



# **Living With Your Transplant: Kidney/Pancreas**



**THE OHIO STATE UNIVERSITY**  
WEXNER MEDICAL CENTER



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**This book is for informational purposes only. Talk to your healthcare provider if you have any questions about your care.**

For more health information, go to [wexnermedical.osu.edu/patiented](http://wexnermedical.osu.edu/patiented) or contact the Library for Health Information at 614-293-3707 or [health-info@osu.edu](mailto:health-info@osu.edu).

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or go to [go.osu.edu/pted3541](https://go.osu.edu/pted3541).



# Congratulations on Getting Your Transplant

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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 also 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.

**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 explain it in another way.

**You will be on anti-rejection medicines that you need to maintain your transplant. These medicines must be taken as ordered every day. You need to call the Transplant Center if you are not able to take your medicines for any reason.**

## Transplant center contact numbers

Main number:  
614-293-8746  
Monday to Friday  
7:30 a.m. to 4 p.m.

24-hour pager:  
800-626-2538

## My transplant information

Date of my transplant:

\_\_\_\_\_

My post-transplant coordinator's name:

\_\_\_\_\_

My transplant doctor's name:

\_\_\_\_\_

My primary care doctor's name:

\_\_\_\_\_

# My Responsibilities After Organ Transplant

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I have agreed to these new responsibilities to protect my health and transplant:

- **Review the contents of this book** and become familiar with the lifestyle changes I will need to maintain after transplant surgery.
- **Call my transplant coordinator right away with any health changes.** I know my immune system is suppressed and weaker, and infections are serious.
- **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 1 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.
- **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.

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Signature

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Date

# Your First Clinic Visit

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## Arrive at least 15 minutes before your appointment time with:

- Your driver's license or other form of ID and your insurance card(s).
- 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 in case you get delayed at the clinic.
- A list of any questions you want to ask at your visit.

## During your visit

- When you arrive, sign in with the receptionist and tell them what time you took your anti-rejection medicines. This is to make sure 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.
- You will meet with your transplant coordinator who will ask about your health.
- You will meet with the transplant surgeon, transplant nephrologist, or an advanced practice provider who will review your progress and discuss future treatment plans.
- Your staples will be removed during a follow up visit as set by your provider.
- Your next visit will be scheduled.
- You need to have 2 blood draws each week for the first few months. One blood draw is taken during the clinic visit, so **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 make appointments for more testing.

## Transplant clinic location

### Comprehensive Transplant Center

300 W. 10th Ave.  
11th floor, Suite 1150  
Columbus, OH 43210

614-293-8746 or  
800-626-2538

- You can use valet parking in front of the building for a small fee.
- You may also park for an hourly rate in the 12th Ave. Parking Garage at 340 W. 12th Avenue, Columbus.
- Ask for a discount parking voucher at the end of your clinic visit.

## Arrive late or need to reschedule?

If you are going to be late for your visit or if you cannot make it to your appointment, please call:

**614-293-8746** or  
**800-626-2538**

to reschedule.

# Lab Work Appointments

Mondays and Thursdays for First 3 months

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## Blood tests are important

Lab work is to be done every Monday and Thursday for the first 3 months after transplant. After that, regular blood tests are needed for the rest of your life. These check for:

- How your transplanted organ is working
- The amount of medicine in your body to prevent organ rejection
- Signs of possible rejection
- Signs of infection or other problems

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

Medicine name	Lab day instructions
Tacrolimus (Prograf)	Take medicine AFTER labs draws

## 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.

## Testing less often over time

- Your doctor will change how often you need to have your lab work as you live with your transplanted organ.
- Moving to less often blood testing depends on your lab values, your overall health, and your doctor's orders.

# Transplant Medicines

After your transplant, you will take immunosuppression medicines to keep your transplanted organ healthy and prevent rejection.

- It is important to take these medicines correctly to prevent organ rejection. Never stop taking your medicines without talking to the transplant team first.
- Do not start any new medicines, vitamins, or supplements without talking to your transplant team.
- If you are able to become pregnant, please talk about birth control with your transplant team to avoid an accidental pregnancy. Mycophenolate mofetil and mycophenolate sodium may lead to birth defects or risk of pregnancy loss in the first trimester. If you do accidentally become pregnant, tell your transplant team right away.

