

# **Living with Your Kidney, Kidney/Pancreas or Pancreas Transplant**



**THE OHIO STATE UNIVERSITY**

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WEXNER MEDICAL CENTER

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\* Indicates topics to review in the hospital

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**Talk to your doctor or health care team if you have any questions about your care.**

The Library for Health Information is available to help you find more health information at (614) 293-3707 or e-mail: [health-info@osu.edu](mailto:health-info@osu.edu).

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# Congratulations

## Congratulations on getting your transplant!

Ohio State's Comprehensive Transplant Center's doctors and staff are here to help you in your recovery. We will closely check your transplanted organ and your general health. We will coordinate your care with your other doctors.

## Your post-transplant coordinator is a nurse and is your main contact for questions and concerns about your transplant.

The post-transplant office staff can also help you with transplant issues, prescriptions, insurance questions and clinic appointments.

## For the long term success of your transplant, you must follow good health practices to prevent illness:

- Take your anti-rejection (immunosuppressant) medicines as ordered.
- Have your blood work drawn as ordered.
- Check your weight, blood pressure, pulse and temperature on a regular basis.
- Keep your appointments.

**Use this book as a resource to help you with your care after a transplant.** You will find information about good healthcare practices. There are also instructions about your anti-rejection medicines, blood work, diet, exercise and other care after your transplant. Your transplant care team will review the information in this book with you. They will answer any questions you or your family may have before you are discharged. Your post-transplant coordinator will also review the information with you at clinic visits.

**Please ask questions.** There is a lot of information and we want you to understand your care. If we tell you something and you do not understand, please let us know so we can try to explain it in another way.

## To your clinic appointments, please bring:

- A record of your vital signs to review with your coordinator.
- A list of your questions and concerns, so those can be answered while you are with us.

## My transplant information

Date of my transplant:

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My post-transplant coordinator's name is:

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My transplant doctor's name is:

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My primary care doctor's name is:

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I am on anti-rejection medicines that I need to maintain my transplant. These medicines must be continued as ordered every day. **I need to call the Transplant Center if I am not able to take my medicines by mouth.**

If I have questions about my care or my anti-rejection medicines, I will call the Transplant Center at:

- **614-293-8746**  
Monday through Friday between 7:30 AM and 4:00 PM.
- 24-hour pager: **800-626-2538**

# My Responsibilities after an Organ Transplant

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I agree to these new responsibilities to protect my health and transplant:

- **Call my transplant coordinator right away with any health changes.** I know my immune system is suppressed, and infections are serious. I will learn the signs of rejection and call my coordinator right away if I have any signs.
- **Learn signs of rejection** and contact my transplant coordinator if I have any signs.
- **Call 911** if I have chest pain, shortness of breath or other medical emergencies.
- **Take my medicines as ordered each day.** I will report any unusual side effects to my transplant coordinator right away.
- **Keep my lab appointments for blood tests.** I know I will have lab work done at least 2 times each week for the first 3 months. I know I will need to have lab work done at least one time each month for the rest of my life. If I see changes in my lab work, I will call my transplant coordinator.
- **Record my vital signs** as ordered by my transplant care team. This includes my weight, blood pressure, pulse and temperature. **I will also call in my vital signs on the days I have lab draws to 614-293-8746.**
- **Remain active in my treatment by taking my anti-rejection medicines on schedule as ordered.** If I have a temporary money problems and will not be able to pay for my medicines, I will call my transplant social worker for help **3 weeks before my last dose of medicine runs out.**
- **Keep health insurance to the best of my ability after my transplant.** If I am eligible for Medicare, Medicaid or any other health insurance, I will complete an application to enroll in a timely manner. I understand that taking anti-rejection medicines increases the success of my transplant.

I understand these responsibilities will continue for the rest of my life.

# Your Transplant Care Team

Many people work together to provide your care while you are in the hospital. Here is a list of the key people who may be part of your care team.

Staff member	What they do
Attending Doctor	Oversees your treatment and coordinates your care with other doctors and staff on the care team. This doctor leads your discharge planning.
Fellow	A doctor who is getting more training in a special area of medicine. He or she is becoming a specialist in transplant.
Resident Doctor	A doctor who is taking more medical training. He or she is supervised by your attending doctor.
Medical Student	Third year medical students from The Ohio State University College of Medicine are placed on the unit as a part of their training. They are supervised by a doctor.
Physician Assistant	Staff member who is able to assist with patient medical care and treatment plans under the supervision of a doctor.
Registered Nurse (RN)	Plans and oversees your nursing care. Nurses carry out the doctor's orders and teach you how to care for yourself.
Nurse Manager or Assistant Nurse Manager	Manages the nursing care of the unit.
Nurse Practitioner (NP)	A nurse with advanced training who may prescribe treatments and do procedures.
Clinical Nurse Specialist (CNS)	A nurse with advanced training who helps with patient care and oversees daily nursing activities.
Patient Care Associate (PCA) or Student Nurse Associate (SNA)	Staff member who is trained in certain nursing care procedures. The PCA or SNA helps the nurse provide care.
Patient Care Resource Manager (PCRM)	A case manager who helps coordinate care for you when you leave the hospital.
Social Worker	Helps you and your family with concerns, such as your care after the hospital, coping or resource needs.

Staff member	What they do
Registered Dietitian	Helps with nutrition, learning and food choices. Diet techs see you soon after admission.
Transplant Psychologist	Helps with coping skills and behaviors for daily living to help you to recover from transplant.
Chaplain or Pastoral Care	Helps with spiritual needs. Chaplains can assist persons with or without a religious belief.
Pain and Palliative Care Team	Staff who work with the doctor to help manage your pain.
Patient Relations Representative	Patient Experience staff member who can help you resolve any concerns or questions related to your hospital stay.
Transplant Pharmacist	Oversees the medicines you need for transplant.
Transplant Coordinator	Oversees your care from before transplant to recovery, including post-transplant support and resources.
Physical, Speech or Occupational Therapists	If you have physical or functional changes, you may see one of these therapists. They can help you with walking, self-care, speech and other abilities.
Respiratory Therapist	Helps with breathing problems and takes care of oxygen equipment if needed.
Transport Staff	Help you safely move to other places in the hospital.
Unit Clerical Associate (UCA)	Unit secretary who manages calls and requests and answers when you use your call button.

# Your Care in the Hospital

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For the first 24 hours after surgery, you will stay in a special care room on the transplant unit. You will have your vital signs and urine output checked often. This room is not able to accommodate family overnight. After 24 hours, you will be moved to a regular room on the transplant unit.

**Children under 12 and live flowers are not allowed on the unit** to protect our patients.

- A narrow, flexible tube, called a **Foley catheter**, was placed during surgery to drain urine and to allow time for the connection between your bladder and your new transplanted organ to heal. The catheter is removed a few days after surgery. Keep the catheter clean to prevent infection. After the catheter is removed, ask for help to go to the bathroom. You will have blood tests to check how your new organ is working.
- Medicines will be ordered to help manage your pain. Tell your doctor or nurse how well the medicines are controlling your pain.
- A stool softener medicine will be ordered to help you pass stool without straining.
- Do deep breathing and coughing every hour you are awake to clear your lungs after surgery. Use a pillow to support your incision. Your nurse will teach you how to use a device called an **incentive spirometer**.
- A **compression device** will be used to prevent blood clots. The device is a pump and lower leg wraps or foot wraps. The wrap is placed on the leg and is held in place by Velcro strips. A tube connects to the wrap from the pump. When the pump is turned on, air is pumped into the wrap, causing it to feel snug on your leg or foot. This pressure keeps the blood flowing through your veins. **Wear the device when you are in bed or sitting up in a chair.** If you need help to remove or replace the wraps when you get up to use the bathroom or walk, let your nurse know.
- Staff will help you get out of bed and walk short distances. This helps to rebuild strength, prevent blood clots and improve blood circulating to the new organ.
- Gas pains are common after surgery. Tell your team how you feel. Walking several times a day can help to improve your comfort.
- When your bowel function returns after surgery, you will be given fluids to drink and then solid food to eat as your stomach is able to tolerate foods. Your IV will be removed when you are able to drink enough liquids.
- **You need to drink bottled water in the hospital, and you need to run the shower for 10 minutes before getting in** to flush the water lines to reduce the risk of infection.
- You need to take anti-rejection medicines every day for the rest of your life. You will be taught about your medicines. Do not skip doses or it may put your transplant at greater risk for rejection.
- You will be taught how to take your vital signs and check your temperature and weight. If you have questions or concerns about what equipment to use or how to take your blood pressure or pulse, please ask your nurse or others on the team.
- You will be taught how to care for your incision before going home. Staples hold your incision closed. No dressing is needed unless you are having drainage. Keep the incision clean and dry.
- When you go home, follow your discharge instructions.



# Your Care at Home

Our goal is to help you be the best you can be, prevent infection and find early signs of rejection. **Use these instructions along with the discharge instructions you were given for your care at home.** Refer to other sections of this book for more information. You can also call your transplant coordinator if you have questions.

## Daily checks

- **Weigh yourself each day at the same time before breakfast.** Be sure to urinate first, wear the same amount of clothing and use the same scale each day. Record your weight each day.
- **Take your blood pressure, pulse and temperature 3 times each day for the first 3 months or as ordered.** Check when you wake, at lunch and at bedtime. **Record your vital signs as ordered by your transplant care team** or track your vital signs in the *Weight, Blood Pressure, Pulse and Temperature Record* included in this book. Make copies of this record for ongoing tracking of your vital signs to share with your transplant coordinator at clinic visits.
- **Call your transplant coordinator right away if you:**
  - Gain 2 pounds or more in 1 day or 5 pounds or more in 1 week.
  - Have high blood pressure where your top number or systolic pressure is staying at or above 160, or you see that your blood pressure readings are trending higher each day.
  - Have a pulse of less than 60 or greater than 100.
  - Have an oral temperature greater than 101 degrees F or 38 degrees Celsius.

## Lab work appointments

Regular blood tests are needed after transplant. **Lab work is to be done every Monday and Thursday for the first 3 months.** Over time, you will move to less frequent testing as ordered by your doctor.

**Follow these instructions based on the anti-rejection medicines you take:**

### Cyclosporine (Neoral):

- Take with your morning medicines.
- **Have your level drawn as close as possible to 2 hours after you take cyclosporine (Neoral).** You have a 15-minute window before and after that time to get an accurate result. For example, if you take cyclosporine at 8:00 AM then your blood should be drawn as close to 10:00 AM as possible.

### Everolimus (Zortress):

- Hold your dose the morning of your blood draw.
- Bring this medicine with you to your lab work appointment, so you can take it right after your blood is drawn.

**Sirolimus (Rapamune):**

- If you are also on cyclosporine (Neoral), take your dose at least 4 hours after cyclosporine.
- If you are also on cyclosporine (Neoral), the level will be drawn at the same time as your cyclosporine level.
- If you are NOT on cyclosporine (Neoral), have your level drawn before you take your dose for the day.

