In time, your care will be transferred from the Transplant Clinic back to your primary care provider or nephrologist who referred you for your transplant. When this transfer of care happens depends on how well your new kidney or pancreas is working.

Even after your care is transferred, you will still be seen in the Transplant Clinic during the first year after your transplant. But, these visits will be less often than they have been. After the first year, you will be seen once a year in the Long-Term Follow-up Clinic.

Your Long-Term Self-care and Follow-up

The goal of a kidney or pancreas transplant is to allow you to have a better quality of life and a more normal lifestyle. But, transplants are 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. Over time, your new routines and lifestyle will feel normal to you.

Here are some common transplant-related responsibilities to consider:

**Doctor Visits**

- Report a fever or illnesses to your doctor 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 covering for your doctor before you call the transplant center.
- See your doctor on a regular basis to check the function of your new kidney or pancreas.
- Report any health problems to your doctor. Be open and honest with your doctor when talking about your health issues.
- Have blood draws to check kidney and pancreas function and anti-rejection medication levels on a regular basis.
- Maintain your vaccination schedules. This includes getting a yearly flu shot and a tetanus booster every 10 years.
- Do not ever get live virus vaccines.
- Have your body systems checked regularly. 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).

Men: Have screening tests for prostate and testicular health.

If you plan to travel outside the United States: Go to a travel medicine clinic before your trip. Be sure to tell the clinic staff that you have had a kidney or pancreas transplant.

Take Your Medications

You will take anti-rejection medications on a strict schedule for the life of your new pancreas and/or kidney. If you miss a dose, it can lead to rejection.

- Take all your medications as prescribed.
- Plan ahead to get refills of your medications so you do not run out.
- If any of your medications make you ill, keep taking them as prescribed and call your doctor before making any changes in your medication plan.
- Do not take any medications prescribed for other family members or friends, or any of your pre-transplant medications. Do not take herbal products or any other medicines without first checking with your doctor.

Rejection

Rejection of the graft (organ) is a process of your natural immune defense system. Your immune system tries to destroy the new organ because it does not recognize it as being a part of you. Anti-rejection medications interfere with your body’s natural rejection process by blocking the work of the lymphocytes (white blood cells in your immune system that “fight” your graft). The body’s immune system is so strong that even with today’s strong anti-rejection medications, rejection can still occur.

Types of Rejection

Most rejections occur in the first 6 months after transplant. These are called acute rejections. Usually, acute rejections can be reversed by taking intravenous (IV) medications.

But, late rejections can also occur. These are called chronic rejections. Chronic rejections occur 1 or more years after transplant, develop more slowly, and can cause damage that cannot be repaired. This may lead to graft loss. Signs of chronic rejection are usually subtle, such as a slow
rise in creatinine. Chronic rejection may be caused by infections, not taking medications as prescribed, or a change in drug levels for some other reason. 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 detect possible signs of rejection.

**Preventing Rejection**

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

- Take your anti-rejection medications as prescribed by your doctor, in the right amounts and at the right times.
- Tell your doctor or the transplant team if you run out of your medications or if you are unable to buy them for any reason.
- Have your lab tests done on the recommended schedule.
- Tell your doctor right away if you notice a change in how you are feeling or there is a change in your lab results.
- Keep all your routine doctor visits, even if you feel fine.

**Diagnosing Rejection**

Biopsy is sometimes the only way to diagnose rejection. If rejection is suspected, your doctor will order a biopsy to confirm the diagnosis. The results will tell the type of rejection, which can be acute or chronic, and the grade of rejection, which can be mild, moderate, or severe. See Chapter 16, “Transplant Renal Biopsy,” to learn more.

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 organ to take a small tissue sample. This process is done 2 to 4 times.

The tissue taken during the biopsy is sent to the pathology department, where it is 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. This may require a hospital stay or many outpatient visits. After your treatment is finished, you may have a follow-up biopsy to check on your progress.
Graft Loss

Sometimes, your organ cannot be rescued from rejection, infection, or recurrent disease. Graft loss is emotionally hard, 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 health care visits, and done dialysis as needed. If the transplant team decides you have not complied with your care plan or if you are actively smoking, you will be denied retransplant at our center.