Medicine: generic (brand)	What it is used for	Possible side effects	Tips
Tacrolimus (Prograf)	Prevents rejection	<ul style="list-style-type: none"> <li>• Headache</li> <li>• Tremor/shakiness</li> <li>• High potassium level</li> <li>• Low magnesium level</li> </ul>	Take medicine AFTER your lab draws. Dose will be adjusted based on the level in your blood.
Mycophenolate mofetil (CellCept)	Prevents rejection	<ul style="list-style-type: none"> <li>• Upset stomach, nausea, or diarrhea</li> <li>• Low white blood cells</li> </ul>	
Prednisone (Deltasone)	Prevents rejection in certain patients	<ul style="list-style-type: none"> <li>• Increased blood sugar and blood pressure</li> </ul>	
Valganciclovir (Valcyte) -- or -- Acyclovir (Zovirax)	Prevents infections caused by common viruses	<ul style="list-style-type: none"> <li>• Low white blood cells (valganciclovir)</li> </ul>	Take acyclovir with a full glass of water
Sulfamethoxazole/Trimethoprim (Bactrim)	Prevents a type of lung infection	<ul style="list-style-type: none"> <li>• Rash</li> <li>• High potassium levels</li> <li>• Sun sensitivity</li> </ul>	Take with a full glass of water. Wear sunscreen when outside.
Nystatin (Mycostatin)	Prevents a mouth infection, called thrush	<ul style="list-style-type: none"> <li>• Nausea</li> </ul>	Swish for at least 30 seconds and swallow after meals and at bedtime.

# 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, also called immunosuppressants, 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.



- **Do not miss any doses of your medicines.**
  - If you do miss a dose: If it is less than 4 hours late, take your medicine as soon as you remember. Take your next dose at the regularly scheduled time. If it is more than 4 hours late, skip that dose and take your next dose at the regularly scheduled time. Let your coordinator know if you miss more than 1 dose.
  - Do not ever take extra doses of your anti-rejection medicine or attempt to “catch up.”
- If you are not able to take your medicine because of nausea, try again in an hour or two.

**If you are not able to get or take your medicines for any reason, please contact your coordinator for recommendations.**

## Working with your primary care doctor

After your 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. Learn more about these on page 16.**

# Paying for Your Medicines

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Post-transplant medicines can be paid through private insurance, Medicare, or Medicaid. The cost of medicines after transplant can be very high.

## Here are some ways to help with the cost

- **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.

- **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 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.
- **Please reach out to your coordinator if you are concerned about the costs of 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

## Overall guidelines after transplant

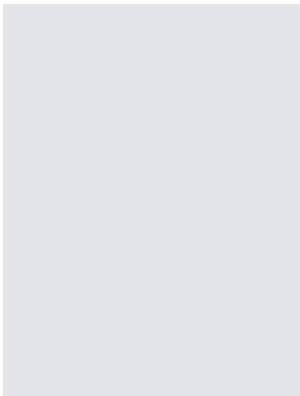
- Do not take any medicine, including herbal medicine, dietary supplements, or vitamins, without first talking to your transplant provider, transplant coordinator, or transplant pharmacist.
- Read medicine labels carefully as ingredients may change.
- Follow the package directions for how much to take and how often.
- Read the medicine label of all drug products to see if acetaminophen is a listed ingredient.
- Do not take more than 3000 mg of acetaminophen (Tylenol) in 24 hours.

## Medicines for minor problems

Listed below are medicines you can use for minor problems. If you have trouble finding a product or have questions, ask the pharmacist for help. When in doubt, reach out to your coordinator.