**Tacrolimus (Prograf):**

- Hold your dose the morning of your blood draw.
- Bring this medicine with you to your lab work appointment, so you can take it right after your blood is drawn.

**Daily living**

- **You may shower.** No tub baths until after your incision has completely healed.
- **Eat healthy meals 3 times each day.**
- **Drink 3 liters (96 ounces or twelve, 8-ounce cups) of fluid each day** unless you have been instructed by your transplant care team to follow a different limit. One, 8-ounce cup is 240 milliliters. One liter is just a little more than four, 8-ounce cups of fluid, or two, 16.9-ounce bottled waters. **Dehydration of the new organ is one reason many transplant patients need to come back to the hospital.**
- **Start a walking program.** No special equipment is needed other than good walking shoes.
- **No lifting, pulling or pushing over 10 pounds until your 6-week check up.** A gallon of milk weighs about 8 pounds.
- You may need to **wear an abdominal binder when you are out of bed.** It is a wide, stretchy band that helps to support your belly muscles while you heal. Wear the binder for 2 weeks or until your doctor tells you it is okay to stop.
- **Prevent infection:**
  - Wash your hands often with soap and water or use alcohol-based hand sanitizer.
  - Use separate towels from others in your home. Change your towels every few days or as they get dirty.
  - Avoid crowds. You may be told to wear a simple face mask during the first 6 months after transplant when you need to come to the hospital or if you are going to be in crowds. This is very important during cold and flu season.
  - Avoid people with infections, such as colds or the flu.
  - Avoid handling animal waste or cleaning litter boxes, cages and fish tanks.
  - Avoid fresh plants, construction dust and working in the soil during the first 6 months after transplant. Wear gloves and a N-95 face mask after the first 6 months when working in the soil.
- **Prevent rejection:**
  - Take your anti-rejection medicines each day as ordered.
  - Drink your recommended amount of fluids.
  - Keep your blood pressure under control and in your target range.
  - If you have diabetes, keep your blood sugar under control.

# Preventing Infection

The medicines you take to prevent organ rejection make it harder for your body to fight infections. **If you have any signs of infection, call your doctor and transplant coordinator to get treatment started as soon as possible.** Some infections may require hospital treatment.

## Ways to prevent infection

- **Practice good hygiene.** Shower or bathe and wash your hair each day.
- **Wash your hands often with soap and water, or use an alcohol-based hand sanitizer.** Be sure to wash after sneezing, coughing, using the toilet, before and after handling food and any time your hands are dirty.
- **Do not eat food or consume drinks prepared from unpasteurized milk, fruit juices or vegetable juices. Avoid eating raw or under cooked eggs, meat, poultry, fish or seafood, as well as soft cheeses like feta, Brie or Camembert.** For more information, read, *Nutrition and Diet* and *Immunocompromised Diet Guidelines*, in this book.
- **Avoid use of well water if possible, and do not swim in or drink water from freshwater lakes, rivers and pools.**
- **Take care of cuts, sores and scratches.** Clean any cut or scratch with soap and water or an antiseptic like hydrogen peroxide. Keep the site clean and dry by covering it with a band-aid or other dressing.
- **Stay away from sick people.** Be very careful around any children who may be sick.
- **Avoid gardening, construction dust and working in soil for the first 6 months after transplant. Wear gloves and a mask for gardening.** Ideally use an FDA approved N-95 mask. These can be purchased in any hardware or household goods store. Remove houseplants since the dirt can carry molds.
- Have someone clean up after pets in the home, such as a dog or cat. **Do not clean the litter box or fish tanks.** Birds, reptiles, amphibians and small rodents, such as mice, gerbils and hamsters carry many germs that can be life threatening to someone with a transplant. You may need to find a new home for them. **Talk to your transplant coordinator to be sure it is safe for you to have any pet around.**
- **Avoid crowds the first month** after transplant as much as possible. You may be told to **wear a simple face mask during your first 6 months after transplant when you need to come to the hospital or be in large crowds, especially during cold and flu season.**
- **If you plan to travel outside of the country, talk to your transplant coordinator to get the vaccines and medicines you need to prevent infections.**

# Infections after Organ Transplant

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Infections can be caused by different kinds of germs called viruses, bacteria, parasites or fungi. Here are some common infections in transplant recipients:

- **Cytomegalovirus (CMV)** is caused by a virus. The risk for CMV is highest the first 3 months after your transplant. Signs may include: fever, muscle weakness, fatigue and shortness of breath. Joint pain, vision changes, headaches and abdominal pain are other signs. Treatment may require IV or oral medicines for weeks or months.
- **BK Viral Nephritis (BKVN)** is caused by a virus. The risk is highest at the end of the first year of transplant, but can happen anytime between 6 months and 5 years. The virus causes the tubes, called ureters, that drain urine from the kidneys to the bladder to swell. Urine can be blocked. Signs may include: blood in urine, hard to urinate, rise in creatinine or BUN lab values. People otherwise feel well and do not have the kinds of symptoms one expects with a viral infection.
- **Shingles** is caused by a virus known as herpes zoster. It often starts as a rash or small water blisters on the skin of the chest, back or hip. The rash may or may not be painful or itchy. It may occur in people who had chicken pox at a younger age. The vaccine for shingles should be avoided after a transplant since it contains live virus that could make you sick.
- **Chicken Pox** is caused by a virus called varicella zoster. This often shows as a rash or small blisters. **If you have been exposed to someone with chicken pox and you did not have chicken pox at a younger age, call your transplant coordinator right away.**
- **Candida** is the fungus that causes a common yeast infection. In the mouth or throat, it is called thrush. This infection often starts in the mouth or throat, but it may cause a wound or vaginal infection. Candida can show as white patches on the tongue or cheeks and may cause pain and problems with swallowing. Women may have vaginal infections that cause yellow or white discharge and itching.
- **Wound infections** are often caused by bacteria. Fever and redness, swelling, tenderness or drainage from your surgery wound are signs of a wound infection. **If you have any of these signs, call your transplant coordinator right away.** Treatment includes antibiotics and sometimes surgery.
- **Pneumocystis Jiroveci Pneumonia (PJP)** is caused by a fungus and can be life-threatening. A dry cough and fever are common signs. **If you think you have the flu or a cold that is not getting better, call your transplant coordinator.** Treatment includes antibiotics.
- **Be careful to avoid anyone who is sick with childhood or infectious diseases.** Measles, mumps and tuberculosis are some of the diseases that may cause you severe problems if you were to get exposed when your immune system is weak.

**Talk to your doctor or transplant coordinator about your risk for infections. You may need to take added precautions.**

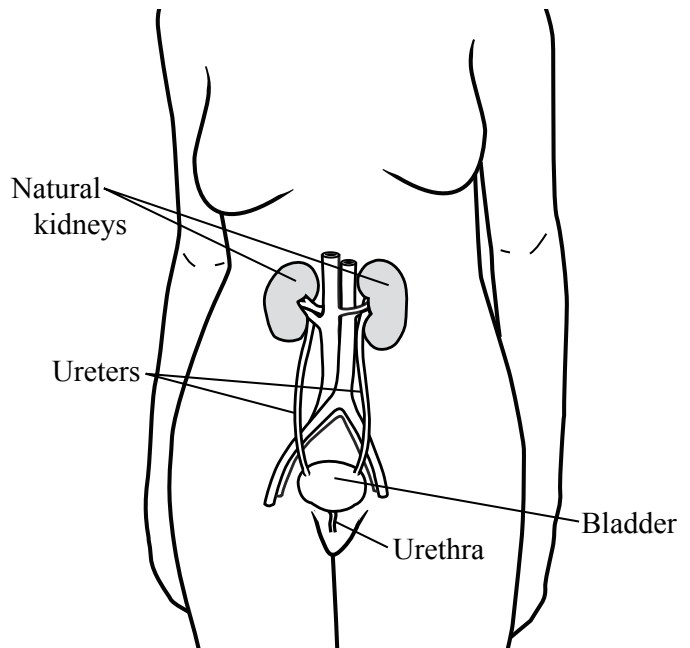
# How to Prevent a Bladder Infection

The best way to prevent a bladder infection after transplant surgery is to know how and why you get them. We will review this information with you and answer any questions that you may have.

## The urinary system

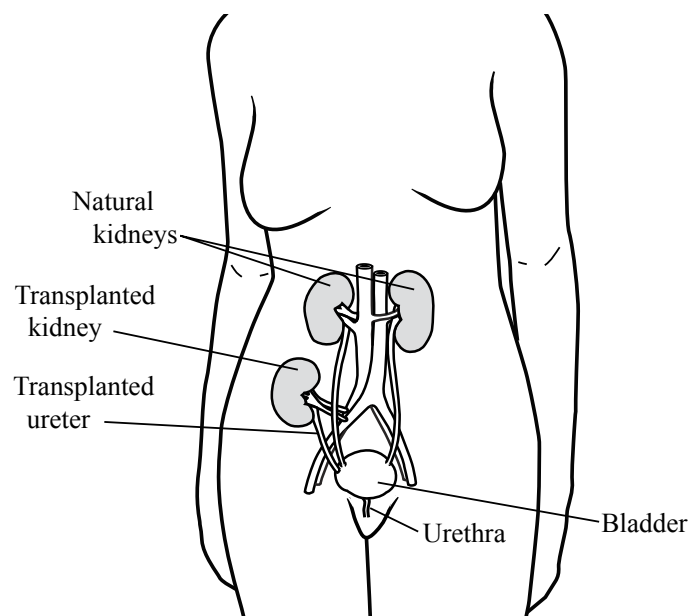
The urinary system includes these organs:

- **Two kidneys:** Your kidneys filter waste from the blood. The waste is passed out of the body in the urine. Each kidney is about 5 inches long and 2 inches wide. They are located just inside the lower ribs in the back.
- **Two ureters:** Tubes that come from each kidney to drain urine from the kidneys to the bladder.
- **The bladder:** Holds the urine until you urinate.
- **The urethra:** The tube that carries the urine from the bladder out of the body.



## After kidney transplant

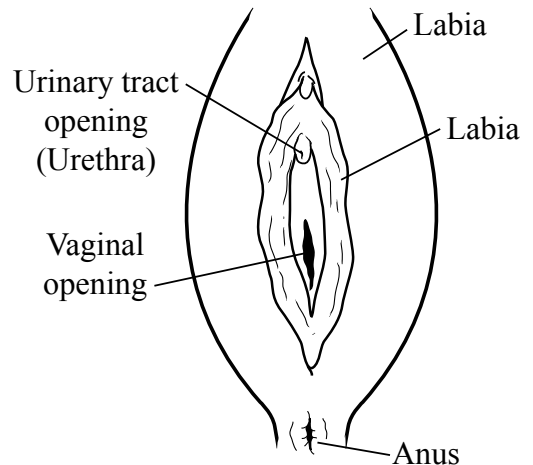
- **Transplanted kidney:** Your new kidney filters the waste from the blood. This waste is passed out of the body in urine. The transplanted kidney is put in the lower abdomen. It can be on the right or the left side. Your natural kidneys remain where they are.
- **Transplanted ureter:** The ureter is sewn into the bladder to carry urine from the new kidney to the bladder.



