

Preparing for a Heart Transplant



Yakini, heart recipient (transplanted September 2019)



THE OHIO STATE UNIVERSITY

WEXNER MEDICAL CENTER

Welcome

The Ohio State University Wexner Medical Center Comprehensive Transplant Center welcomes you as a heart transplant candidate.

Our Comprehensive Transplant Center has one of the largest organ transplant programs in the nation and is a preferred provider for all major insurance companies. We perform more than 600 heart, lung, liver, pancreas and kidney transplants each year. Since our program began in 1967, we have performed more than 12,000 lifesaving transplants, including over 500 heart transplants.

As you begin this journey, you and your family will have many questions and concerns. We hope this information helps you feel more comfortable about the heart transplant process so you know what to expect.

The goal of a heart transplant is to allow you to live a more normal life. But there are changes you will need to make after transplantation to have the best outcome.

For More Information

It is common to feel both concerned and excited as you consider a heart transplant.

Please call to talk with a pre-transplant coordinator to get more information and address your questions and concerns.

Phone: 614-293-3787 or 800-538-1886
Monday through Friday
8 a.m. to 4 p.m.

After hours, follow the prompts in the phone tree to leave a message.

Ohio State Heart Transplant Program

Ross Heart Hospital
452 W. 10th Ave.
Columbus, OH 43210
Fax: 614-293-9038

About the Heart

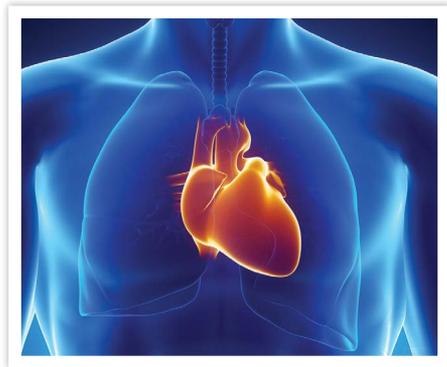


Gigi, heart recipient (transplanted September 2021)



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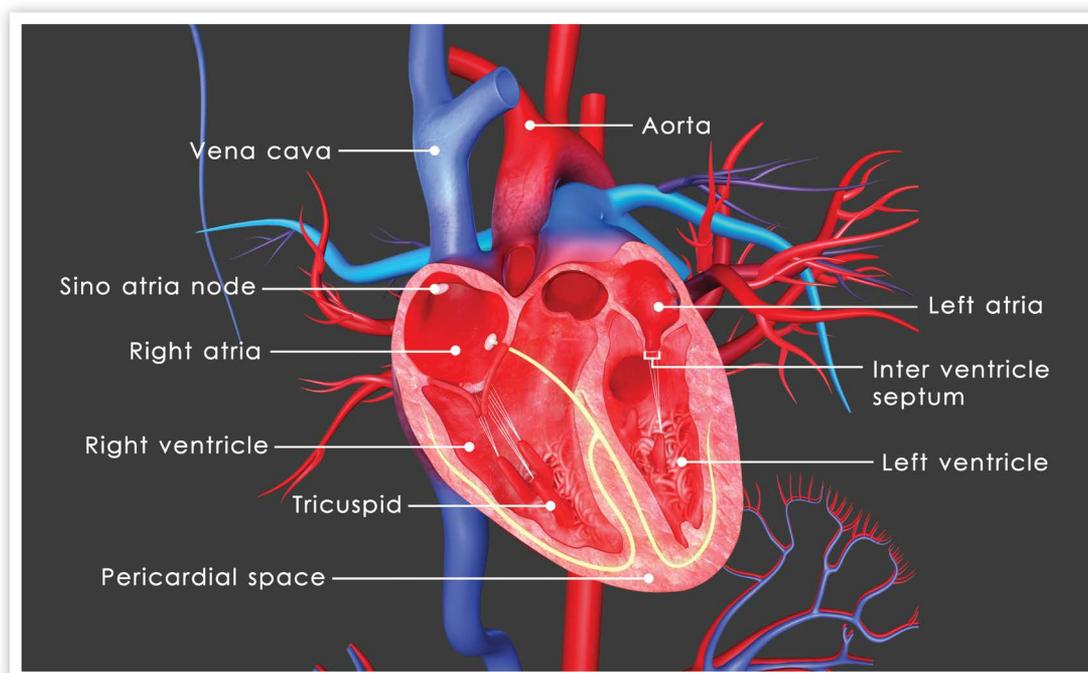
About the Heart



The heart is an organ that pumps blood, oxygen and nutrients throughout the body. It is responsible for removing carbon dioxide and other waste products as well. The heart is approximately the size of a fist and weighs around 10 ounces. The heart is located between the lungs and above the diaphragm.