Symptom	Medicines
Minor aches, pain, or headache	<ul style="list-style-type: none"><li>• acetaminophen (Tylenol), but no more than 3000 milligrams in 24 hours</li><li>• <b>Do NOT</b> take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil, Motrin) or naproxen (Aleve)</li><li>• Low doses of aspirin (81 mg or 325 mg once daily) are safe. Do not take any extra aspirin for pain</li></ul>
Diarrhea	<ul style="list-style-type: none"><li>• ioperamide (Imodium). Do not use for more than 24 hours unless directed by your transplant coordinator</li><li>• Call your coordinator if diarrhea lasts more than 8 hours</li></ul>
Upset stomach	<ul style="list-style-type: none"><li>• famotidine (Pepcid)</li><li>• simethicone (Gas-X)</li></ul> <p>Ask your coordinator before taking any antacids such as calcium carbonate (Tums, Alka-Seltzer, Rolaids)</p> <p><b>Do NOT</b> take bismuth subsalicylate (Pepto Bismol) or cimetidine</p>
Cough	<ul style="list-style-type: none"><li>• guaifenesin (Mucinex)</li><li>• dextromethorphan (Delsym)</li></ul>

Symptom	Medicines
Constipation	<ul style="list-style-type: none"> <li>polyethylene glycol (MiraLAX)</li> <li>docusate (Colace)</li> <li>bisacodyl (Dulcolax)</li> <li>psyllium (Metamucil)</li> <li>senna (Senokot)</li> </ul>
Allergy or cold symptoms	<ul style="list-style-type: none"> <li>oratadine (Claritin)</li> <li>cetirizine (Zyrtec)</li> <li>fexofenadine (Allegra)</li> <li>diphenhydramine (Benadryl)</li> <li>saline nasal spray</li> <li>phenol (Chloraseptic) lozenges or numbing spray</li> </ul> <p><b>Do NOT</b> take products that contain pseudoephedrine, phenylephrine, or oxymetazoline. Avoid any products with a decongestant or “D” in the name of the medicine</p>
Sleep	<ul style="list-style-type: none"> <li>melatonin</li> </ul>
Hair loss	<ul style="list-style-type: none"> <li>biotin</li> <li>topical minoxidil (Rogaine)</li> </ul>



# Infections After Organ Transplant

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## Prevent infections

Talk to your doctor or transplant coordinator about your risk for infections. You may need to take added steps. Infections can be caused by different kinds of germs called viruses, bacteria, parasites, or fungi.

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 get exposed when your immune system is weak.



### Key ways to prevent infection include:

- Wash your hands often with soap and water or use alcohol-based hand sanitizer. Be sure to wash after sneezing, coughing, using the toilet, before and after handling food, and any time that your hands are dirty.
  - Shower or bathe and wash your hair each day.
  - Brush your teeth twice each day and floss your teeth daily.
  - Use separate towels from others in your home. Change your towels every few days or as they get dirty.
- 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 bandage or other dressing. Wash your hands before and after doing this care.

## Common infections after transplant

### Wound Infections

Wound infections are often caused by bacteria, which then get inside a break in the skin surface. Fever, redness, tenderness, swelling, or drainage from your surgery site 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.

### Chickenpox

Chickenpox is caused by a virus called varicella zoster. It is passed from person to person by directly touching the blisters, saliva, or mucus of an infected person. The virus can also be passed through the air by coughing and sneezing. It often shows as a rash or small blisters. **If you have been exposed to someone with chickenpox and you did not have chickenpox at a younger age, call your transplant coordinator right away.**

## **Cytomegalovirus (CMV)**

CMV is caused by a virus mainly spread through close contact with someone who already has it. Your risk of CMV is highest in 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.

## **Shingles (Herpes Zoster)**

Shingles is caused by the varicella-zoster virus, which is the same virus that causes chickenpox. Shingles can be spread through direct contact with the fluid from the rash blisters or breathing in virus particles from the blisters, but anyone who has had chickenpox may develop shingles later. 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.

## **Candida**

Candida is a 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. Vaginal infections can cause yellow or white discharge and itching.

## **BK Viral Nephritis (BKVN)**

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 that drain urine from the kidneys to the bladder, called ureters, to swell. Urine can be blocked. Signs may include blood in urine, trouble urinating, or a rise in creatinine or BUN lab values. People otherwise feel well and may not have other symptoms.