## Why women get more bladder infections

Women, in general, tend to get more bladder infections than men, even before a transplant because:

- A women's urethra is about 1 ½ inches long. This means the **bacteria have only a short way to travel to reach the bladder.**
- Sexual intercourse can irritate the urethra. It is also a way that bacteria transfer from person to person.
- When taking a tub bath, the water can enter the urethra. This water can stay in the urethra and allow bacteria to grow.



Transplant further increases the chance of bladder infection because:

- The medicines you take to prevent organ rejection lower your body's ability to fight off infection.
- The surgery includes sewing the ureter to the bladder. Any surgery to the bladder increases the chance of infection.
- Urine is normally acidic. After a kidney/pancreas transplant, the urine becomes non-acidic. Bacteria grow quickly in non-acid urine.

## How to prevent a bladder infection

Follow these steps at home to reduce the chance of a bladder infection:

- **Drink 3 liters (96 ounces or twelve, 8-ounce cups) of fluid each day** unless you have been instructed by your transplant care team to follow a different limit. This will increase the amount of urine you make and will flush out your bladder and urethra.
- Do not hold your urine. Go to the bathroom as soon as you feel the urge. Bacteria grow quickly in urine.
- Urinate after sexual intercourse.
- After you urinate or have a bowel movement, wipe yourself from front to back. This decreases the chance of bacteria moving from the vagina or anus to the urethra and bladder.
- Do not wear tight-fitting clothes or stay in a wet bathing suit. These do not allow air to move. If the area stays moist, bacteria can grow.
- Wear cotton underpants to keep the urethra opening dry.
- Take showers, not baths. Bathing allows water to stay in the urethra where bacteria can grow.
- Women should use tampons or change sanitary pads every 3 to 4 hours. This decreases the time bacteria from the vagina is in contact with the urethra.

## Call the Transplant Center at 800-626-2538 if you have these signs of bladder infection:

- A fever over 101 degrees Fahrenheit or 38 degrees Celsius.
- Frequent urination.
- An urge to urinate, but you are not able to urinate.
- Burning when you urinate.
- Foul smelling urine.
- Cloudy urine.
- Low back or abdominal pain.

Some patients may not have signs, but if you do, get help. **Do not wait for your next appointment to mention the problem.**

## Tips to help you recover

It is possible to develop an infection, even if you are careful to prevent one. Bladder infections occur in about 20 to 50% of patients with kidney transplants in the first 3 months after surgery. Here are some tips to help you recover from a bladder infection:

- **Drink at least 3 liters (96 ounces or twelve, 8-ounce cups) of fluid a day or the amount recommended by your Transplant Care Team.** This will increase the amount of urine you make and will flush out the kidneys and bladder.
- Some foods and fluids may irritate the bladder during recovery. Avoid carbonated drinks, caffeine, such as coffee, tea and chocolate, citrus juices, such as orange and pineapple, alcohol, and strong spicy foods.
- If you are given an antibiotic, take all doses as ordered. If you do not take all of the medicine, the infection may not clear up.

# Cytomegalovirus (CMV)

## Risk for the Transplant Patient

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Cytomegalovirus is part of the herpes virus family. It is often harmless to people with healthy immune systems. After the transplant, you will be on several drugs to prevent rejection of your new organ. These drugs suppress your immune system, so you may be at higher risk for CMV infection.

- Shortness of breath
- Muscle weakness
- Headache, confusion, seizure
- Blurry vision or loss of vision in one eye
- Blood in stool, abdominal discomfort, nausea and vomiting

### How do I know if I have CMV?

Blood is drawn during your transplant work up to check for CMV in your system. A careful screening is also done to check for the virus in the donor. Even if you have never been exposed to CMV, the person who donated your organ may have been exposed. Knowing if one or both of you have been exposed helps the transplant care team take care of you after the transplant.

Most people with strong immune systems do not know that they have been exposed to CMV. CMV may remain inactive or dormant in your body for life but can become active at any time when your immune system is weak or suppressed.

CMV is spread by close contact with body fluids. Body fluids are urine, saliva, blood, tears and sexual fluids.

### Signs of CMV infection

CMV can infect any organ. Some signs of CMV infection include:

- Fever greater than 101 degrees F or 38 degrees C
- Fatigue
- Pain in joints

### How is CMV diagnosed?

Samples of blood, urine and sputum may be tested to see if the CMV virus is active. Other blood tests may also be done. In some cases, a biopsy of the infected organ is done. This means a sample of tissue is removed from the organ for testing.

### Prevention and treatment

If blood tests show that you have CMV before your transplant, antiviral medicines are given. Other tests may be used to check your condition.

Because this virus lays dormant in your body, it is possible that you may become infected at any time during your life after transplant. Even if you show no sign of infection, you may be given antiviral medicines after transplant to reduce your risk of infection.

Not every transplant patient develops CMV. However, an infection can be very serious. Antiviral medicines may be given to prevent the spread of infection, but these medicines do not cure CMV.

**Call your transplant care team right away when you are not feeling well.**



# BK Virus and Kidney Infection

BK virus causes kidney problems for patients with organ transplants. The virus causes a condition called BK Viral Nephritis or BKVN. Transplant patients are more likely to have signs of BK the first 1 to 5 years after transplant, but it can happen at anytime.

## About BK virus

Most people are exposed to the BK virus by the time they are adults, but it is often harmless in people with healthy immune systems.

Anti-rejection medicines put you at greater risk for infection. If you had the BK virus before the transplant, a weakened immune system may let the virus become active.

The BK virus causes swelling in the tubes (ureters) that allow urine to drain from the kidneys to the bladder. This makes it hard to urinate. You may want to go to the bathroom but feel like you cannot empty your bladder. As the virus spreads, the bladder can also be injured.

## Signs of BK virus

If you have any of these signs, call your Transplant Coordinator:

- Increase in creatine or BUN lab values.
- Pain, discomfort or problems urinating.
- Urinating, but not able to empty the bladder completely.
- Blood in urine or a reddish-brown color.
- Changes in vital signs (blood pressure, pulse, temperature).
- Weight gain of 4 pounds in 1 or 2 days.
- Pain in the abdomen (stomach) area or lower back.

## Testing

Bring these records to a physical exam:

- Recent lab values.
- Record of your blood pressure, pulse, weight and temperature.

You will have blood and urine tests done. A kidney biopsy that removes a sample of kidney tissue will be taken. For more information, read, *Transplant Kidney Biopsy*, in this book.

## Treatment

If you have BK virus, your doctor may:

- Change your anti-rejection medicines.
- Give medicines to boost your immune system.
- Give you antiviral medicines to lower the amount of virus in the body.
- Give you antibiotics if a secondary infection has happened. BK virus can spread to the eyes, lungs or brain.

# Kidney Transplant Rejection

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**Rejection is most common in the first 6 months after transplant surgery, but it can happen at any time.** Treatment is most effective if rejection is caught early.

Your immune system is made up of white blood cells and antibodies. Together, they work to get rid of germs and disease that may be harmful to the body. The newly transplanted organ is viewed by the immune system as a foreign object that is harmful to the body. Your immune system will try to get rid of it, and this is known as rejection.

**Anti-rejection medicines must be taken every day, as ordered, to prevent rejection.** These medicines weaken the immune system, but they allow the body to accept the transplanted organ.

## Warning signs of rejection

Learn these signs of rejection while in the hospital, so you can be aware of them when you go home. **Call your Transplant Coordinator right away if you see any of these signs:**

- A fever over 101 degrees F or 38 degrees Celsius.
- Sudden weight gain of 2 pounds or more in 1 day, or 5 pounds or more in 1 week.
- Swelling in the face, abdomen, arms, hands, legs or feet.
- Not feeling well or constant fatigue.
- Decreased urine output, either going less often or passing less urine.
- High blood pressure - top number, called systolic pressure, is 160 or higher, or your pressures are trending higher than your usual readings.
- Elevated creatinine or BUN lab values.

If the transplant team thinks you may be having rejection, testing is done to check if rejection is happening in your kidney. Tests may include:

- More blood work to check your creatinine or BUN lab values.
- Ultrasound.
- Kidney biopsy.

## Treatments for rejection

**To reduce your chance of rejection, take your medicines as ordered every day, and do not skip doses. Have your blood tests taken as scheduled, and attend all follow up visits.**

Rejection is a part of transplantation. Although every precaution is taken to prevent it, rejection can still happen.

If your kidney shows signs of rejection, there are several treatment options:

- Dose or amounts of your anti-rejection medicine may be changed.
- Anti-rejection medicines may be changed.
- If a biopsy shows rejection, you may be hospitalized for more intensive care or treatment.

# Transplant Kidney Biopsy

If you have problems with your transplanted kidney, your transplant doctor may order a kidney biopsy, also called a renal biopsy. A needle is used to collect small pieces of kidney tissue to be checked in the lab. The tissue is checked under a microscope to find the cause of the kidney problem.

A kidney biopsy may be done for many reasons. It is often done to check why creatinine or BUN lab values are high or why protein levels are high in urine.

## To prepare for the biopsy

- If you take medicine to thin your blood, such as warfarin (Coumadin, Jantoven), clopidogrel (Plavix) or aspirin, you may be told to stop taking it before this test. Check with your doctor about when to stop and when to restart the medicine after the test.
- Take all of your medicines the morning of your test, except the blood thinners. Be sure to include your anti-rejection medicines and insulin, if you are on it.
- You may have a light breakfast on the day of test.
- Bring a list of all of your medicines. Be sure to include all prescription and over the counter medicines, and vitamin and mineral supplements.
- Bring any medicines you are scheduled to take through the rest of the day.
- **For your safety, you need to have an adult with you to take you home after the test. You should not leave alone or drive yourself.**

## The day of the biopsy

**Please be ready to spend most of the day in the hospital** because after your test, you will need to stay for a recovery time of 4 hours or more. This test takes 30 minutes to one hour. The staff will work to keep you comfortable during the test. Tell the staff if you have any discomfort.

- Be sure to use the bathroom to empty your bladder before this test.
- Your doctor will talk to you about the test and the risks of the test. Be sure to ask the doctor any questions you have about the test. You will be asked to sign a consent form.
- You will be awake during the test. Medicine is used to numb the skin over the kidney. You will lie on your back. The doctor will mark the entry site, clean the skin and inject a numbing medicine.
- The doctor will use ultrasound to find the right spot to put the needle into the kidney. You may feel a small “pop” as the needle enters the kidney. The doctor may need to collect more than one kidney sample.

## Where to check in for the biopsy

- **Register on the 2nd floor of Doan Hall in University Hospital.** After you register, you will go to Radiology Prep and Recovery.
- The nurse will prepare you for the test. This includes placing an IV line and drawing blood for routine labs.
- You will be taken to the procedure room for your test.