Facts about the heart:

- Beats over 100,000 times per day!
- Pumps around 8 liters of blood per minute and 5,000 gallons of blood per day.
- Contains four chambers: right atria, right ventricle, left atria and left ventricle, which are separated by a septal wall.
- The atria and ventricles are connected by the tricuspid and mitral valves.
- Coronary arteries supply the heart with constant blood and oxygen.
- Atherosclerosis, also called hardening of the arteries, is a buildup of plaque (cholesterol and fatty deposits) within the coronary arteries.
- When the coronary arteries are blocked, the heart becomes starved of oxygen and nutrients, leading to chest pain (angina) and damage (heart attack) or death.



Heart Disease

There are many different kinds of heart disease, and not everyone who has heart disease will have the same symptoms. Your heart doctor, called a cardiologist, can help you understand your heart disease.

Signs of Heart Disease

Problems or signs that are often seen include:

- Feeling tired or weak
- Shortness of breath
- Loss of appetite, nausea and weight loss
- Swelling
- Mental status change
- Passing out
- Low blood pressure
- Reduced tolerance for daily activities



*Lonnie, heart recipient
(transplanted May 2012)
pictured with his wife, Ellen*

Most Common Reasons for Heart Transplantation

- **Nonischemic Cardiomyopathy:** The heart becomes enlarged in size (dilated), thick and rigid, usually due to an inherited condition. Types of nonischemic cardiomyopathy include:
 - Viral
 - Familial
 - Postpartum
 - Restrictive
 - Congenital
 - Valvular
- **Ischemic Cardiomyopathy:** Weakened heart function due to a blockage in a coronary artery, which carries blood and oxygen to the heart. Causes of ischemic cardiomyopathy include:
 - Myocardial infarction (heart attack)
 - Coronary artery disease
 - Atherosclerosis (hardening of the arteries)
- **Arrhythmia:** Potentially fatal heart rate due to improper electrical activity in the ventricles of the heart. Types of arrhythmia include:
 - Ventricular fibrillation
 - Ventricular tachycardia
- **Re-Transplant:** This is needed when the previous transplanted heart no longer functions properly.
- **Congenital Heart Disease:** One or more abnormalities in the heart's structure that occurs at birth.

Heart Transplant Process



John, heart recipient (transplanted March 2022)



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Heart Transplant Process

We strongly encourage you to have at least one support person attend your testing appointment, education session and office visits with you.

Transplant Process Steps

The journey through the process of organ transplant requires several steps:

- 1. Referral Call**
- 2. Tier One Evaluation**
- 3. Tier Two Evaluation**
- 4. Patient Selection Committee (PSC)**
- 5. Ohio Solid Organ Transplantation Consortium (OSOTC) Approval**
- 6. Transplant Wait List**
- 7. Getting the Call**

We will review each of these steps to help you know what you can expect. Please ask any questions you may have and let us know if there is anything that you do not understand.

Step 1: Referral Call

You will receive a phone call from the Heart Transplant Program after receiving your referral and your records have been received.

You can also refer yourself for transplant.

During this phone call, we will review the following:

1. Demographics
2. Insurance
3. Caregiver Support
4. Recent Test Results
5. Substance Use
6. Education Session
7. Medical Clearance Forms
8. Vaccination History

If your medical team needs to send additional records, please have them faxed to [614-293-9038](tel:614-293-9038).

Step 2: Tier One Evaluation

You may hear staff refer to this process as the “Advanced Therapy Evaluation.” An Advanced Therapy Evaluation includes testing for a heart transplant and/or mechanical support (such as a left ventricular assist device, or LVAD). The evaluation process for heart transplant and mechanical support are the same.

Your transplant coordinator will review what you need to complete. Please wait for instructions before starting.

The Tier One Evaluation consists of the following:

Heart Transplant Education Session

If you are considering a heart transplant, the next step in the process is to attend an education session. All candidates must attend, and you will need to attend this class with your primary caregiver.