## **Pneumocystis Jiroveci Pneumonia (PJP)**

PJP is caused by a fungus and can be life-threatening. PCP is a rare, serious lung infection. Most people with PCP have a weakened immune system due to a medical condition. A dry cough and fever are common signs. Treatment includes antibiotics. **If you think you have the flu or a cold that is not getting better, call your transplant coordinator.**

# 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.

## Why rejection happens

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 allow the body to accept the transplanted organ.

## Warning signs of rejection

Learn these signs of rejection so you can watch for them after you go home. **Call your Transplant Coordinator right away if you see any of these signs:**

- A fever over 100.5 degrees F (38 degrees C)
- 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 going 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.

# 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 Transplant Center right away with urgent medical needs

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

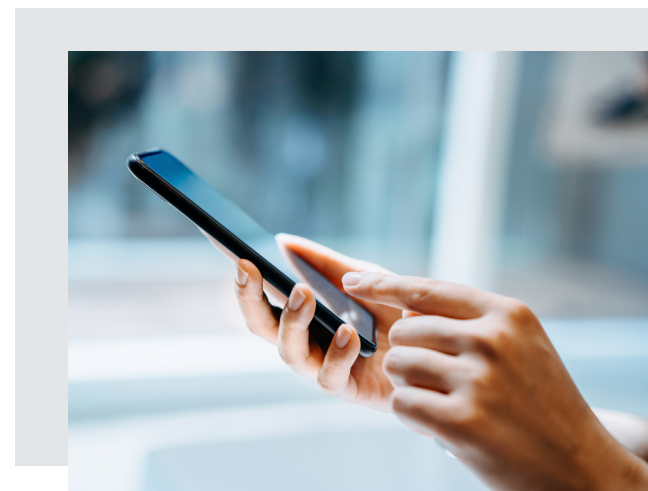
- A fever with oral temperature greater than 100.5 degrees F (38 degrees C)
- Missed more than 1 dose of your anti-rejection medicines or have problems getting them
- Nausea, vomiting, or diarrhea for more than 8 hours or cannot keep medicine down
- Dizziness or feel light-headed
- Severe pain over the transplant site
- Signs of infection at incision site, including redness, warmth, swelling, increased drainage, or drainage that 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 getting 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 a.m. and 4 p.m. 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 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.**

## Returning to the community

Based on your kidney function and overall health after your transplant, you may be able to transition your care to your primary or referring nephrologist. This would allow you to complete testing and clinic visits in a location that may be closer to your home.

Please begin to speak with your post-transplant coordinator about this option after your kidney function has returned to normal.

# 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.

### Donor connection

After receiving the gift of life, a deceased donor recipient may want to write to their donor's family to offer sympathy and gratitude and learn more about their donor. While many recipients and donor families find communication to be impactful and healing, we know this is a personal decision.

Lifeline of Ohio's Aftercare Team is here to support you in any way we can. If you're interested in connecting with your donor's family, you can start with a letter, which can bring comfort to the grieving family. Use this QR code to learn more about the writing process.



Contact the Aftercare Team at 800-525-5667 or [aftercare@lifelineofohio.org](mailto:aftercare@lifelineofohio.org) with questions.

### Volunteers

You may want to become a Donate Life Ambassador or volunteer to help Lifeline of Ohio promote organ and tissue donation. Organ recipients, donors, family members, and others who believe in the cause are welcome. Visit [lifelineofohio.org/beavolunteer](http://lifelineofohio.org/beavolunteer) or follow this QR code to get connected.



Here are some ways that Lifeline of Ohio suggests that you can get involved and share the Donate Life message!

- Take your temperature, BP, and pulse sitting up.
- Share your story through public speaking and media opportunities.
- Take the Donate Life message into your workplace, faith organization, or community group.
- Spread awareness and education in the community and register new individuals to be an organ, eye, and tissue donor.
- Assist with office projects (at Lifeline of Ohio office in Columbus).
- Knit or crochet beautiful shawls for donor families.
- Help with special events like our Candlelight Ceremony, Donate Life Day at the Ohio State Fair, or the annual 5K, the Dash for Donation.
- Spread the donation message as Lifeline of Ohio's mascot, Honey Bee.

# Vaccines After Organ Transplant

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## Talk to your transplant team before getting any vaccines

You may begin to get vaccines 6 months after transplant, but talk to your transplant team first.