## After the biopsy

- You should lie on your back for about 4 hours. This is done to prevent bleeding at the site. You may have sips of water. It can be hard to eat when you are flat on your back, but try small bites.
- You may notice some blood in your urine after the test. Save the urine in the bathroom for the nurse to check for any bleeding.
- Your blood pressure and pulse will be checked often. The nurse will check any urine that you pass.
- Blood tests will be done to check your hemoglobin level. If too much blood was lost with bleeding, you may need a blood transfusion, but this is rare.
- If your test shows you need urgent treatment or there are problems after the biopsy, you will need to stay at the hospital. The most common concerns after biopsy are bleeding in and around the site or problems caused by the needle used during the biopsy. A fistula can occur if an artery or vein is injured during the test. Otherwise, when you are ready to go home, the nurse will talk to you about home care.

- **If you have mild pain or discomfort after the test, take acetaminophen (Tylenol)** as ordered on the medicine label. Do not take ibuprofen (Advil, Motrin) or naproxen (Aleve).
- Your doctor will get the test results in about 3 days. Your Transplant Coordinator or doctor will call you to talk about the results.

## Call your doctor right away if you have any of these signs:

- Feel faint or dizzy.
- Swelling or bloating in the abdomen.
- Pain gets worse at the test site, back or is not relieved by taking acetaminophen (Tylenol).
- Problems or difficulty urinating or blood in your urine for more than 24 hours after the test.
- Fever.

# Blood Tests

After transplant, regular blood tests are needed for the rest of your life. They are used to check:

- How your transplanted organ is working.
- Medicine amounts (doses) in the body to prevent organ rejection.
- Signs of possible rejection.
- Signs of infection or other problems.

Blood tests will be done often at first and then less often as determined by your doctor. Your transplant coordinator will talk with you about the lab work and tell you how often you need to have it done.

Months after transplant	Blood test schedule	
0 to 3 months	2 times each week (Monday and Thursday)	Moving to less frequent testing depends on your doctor's orders, your lab values and your overall health.
3 to 6 months	1 time each week	
6 to 12 months	1 time every other week (2 times a month)	
13 months or more	1 time a month	

## Your responsibilities

- **Work with your coordinator to find a lab near your home that can draw your blood and send the results to the Transplant Center.**
- **Take your lab order to your first lab visit.** Your lab order is good for 1 year. If your lab order changes, you will be given a new lab order. If you need a copy of your lab order, please contact your coordinator.
- Check and make sure that all ordered lab tests are drawn at each lab visit. If you have a problem getting your labs done, call your coordinator.

Follow the trend of your kidney function by checking your creatinine and BUN lab values. **If you see a sudden jump or drop in your lab values, call your coordinator right away.** Do not wait until your next doctor visit or lab check to talk about these findings.

# Who to Call with Problems

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## Call 911 right away or go to the nearest Emergency Department if you have:

- Chest pain.
- Shortness of breath.
- Other medical emergencies.

## Call the Transplant Center right away with urgent medical needs

Call 800-626-2538, 24 hours a day, 7 days a week if you have:

- A fever with oral temperature greater than 101 degrees F or 38 degrees C.
- Missed more than one dose of your anti-rejection medicines or have problems obtaining them.
- Nausea, vomiting or diarrhea for more than 8 hours or cannot keep medicine down.
- Dizziness or feel light-headed.
- Severe pain over the transplant site.
- Signs of infection at incision site, including redness, warmth, swelling, increased drainage or drainage looks like pus or smells bad.
- Weight gain of 2 pounds or more in 1 day or 5 pounds or more in 1 week.
- Bleeding from the incision site.
- Have high blood pressure where your top number or systolic pressure is staying at or above 160, or you see that your blood pressure readings are trending higher each day.
- Have a pulse of less than 60 or greater than 100.

If you call outside of normal clinic hours, stay on the line through the full message until the answering service picks up the call. The answering service will contact the on-call coordinator to call you about your problem.

## Call your transplant coordinator with non-urgent medical needs

Call your coordinator Monday through Friday between 7:30 AM and 4:00 PM at 614-293-8746 or 800-626-2538 to ask about any non-urgent medical needs, including:

- Medicine refills. **We request at least one week notice for prescription refills.**
- Financial or insurance issues.
- Questions or concerns.

## Call your primary care doctor with non-transplant related health concerns

These include:

- Preventive health maintenance.
- A common cold or flu.
- Minor skin infections.
- Constipation.
- Depression or anxiety.
- Hormone replacement therapy.

**Tell your transplant coordinator about any medicine that is ordered by your primary care doctor.**

# Your First Clinic Visit

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## Transplant Clinic Location

### Comprehensive Transplant Center

300 West 10th Avenue

11th floor, Suite 1150

Columbus, OH 43210

614-293-8746 or 800-626-2538

Valet parking is available in front of the building. You may also park in the 12th Avenue Parking Garage at 340 West 12th Avenue, Columbus, OH 43210. Ask for a discount parking voucher at the end of your clinic visit.

## Prepare for your visit

Please arrive on time and bring these materials to your first clinic visit:

- Your weight, blood pressure, pulse and temperature record.
- Your medicine list.
- Your glucose readings if you have diabetes.
- Any medicines you may need to take during the day if you get delayed at the clinic.
- A list of any questions you want to ask about during your visit.

## During your visit

- When you arrive at the clinic, sign in with the receptionist. Tell the receptionist what time you took your anti-rejection medicines. This is to ensure blood draws during the clinic visit happen at the right time. Blood draws may be before or after meeting with the transplant surgeon.
- You will have your vital signs checked by a patient care technician.
- You will meet with your transplant coordinator who will ask about your health.
- You will meet with the transplant surgeon, who will remove your staples.
- Before you leave the clinic, your next visit will be scheduled.
- After transplant, you need to have 2 blood draws each week for the first few months. As one blood draw is taken during the clinic visit, **you will only need 1 more blood draw this week.**

## After your visit

Your lab tests will be reviewed. You will be called if there are any changes that need to be made to your medicines, or if more testing is needed. A transplant scheduler will help you to make appointments for additional testing.

## Late arriving for visit or to reschedule

If you are going to be late for your visit or if you can not make it to your appointment, please call 614-293-8746 or 800-626-2538 for help.

# Your General Health Care

It is important to take care of your health after your transplant. Work with your transplant care team, primary care doctor and kidney doctor (nephrologist) to manage your care.

## Exercise

You will need to exercise regularly to combat the side effects of your anti-rejection medicines. Exercise is also good for your mental health and physical well being. Slowly increase your level of exercise over time to avoid strain and serious injury.

Before starting any exercise program, check with your transplant care team. They will help you plan an exercise routine that will best meet your needs.

**If you are exercising and you have any of these problems, stop the exercise until you talk with your transplant coordinator:**

- Pain or pressure in your chest, neck or jaw.
- Feeling tired even though you have been sleeping well.
- Feeling more shortness of breath.
- Dizziness or feeling light-headed during or after exercise.
- Irregular heart beats during or after exercise.

**If any of these problems persist after stopping exercise, call 911.**

## Emotional health

It is important to take care of yourself in the first months after transplant. You may have changes in emotions or moods from the new medicines and new routines.

Find positive ways to reduce stress and cope with your life changes. Let your transplant coordinator know if you need support.

Many transplant patients and their families find it helpful to talk with other transplant patients and families through support groups. Others find it helpful to seek some counseling with a social worker or counselor. Visit [www.lifelineofohio.org](http://www.lifelineofohio.org) for support group information, including meeting times and locations.

**If you ever start to feel hopeless, have trouble sleeping, eating or problems thinking, talk with your transplant doctor, social worker or coordinator about resources.** You may need changes in medicines, or there may be ways to cope with side effects of medicines.

**If you ever have thoughts of harming yourself or others, call your coordinator or go to the nearest emergency department for help.**

## Sexual activity

Talk to your transplant care team at your first clinic visit after surgery about resuming sexual activity. You may be told it is safe when you feel well enough to do so or when you can climb 2 flights of stairs with no symptoms. Sexual functioning may be affected by the medicines you are taking and your transplant. Use birth control to prevent pregnancy.

## Hair care

Cyclosporine, an anti-rejection medicine, may cause thicker, faster growing hair. **Wait at least 6 months before using over the counter hair removal products.**



## Sun exposure

Transplant patients have a high risk of skin and lip cancers. Since the risk increases over time, you must always protect your skin and lips from the sun's ultraviolet rays.

- Use skin protective factor (SPF) of 30 or greater in sun block and lip balm, and reapply often. You should apply sun block 30 minutes before outdoor activities and reapply every 2 hours while outside.
- Avoid time in the sun between 10:00 AM and 4:00 PM when the sun's rays are the strongest.
- Wear a hat with a 4-inch brim, long sleeve clothing, and pants or long skirts.
- Do not use tanning beds.
- Get your skin checked once a year by a Dermatologist or any time you see any changes in your skin.

## Travel

**Talk to your transplant care team about travel.** You may be told it is fine to:

- Be driven for short trips after discharge from the hospital when you are able to wear a seat belt with no discomfort.
- Drive locally in 2 to 6 weeks if you are off of all narcotic pain medicines.
- Do overnight trips in 6 weeks.
- Do longer trips of 3 days or more in 8 weeks.

**Talk to your transplant doctor about airplane travel.**

**If you plan to travel outside of the country, talk to your transplant coordinator to get the vaccines and medicines you need to prevent infections.** Travel to some countries may not be safe since you cannot get some vaccines. If you decide to travel without being vaccinated, your transplant care team will need to send a letter to your local passport bureau stating that you cannot receive the needed vaccines.

## Returning to work or school

Talk to your transplant care team at your clinic visits about returning to work or school. The timing will depend on your recovery and the type of work you do. Most transplant patients can return to work and continue their health benefits. You may need some job training before you can return to work. Be aware that disability benefits are available for a limited time. Talk to your social worker about your concerns.

## Dental care

- Anti-rejection medicines can cause infections in your mouth. **Brush your teeth 2 times a day and brush your tongue and top of your mouth each day** to prevent infection. **Floss your teeth each day** to help prevent gum disease.
- **Resume your routine dental care 3 months after your transplant.** Let your transplant coordinator know about dental appointments. Tell your dentist that you have had a transplant when having dental work done. **Antibiotics should be taken before all dental appointments to prevent infections.**
- **Call your transplant coordinator if you have sores, gum overgrowth or white patches in your mouth.**

## Eye care

- Prednisone, a steroid medicine, may cause some changes in vision. Cataracts can form. **See an eye doctor if you have any changes in your eyesight**, such as blurring or seeing halos around lights.
- See an eye doctor each year for a routine check up.
- **Report any vision changes or problems to your transplant coordinator.**

## Skin care

- **Call your transplant coordinator if you find any unusual skin growths, rashes or discoloration.**
- Prednisone and aspirin may make you prone to bruising. Be careful to avoid bumps and falls.

## Pregnancy

**Women should avoid pregnancy for at least one year after transplant.** Talk to your transplant care team or primary care doctor about birth control. Talk to your transplant care team about your plans for pregnancy, so health risks can be discussed.

## Caring for plants

**Avoid contact with live plants, mulch and soil during the first 3 months after your transplant.** Many organisms live and grow in the soil.

