



Heart Transplant Education Session Guide

Ohio State Heart Transplant Program



THE OHIO STATE UNIVERSITY

WEXNER MEDICAL CENTER



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.

Table of Contents

Transplant Team	3
Evaluation Process	4
Patient Selection Committee	6
Options Other Than Heart Transplant	7
Heart Transplant Allocation System	8
While You Are Waiting For a Donor	10
Getting the Call	11
Donors and Infectious Diseases	13
The Surgical Experience	14
Going Home After Heart Transplant	15
Possible Complications After Transplant	16
Understanding Rejection	17
Primary Care Doctor Follow Up and Routine Health Care	18

For a digital copy of this book, go to go.osu.edu/pted5344.

This book is for informational purposes only. Talk to your doctor or health care team if you have any questions about your care.

Transplant Team

Once you have been referred to Ohio State's transplant center, you will be seen by many members of the transplant team, including different physicians, to help you understand the process and what to expect.

- **Heart failure cardiologist:** To consider a heart transplant, you will need to be seen by an Ohio State heart transplant cardiologist, a doctor who treats heart failure and specializes in heart transplantation. This doctor will review your records to determine the amount of damage to your heart and if transplantation may be a good treatment option for you.
- **Cardiothoracic surgeon:** Doctor who will review your history and do an exam. This doctor or another transplant surgeon may do the transplant surgery.
- **Transplant coordinator:** Registered nurse (RN) who will work with you through the process from your referral until transplant surgery. You will need to let this coordinator know about any hospital stays, changes in your health or any changes in your contact information. After surgery, you will have a post transplant coordinator, who is also a registered nurse and is highly trained in care after transplant.
- **Transplant social worker:** Works with you to check that you have support and coping skills to deal with the transplant process. If you have a history of problems with drug or alcohol use, the social worker will also assist you with meeting transplant guidelines and may refer you to a psychologist if needed.
- **Transplant financial coordinator:** Works with you to help you understand the costs of transplantation and any benefits you may be eligible for.
- **Transplant psychologist:** Works with you, if needed, to be sure you have the support and coping skills to handle the stress of the transplant process or coordinate alcohol and/or drug counseling.
- **Transplant dietitian:** Works with you to review your eating habits and diet and help you make adjustments to manage your health.
- **Palliative care provider:** Works with you to help you manage symptoms, pain, or side effects from treatment. This provider can also help you decide about treatment choices and help you communicate better with your care providers, family, and friends.

Your referring doctor will also be notified of your care.

Contact

Transplant Coordinator:
614-293-3787

- Monday through Friday: 8 a.m. to 4 p.m.
- After hours, follow the prompts in the phone tree to leave a message.

Use MyChart to contact your team and manage your care.

Location:

Ross Heart Hospital
452 W. 10th Ave.
Columbus, OH 43210

Fax: 614-293-9038

Evaluation Process

Why is an evaluation needed?

A thorough evaluation is necessary to diagnosis any unknown disease process that could impair your health or make you worse after transplant. Examples of why an evaluation is needed include:

- You need a lot of dental care to avoid the risk of serious blood infections after transplant.
- You have a history of smoking and pulmonary disease that may prevent you from stopping ventilator use after surgery.
- You need a plan to manage a mental health issue that could get in the way of following critical directions for your implant success.
- You have a bone disease that would get in the way of your rehabilitation after surgery.

Tier 1 evaluation

Tier 1 evaluation consists of 4 steps:

1. Education Session
2. Medical Clearance Forms
3. 24-hour Urine Collection
4. Vaccinations

Education Session

You are attending the education session with your primary care giver. If you are interested in going ahead with your evaluation after attending this education session, there are forms you will need to sign after the education session. These include:

- Informed Consent for Transplant Candidate Evaluation
- Patient Education Acknowledgement Form
- Multiple Listing and Wait Time Transfer
- Pre-Transplant Financial Assessment

Medical Clearance Forms

All heart transplant candidates must complete the following, if instructed by your coordinator or doctor:

Colonoscopy: Colonoscopy checks for diseases of the colon and rectum. Your medical history and age will help us to determine if you need to complete this test. Not everyone will need to have a colonoscopy.