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. To protect your health, no one else living in the household should have live virus or inhaled vaccines either.** If you have children who require live vaccines, please call your coordinator for further information.

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 not a complete list, so **talk to your transplant care team before you receive any vaccines.**

- Inhaled influenza or live flu virus
- Japanese encephalitis
- Measles, mumps, and rubella (MMR)
- Oral polio or 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.

## First 0 to 3 months after transplant

Your body needs balanced nutrition to promote healing, fight infection, and build muscle. The carbohydrates and fat you eat give you energy to return to your normal activities. Proteins are the building blocks of our bodies and keep our bodies working well.

Our bodies use protein to:

- Build and maintain bones, muscles, and skin.
- Heal wounds.
- Promote growth.
- Maintain healthy organs.

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. Having an eating schedule may help. You can make mini meals or snacks by combining carbohydrates and proteins. Your doctor or dietitian may also order a nutritional supplement rich in protein and other nutrients.

## Choose nutrient-dense foods

Carbohydrates	Proteins
<ul style="list-style-type: none"><li>• 1 small apple</li><li>• ½ large banana</li><li>• ½ cup fruit, such as grapes, pineapple, peaches, or blueberries</li><li>• 2 tablespoons dried fruit, such as raisins</li><li>• 1 cup non-starchy vegetables, such as carrots, cucumber, or bell pepper strips</li><li>• ½ cup cooked oatmeal</li><li>• 5 to 6 low salt crackers</li><li>• 3 (2.5 inch) graham crackers</li><li>• ½ whole wheat pita</li><li>• 1 slice whole wheat toast</li><li>• ½ whole wheat toasted English muffin</li><li>• 3 cups unsalted popcorn</li></ul>	<ul style="list-style-type: none"><li>• 1 tablespoon natural, unsalted peanut butter or other nut butter</li><li>• ½ cup tuna, chicken, or egg salad made with mayonnaise</li><li>• 1 hard boiled or scrambled egg</li><li>• ¼ cup unsalted nuts, such as almonds</li><li>• 1 ounce cheese, such as Swiss cheese or string cheese</li><li>• ½ cup low fat cottage cheese</li><li>• 6 ounces Greek or other yogurt</li><li>• ⅓ cup hummus</li><li>• 2 to 3 slices of low fat lunch meat</li><li>• ½ cup unsalted roasted chickpeas</li><li>• 1 ounce of unsalted seeds, such as sunflower or pumpkin seeds</li></ul>

## Stay well by following a generally healthy diet

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.



- Every day, eat a variety of fruits and vegetables in a range of colors.
  - Be sure to include lots of dark green, red, blue/purple, and orange vegetables.
  - Choose whole grains for at least half of your grain selections.
- Eat more beans, peas, and lentils.
- Try meatless alternatives to get protein.
- Keep your salt intake to less than 2300 mg daily.
- Limit your sugar intake.
  - It is best to choose products without added sugar, but if you do eat them, read labels carefully so you know how much sugar is in each portion.
- It is better to eat unsaturated fats than saturated fats.
  - Many processed foods, fried foods, fast food items, convenience foods like frozen pizza and snack foods, and sweets, including pies, cookies, and other pastries are high in fat. Check nutrition labels and choose these foods less often.

## Fluids

Fluids are needed to prevent dehydration and to keep your body and transplanted organ working well.

- **For Kidney Transplant:** 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.
- **For Pancreas Transplant:** Discuss your specific needs with your dietitians and providers. Follow food safety guidelines and avoid foods/drinks that may put you at risk for infection.
- Caffeine may lead to dehydration, so it is important to limit intake.
- Water:
  - Do not drink well water unless you have had it tested for parasites and it is clear, or you have a reverse osmosis system with an absolute 1 micron or small filter or “one-micron absolute.”
  - You do not need to drink bottled water unless your water source is not safe, or your well water has parasites.
  - 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.” Avoid fountain soda pop and public drinking fountains.



## Food

What may be safe to eat for a healthy person can be a risk for a person who takes anti-rejection medicines. Use these general guidelines to prevent infection from the foods you eat. For more information, ask your dietitian.