After the first 3 months, if you like to garden and work with plants, always wear gloves and a N-95 face mask when working in the soil. Wash your hands with soap and water after contact with plants and soil.

## Caring for animals

We know that pets can be an important part of your family. You will need to find a new home for pet birds, reptiles and turtles. For other pets, follow these safety tips:

- Do not handle animal waste.
- Do not clean litter boxes, cages and fish tanks.

Feces of some animals contain parasites. Fungus can grow in fish tanks.

## Tattoos and body piercings

**Getting tattoos and body piercings after transplant are highly discouraged due to the risk of infection.**

## Smoking and tobacco use

**Smoking and tobacco use should be avoided after organ transplant.**

Smoking is harmful to anyone taking anti-rejection medicines. It damages the transplanted organ(s) and can lead to an increased chance of infection. It can also increase the risk of cancer.

If you are a smoker, join a tobacco cessation program in your area and talk to your primary care doctor for support or call:

- Ohio Tobacco Quit Line at 1-800-QUIT-NOW (784-8669)
- Quit for Life program from the American Cancer Society Quit Line at 1-800-227-2345
- American Lung Association at 1-800-586-4872
- BeTobaccoFree.gov Smoking Quit Line at 877-448-7848

You may also call one of these Ohio State Clinics:

- Ross Heart Hospital Smoking Cessation Clinic at 614-293-0932
- The Lung Center, Tobacco Dependence Clinic at 614-293-4925

# General Medicine Instructions

After transplant, you will be taking many medicines. Take your medicines as ordered by your transplant and primary care doctors.

## Anti-rejection medicines

You will take anti-rejection medicines for the rest of your life. Your transplant doctors will adjust the doses of your transplant medicines based on the results of your lab values and vital signs.

**Do not miss any doses of your medicines. If you do miss a dose, you will need to carefully consider retiming that day's doses.**

- Take the missed dose up to 5 hours past the time it was scheduled, and then retime your medicines so they are spaced out throughout the rest of the day. Call your transplant coordinator if you have questions.
- Skip the missed dose if it is almost time for your next dose, and then go back to your regular schedule.
- **Do not ever take an extra dose of your anti-rejection medicine in an attempt to “catch up.”**

**If you are not able to take your medicine because of nausea, retry in an hour or two.** Try clear liquids and the BRAT diet (bananas, rice, applesauce and dry toast) to see if the nausea goes away. **If you are not able to take your medicine, or you are not able to keep it down after 2 to 3 hours, call your coordinator.**

After your transplant, your nurse will set up a self-administered medicine program for you in the hospital. This program will help you learn about your medicines — what they look like, what they are used for, when you take each medicine and about their side effects. You will be expected to take your medicines as if you were at home.

## Cautions

**Avoid grapefruit and pomegranate** as these fruits affect how some transplant medicines are absorbed in the body. **Read blended juice labels to check for these ingredients.**

**Do not take herbal products** after your transplant. Herbal products are sold as food supplements, and they are not checked like other medicines. Information on their safety, side effects or drug interactions are not always known. Some herbs can interact with your transplant medicines.

**Talk to your transplant doctor, pharmacist or transplant coordinator if you have any questions about the medicines you take.**

## Working with your primary care doctor

After transplant, you need to keep both your primary care and transplant doctor as health partners. They need to work closely with each other to adjust your other medicines.

**Tell your transplant coordinator right away if your primary care doctor:**

- Changes any doses of your other medicines.
- Starts you on a new medicine.
- Stops a current medicine.

This is done to keep your medicine record up to date.

Call your coordinator if you have questions about over the counter medicines.

# Names for Medicines Commonly Used after Transplant

Most medicines have both a generic and brand name. Hospitals and pharmacies can use either name to identify the medicine your doctor prescribes. This list has generic and brand names of some common medicines used after transplant. Check with your pharmacist, nurse or doctor to be sure you have the right medicine. **For some anti-rejection medicines, we request that you take the brand name version of the medicine only.**

Generic name	Brand name	Reason for taking
Azathioprine	Imuran	To prevent rejection
Belatacept	Nulojix	To prevent rejection
Clotrimazole	Mycelex	To prevent infection
Cyclosporine	Neoral, Gengraf	To prevent rejection
Docusate	Colace	To prevent constipation
Everolimus	Zortress	To prevent rejection
Sirolimus	Rapamune	To prevent rejection
Tacrolimus	Prograf, Hecoria	To prevent rejection
Prednisone		To prevent rejection
Mycophenolate mofetil	Cellcept	To prevent rejection
Mycophenolate sodium	Myfortic	To prevent rejection
Nystatin		To prevent infection
Sulfamethoxazole/Trimethoprim	Bactrim DS	To prevent infection
Valacyclovir	Valtrex	To prevent infection
Valganciclovir	Valcyte	To prevent infection
Voriconazole	Vfend	To prevent infection

# Paying for Your Medicines

Post-transplant medicines can be paid through private insurance, Medicare or Medicaid. These insurance and financial support programs will pay 80 to 100% of the cost of medicines.

We wish we could guarantee that all of the medicines you need for your transplanted organ will always be paid for. Unfortunately, we cannot make such a promise. The cost of medicines after transplant can be very high. Below are some suggestions to help.

- **Know what your insurance covers and any specific requirements for coverage.** Some insurance companies require that you use certain pharmacies and others offer better prices if you use one of their mail order companies. Many insurance policies have a Lifetime Maximum amount above which they will not pay for medicines. If you have any questions about your coverage, call your insurance provider or your place of employment. Medicare covers up to 80% of the anti-rejection medicines for as long as you are on Medicare. **Have a plan for how you will pay for the medicines and co-payments when Medicare no longer pays.** Do not wait until your Medicare coverage runs out to decide what to do. Then it is a crisis. Be aware of your Medicaid spend down and work with your caseworker at the Department of Human Services to make a plan to meet the spend down every month.
- **Include the cost of medicines in your monthly budget.** Know in advance whether you can afford your share of the cost.
- **Find out about sources of financial support to pay for your medicines.**
- **Do not wait until you are out of medicine or have only a few weeks left to find sources of support.** Most agencies provide service to many people, and they need time to process applications. It may take 8 to 10 weeks to get help from an agency.
- **Talk to your social worker to help you identify resources to help you pay for your medicines.** Call 800-626-2538 to talk with a social worker about your needs.

# Over the Counter Medicines

After your transplant, it is important that you:

- Do not take any herbal products.
- Do not take any medicine without first talking to your transplant provider, transplant coordinator, or pharmacist.
- Read medicine labels carefully as ingredients may change over time.

Listed are some medicines you can use for minor problems. If you have trouble finding a product or you have questions, ask the pharmacist for help. Follow the package directions for how much to take and how often. Ask the pharmacist if there is a less expensive generic product for a brand name product.

## Minor aches, pain, or headache

- Use acetaminophen (Tylenol), but do not take more than 2,000 mg in 24 hours.
- Read the medicine label of all drug products to see if acetaminophen is a listed ingredient. Do not take more than 2,000 mg in 24 hours.
- Do not take non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil, Motrin) or naproxen (Aleve) unless instructed by your transplant provider.

## Diarrhea

- Call your transplant coordinator if diarrhea lasts longer than 2 days.
- Use loperamide (Imodium) no more than 24 hours unless instructed by your transplant provider.

## Cough

- Use guaifenesin (Mucinex), dextromethorphan (Delsym), diphenhydramine (Benadryl), or a combination of guaifenesin and dextromethorphan (Be sure to read the medicine labels of Robitussin and Vicks products to identify ingredients).
- Read the medicine label of all drug products to see if acetaminophen is a listed ingredient. Do not take more than 2,000 mg in 24 hours.
- Do not take non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil, Motrin) or naproxen (Aleve) unless instructed by your transplant provider.

## Allergy, cold symptoms

- If you have high blood pressure, use Coricidin HBP Cough and Cold, diphenhydramine (Benadryl), loratadine (Claritin), cetirizine (Zyrtec), or a saline nasal spray.
  - Do not use products that contain pseudoephedrine, phenylephrine, or oxymetazoline, such as Sudafed, Dayquil, Alka-Seltzer Plus Cold and Cough, Claritin-D, Zyrtec-D, Cetiri-D, and Afrin unless instructed by your transplant provider.
- If you do not have high blood pressure, it is okay to use pseudoephedrine (Sudafed), phenylephrine (Sudafed PE), diphenhydramine (Benadryl), loratadine (Claritin, Alavert), cetirizine (Zyrtec), oxymetazoline (Afrin), or a product that contains a combination of these ingredients, such as Zyrtec-D, Cetiri-D, Alka-Seltzer Plus Cold and Cough, or Claritin-D.
- Read the medicine label of all drug products to see if acetaminophen is a listed ingredient. Do not take more than 2,000 mg in 24 hours.
- Do not take non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil, Motrin) or naproxen (Aleve) unless instructed by your transplant provider.

## Constipation

- Use psyllium (Metamucil), polycarbophil (Fiber-Con), polyethelene glycol (MiraLAX), docusate, (Colace), or bisacodyl (Dulcolax).
- Call your transplant coordinator if constipation lasts more than 3 days.

# Vaccines after Organ Transplant

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**Talk to your transplant team before you receive any vaccines. You may begin to get vaccines 6 months after transplant.**

Vaccines help to prevent disease. After getting a vaccine, your body makes antibodies as though you had been exposed to the disease. Vaccines may be given as a single dose or several doses given over time. The full number of doses for each vaccine must be completed for the vaccine to protect you from the disease.

Some vaccines are live virus, while others contain part of the dead virus or weakened bacteria. As a transplant patient, you have a weaker immune system (immunocompromised). **You are not allowed to have live virus or inhaled vaccines. No one else living in the household should have live virus or inhaled vaccines either to protect your health.**

Vaccines are safe medicines that rarely cause problems. Some side effects may occur, such as a sore or tender area at the injection site or a mild fever.

## Vaccines to avoid after transplant

This is an incomplete list, so **talk to your transplant care team before you receive any vaccines.**

- Inhaled influenza (live flu virus)
- Japanese encephalitis
- Measles, mumps and rubella (MMR)
- Oral polio (live poliovirus)
- Oral typhoid
- Shingles
- Varicella
- Yellow fever



# Nutrition and Diet

Take care of your transplanted organ by eating a healthy diet and following these nutrition guidelines. Talk with your doctor and dietitian about your nutrition needs.

## The first 2 months after transplant

Your body needs nutrition, especially protein, to promote healing, fight infection and build muscle. The carbohydrates and fat you eat give you energy to return to your normal activities.

You may not feel hungry or foods may taste different while you are taking large amounts of medicine. You still need to eat even if you have less of an appetite. Do not skip meals as this may slow your recovery.

**Eat smaller, high nutrient snacks every couple hours** instead of 3 meals each day if you do not feel hungry or have much of an appetite. **Choose nutrient dense foods, such as high protein foods.** Protein is one of the most important foods for your healing body. **Choose a protein food each time you eat.** High protein foods include:

- Lean meats, like beef, pork and poultry.
- Fish and seafood.
- Peanuts, nuts and nut butters.
- Dairy products, like milk cheese, yogurt and cottage cheese. Choose lactose-free if you are lactose intolerant.
- Beans, peas and tofu.
- Eggs.