Dental Exam: You will need to see a dentist within the past 6 months and have had a panoramic X-ray (full mouth) within 12 months

Mammogram: All women must complete mammogram within the past 12 months.

Pap Test: All women must have had a Pap smear within the past 12 months.

24-hour Urine Collection: Test to measure kidney function. Some candidates will need this test.

Vaccinations: You will be instructed on what vaccines are required. You will need to provide proof before you can be listed for a heart transplant.

Tier 2 evaluation

After you have completed all the steps in the tier 1 evaluation, you are ready to move to the tier 2 evaluation. The tier 2 evaluation will take place in 3 back-to-back days.

Day 1

On day 1, you will go to an outpatient location to do the testing needed for your evaluation.

- Ankle-brachial index (ABI) – blood pressure in your upper and lower limbs is compared to check for differences that may indicate blockages
- Carotid duplex – an ultrasound test that shows how well blood is flowing through the carotid arteries, which are located in your neck and supply blood to the brain
- Pulmonary function test – measures breathing and how well your lungs are working
- Six-minute walk test – checks how your heart and lungs respond to light exercise
- Chest CT scan – checks for diseases of the chest organs
- Head CT scan – checks for diseases of the brain
- Liver ultrasound – checks the blood flow of the liver
- Bone density test – checks bone density, or hardness, to see if you are at risk for bone fractures
- Blood and urine studies

Day 2

On day 2, you will report to the Ross Heart Hospital to complete the consultations required for your evaluation.

You will meet with some of the following team members:

- Cardiologist
- Cardiac surgeon
- Transplant coordinator
- Social worker
- Palliative team
- Dietitian

Day 3

Nutrition Assessment: On day 3 of your evaluation, you will have a virtual assessment with the dietitian, so you do this visit from home. The dietician will assess your current dietary habits and recommend any changes you may need to make.

Financial Counseling Session: During the tier 2 evaluation, you will review your insurance and benefits with the financial team. The financial assessment you completed during the tier 1 evaluation will help the financial counselor make recommends.

You may discuss:

- Your income and monthly expenses
- Insurance and benefits
- Medicaid application, as needed
- Veterans insurance (VA), if it applies

Patient Selection Committee

When both the tier 1 and tier 2 evaluations are completed, your test results will be presented to the Patient Selection committee. The Patient Selection Committee is a team made up of many of the people you met during your evaluation. They, not your doctor or any 1 person, make the decisions.

Possible outcomes

- Accepted for heart transplant
- Not accepted for heart transplant
- Deferred, more testing has been requested

Common reasons why people are not accepted

- You have had cancer within 5 years
- Diabetes with end-organ damage
- Currently smoke or using another type of tobacco
- Illegal or non-prescribed drug use
- Infection
- Neurocognitive impairment (decreased mental function)
- Obesity (Body Mass Index greater than 38)
- Pulmonary hypertension, which is a type of pressure that affects the heart
- Missed appointments
- Not following directions
- Not having enough support at home



Options Other Than Heart Transplant

If you are not a candidate for a heart transplant, another option may be recommended by the team.

Mechanical support

- **Left Ventricular Assist Device (LVAD):** An implanted pump that helps circulate blood through the body.
- **Total Artificial Heart:** An artificial heart is an artificial organ device that replaces the heart.

Inotrope

Inotropic agents, or inotropes, are medicines that change the force of your heart's contractions.

Continuous 24 hour a day infusion: These are medicines that are given to you using an IV (through a tube put into a vein in your arm) all the time, meaning 24 hours a day, 7 days a week, 52 weeks a year. Medicine examples are dobutamine and milrinone.

Continue goal directed medical therapy

Your doctor prescribes a combination of medicines to treat your different symptoms.