You cannot enter the education session late. If you arrive late, you will need to call the transplant office to reschedule.

The class will last approximately two hours.

In the first hour, the following topics will be reviewed:

- Heart Disease
- Reason for Referral
- Heart Transplant Evaluation
- Medical Clearance Forms
- Dental
- Colonoscopy
- PAP/Mammogram
- Evaluation Testing
- Patient Selection Committee
- Contraindications to Transplant (reasons someone would not be a good transplant candidate)
- Heart Transplant Waitlist
- Surgery
- Medications
- Care at Home

Individuals who are interested in proceeding with their evaluation will sign mandatory documentation following the education portion.

Mandatory Documentation Includes:

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

Completion of Medical Clearance Forms:

- Dental
- Colonoscopy
- PAP
- Mammogram

Completion of 24-hour Urine Specimen

Vaccinations

When Tier One is completed, and all documentation has been received by the transplant office, you will move on to Tier Two Evaluation.



Please attempt to complete Tier One of the evaluation process within 30 days. If for any reason you cannot complete Tier One during this time frame, please notify the transplant office. **Please note: Your lab work orders could expire if Tier One evaluations are not completed within the 30-day time frame.**

*Mary, heart recipient
(transplanted May 1998)*

Step 3: Tier Two Evaluation

The Advanced Therapy Evaluation will take place over three consecutive days.

Day One: You will complete all required testing at one location.

Commonly Ordered Tests

- Echocardiogram (ultrasound of heart)
- Right heart catheterization (internal procedure to measure heart function and pressure)
- Cardiopulmonary stress test (commonly referred to as V02 or CPX)
- Electrocardiogram (EKG or ECG to check heart electrical function)
- Abdominal ultrasound
- Carotid ultrasound
- ABI (noninvasive circulation test on your legs)
- Pulmonary function tests (determines lung function)
- Arterial blood gas test (ABG)
- Six-minute walking test
- Chest CT scan
- Chest X-ray
- Blood and urine studies

Day Two: You will complete consultations at The Ross Heart Hospital

- Common Consultations
- Heart Failure Cardiologist
- Cardiac Surgeon
- Heart Transplant Coordinator
- Social Worker

Day Three: Virtual Dietitian Appointment

All patients are responsible for viewing MyChart for possible changes.

If you need to reschedule, you will be responsible for calling the scheduling department at [614-293-7677](tel:614-293-7677).

Step 4: Patient Selection Committee

When your testing and evaluations are completed, you will be presented as a heart transplant candidate at the Patient Selection Committee (PSC) meeting. This is a multidisciplinary committee team of physicians and nonphysicians, some of whom you have met throughout your evaluation process. The committee has the responsibility of thoroughly reviewing each patient case and must determine not only if you are an acceptable candidate for transplant, but if there is any other intervention possible before proceeding with transplant.

All aspects of your evaluation will be discussed, and a decision will be made about your candidacy. There are three possible results:

1. You are approved for the heart transplant wait list.
2. No decision has been made about your candidacy and you may be asked to complete additional testing.
3. You are not approved for the heart transplant wait list. This may be a permanent or temporary decision. Continue your care with your cardiologist. You may be referred back for transplant evaluation in the future.

While your physician will advocate on your behalf, it is important to know that the decision made about your candidacy in the PSC meeting is a group decision, not an individual decision.

Your cardiologist or pre-transplant coordinator will contact you to let you know the decision from the PSC about your case. A letter stating the decision will also be mailed to you.

Step 5: OSOTC Approval

If you are accepted for the heart transplant waitlist, your medical information will be sent to the Ohio Solid Organ Transplantation Consortium (OSOTC) for approval if you have Medicaid prior to being listed for transplant.

Established in 1984, the OSOTC is unique to Ohio and helps ensure that all people have equal access to organs. Once your medical information is submitted, you can expect to hear a result in approximately 48 hours. In the rare circumstance that the OSOTC requires clarification or additional information about your medical history, a physician phone call may be required and will delay the response time.

The OSOTC has criteria specific to alcohol and substance use disorders. Some individuals may be required to complete additional counseling or testing prior to approval. If the consortium requests additional information or declines you for transplant, your social worker and psychologist will work closely with you.