Your doctor or dietitian may also order a nutritional supplement rich in protein and other nutrients.

**Avoid caffeine for 2 weeks and avoid alcohol.** Caffeine is a stimulant and raises blood pressure, putting stress on your

body after a transplant. Alcohol should be avoided after transplant. Alcohol can increase triglycerides in the blood and impair liver function. It can also interact with transplant medicines.

- **After 2 weeks, limit caffeine in the diet to no more than 1 serving a day for women or 2 servings a day for men.** One beverage serving equals 8 ounces.
- Talk with your transplant doctor about alcohol use.

## Taking care of your health

As you continue to heal, more changes will be needed in your diet to keep your transplanted organ healthy. If you have questions or concerns, please talk with your doctor or dietitian.

1. **Drink 3 liters (96 ounces or twelve, 8-ounce cups) of fluid each day** unless you have been instructed by your transplant care team to follow a different limit. Fluids are needed to prevent dehydration and to keep your body and especially your transplanted organ working well. Dehydration is also called fluid loss.
2. **Follow food safety guidelines and avoid foods and drinks that may put you at risk for infection.** What may be safe to eat for the healthy person can be a risk for a person that takes anti-rejection medicines. Use the general guidelines on the next page to prevent infection from the foods you eat. For more information, read, *Immunocompromised Diet Guidelines*, later in this book.

- **Dairy products** – Avoid drinking or eating food made with unpasteurized milk. Avoid soft cheeses like feta, Brie, Camembert or any cheese made with unpasteurized milk.
- **Eggs** – Eat eggs that are fully cooked. Avoid raw or under cooked eggs and foods that may contain raw or under cooked eggs, such as cake batter, cookie dough, Caesar salad dressing, mayonnaise and hollandaise sauce.
- **Meat and poultry** – All meat and poultry should be cooked, so the juices run clear. Avoid rare meats and pink animal meat.
- **Seafood** – Avoid all raw or under cooked oysters, clams or mussels. Make sure shellfish is well cooked and firm.
- **Fruits and vegetables** – Use a scrub brush to wash fruits and vegetables, even when you are not going to eat the peel or they are prepackaged. Avoid salad bars. **Do not drink unpasteurized fruit or vegetable juices or cider.**
- **Keep food prep areas clean and keep cooked and raw foods separate.** Clean cutting boards between cutting meats and vegetables. Be sure to clean counter surfaces well.
- **When dining out, order meat, seafood and poultry cooked well done.**

### 3. If you have nausea, vomiting or diarrhea, drink clear liquids and follow the BRAT diet for 8 to 12 hours.

- Clear liquids include water, lemon-lime soda and fruit juices that have no pulp like apple, grape and cranberry.
- **The BRAT diet includes bananas, rice, applesauce and dry toast.** These bland foods can help you ease back into your normal diet. Do not add dairy products, sugary or fatty foods right away until you are sure the vomiting and diarrhea has stopped.

### 4. Maintain a healthy weight.

To avoid weight gain:

- Get moving. Be as active as you can be.
- Eat smaller portions and avoid second helpings.
- Limit the amount of added fats eaten.
- Trim fat and skin from meats before cooking.
- Avoid high fat gravies and sauces.
- Avoid fried foods.
- Avoid cakes, cookies, sugary beverages and other sweets that are high in calories and low in nutrition.
- Choose high quality snacks, such as fresh fruits and vegetables and popcorn.
- Bake, broil, grill, poach, boil or microwave foods.

### 5. Limit sodium or salt.

Avoid food and drinks with a lot of salt. A low sodium diet is healthy for everyone. Many medicines needed for transplant health may cause fluid retention. Large amounts of salt in your body can make you retain fluids as well. Too much fluid in the body can lead to transplant problems. Choose as many fresh, unprocessed foods as possible. Look for no salt or low salt products. **Avoid salt substitute products as most contain potassium.** Spices and herbs can be used as alternatives to salt.

**AVOID these foods that are high in sodium:**

- Processed meats, like lunch meat, bacon and some cheeses.
- Canned foods, like soups, vegetables and sauces.
- Fast food and pre-packaged convenience foods, like macaroni and cheese.
- Chips and crackers with added salt.
- Foods with added sauces.

Ask your dietitian for more information about eating a low sodium diet.

## 6. Reduce and prevent high cholesterol.

Transplant patients are at risk for heart disease. One reason is the weight gain that some patients experience. Some transplant medicines can also raise cholesterol levels.

- Limit egg yolks to 4 per week or use an egg substitute.
- Use nonfat or low fat dairy products.
- Trim fat from meat. Avoid processed meats, like sausage, hot dogs and bacon. Remove skin from poultry.
- Eat fish and seafood.
- Avoid fried foods.
- Avoid butter, lard, shortening, ice cream and other sweets.
- Use moderate amounts of monounsaturated (olive, canola or peanut oil) or polyunsaturated (safflower, corn or sunflower oil) fats.
- Increase fiber in your diet. Fiber can help lower cholesterol levels. Choose whole fruits and vegetables and 100% whole grain breads, pastas and oats.

## 7. Avoid grapefruit and pomegranate.

These fruits or products that contain them affect how some transplant medicines are absorbed in the body.

**Read blended juice labels to check for these ingredients.**

## 8. Watch your potassium levels.

After a transplant, keep track of your potassium levels. Some medicines can make your body hold onto potassium. Other medicines, such as diuretics to lose water weight, can make your body lose potassium.

**If your potassium is too low**, eat more high potassium foods, such as:

- Bananas.
- Cantaloupes, honeydew melons.

- Dried beans and peas.
- Oranges and orange juice.
- Potatoes, both white and sweet.
- Prunes, prune juice.
- Raw broccoli, spinach.
- Tomatoes and tomato products, low sodium V-8 juice.

**If your potassium is too high**, eat less high potassium foods.

## 9. Prevent bone disease.

Calcium is a mineral that makes your bones and teeth strong. Steroids make it hard to absorb calcium. If you have low calcium levels, this may lead to fractures.

- Eat foods high in calcium. Three, 8-ounce glasses of low-fat milk provide most of the calcium you need each day. If you do not drink milk or eat dairy products, ask your doctor about taking a calcium supplement.
- Vitamin D is also needed, so your body can use the calcium you eat to build strong bones. Ask your doctor if you need to take a supplement.
- Weight bearing exercise, such as walking, can also prevent bone disease.

## 10. Talk to your doctor or dietitian about taking a multivitamin and avoid herbal supplements.

Many vitamins and minerals work together to keep your body healthy. Depending on your health and nutrition needs, you may need more than a multivitamin for your health.

When taking a multivitamin, read the label to see if it fits your nutrition plan. The vitamin should not provide more than 200% of the Recommended Dietary Allowance (RDA). If you take a multivitamin, be sure to take one for your age and gender.

# Immunocompromised Diet Guidelines

After transplant surgery, you will need to follow an immunocompromised diet, also called a low bacterial diet, to help decrease the amount of bacteria you eat. The anti-rejection medicines you take weaken your immune system. You will need to follow general food safety guidelines and avoid some foods to reduce your risk of getting sick from food.

## General food safety guidelines

The list below highlights food safety guidelines to follow. For a full list of guidelines, ask for the handout, *Food Safety Guide*.

- **Wash your hands and surfaces often when handling food.**
  - Wash your hands using warm water and soap. Rub your hands together with good friction for at least 20 seconds.
  - Use clean dishcloths every day. Bacteria grow easily in dirty, wet dishcloths.
  - Avoid using sponges to clean dishes and utensils. Sponges can hold germs that contaminate food and dishes.
- **Do not cross contaminate.** Use separate cutting boards, plates and utensils for raw and cooked foods.
- **When preparing food:**
  - Wash all fruits and vegetables thoroughly under running water with friction before peeling and cutting.
  - Cook foods to proper temperature. Use a food thermometer to test for doneness. Ask for the handout, *Food Safety Guide*, for more information.
  - Keep hot foods hot (above 140 degrees Fahrenheit) and cold foods cold (below 41 degrees Fahrenheit).
  - If a home or store bought canned food has a lid bulging, or if the food has any bad odors or looks strange after opening, throw it out!
- **Refrigerate foods right away.** Refrigerate only as much as can be eaten in 3 to 5 days. Freeze the rest within two hours of cooking!
- **Reheated foods should reach 165 degrees Fahrenheit or a rolling boil before being eaten.**
- **When storing food:**
  - Check expiration dates. Throw away foods older than their “use by” dates.
  - Throw away all prepared refrigerated foods after 4 to 5 days.
- **When in doubt, throw it out!**

## Eating guidelines by food group

### Milk and Dairy Products

Most dairy products sold in the grocery store are safe to eat.

#### Foods to AVOID:

- Moldy cheeses, like blue cheese and Gorgonzola.
- Probiotic yogurts, like Activia.
- Unpasteurized dairy and cheese products:
  - To tell if a dairy or cheese product is pasteurized, look at the food label. The label will either say “pasteurized” on it or the ingredient list will list “pasteurized milk” as an ingredient.
  - If you purchase items at a small, local dairy, ask if it is pasteurized.
  - If a dairy product is labeled as “raw” it most often means it is not pasteurized.

### Meat or Meat Substitutes

If your meat is cooked to the proper temperature, it is safe for you to eat.

#### Foods to AVOID:

- All raw or under cooked meats, seafood and eggs.
- Products containing raw or under cooked meats, seafood and eggs, such as sushi and homemade Caesar dressing.
- Raw or under cooked tofu sold in the refrigerated section.
  - Shelf stable tofu has been heat treated and is safe to eat without cooking.
- Refrigerated smoked seafood and pickled fish.
- Eggs with a runny yolk, such as over easy and poached eggs.
  - If you want to eat runny yolk eggs, you can purchase pasteurized in the shell eggs made by Davidson’s. They are called Davidson’s Safest Choice Pasteurized Eggs. To see if they are sold at any stores in your area, use their store locator available at [www.safeeggs.com/store-locator](http://www.safeeggs.com/store-locator).
- Deli meats, both pre-packaged and deli counter sliced meats, as well as hotdogs or sausages, unless heated to steaming before eating.

### Fruits and Vegetables

Most fruits and vegetables are safe for you to eat if you wash them well. Remember to also wash the skins of fruits that you peel.

#### To wash your fruits and vegetables:

- First inspect them to make sure they have no bruises, holes in the skin or signs of insect damage.
- Then run them under running water and rub with friction for 20 seconds. For extra dirty fruits and vegetables, like melon and potatoes, you can scrub with a soft brush to remove dirt.
- You do not need to peel the fruit or vegetable after washing it unless you prefer it this way.

#### Foods to AVOID:

- Unwashed fresh fruits, vegetables and herbs.