- Always reference the **Food Safety Guidelines**.
- **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.
- **Dairy products:** Avoid drinking or eating food made with unpasteurized milk. Avoid soft cheeses like feta, Brie, Camembert, moldy cheeses, and any cheese made with unpasteurized/raw 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, homemade mayonnaise, and hollandaise sauce.
- **Meat and poultry:** All meat and poultry should be cooked, so the juices run clear, and use a meat thermometer to confirm the item has reached its goal cooking temperature. Avoid rare animal meat.
- **Seafood:** Avoid all raw or under cooked oysters, clams, or mussels. Make sure shellfish is well cooked and firm.
- **Fruits and vegetables:** Thoroughly 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.
  - Avoid grapefruit. Fruit or products that contain it affects how some transplant medicines are absorbed in the body. Make sure to check blended juice labels.
- **Other unpasteurized products:**
  - Honey: Avoid raw or unpasteurized honey.
  - Miso: Avoid unpasteurized miso. Most commercial miso products are fine to eat.
- **Dining out:**
  - Order meat, seafood, and poultry cooked “well done.”
  - 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 through the line to make your plate.



**Your registered dietitian or provider may provide a more specific diet based on your individual needs, diagnosis, and personal and/or cultural preferences. Please discuss with them if you have questions or concerns.**

## Nausea and vomiting

- You should continue to take your medicines as prescribed by your doctors.
- After vomiting stops, start by sucking on ice chips and then begin to drink small amounts of clear liquids such as broth, apple juice, or gelatin.
  - When you have gone for at least 8 hours without vomiting, you can start eating solid foods.
  - Start with one food at a time and eat very small amounts.
  - Begin with odorless foods that are low in fat and fiber.

### Foods to Try When Vomiting Stops

- Applesauce
- Baked chicken
- Banana
- Juices
- Potato
- Pretzels
- Rice
- Clear broths
- Rice cereal
- Sherbet
- Yogurt
- Popsicles
- Crackers
- Dry toast
- Egg cooked without fat

## Diarrhea

- Eat small meals often and sip liquids slowly.
- Drink at least 8 to 10 large glasses of liquid each day to replace the fluid you are losing. Water or watered-down sports drinks with electrolytes are best.
- Only use nutritional supplements as directed by your dietitian or doctor as they can make diarrhea worse.
- Eat bland foods low in fiber and high in protein and calories.

### Foods for Diarrhea

- Bananas
- Rice
- Applesauce
- White bread, toast
- Yogurt
- Gelatin
- Smooth peanut butter
- Cooked potatoes
- Crackers
- Pretzels
- Rice pudding
- Cheese
- Cooked mild vegetables (like green beans, wax beans, or carrots)
- Meat, fish, or poultry (skinless white meat)
- Eggs (cooked)
- Instant oatmeal

### Avoid These Foods with Diarrhea

- Whole grain bread or cereal
- Nuts, seeds, or coconut
- Fried, greasy, or fatty foods
- Raw fruits or vegetables
- Strong spices or herbs
- Broccoli, onions, or cabbage
- Caffeine
- Alcoholic drinks
- Fruit juices
- Cigarettes
- Foods high in simple sugars
- Sugarless gum or candies
- Potato chips
- Popcorn
- Carbonated beverages

# Your General Health Care

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## Emotional health

Take care of yourself, especially 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 or have trouble sleeping, eating, or 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 the side effects of medicines.



**If you ever have thoughts of harming yourself or others, go to the nearest emergency department for help or call 911.**

## 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.

## Risk for diabetes after 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.

## Gardening and 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 long sleeves, gloves, and a face mask when working in the soil. Wash your hands with soap and water after contact with plants and soil.

## Travel

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

- Be driven for short trips after leaving the hospital if you can wear a seat belt with no discomfort.
- Drive locally after 2 to 6 weeks if you are off all narcotic pain medicines.
- Do overnight trips after 6 weeks.
- Do trips longer than 3 days after 8 weeks.
- Travel by motorcycle after 12 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.

## 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 sunblock and lip balm and reapply often.
- Apply sunblock 30 minutes before outdoor activities and reapply every 2 hours while outside.
  - Avoid time in the sun between 10 a.m. and 4 p.m. 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.