Step 6: Transplant Wait List

Once you have been approved by the PSC and by the OSOTC, you will be added to the national wait list for heart transplantation. You will receive a letter and a phone call when you have been placed on the heart transplant wait list. There are several factors that determine your placement on the wait list.

Heart Transplant Status

There are six active statuses for heart transplantation. Your status will depend greatly upon your health at the time of your wait-listing. The sickest candidates are listed as status 1 or 2 (identifying an urgent need for transplantation) and are required to be hospitalized. The lowest status ranking, status 6, identifies the least-urgent patients for transplant who are being maintained on oral medications.

This list identifies a few examples of listing status: You will know your status at all times and will know if your status ever changes.

STATUS RATING	HEALTH CONDITION
Status 1 (most urgent)	ECMO Biventricular Support
Status 2	Intra-aortic balloon pump CentriMag TAH LVAD malfunction Arrhythmia
Status 3	LVAD complications LVAD with 30 discretionary days Inotropes with hemodynamic monitoring
Status 4	LVAD without 30 discretionary days Inotropes without hemodynamic monitoring Congenital disease Angina Re-transplant
Status 5	Registered on the wait list for at least one other organ, if candidate does not meet qualifications for a higher status
Status 6 (least urgent)	All those who do not meet qualification of statuses 1-5
Status 7	Wait list hold

You will know your status at all times and will know if your status ever changes.

Waiting

All candidates are instructed to stay within 2 to 3 hours of the medical center while waiting for a heart transplant. The candidate and support person must ensure that phones are in proper working order 24 hours a day.

It is essential that you stay in close communication with the heart transplant team while you are on the wait list. Let the coordinator know the following right away:

- If you have changes in your health
- If you are at an outside medical center
- If you make changes to your contact information
- If you make any changes to your support system
- If you make any changes to your insurance

You should have plans ready for child and pet care, if needed, as well as transportation arranged, so you are prepared to leave home within 30 minutes after you receive the phone call.

You are expected to abstain from using drugs or alcohol while you are on the transplant list. You may be required to have random drug screenings done while you are on the transplant list.

Please continue to see your family doctor while you are on the transplant list.

Status 7 – Wait List Hold

You may be placed on a wait list hold for many reasons. Being on hold means that you are not eligible for donor offers, but you have not been removed from the list.

Reasons you may be placed on hold:

- You are too sick for transplant surgery
- You did not follow through with your medical plan
- Loss of health insurance
- Positive drug or nicotine test

If you are placed on wait list hold status or removed from the transplant wait list, you will receive a phone call and a letter of notification.

Step 7: Getting the Call

You will receive a call from a heart transplant coordinator when an organ has been accepted for transplant. The phone number that the coordinator is calling from will not always show as an Ohio State number on your caller ID. Please do not decline calls, as you may miss the call for an organ offer. Please note that if the coordinator cannot reach you by phone, they will likely call the emergency contact or your support person.

Upon receiving the call, you should be prepared to leave home within 30 minutes.

The transplant coordinator might ask you some of these questions:

- What was your last INR result?
- Have you had any abnormal bleeding?
- Do you have any signs of infection?
- Are you on antibiotics?

Donor Infectious Disease Transmission

All organ donors are tested for different infectious diseases. Examples of some of the infectious diseases that will be tested on your organ donor include:

- Hepatitis A
- Hepatitis B
- Hepatitis C
- Human Immunodeficiency Virus
- Cytomegalovirus
- Epstein Barr Virus

Some organ donors engage in behavior that would put that at risk for contracting an infectious disease. These donors are referred to as “Risk Criteria Donors”.

The chance that a donor would have an infectious disease that did not show up on blood work is approximately one per 1 million donors

Hepatitis C Donors

Many transplant centers accept donors that have hepatitis C.

Hepatitis is inflammation of the liver. It is estimated that 4 million people could have Hepatitis C in the United States.

Why do we accept organs that are Hepatitis C Positive?

- Hepatitis C is now curable with medicine.
- It helps to expand your donor population.
- You may spend less time waiting for an organ.

Hepatitis C is transmitted via blood.

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

There is no known difference in 1-year survival, rejection rates, or complications if you accept a risk criteria donor.