- Raw fruit with a rough texture, such as raspberries and strawberries.
- Unpasteurized fruit and vegetable juice.
- Restaurant or deli foods that contain raw fruits or vegetables. Pre-cut fresh fruits and vegetables should also be avoided unless you rewash them before eating.
- Uncooked, raw nuts and roasted nuts in the shell.
- All vegetable sprouts.

## Breads and Cereals

Breads and cereals are safe for you to eat.

### Foods to AVOID:

- Products with uncooked brewer's yeast, like unpasteurized beer.
- Avoid contact with raw yeast. You can eat any foods made with it. You just do not want to knead or mix dough with raw yeast due to the risk of breathing in the raw yeast.

## Water

- Do not drink well water. Ask your doctor if city water is safe for you to drink.
- You will need to drink bottled water in the hospital.
- When choosing bottled water, make sure that it has been treated to be safe. Look for a water that has been reverse osmosis treated, distilled and filtered through an absolute 1 micron or smaller filter or "one micron absolute."
- If you are told to drink bottled water, you should also avoid fountain soda pop because it is mixed with water that is not bottled.

Size of bottled water	Number of bottles needed for <b>3 liters</b> each day	Number of bottles needed for <b>2 liters</b> each day
8 ounces	12	8
16.9 ounces	6	4
20 ounces	5	3
24 ounces	4	3
32 ounces	3	2

## Other Foods to AVOID

- Raw or unpasteurized honey.
- Avoid salad bars, buffets, bulk food bins in stores, food samples or snacks that are out in the open where others may touch them.
  - If you are going to a family function where the food will be set out "buffet style", you can still eat. Try to be one of the first people though the line to make your plate.
- Unpasteurized miso products. Most commercial miso products are fine to eat.
- Yerba Mate tea.

**If you have questions or concerns about food safety or foods to avoid on this diet, please talk with your doctor or dietitian.**

# Activity Guidelines

Use these guidelines after transplant surgery to help you return to activities. You will gradually start to take care of yourself and walk while you are in the hospital. Activity makes your muscles stronger and improves how your heart and lungs work. You will know when to do more activities by checking how your body tolerates each activity.

## Walking and exercise

After you go home, walk as much as you were doing before you left the hospital. Slowly increase the distance and speed or pace of your walking. You should walk every day.

- Walk on level ground. If you must walk up hills, slow your speed.
- Plan where you will walk before you start. Consider the distance to get back, so you do not get too tired.
- Walk after a rest period. Do not walk right after you eat or after vigorous activity.
- **In the winter**, walk in late morning or early afternoon when it is warmest. Cover your mouth and nose with a scarf. Avoid walking against the wind.
- **In bad weather**, walk inside, such as in your home, office, hallways or shopping mall.
- **In the summer**, walk during the coolest part of the day. Avoid walking when the humidity is high.

## Sexual activity

- You may have sex when you feel comfortable enough to do so.
- Women who did not have regular periods often begin to have periods within 6 months after surgery.

- Talk to your doctor before starting any birth control. A woman can get pregnant even without menstrual periods.
- Unplanned pregnancies are highly discouraged and can be dangerous. If you become pregnant, call both your gynecologist and transplant doctor right away.
- Women should get a Pap smear at least once a year or as ordered by their doctor. This is a routine check for cancer of the cervix. Women should also do a self-breast exam once a month.
- Men who have been impotent or unable to have an erection may regain sexual function after the transplant. If impotency persists 6 months after surgery, talk to your transplant doctor or nurse.
- Men should do once a month self-testicular exams and have a yearly physical exam.

## Driving

**No driving for at least 2 weeks after your transplant.** Before you start driving, you must be off of all narcotic pain medicines. You must also be able to turn your head to see the side mirrors and wear a seat belt with shoulder strap with no discomfort. You must also be able to apply pressure to the pedals quickly and without pain. When you begin to drive, start with short drives, so you do not get too tired.

## Lifting

We can not stress enough the amount of time the body needs to heal after a transplant. **Your body needs 3 months to heal. Do not lift, push or pull anything that weighs more than 10 pounds for 6 weeks.**

A gallon of milk weighs 8 pounds.

Avoid movements or activities that put pressure on your chest, such as using a shovel or pushing a lawn mower.

- Get firm footing by placing your feet shoulder width apart.
- Bend at your knees, not at your waist.
- Lift with your leg muscles. Keep your back straight and avoid any twisting motion.
- Exhale as you lift. Do not hold your breath.
- Keep the load close to you to prevent back strain and to limit the amount of work your arms have to do.
- Think before you lift. Get help if the load is too heavy or bulky for you to lift alone. Always push a load, do not pull.

## Stair climbing

- Climb one step at a time pausing a few seconds between each step.
- If effort symptoms develop, stop and rest where you are.
- Arrange your schedule, so you are not going up and down stairs often. This activity requires your body to work harder.
- As your activity tolerance increases, you may climb stairs more frequently and at a faster pace.

## Household tasks

- When you are comfortable, you can gradually return to light household work. Dusting, washing dishes, cooking and sweeping are light work.
- **Do not to lift, push or pull anything heavier than 10 pounds for the first 6 weeks.** A gallon of milk weighs 8 pounds. This means you may not be able to carry wet clothes or groceries.
- Only you know when you have done too much. If you feel tired or if you begin to have pain, stop and rest.
- **Wait until after the first 3 months to do heavy household chores, like vacuuming and heavy yard work.**

## Recreation

- When you return to recreational activities, **remember not to lift, push or pull anything heavier than 10 pounds for 6 weeks after your surgery.** A gallon of milk weighs 8 pounds.
- After three months, you can play sports except contact sports. Examples of contact sports are football, wrestling, hockey and boxing.
- If you want to play softball or baseball, place a protective pad over the transplant. These pads are available at sporting goods stores.
- Remember to stay hydrated and drink plenty of fluids when exercising.



## Other activities

Activity	Time can start	Comment
Be driven in a car	As soon as discharged	Short distance when you are able to wear a seat belt with no discomfort.
Walk inside the house	As soon as discharged	Walk 3 to 5 times a day for 5 minutes each time.
Climb 1 flight of stairs	As soon as discharged	Pause between each step.
Sit in the yard	As soon as discharged	In comfortable weather.
Walk in the yard	As soon as discharged	Leisurely walk 5 to 10 minutes.
Attend religious services	5 to 7 days	Avoid people who show signs of illness.
Alcoholic drinks		Talk to your Transplant Doctor about any alcohol use.
Walk around 2 blocks	1 to 2 weeks	Leisurely pace for 5 to 10 minutes.
Walk dog	1 to 2 weeks	If dog doesn't pull leash.
Visit friends	1 to 2 weeks	Short drives or walks.
Make bed, cook, clean-up	1 to 2 weeks	Do each activity slowly as you recover.
Dusting	2 weeks	
Attend movie or play	2 weeks	
Shopping	2 to 3 weeks	Do not carry bags. Walk short distances of 10 minutes then rest 5 minutes and repeat.
Restaurant dinner	2 to 3 weeks	Watch what you eat! Refer to your diet and food safety guidelines.
Drive locally	2 weeks or as directed	Refer to driving activity guidelines.
Sexual relations	6 weeks or after first clinic visit after surgery	When you can climb 2 flights of stairs with no symptoms.
Grocery shopping	3 to 4 weeks	Carry no more than 5 pounds at a time.
Laundry	3 to 4 weeks	Do one load at a time. Ask for help to put wet clothes in dryer. Do not carry laundry up or down stairs for 6 to 12 weeks.
Water lawn	3 to 4 weeks	
Put out trash	4 to 6 weeks	Small size bags, one at a time that are not more than 5 to 10 pounds.
Return to work	Depends on type of work	Talk to your Transplant Doctor.
Lift no more than 5 to 10 pounds	6 weeks or as directed	Talk to your Transplant Doctor about lifting restrictions.
Attend recreational games	6 weeks	In comfortable weather. Be aware of the crowd and avoid anyone who is ill.

Activity	Time can start	Comment
Overnight trips	6 weeks	Talk to your transplant doctor.
Airplane travel		Talk to your transplant doctor.
Golf with riding cart	6 to 8 weeks	In comfortable weather. Start with putting, chipping and then 9 holes.
Longer trips of 3 days or more	8 weeks	
Swimming <b>NO HOT TUBS and NO SAUNAS.</b>	10 to 12 weeks	In large bodies of water (no small lakes or ponds due to bacterial growth). After incision is completely healed. Go in slowly and do not jump in.
Vacuum	12 weeks	Do not vacuum for the first 6 weeks.
Mowing lawn, push	12 weeks	Talk to your transplant doctor.
Play recreational sports	12 weeks	Talk to your transplant doctor and drink plenty of fluids for hydration.
Golf with pull cart	12 weeks	In comfortable weather. Start with putting, chipping and then 9 holes.
Motorcycle riding	12 weeks	Talk to your transplant doctor.
Gardening	After 6 months	<p><b>Avoid contact with live plants, mulch and soil during the first 6 months after your transplant.</b> Many organisms live and grow in the soil.</p> <p>After the first 6 months, if you like to garden and work with plants, <b>always wear gloves and N-95 face mask when working in the soil.</b> Wash your hands with soap and water after contact with plants and soil.</p>

# Your Risk for Diabetes after an Organ Transplant

Some of the medicines you take after organ transplant can increase your risk for diabetes. If you had diabetes before your transplant, you may have some problems controlling your blood sugar after your transplant because of these medicines. Control of your blood sugar is key to protecting your new organ. Learn more about diabetes and work with your healthcare team to check your blood sugar.

## Diabetes is most common in people who are:

- Overweight.
- Not active.
- Over 40 years of age.
- Related to someone with diabetes.
- Pregnant.
- African American, Asian American, Hispanic, Native American or Pacific Islander.
- Women who delivered babies weighing more than 9 pounds or who had diabetes during pregnancy.
- Transplant recipients.

## About diabetes

Diabetes is a disease where your body is not able to use the foods you eat for energy to keep your body working. Your body's cells need fuel to grow and live. This fuel comes from the foods you eat. Your body breaks down most of the foods you eat into a form of energy called glucose. Glucose is another word for sugar and is also called blood sugar. Insulin is a hormone that helps glucose move from your blood stream into your body's cells. Your pancreas makes insulin. A person cannot live without insulin.

When a person has diabetes, there are problems with how the body uses glucose and insulin. The most common problems are:

- The pancreas does not make insulin.
- The pancreas does not make **enough** insulin.
- The body is not able to use the insulin that it makes.

Diabetes is a chronic disease. There is no cure, but it can be treated and controlled.

## Warning signs of diabetes

- Having to pass urine often.
- Feeling thirsty, even though you are drinking fluids.
- Losing weight.
- Blurry vision.
- Healing is slow for cuts or scrapes on your skin.
- Feeling tired.
- Feeling hungry.
- Being irritable or grumpy.

Often people have no signs of diabetes. About 1/3 of the people with diabetes do not know that they have the disease. If you think you may be at risk, talk to your doctor or nurse about having your blood sugar checked.