Palliative or hospice care

- **Palliative care:** This treatment helps you feel better physically, emotionally, and spiritually while doctors also treat your illness. Your care may include pain relief, counseling, or nutrition advice.
- **Hospice care:** Goal of this type of care is also to help you feel better, but you no longer get treatment to try to cure your illness.

Heart Transplant Allocation System

Everyone listed for heart transplant will be assigned an urgency status. The status is based on specific medical criteria. The heart transplant allocation system allows for the sickest people to be transplanted first as they require advanced life support. Status 1 is the most urgent and status 6 is the least urgent. You will always be aware of your listing status.

There are 6 active listing statuses

- Active Listing Status: 1, 2, 3, 4, 5, 6
 - You can also be inactive on the heart transplant list.
- Inactive Listing Status: 7
Examples of why you may be a status 7:
 - Too sick or too well
 - Lack of compliance or communication
 - Insurance
 - Smoking
 - Weight gain

Status

How do I get matched with a donor heart?

- Listing status
- Blood type
- Size
- Antibodies (may or may not pertain to you)

Examples of medical criteria for status 1 through 6

Status 1

- Hospitalized
- Life threatening conditions
- Full ICU support to keep you alive until transplant
- Breathing machine attached

Status 2

- Hospitalized
- Life threatening conditions
- Large amount of ICU support

Status 3

- May or may not be hospitalized
- LVAD has complications
- LVAD using “discretionary days”: All LVAD patients are allowed 30 days to use as a status 3, per guidelines
- Hospitalized with 2 IV medicines and Swan Ganz catheter

Status 4

- LVAD not using discretionary days
- Home on 1 IV medicine
- Diagnosis of 1 of the following:
 - Congenital heart disease (CHD): defects at birth that impact how the heart functions
 - Ischemic heart disease with intractable angina: reoccurs event with treatment, and chest pain that limits ordinary physical activity
 - Hypertrophic cardiomyopathy: disease in which the heart muscle becomes thickened
 - Restrictive cardiomyopathy: heart ventricles become stiff
 - Amyloidosis: buildup of proteins in heart tissue that affect the heart’s function

Status 5

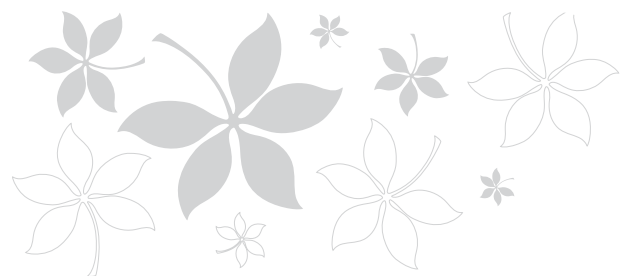
- On the wait list for at least 1 other organ at the same hospital

Status 6

- All remaining active candidates

Match run

- Match run is electronically generated by computer.
- You are assigned a number in the match run. All match runs are different.
- You are assigned a number.
- Your medical team has NO control over matching.
- Review donor heart after all other centers decline.



While You Are Waiting For a Donor

Follow up

You will be required to have clinic visits with the heart failure doctors at Ohio State Richard M. Ross Heart Hospital.

We ask that you contact our office if you notice worsening symptoms, such as:

- Loss of appetite
- Dry heaves, nausea, or vomiting
- Weight loss or weight gain
- Extreme fatigue or sleeping too much
- Fever or signs of infection
- Irregular heartbeat and ICD (implantable cardioverter defibrillator) shocks

If you are at a local hospital system, other than Ohio State, please request that you are transferred to our facility. Not all medical centers are trained to care for heart failure and heart transplant.

Always be ready

- Remain within 3 hours of the medical center.
- Vacations are prohibited.
- You must have 2 active phone numbers.
- Know your plan for getting to the hospital.
- Have your bag packed (leave valuables at home).
- Keep your phone ready. Have your voice mail set up as a back up to make sure you get the message. Check any missed calls right away. Make sure a call will wake you up at night.