Insurance Coverage

Be sure to maintain your insurance coverage for prescription medications. The anti-rejection medications typically cost over $1,000 a month and must be taken regularly. If paying for them is an issue, the transplant team 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 because of your age or if you have conditions other than kidney failure.

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

Your New Lifestyle

*Stay Healthy and Active*

Once your doctor tells you it is OK, you may do all your usual activities. This will help with your long-term recovery and improve your mental and physical health.

Take good care of yourself. This means staying active and getting regular exercise, eating a healthy diet, and limiting how much alcohol you drink.
Remember, smoking or using any tobacco product will make you ineligible for a retransplant. Tobacco increases your risk for heart attack, infection, and cancer.

Keeping up with your health also involves getting yearly flu shots and other vaccinations.

**Rethink Your Self Image**

Start thinking of yourself as a healthy person again, not as a “patient.” Even though you will never get away from medical management, you can still 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 transplant patients you can talk with for support.

**For Women**

*Menstruation, Contraception, and Pregnancy*

It is common not to have your periods or to have them off and on during 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.

- 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.

- Intrauterine devices (IUDs) may increase your risk of infection.

- If you find out you are pregnant, tell your transplant doctor right away.

Women can still have children after transplant, but we advise waiting at least 2 years after transplant surgery before getting pregnant. Waiting to get pregnant will lower your risk of kidney rejection. It also allows time to ensure that kidney function is stable and that your maintenance immunosuppressive medications are working well.
Pregnancy makes your new kidney work harder, and it also increases your risk of losing your graft. Pregnancies are considered “high risk” for transplant patients. It is common for the baby to be premature and require a hospital stay. We recommend you 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 other genital infections. Even if you consider yourself to be in a monogamous relationship, your partner may not be.

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 provide protection 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. Common infections that may occur during the first several months after transplant are:

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

These and other less common infections can show up in your bloodstream, or anywhere in your body. Infections 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 medications to help prevent infections. If you develop an infection, more medications are often prescribed. Treatment for some infections requires a hospital stay. Sometimes, severe infections can lead to loss of your transplant.
## Common Infections in Transplant Patients

