Heart Transplantation at Temple University Hospital

This booklet provides an in-depth guide through the heart transplant process. In it, you will find details related to all stages of the process, from the tests you will take during evaluation, to the surgery itself and through the post-transplant rehabilitation period, including a guide to your medications and follow-up testing.

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INTRODUCTION

WELCOME

Over the past two decades, organ transplantation has become an accepted medical treatment for end-stage organ disease. It can offer patients hope of returning to a better quality of life.

In this notebook, you will learn about each step in the process you’re about to face as a transplant candidate and who to turn to when you have questions. We’re here to help you understand and manage your condition.

The heart transplant program at Temple University Hospital began in April of 1984. Today, the Temple Heart Center continues to perform numerous heart transplants each year. Our physicians are dedicated to training future transplant surgeons and continuing to pioneer groundbreaking research, making Temple one of the leading heart transplant programs in the country.

Temple University Hospital offers one of the most comprehensive medical and surgical cardiac care programs in the country. This allows us to treat the region’s most difficult cardiac cases. With almost 1,000 heart transplants behind us, our one-year survival rate is well above the national average.

HISTORY OF HEART TRANSPLANTATION AT TEMPLE UNIVERSITY HOSPITAL

Cardiac transplantation was first attempted in the early 1900’s in animals. The first human cardiac transplant (chimpanzee heart to human) was performed in 1964, and the first human-human heart transplant was performed in 1967. Over the next several years, over 200 transplants were performed, but patients often died soon after the operation, usually due to infection.

Over the following decade, research efforts were focused on immunosuppressive therapy and infection management, which dramatically improved survival rates. Today, cardiac transplantation is widely recognized as definitive therapy for end-stage heart failure and is routinely performed worldwide.

Heart Transplant Today

Heart transplantation, although becoming more common, is a last resort in most cases, reserved for patients in the end-stage of cardiac (heart) disease, and therefore, in need of drastic intervention. Transplant is, in fact, only an option after all other possible medical therapies have been tried, and no other surgical procedures are considered viable options to improve your condition. We will be working closely with you and your referring physician to evaluate your health
and determine the best course of action for your specific condition. If there are intermediate steps we can try before transplantation, we will recommend them first.

One of these options is a technique that uses an implant called a ventricular assist device (VAD). These devices help patients with severe cardiac disease improve their quality of life, not only allowing them to get back to day-to-day activities, but also enabling them to get in better shape while preparing for heart transplantation. Temple surgeons have performed over 150 of these ventricular assist surgeries in the last decade, helping patients who otherwise may not have survived until transplant.

THE TEMPLE UNIVERSITY HOSPITAL HEART TRANSPLANT TEAM

These are the people who will be working closely with you to make your transplant as successful as possible. Each team member is an expert in a different area of transplantation.

Currently, there is a team of coordinators and physicians who care for patients who are being evaluated for transplant, those who are listed for transplant, and those who have been transplanted. These individuals rotate through the pre- and post-transplant setting, so you may not see the same coordinator or physician from visit to visit in the office or hospital, but you will meet everyone at some point during your time on the waiting list. The entire team is updated regarding your status at weekly transplant meetings, regardless of who you've actually seen that week.

**Cardiologist:** A cardiologist will assess your heart function by reviewing your cardiac testing. The purpose of the tests is to determine the appropriate course of treatment.

**Cardiothoracic Surgeon:** The transplant surgeon performs the operation and will meet with you to evaluate your specific needs, discuss the surgical procedure, and answer questions while you are in the hospital.

**Transplant Nurse Coordinator:** The transplant nurse coordinator coordinates your care with all members of the transplant team. This is the person who will meet with you in the cardiac clinic both prior to and after transplant. This is also the person who will educate you on the journey on which you are about to embark.

**Psychologist:** A clinical psychologist will meet with you and your family to examine and assess neuro-psychological function and to provide emotional support during this highly stressful time. This emotional and behavioral testing information helps us prepare and care for you during and after the transplant.
Outpatient Rehabilitation Team: Patients accepted as transplant candidates will be enrolled in a specialized exercise program designed to increase cardiovascular fitness and strength prior to surgery, and improve ability to perform daily activities until the transplant.