## Swimming

- **Do not use hot tubs, saunas, or public swimming pools.**
- Talk to your transplant doctor about using any personal swimming pool.
- You may swim in large bodies of water after 10 to 12 weeks and incision is completely healed, but no small lakes or ponds due to bacterial growth.
- Go in slowly and do not jump in.

## 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.

## Skin care

- **Call your transplant coordinator if you have any unusual skin growths, rashes, or color changes.**
- Get annual skin checks by a dermatologist or any time you see any changes on your skin.
- Prednisone and aspirin may make you prone to bruising. Be careful to avoid bumps and falls.

## 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.
- You can go back to your routine dental care 3 months after your transplant.
- Call your transplant coordinator if you find mouth sores, white patches, or gum overgrowth (swollen and covering more of the tooth).

## 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 checkup.
- Report any vision changes or problems to your transplant coordinator.

## Caring for animals

- Pets can be an important part of your family, but some put you at risk for infection. You will need to find a new home for pet birds, reptiles, and turtles.
- For other pets, do not handle animal waste or clean litter boxes, cages, or fish tanks. Feces of some animals contain parasites. Fungus can grow in fish tanks, so someone else will need to clean and care for the tank.

## Tattoos and body piercings

- Tattoos and body piercings after transplant are highly discouraged due to infection risk.

## Smoking, vaping, and other 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. Please discuss any tobacco use with your transplant team.

## Cannabis use

- Using **cannabis or marijuana products may interact with your anti-rejection medicines.** Please talk to the transplant team if you use these products.

## Alcohol use

- Alcohol should be avoided after transplant. It can increase triglycerides in the blood to damage liver function. **Alcohol also can interact with transplant medicines.** Talk with your transplant doctor about alcohol use.

## Pregnancy

- Talk to your transplant care team or primary care doctor about birth control. **Avoid becoming pregnant for at least 1 year after transplant.**
- Talk to your transplant care team about your plans for pregnancy so risks can be discussed. Your medicines may need to be adjusted as they may be harmful to a developing baby.

# Activity Guidelines

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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.
- If you are someone who did not have regular periods, you may begin to have periods within 6 months after surgery.
- Talk to your doctor before starting any birth control. Pregnancy can happen 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.
- People with female anatomy 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. They should also do a breast self-exam once a month.
- People with male anatomy 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. They should also do a monthly testicular self-exam 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 that **your body needs 3 months to heal after a transplant.**

- **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.
- When you are able to lift, use good body mechanics to avoid injury.
  - 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 you get tired or out of breath, 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 3 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.

# Abdominal Hernia

## Prevention and Treatment

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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

- 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.
- See “Activity Guidelines” on page 27 for more information.

### 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

# Tracking Your Vital Signs

Your doctor wants you to take your urine output, weight, blood pressure (BP), pulse, temperature, and blood sugar each day. For the first 3 months after transplant, you will be taking your BP, pulse, and temperature at least 3 times each day.

Do your checks as often as directed by your care team.

## Instructions

- Take your weight right after using the bathroom in the morning, using the same scale and wearing the same amount of clothes.
- Take your temperature, blood pressure, and pulse sitting up.
- **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 100.5 degrees F (38 degrees C).
- Record your numbers on the next 2 pages to share with your provider. Example:

Date and time	Urine output	Weight	Blood Pressure	Pulse	Temperature	Blood sugar
9/22 at 8 am	35 mL	165	122/74	77	98.7	127

## Download more copies of the record

Download and print copies of the record for ongoing tracking of your vital signs to share at clinic visits. Go to [go.osu.edu/pted4375](https://go.osu.edu/pted4375).





# My Notes



We want you and your family to learn about your care. **Write down your questions and concerns**, so you do not forget to ask. It is often hard to remember, or you may feel rushed, so it can help to write your questions down. **If you do not understand something, please ask us to explain it in a different way.**

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*Annual Pinwheel Garden* – Every April, thousands of pinwheels are planted to represent a lifesaving organ transplant done at Ohio State. Each has 1 stem supporting 8 spokes, symbolizing the power of 1 HERO to save up to 8 lives through organ donation.



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