Getting the Call

About the call

- The transplant coordinator will call you when a donor heart has been accepted for transplant. This can happen at any time of the day or night.
- **Answer ALL phone calls 24 hours a day.** Keep in mind the call might be from a different area code.
- You will be told where to go.
- **Be prepared to leave your home within 30 minutes.**
- Do not eat or drink anything from the time you get the call.
- If you are on a blood thinner (anticoagulant) medicine, please do not take this medicine until you are instructed to start it again.

Dry runs

Transplants can be canceled at any time. This is called a dry run.

If your transplant is canceled:

- You will return home.
- You will remain on the list for a transplant.

Common reasons why a transplant might be canceled:

- There were complications with your donor.
- You become too ill.



Facts about organ donors

The hospital where the donor is getting care will evaluate the organ donor with extensive testing and that testing is shared with your medical team.

The medical team reviews the medical history and test results of the organ donor and decides this is a suitable match for you. Not all organs that are offered for transplant will be accepted as a good match.

- The donor will receive extensive testing that is shared with your medical team.
- Your organ donor will be anonymous.
- Your donor is someone who has suffered a sudden and traumatic injury or event, such as a brain injury, gunshot wound, or car accident.
- Their families have agreed to graciously donate their loved one's organs.
- The person may be any gender, race, or religion.
- Recipient and donor information is kept highly confidential, so you may never know who the donor was.

2 types of organ donors

DBD: Donation After Brain Death

- Person suffered devastating injury that cannot be healed, and is not expected to survive in a meaningful way
- Brain death has been verified by 2 different doctors
- Donor remains on a ventilator during procurement

DCD: Donation After Cardiac Death

- Person suffered devastating injury that cannot be healed, and is not expected to survive in a meaningful way
- Person cannot survive without a ventilator
- Donor will pass within 1 to 2 hours
- Surgical team starts organ procurement about 5 minutes after cardiac death
- Could increase the chance of dry runs



Donors and Infectious Diseases

All organ donors are tested for infectious diseases

Examples of infectious diseases tested for include:

- Hepatitis B virus (HBV)
- Hepatitis C virus (HCV)
- Human immunodeficiency virus (HIV)
- Cytomegalovirus (CMV)
- Epstein Barr virus (EBV)

Classifications of organ donors are based on exposure to infectious disease

Organ donor infection risk classes:

- Donors without risk criteria behaviors
- Donors with risk criteria behaviors
- Donors who tested positive for hepatitis C
- Combination of above

Levels of infection risk

There are different classifications of organ donors, according to the risk of infection. Risk criteria behaviors are actions that put them at risk for having an infectious disease.

These behaviors include:

- Sex with a person known or suspected to have HIV, HBV, or HCV infection
- Sex in exchange for money or drugs
- Sex with a person who had sex in exchange for money or drugs
- Drug injection for non-medical reasons
- Sex with a person who injected drugs for non-medical reasons
- Being incarcerated (jail, prison, or juvenile correction facility) for 72 hours or more
- Unknown medical or social history

According to the Centers for Disease Control and Prevention:

- The risk for the donor having HIV, HBV, or HCV infection that has not been detected is very low, but it is not zero.
- Recipients will be tested for HIV, HBV, and HCV infections after transplant. If transmission of 1 of these infections occurs, effective therapies are available to treat it.
- You will sign a consent form acknowledging the risk behavior status of your organ donor at the time of transplant.

Accepting a donor organ with hepatitis C

It is estimated that there are up to 4 million people with hepatitis C in the United States. Hepatitis C transmitted through infected blood. This can happen by:

- Sharing syringes
- Blood transfusions
- Sexual contact
- Non-sterile tattoos

Why do we accept organs infected with hepatitis C?

- Hepatitis C is now curable with highly effective antiviral agents.
- This helps expand the donor population.
- Your wait may be less for an organ.
- There is no statistical difference in survival at 1 year, rejection rates, or complications for someone who gets an donor organ with hepatitis C or without hepatitis C.

Still have questions?

If you still have questions about donor infectious disease risk after the education session and discussing it with your medical team, please let us know.