Social Worker: A social worker will help you with your social and financial needs. The social worker will also provide emotional support and counseling throughout the transplantation process.

Financial Counselor: In addition to the social worker, a financial counselor is available to meet with you and your family with regard to insurance issues and other billing related concerns.

Dietitian: Your dietitian will review your eating habits and nutritional status. Good nutritional status has been proven to significantly enhance healing and outcome following surgery.

Anesthesiologist: The anesthesiologist not only administers the anesthesia at the onset of the operation, but also monitors your vital signs throughout your operation and, along with the surgeon and the cardiologist, will direct your care in the Intensive Care Unit after surgery.

Dentist: A dentist (you are free to use your own) will be required to assess the health and hygiene of your teeth and gums and write a letter to your transplant team giving you medical clearance. An undetected oral hygiene problem could pose an infection risk after surgery and jeopardize your recovery.

Additional consultations not listed here might be requested depending on your individual condition and situation.
PRIOR TO TRANSPLANT

EVALUATION AND DETERMINING CANDIDACY

The first step in the process is an evaluation. The first person you’ll meet is the cardiologist for a consultation. Your medical records (submitted by your referring physician), along with other data obtained as part of the transplant evaluation, will be reviewed. Your general health will also be evaluated for any other medical illnesses that would make a heart transplant inadvisable.

At this stage, if different treatments can be found that could make heart transplantation unnecessary (or even postpone it for a while), these options will be discussed with you. These treatments can be minor, such as a modification to your regimen of medications or equipping you with a special pacemaker. Or, your condition may be alleviated by an intermediate-level surgery, such as bypass or valve surgery. Our goal is for you to keep your own heart for as long as possible without compromising other organ function.

Unless transplantation is completely ruled out at this point, the cardiologist will then prescribe a series of tests, including several types of laboratory and diagnostic tests, some inpatient and some outpatient (see below).

You will also have consultations with the other members of the transplantation team, who will review your medical history, the progression of your heart disease, and your social support system. Remember, to be considered for a transplant, patients must be highly motivated, compliant with all phases of their medical care, and have a strong support system.

This process, from initial consultation to receiving test results, can take anywhere from one week to three months, and occasionally even longer under circumstances where intermediate treatments have been prescribed which require additional time to observe results.

Testing

In addition to the tests discussed in the General booklet (24-Hour Urine Test, Blood Test, Chest X-ray, Echocardiogram, Cardiac Catheterization, General Health), you may undergo the following examinations that are specifically related to the heart transplant.

Pulmonary Function Studies – You will be given this test if you are a smoker or if you are receiving a heart-lung transplant. You will be asked to breathe into a tube attached to a measuring device, which will show how well your lungs are working and determine your blood’s capacity to carry oxygen.
CAT Scan – This is a method of combining images from multiple x-rays to produce pictures of internal organs, which can be used to identify abnormalities. CAT scans of the chest tell us the extent of damage to heart tissue.

DEXA Scan – This test measures bone mineral density to check for possible bone loss. Bone loss is serious but treatable, and early detection allows us to prescribe appropriate medication.

VO2/Stress Test – This test evaluates your heart and lung function while exercising. You will breathe through a mouthpiece connected to a device that measures the oxygen and carbon dioxide you are inhaling and exhaling while you exercise. This allows us to determine if you are sick enough to need a transplant and prove that the limiting factor is heart-function-related, not lung-function-related.

Persantine Thallium Stress Test – This x-ray of the heart shows blood flow to your heart muscle. You will be given special medication through an IV, which accumulates in the heart muscle and allows us to see any blockages in your coronary arteries. Blockages may be treatable with bypass surgery (rather than requiring a transplant).

TB Skin Test – This skin test determines whether you have bacteria cells in your body which indicate an infection that could affect the strength of your immune system. The test involves injecting a small amount of fluid just under the first layer of the skin of your inner forearm. A healthcare worker will check the site of the injection at 48 and 72 hours to see if a (local) skin reaction has occurred.