<table>
<thead>
<tr>
<th>Infection</th>
<th>Cause</th>
<th>How to Prevent</th>
<th>How to Treat</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Colds and flu</strong></td>
<td>- Virus</td>
<td>- Good hand washing</td>
<td>- Drink plenty of fluids</td>
</tr>
<tr>
<td></td>
<td>- Being in contact with others who are ill</td>
<td>- Yearly flu shot</td>
<td>- Rest</td>
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<tr>
<td></td>
<td>- Environmental or hand-to-eye contamination</td>
<td>- Keeping your hands away from your face</td>
<td>- Take antihistamines or decongestants if your doctor says they are OK</td>
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<td></td>
<td></td>
<td></td>
<td>- Call your doctor if you have vomiting or diarrhea</td>
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<td></td>
<td></td>
<td>- Take acetaminophen, but avoid ibuprofen (Advil, Motrin) and products that contain aspirin</td>
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<tr>
<td><strong>Urinary tract infections (UTIs)</strong></td>
<td>- Bacteria entering the bladder (which is usually free of bacteria)</td>
<td>- Shower every day</td>
<td>- Drink plenty of fluids</td>
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<tr>
<td></td>
<td>- Catherization, poor hygiene, or not emptying bladder completely when voiding</td>
<td>- Wear clean underwear</td>
<td>- Urinate often and empty your bladder completely each time</td>
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<tr>
<td></td>
<td></td>
<td>- Wipe from front to back</td>
<td>- Take antibiotics as prescribed</td>
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<tr>
<td></td>
<td></td>
<td>- Avoid tub baths and hot tubs</td>
<td>- Take cranberry tablets to block bacteria growth in the urinary tract</td>
</tr>
<tr>
<td><strong>Wound infections</strong></td>
<td>- Bacterial contamination</td>
<td>- Keep wounds clean</td>
<td>- Take antibiotics as prescribed</td>
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<tr>
<td></td>
<td></td>
<td>- Keep wounds covered when bathing</td>
<td>- Incision may need to be opened, and dressing may need to be applied</td>
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<tr>
<td></td>
<td></td>
<td>- Change dressing often</td>
<td></td>
</tr>
<tr>
<td><strong>Pneumocystis</strong></td>
<td>- Environmental exposure</td>
<td>- Trim/Sulfa</td>
<td>- Trim/Sulfa</td>
</tr>
<tr>
<td><strong>Cytomegalovirus</strong></td>
<td>- Virus</td>
<td>- Antiviral medicines such as valganciclovir</td>
<td>- If severe, hospital stay and antiviral medication given by IV</td>
</tr>
<tr>
<td><strong>Chicken pox and shingles</strong></td>
<td>- Droplets from direct contact with an infected person</td>
<td>- Vaccine before transplant</td>
<td>- Antiviral medications</td>
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<tr>
<td></td>
<td></td>
<td>- Immunity from childhood episode of chicken pox</td>
<td>- Tell your doctor if you have a fever, skin pain, or a rash or itching (avoid scratching)</td>
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<tr>
<td></td>
<td></td>
<td>- Antiviral medications</td>
<td>- If you have immunity, you are at low risk to develop chickenpox</td>
</tr>
<tr>
<td><strong>Other viruses and bacterial infections</strong></td>
<td>- Environmental exposure</td>
<td>- Good personal hygiene</td>
<td>- Antiviral medications</td>
</tr>
<tr>
<td></td>
<td>- Secondary infections from antibiotic resistance, dormant virus, or donor</td>
<td>- Avoid being around people who are ill</td>
<td>- Antibacterial medicines</td>
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<td></td>
<td></td>
<td></td>
<td>- Experimental medications</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- Take entire prescription of antibiotics as directed</td>
</tr>
</tbody>
</table>
Protect Yourself from Infections

Hygiene

- 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.
- Clean your computer keyboard and mouse, and the mouthpieces of your phones every day.

Food

- Do not eat food that has been sitting at room temperature or outside.
- Do not eat food if you do not know who prepared it.
- Avoid potluck meals.

Outside Activities

- Do not 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 medications and certain antibiotics may make your skin more sensitive to the sun. Long and repeated exposure to the sun’s rays may cause permanent skin changes over time. Skin and lip cancers occur more often in those who have long exposures to the sun.

Transplant recipients are 10 times more likely to develop these cancers than the general population. This risk increases with time after transplant.

To reduce your risk of skin cancer, always protect your skin from sun exposure. Follow these guidelines:

- 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 bald
• For extra protection, wear hats with brims, long sleeve shirts, gloves, and long pants when you are outdoors.
• If possible, avoid the midday sun (10 a.m. to 2 p.m.), since ultraviolet rays 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 you medically.
• Pack your medicines in your carry-on bag.
• Carry your medicines in their original containers. You can transfer them to 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.
• Vaccinations for travel must not include 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 regulations 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.
  - Ask for a copy of the handout “Travel Tips: For people with diabetes.”

Hair and Skin Care
Immunosuppressant medicines may affect the condition of your hair. Prednisone or cyclosporine may cause increased or unwanted hair growth.
Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC clinic staff are also available to help.

Transplant Services: 206-598-8881

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This may be especially 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:

- Take a shower every day to keep your skin clean.
- Use soaps with anti-drying agents. 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 recommended 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 accidentally injures your mouth or gum tissue.

For all visits to the dentist:

- Tell your dentist that you are a transplant recipient.
- **Do not allow the dentist or hygienist to pick, clean, or polish your teeth at first.** When you have any dental work done, including cleaning and polishing, you will need to take an antibiotic before the work is done to prevent infection. Your dentist may write a prescription for 2 gm Amoxicillin to take 1 hour before your procedure. Tell your dentist if you are allergic to penicillin.
  
  - The dentist may take X-rays if needed.
  - Have the dentist examine your mouth and teeth.
  - When the dentist knows what work must be done, schedule another visit. If several visits are needed, schedule them as closely together as possible.