The Surgical Experience

During surgery

- Consent for transplant with your surgical team
- You will be in the operating room for about 6 to 8 hours
- Open chest procedure
- Recovery on the 4th floor of Ohio State Richard M. Ross Heart Hospital
- Limited family visits during the first 24 hours

ICU (intensive care unit) environment after surgery

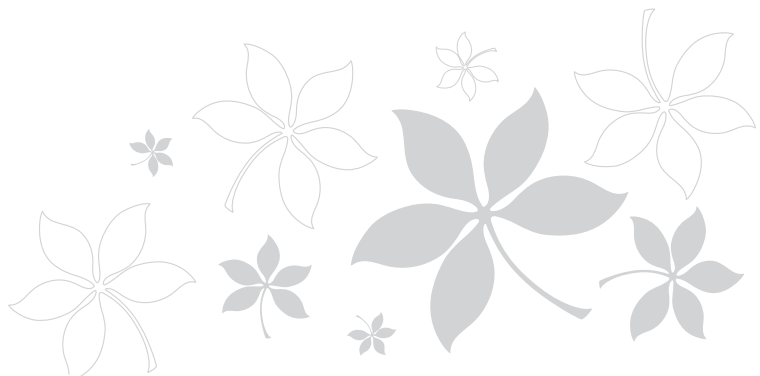
- Sedation
- Breathing machine
- Chest tubes
- Multiple IV lines
- Swan-Ganz catheter in your neck
- Telemetry (machine monitoring your breathing, oxygen levels, and heart rate)
- Loud noises
- Large medical team

Goals after surgery

- Extubated (removing tube from your throat and windpipe) within 24 hours
- Sitting up in a chair and taking oral medicine within 2 to 3 days
- Walking and oral intake within 3 to 4 days
- Discharge in 14 days or less

Planning for discharge

- You will receive education after transplant with your transplant coordinator.
- You will start SAMS (self-administered medications) in the hospital.
- You will leave the hospital with 30 days of medicines.
- Patients will have high blood sugar due to the use of prednisone. It is common for patient to be discharged home with diabetes supplies, insulin, and/or oral medication. You may be asked to check your blood sugars up to 4 times a day following transplant. For those who were not already diabetic going into transplant, your blood sugars should normalize after a few months with reduced doses of prednisone.
- If you live outside Franklin County, you may be asked to stay locally for up to 1 week.
- For those who require additional rehabilitation, you may be referred to Dodd Rehabilitation Hospital for care.



Going Home After Heart Transplant

Key points

- After you are discharged to go home, you should be able to dress, bathe, and use stairs on your own or with limited assistance. You should not need any assist devices such as walkers, wheelchairs, or canes. Patients are typically not discharged with home health.
- You will be instructed on how to monitor your health after returning home. This includes checking your vital signs and monitoring your blood sugar every day.
- You will start cardiac rehabilitation about 4 to 6 weeks after discharge. You may complete cardiac rehab at the facility of your choice.
- You will be provided with a schedule of clinic visits for the first 12 weeks following your heart transplant.
- If you choose to transfer medical care, please wait at least 1 year following transplant.

Restrictions at home

- Sternal precautions (limits) for 12 weeks, which lets the sternum to heal properly after surgery
- No driving
- No lifting, pulling, or pushing more than 10 pounds
- Strict infection control:
 - Handwashing and using hand sanitizer will reduce your risk of infection
 - Avoid sick people
 - Stay up to date with recommended vaccinations
 - Wear a mask in public for 4 to 5 months
- Travel will be limited for the first year and only at the direction of the medical team

What to expect the first year

- Medicines
- Many clinic appointments
- Close contact with heart transplant team
- Checking your vital signs often
- Extra blood draws
- Possible hospital re-admission

Immunosuppressive medicines

- You will remain on immunosuppressive medication you entire life
- These medicines will reduce your risk of rejection
- Dosing is based on levels, labs, and side effects
- Most are available in generics

Names of commonly used immunosuppressant medicines:

- Tacrolimus (Prograf)
- Mycophenolate mofetil (CellCept)
- Prednisone



What is the key to success? Remember your medications!