Hospital Admission Reminders

- Bring photo ID and insurance card
- Bring current list of all medicines
- Bring power of attorney or living will documents, if new to your medical record
- Do not bring jewelry or other valuables with you to the hospital
- VAD patients should bring all VAD equipment to the hospital



Margaret, heart recipient (transplanted August 2018) pictured with her family

Heart Transplant Surgery



Traves, heart recipient (transplanted February 2020)



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Transplant Surgery

After you receive the call from your transplant coordinator, you will be instructed to report directly to one of three hospital entrances: Emergency Department, Ross Heart Hospital admissions office or the University Hospital – Rhodes Hall admissions office. All three entrances are located on the main campus at The Ohio State University Wexner Medical Center, and there is valet parking at each entrance.

Before Surgery

Upon arrival, you will have multiple lab tests done to ensure you are ready for transplant. You will be given a number of medications, including antibiotics, antifungals and immunosuppressants to prevent you from rejecting your newly transplanted heart.

Some things to expect during surgical preparations:

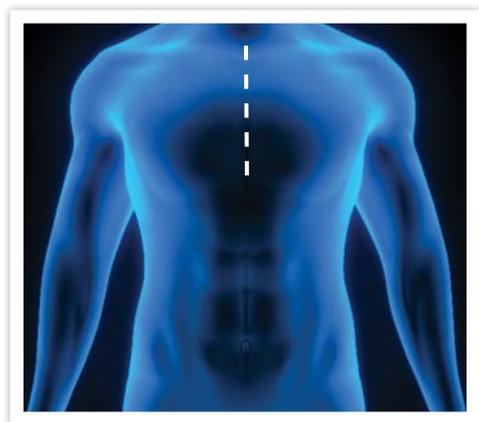
- Blood work
- Urine studies
- X-rays
- Shaving of surgical area
- Anesthesiology
- Surgeons and surgical fellows
- Consent for surgery
- Multiple IV drips

Possible Risks or Problems from Surgery

The doctor will talk with you about risks and benefits of transplant surgery before you sign the surgery consent form. There may be other risks, based on the donor organ and other factors. Ask questions if you do not understand the risks as the doctor explains them to you. Major risks include:

- Bleeding
- Infection
- Pneumonia
- Kidney and liver complications
- Blood clots
- Death

Surgery Can Take Up to Eight Hours



Ideally, surgery is performed as soon as the organ is available. We will do our best to notify you of the time of surgery; however, this could fluctuate significantly depending on the donor's operating room and organ transport (if the donor is located at another hospital). It is a well-orchestrated event. Short delays can be common. But if there is a significant delay in your surgery, you will be notified.

When you are taken to the operating room, you will be given general anesthesia, so you will not be awake during the surgery. The doctors will perform a median sternotomy, which is a vertical inline incision along the breastbone (sternum).

You will have a breathing tube connected to a ventilator and several IV lines in place after the surgery is done. You will also have several chest tubes and/or drains to drain fluid out to allow healing. The incision will be closed with staples. You will also have wraps on your legs to prevent blood clots from forming in your legs. You will also have an external pacemaker.

The transplanted heart will be beating again in your body within 4 to 6 hours after donor procurement.

Care After Surgery



John, heart recipient (transplanted March 2022), pictured with daughter Tiffany and wife Linda



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Care After Surgery

You will spend a few days in the intensive care unit (ICU) following heart transplant. You will have one-to-one care with a nurse, as well as surgery, cardiology and intensive care teams monitoring your progress. Your breathing tube should be removed in less than 24 hours. Many patients can sit in a chair, eat and take pills again within 24 to 48 hours after surgery.

We anticipate that you will be discharged from the hospital within 14 days after your surgery. Your heart post-transplant nurse coordinator will start teaching you about your medications and taking care of yourself when you return home.

As soon as you are ready, the pharmacist will order self-administered medications (referred to as SAMs) so that you can practice taking your medications on your own before you return home. You will be expected to keep track of the doses and check them off in your transplant notebook.

Here are some of the things you can expect to learn after transplant:

- Preventing rejection with immunosuppression medicines
- How to prevent infections
- How to care for your surgical incision
- How to chart in your transplant notebook
- After-hours emergency procedure

Immunosuppression Medicines (Also Called Anti-Rejection Medicines)

Your immune system helps protect your body from infection and fights off things that might be harmful to you. After transplant, your immune system will know the transplanted heart is foreign to your body. Your immune system's natural reaction is to reject it, or get rid of it. Immunosuppression medicines must be taken after transplant surgery to reduce your body's chances of rejecting your newly transplanted heart.