## Treatment for diabetes

Most often, diabetes treatment includes:

- Diet changes to balance the amount and types of food your body takes in during the day.
- Checking your blood sugar results with a home blood sugar monitor.
- Exercising for 30 to 60 minutes at least 3 times each week.
- Weight control to help your body use its own insulin better.
- Medicines to help control your blood sugar.

## Learn more about living with diabetes

Living with diabetes is not easy, but you can learn to keep your blood sugar under control to live a long, healthy life. Work with your doctor, nurse and dietitian to learn more about living well with diabetes.

Talk with your doctor about your treatment after transplant to lessen problems you may have from diabetes. Be sure to have your blood sugar checked when you see your doctor, so you can start or change treatment to help control your diabetes.

Exercise can help prevent or control diabetes. If you are overweight, weight loss can help you to reduce your risk of diabetes or to control your blood sugar if you have diabetes.

For diabetes education programs to learn more about living with diabetes, talk to your doctor about a referral and call 614-685-6251 to register. You might also check with the American Diabetes Association or your local hospital for classes.

# Abdominal Hernia

## Prevention and Treatment

After transplant, it will take months for the incision to heal. Healing may be slower after transplant because of the immune suppression medicines you take. While these medicines help to prevent organ rejection, they also make it harder for wounds to heal.

One problem that can happen after surgery is a hernia. A hernia is a hole in the abdominal wall. It occurs when the wound does not close completely.

### Prevention

Follow these activity guidelines after surgery to prevent a hernia:

- Do not lift, push or pull more than 10 pounds for at least 6 weeks after surgery. For example, a gallon of milk weighs about 8 pounds. This time may be extended to 3 months after transplant.
- If you need to bend over, hold your abdomen for support. Bend at the knees and use your leg muscles.
- You may need to **wear an abdominal binder when you are out of bed** to support your belly muscles while you heal. Wear the binder for 2 to 4 weeks or when your doctor tells you it is okay to stop.
- When coughing, hold a pillow over your abdomen for support. If you have severe coughing, call your transplant coordinator for help.
- Eat healthy foods at meals to help with wound healing.
- Avoid tobacco products. Tobacco prevents wound healing.

### Call your transplant coordinator right away at 800-626-2358 if you have any of these signs:

- Bulge or swelling in the stomach or abdomen area.
- Pain or discomfort in the abdomen that gets worse.
- Any signs of infection in the incision area, such as redness, swelling, drainage or pus, or if you have a fever with any of these signs.
- Staples or sutures closing the incision come out before your post-transplant clinic visit.

## Treatment

Your incision will be checked during a physical exam. Tests, such as x-ray, computerized tomography (CT) scan or other tests may be used to check the abdominal wall.

Your doctor will tell you if surgery is needed. Surgery is often needed to repair a hernia when:

- The intestines are blocked in the opening of the hernia.
- The hernia is too large to close on its own.
- There is a lot of pain or discomfort from the hernia, due to size or pressure on the abdomen.

If surgery is needed, the surgeon may close the hernia with sutures or mesh. Sutures hold the abdominal wall together to help with healing. Mesh is a woven fiber that is laid over the hernia to help hold the abdominal wall together. You may hear your doctor call the mesh a “patch” or a “screen.” Using mesh to close the hernia is also known as a hernioplasty. The incision may be closed again with staples.

Rarely, the area where the intestines have been blocked may also need surgery. If the intestines are twisted or if stool has become trapped, a bowel resection is also done as part of the hernia repair. Resection means that the part of the intestines affected are removed.

## Follow-up care for hernia repair

Follow your treatment plan until the hernia heals. You may need to take antibiotics to prevent infection. Do not stop taking your anti-rejection medicines to protect your transplant.

**If you have questions, call your transplant coordinator.**

# Organ Transplant and Cancer

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Cancer is abnormal cells in a part of the body that grow out of control. Organ transplant increases your risk for cancer. It is not the transplanted organ that increases the risk, but these post-transplant issues:

- Anti-rejection medicines taken to protect your transplanted organ can make it harder for your body to fight infection. If you had a virus before your transplant, a weakened immune system may let the virus become active again. Once active, viruses may increase your risk for cancer.
- Some organ transplant medicines, that are helpful for the transplanted organ, can be harmful to other body systems. Changes in normal healthy cells may lead to cancer.

## Common cancers

Cancers that may develop in people after organ transplant include:

### Blood cancers

- Transplant patients are at risk for Non-Hodgkin's lymphoma, a type of cancer that grows in the lymphatic system. Lymphocytes are special white blood cells that fight against germs (bacteria and viruses). They have an important role in protecting your immune system.
- If you have Epstein-Barr Virus (EBV), this can cause Hodgkin's lymphoma. **If you feel like you have the flu, with fever, chills, fatigue and cold night sweats, or swollen lymph nodes in the body, call your transplant coordinator right away.** Other common signs are itchiness all over the body, weight loss and constant sweating.

- Another type of blood cancer is Kaposi's sarcoma, which can be caused by Human Herpes Virus (HHV) or Human Immunodeficiency Virus (HIV). Kaposi's sarcoma causes small tumor growths in tissue under the skin. They may look red or purple, may be painful and can bleed. Tumors can cluster into larger patches and need ongoing treatment.

### Skin cancer

Organ transplant patients are at risk for skin and lip cancers. The risk increases over time. Your risk for skin cancer increases the longer you take anti-rejection medicine.

- Use sun protective factors (SPF) of 30 or greater in sun block and lip balm, and reapply often. You should apply sun block 30 minutes before outdoor activities and reapply every 2 hours while outside.
- Avoid time in the sun between 10:00 AM and 4:00 PM when the sun's rays are strongest.
- Wear a hat with a 4-inch brim, long sleeve clothing, and pants or long skirts.
- Do not use tanning beds.
- Get your skin checked once a year by a Dermatologist or any time you see any changes in your skin.

## Lung cancer

Lung cancer is also a risk, but more common among people who have had a lung transplant. Cancer in the lungs may be from disease in the non-transplanted lung that has been activated by transplant medicines.

- **If you have a cough that gets worse, blood when coughing, trouble breathing or pain or pressure in the chest, call your transplant coordinator right away.**
- **If you have severe breathing problems or are gasping for breath, call 911 or go to the nearest emergency room.**

## Kidney cancer

Kidney cancer is a risk among all organ transplants. Signs of kidney cancer can include blood in your urine, difficulty or pain when urinating, back pain, or pain or swelling in the abdomen. **If you notice any changes in how your kidneys are working, call your transplant coordinator.**

## Liver cancer

The most common cause of liver cancer is chronic or long-term infection with the Hepatitis Virus. **If you have changes in weight, nausea or vomiting, pain in the abdomen or skin looking yellow (jaundice), call your transplant coordinator right away.**

## Cervical cancer

HPV is a risk factor for the development of cervical cancer. **If you have bleeding from your vagina that is not normal, or have a change in your menstrual cycle (monthly period) or have pain or bleeding from sexual relations, call your primary care doctor or gynecologist for follow up care.** To protect your health, have a Pap smear as part of your yearly pelvic exam.

## Anal cancer

HPV and HIV are risk factors for the development of anal cancer. Anal cancer is less common than other cancers. The anus is the opening at the end of the rectum. **If you have signs of blood in your stool, bleeding around your anus, pain or pressure around the anus, or a lump near the anus, call your primary care doctor right away to schedule a visit.**

## Testing and treatment

After a physical exam, tests will be ordered by your referring doctor. If this is not your primary care doctor, reports of tests can be sent directly to him or her. Always call your transplant coordinator about changes to your health.

Treatment can be given for cancer while protecting your transplanted organ. You may need different treatments depending on the type of cancer you have.



# Lifeline of Ohio

## Support Groups and Volunteers

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### Support Groups

Buckeye GIFT (Giving Inspiration For Transplantation) Network has open meetings for support, education, awareness and advocacy. Anyone whose life has been touched by organ and tissue donation and transplantation may attend monthly meetings. Please visit [www.lifelineofohio.org](http://www.lifelineofohio.org) for more information and to confirm meeting times and locations.

- **Buckeye GIFT Central:**

Meeting place: Lifeline of Ohio, 760 Kinnear Road, 2nd Floor, Columbus, OH 43212.

Meeting time and day: 6:30 PM to 8:00 PM on the second Thursday of every month.

Contact: [volunteers@lifelineofohio.org](mailto:volunteers@lifelineofohio.org).

In February, October and December, Lifeline of Ohio visits transplant patients at Ohio State's Wexner Medical Center. These visits replace regular meetings. Please contact Lifeline of Ohio for more information.

- **Buckeye GIFT East:**

Meeting place: Genesis Health Center Community Room, 61353 Southgate Parkways (State Route 209), Cambridge, Columbus, OH 43725. The meeting place varies, so please contact Kathy for the specific location.

Meeting time and day: 6:30 PM to 8:00 PM on the third Thursday of every month.

Contact: Kathy Warhola at 800-525-5667, ext. 344 or by cell at 740-680-3190

- **Buckeye GIFT Mid-Ohio:**

Meeting place: OSU Mansfield Campus, Riedl Hall, Room 153.

Meeting time and day: 7:00 PM to 8:00 PM on the second Tuesday of every month.

Contact: Amy Baden at 800-525-5667, ext. 348.

- **Buckeye GIFT Southern, Chillicothe:**

Meeting place: Adena Regional Medical Center Hopewell Room, 272 Hospital Road, Chillicothe, OH 45601.

Meeting time and day: 6:30 PM to 8:00 PM on the second Thursday of every month.

Contact: [volunteers@lifelineofohio.org](mailto:volunteers@lifelineofohio.org).

- **Buckeye GIFT Southern, Athens/Meigs:**

Meeting place: The meeting place varies, so please contact John for the specific location.

Meeting time and day: 7:00 PM to 8:00 PM on the third Monday of every month.

Contact: John Bise at 740-797-2402.

## Volunteers

You may want to become a Donate Life Ambassador to help Lifeline of Ohio promote organ and tissue donation. Organ recipients, donors, family members and others that believe in the cause are welcome to volunteer.

There are many ways to offer support:

- Office projects, including mailings, assembly, special events and scrapbooks.
- Educational programs, including schools, civic organizations, churches, hospitals, businesses, health fairs and other interested groups.
- Media interviews.
- Visit newly transplanted patients.
- Take part in special events, such as National Donate Life Month (April), Candlelight Vigil, National Donor Sabbath, National Minority Donor Awareness Day and the Dash for Donation.
- Delivering materials to the BMV offices, doctor's offices, hospitals, etc.
- Donor family quilt projects.

To learn more about being a Lifeline of Ohio volunteer:

- Visit their website at [www.lifelineofohio.org/volunteer](http://www.lifelineofohio.org/volunteer).
- Call the volunteer coordinator at 800-525-5667 ext. 375.

Become a vital volunteer and share a special bond as you work to promote organ and tissue donation in the community.







<b>Date</b>	<b>Time</b>	<b>Weight</b>	<b>BP</b>	<b>Pulse</b>	<b>Temperature</b>



# My Notes

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