely to develop melanoma.

To reduce your risk of skin cancer, always protect your skin from the sun:

- Use sunscreen and lip balm with a sun protective factor (SPF) of **at least 30** every day, rain or shine. Reapply sun protection often, especially after swimming or sweating.

- Use sun protection on your:
 - Face, nose, and lips
 - Tops of your ears
 - Backs of your hands
 - Tops of your feet if you wear sandals
 - Hair part, and on top of your head if you are balding
- For extra protection, wear hats with brims, long-sleeve shirts, gloves, and long pants when you are outdoors.
- If you can, avoid being in the sun in the middle of the day (10 a.m. to 2 p.m.). *Ultraviolet rays* that damage the skin are strongest at that time.
- Check your skin once a month for changes in existing moles and lesions, and for new moles and lesions.
- Visit a *dermatologist* (skin doctor) every year to have your skin checked.

Travel

- Check with your doctor to make sure your travel plans are safe for your health.
- Pack your medicines in your carry-on bag.
- Carry your medicines in their original containers for safety. You can put them in a mediset when you get to your destination. Put them back in their original containers for your return trip.
- Be sure to bring enough supplies and medicines so that you do not run out during your trip. Do not plan on being able to buy extra supplies when you travel to other countries.
- When you get vaccinations for travel, make sure that they are **not** live virus vaccines (measles, smallpox, rubella, chickenpox, yellow fever, or Japanese encephalitis).
- If you have diabetes, before you travel:
 - Call the airlines or visit their website to learn about travel rules for supplies and equipment (needles, lancets).
 - You may need a letter from your doctor that says you have diabetes and that you need insulin shots.

Hair and Skin Care

Immunosuppressant drugs may affect the condition of your hair:

- Prednisone or cyclosporine may cause increased or unwanted hair growth. This may be troubling to women if facial hair increases.
- Perms, foils, dyes, and bleaching may make hair break. Wait for several months after your transplant before coloring or perming your hair.

Some other hair and skin care tips are:

- Use moisturizing soaps and shampoos. These will keep your skin moist without removing healthy oils.
- Do not use special skin products unless you have problems with acne or dry skin.
- Talk with your doctor about removing or bleaching excess hair.
 - Waxing or laser treatments done by a professional are the best way to remove unwanted hair.
 - Electrolysis is not advised because your skin may be weak and sensitive.

Dental Care

- Brush and floss your teeth 2 times every day.
- Get a dental checkup every 6 months.
- Wait 3 to 6 months after your transplant before your first dental checkup. Bacteria in your mouth may cause infection if dental work injures your mouth or gum tissue.

For **all** visits to the dentist:

- Tell your dentist that you are a transplant recipient. Your dentist may write a prescription for 2 gm Amoxicillin for you to take 1 hour before your procedure. Tell your dentist if you are allergic to penicillin.
- The dentist may take X-rays, if needed.
- Ask the dentist to check your mouth and teeth.
- If the dentist tells you that you need dental work, schedule that visit promptly.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882