- **You will need to take these medicines two times each day, every day, for the rest of your life.**
- As a transplant patient, you need to learn the names of the medications, their purpose, when to take them and their possible side effects.
- **You will also need to have lab work done often to check the levels of your medicines. Dosages of medicines often are based on lab results.**
- **DO NOT EVER STOP TAKING YOUR MEDICINES OR CHANGE A DOSE WITHOUT PHYSICIAN INSTRUCTION.**
 - Medicine doses will change frequently. Your post-transplant coordinator will give instructions over the phone. You must keep track of all medication changes and update your medication lists.
 - Only your heart transplant team should make changes to your transplant medicines.

Protecting Yourself From Infections

Because immunosuppression medicines weaken your body's immune system, you need to take extra steps to stay healthy. You will learn how to protect yourself, including:

- Good hand washing and using hand sanitizer is critical
- Avoiding sick people
- Wearing a surgical mask for approximately four to six months after transplant
- No travel for the first year

Working With Your Post-Transplant Coordinator

You will get a call from a post-transplant coordinator 24 to 48 hours after you leave the hospital after your transplant surgery. The coordinator is your contact for any questions you may have about your care. The coordinator will also work with you to coordinate lab work and management of your medicines.

Staying Close to Ohio State

If you live outside Franklin County, you will be asked to stay locally, close to Ohio State Ross Heart Hospital, for one to two weeks after discharge. Many patients stay at the Unverferth House during this time.

Appointments After Transplant

- You should plan to have follow-up appointments every week for the first month.
- Clinic appointments are on Tuesdays.
- You will know the dates and times of each appointment for the first three months at the time of discharge.
- Your support person must be in attendance at every appointment for the first three months.

CLINIC SCHEDULE FOR FIRST YEAR AFTER TRANSPLANT

Weekly the first four weeks after transplant	Month 1: Visit Weeks 1, 2, 3, 4
Then, every other week for four visits	Months 2-3: Visit Weeks 6, 8, 10, 12
After week 12 (three months post-transplant), you will visit monthly until your transplant one-year anniversary	Months 4-12: Visit Each Month

- You will have periodic biopsies throughout your first year of transplant. The biopsy is a tissue sample taken from your new heart during a right heart catheterization procedure. The tissue sample is then evaluated under a microscope for evidence of organ rejection, which is important to ensure your immune system is not attacking your new heart.
- Plan to be at the hospital for most of the day when you are scheduled for a visit and a biopsy.
- All patients will attend cardiac rehabilitation after transplant. This begins around six weeks post-surgery and lasts for 12 weeks. You can go to the center of your choice.
- Within the first few weeks after being home, you should also see your family physician.

Can I Contact the Donor Family?

This is your decision. Every donor family and situation is different. Some donor families want to share about their loved one, while others may find it too difficult.

Please remember that your donor family will still be recovering from a sudden loss in the months after your transplant.

Please contact Lifeline of Ohio at lifelineofohio.org or 800-525-5667 to find out more about contacting your donor family.

Other Treatment Options



Anthony, heart recipient (transplanted May 2010)



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What if Transplant Isn't Right for Me?

Our goal is to ensure that you receive extensive education about heart transplantation and fully understand the required commitments for the surgery to be successful. Transplant is not the right fit for everyone, and if you choose not to proceed, we will support your decision with alternative options.

- **Medical Therapy** – You may choose to continue on your current therapy, such as oral medications.
- **Inotropes** – Inotropes are intravenous medications that will help improve the force of your heart contractions in the hopes of making you feel better, while extending your life. Inotropes are infused through a PICC line (intravenous access meant to stay in for weeks to months).
- **Mechanical Support** – There are a variety of mechanical support options, the most common of which is the LVAD (left ventricular assist device). This is a durable pump that will allow you to be home and remain active.
- **Palliative Care** – Palliative care can help you with your comfort, health care goals and end-of-life care. We encourage all patients and their families to meet with a palliative team, regardless of the path you choose.



*Tim, heart recipient
(transplanted July 2004),
pictured with his wife, Karen*

Preparing for a Heart Transplant

Ohio State Comprehensive Transplant Center
Heart Transplant and VAD Office
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452 W. 10th Ave.
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Phone: 614-293-3787 or 800-538-1886
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