Complications WILL occur if you do not follow instructions. You could experience some or all of the following:

- Reduced heart function
- Arrhythmia
- Heart failure symptoms
- Death

If you have trouble remembering to take your medication, consider the following:

- Stick to a routine
- Rely on your medication book
- Use a pill box
- Set an alarm
- Have your family remind you

Having medicine side effects? We can help!

These are some of the common side effects after transplant:

- Mood changes
- Tremors or shaking
- Headaches
- Nausea or diarrhea
- Muscle weakness
- Minor aches and pains

Remember: NEVER stop or change your medicine without speaking with your medical team first.

Possible Complications After Transplant

Rejection

- The risk of rejection never goes away. You will always need to take immunosuppression (anti-rejection) medicines. Your doctor may lower the dosage, but you should never skip or stop taking these medicines.
- A biopsy of the heart is the best way to know if your body is rejecting your new heart.

Infection

- Immunosuppression medicines can increase the chance of getting infections.

Cancer

- Immunosuppression medicines can raise the risk of getting cancer, especially blood cancer and skin cancer.

Kidney damage or disease

- Diabetes that is not managed can cause renal dysfunction or renal failure, meaning 1 or both of your kidneys do not work well on their own.
- Immunosuppression: Tacrolimus (medicine used along with other medicines to prevent rejection) has been linked with a change in kidney function.

Understanding Rejection

When your body's immune system attacks your transplanted heart, it is called rejection. Rejection can occur when the body recognizes the heart as "an invader" and tries to get rid of it. The body "rejects" the heart.

Rejection can occur at any time after getting your heart transplant. It is most common in the first several weeks. You will need to monitor for rejection for the rest of your life.

Acute rejection

Acute rejection is the most common type of rejection. It is an inflammatory reaction involving the heart muscle. It usually occurs soon after transplant, but can happen at any time.

You may or may not have any symptoms of acute rejection.

Common symptoms of acute rejection include:

- Heart failure symptoms
- Body aches, fever, or chills
- Irregular heart beat (arrhythmia)
- Nausea
- Fatigue

Heart biopsy

Heart biopsy is the best measure to watch for signs of rejection. A biopsy is a tissue sample. Your cardiologist will take tissue samples of your transplanted heart. It will be placed under a microscope for closer inspection. Your biopsy samples will be measured on a scale.

Biopsy Grading Scale

Grade	What this means
Grade 0	No rejection
Grade 1R	Mild rejection
Grade 2R	Moderate rejection
Grade 3R	Severe, diffuse rejection

Treatment for acute rejection

The treatment of acute rejection varies depending on how severe the rejection is.

Common treatments include:

- Steroids given in high doses
- Being admitted to the hospital for treatment
- IV immunosuppressants – medicines that inhibit or decrease the intensity of your immune response

Clinic and biopsy schedule

Clinic visits:

- **Weekly for weeks 1 through 12**
- **Monthly for months 4 to 12**
- **Clinic starts at 7:30 a.m.** Please be prepared to come to clinic early.

Biospies: You will have multiple biopsies during the first year of heart transplant. You will be given a biopsy schedule after transplant. You will have about 6 to 8 biopsies during the first year.

Additional testing:

- 1 time each year on the month you were transplanted, you will have additional testing, such as:
 - **Left heart catheterization:** Left heart catheterization is a test to check for thickening in the walls of the coronary arteries.
 - **Echocardiogram:** An echocardiogram is also called an echo, cardiac ultrasound, or ultrasound of the heart. It is a painless test that takes moving images of the heart using sound waves. This test checks the function of your heart function and valves.

Primary Care Doctor Follow Up and Routine Health Care

You will be required to have a primary care doctor. This doctor will be responsible for caring for your non-cardiac concerns, such as:

- Cold and flu symptoms
- Diabetes
- Arthritis
- Minor aches, pains, and sprains
- Referrals for other specialists





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