As you can see, these tests are extensive, and many HMOs require referrals for each one. We will be happy to work with you and your insurance company to ensure that you have all the necessary clearances and approvals before we begin. The financial coordinator may even suggest that you change your insurance to a plan that offers better or more adequate coverage. Although we will do our best to maximize your coverage, it is likely that you will still be responsible for a certain portion of the expenses, which your financial coordinator will help you figure out.

Note: Additional testing may be required based on your current condition, the assessment of the cardiologist, and/or your specific past medical history. Any extra testing should be explained to you when it is determined that such testing is needed. The cardiologist may also have you see other physicians who specialize in treating other health problems (actual and suspected) that the team might identify during the evaluation phase.
Eligibility Consultation

Once all your testing is complete and the results are in, your case will be presented to the Transplant Committee. This committee meets weekly, and consists of transplant cardiologists, transplant surgeons, pathologists, pharmacists, physical therapists, transplant nurse coordinators, heart failure nurse coordinators, a cardiac rehabilitation nurse, a social worker, an immunologist, a psychologist, and a dietitian. The evaluation process helps the team make appropriate decisions regarding your options.

When the team meets, it is trying to answer the following:

1. Are you sick enough to need a transplant to prolong your life?
   a. Can your current medications be adjusted, or would performing procedures such as angioplasty improve your heart function?
   b. Would performing a surgical procedure such as coronary artery bypass grafting or heart valve repair or replacement improve your cardiac function?

2. Do you have any other health issues that would prevent you from doing well after transplant?

3. Are there other circumstances, such as emotional support or financial concerns, which need to be resolved so that you can have a successful recovery after transplant surgery?

After the committee makes its decision, someone from the transplant team will let you know what its decision was and how it was made.

At this time, the transplant team will share the results of your tests, its decision concerning your eligibility for transplantation, and the risks and benefits of transplantation. There will be a tremendous amount of information discussed at this meeting, and you will have much to think about concerning your health and what is best for you. Remember, even if the team decides that you are a candidate for transplantation, the final decision rests with you.

Be sure to ask as many questions as you need to and do your own research on your condition to become well informed about your situation. Education about transplantation should begin with you and your family during the evaluation phase and continue until long after transplant.

Note: If you have not been listed for heart transplant at this time, either because you are not sick enough to qualify or because other methods are better suited to your condition, you will have the option of continuing to be monitored by a heart failure and transplant cardiologist in the future (ours, at Temple, or your referring cardiologist). It is always possible that your condition will change, so continued evaluation of your condition is recommended.
THE WAITING PERIOD

Once the transplant committee has decided that you are a candidate for transplant, you will be registered on the national waiting list for donor organs, and you begin the process of waiting for your heart, either as an inpatient or outpatient (see below).

Listing and Matching of Candidates

The United Network of Organ Sharing (UNOS) manages the national waiting list and strictly ensures the fair and legal distribution of organs to recipients. This organization is responsible for working with your transplant team to match you with a donor.

The match is based on information about you and your condition.

- For heart transplant candidates, it is based on body size, blood type, the degree of severity of your heart condition, and antibody levels.
- For heart-lung transplant candidates, it is based on body size, blood type, chest dimensions, and antibody levels.
- For heart-kidney transplant candidates, it is based on body size, blood type, and kidney tissue type.

Listing status depends on the severity of illness, and to some extent, length of time waiting. Because organs are donated in a spirit of altruism and are considered a national resource, it is only right they be allocated in an equitable manner.

Listing Categories

There are currently four listing categories for those actively being considered for organs:

Status IA:
Patients who
- only have a few hours or days to live,
- are unable to leave the hospital because of the need for intravenous medications and invasive monitoring, or
- require mechanical assist devices to keep them alive.

Status IB:
Patients who
- require continuous intravenous medications but do not require invasive heart monitoring
- are utilizing an LVAD or other “bridge” therapy that does not require continuous hospitalization
Note: Although patients in Status IB are technically permitted to wait at home, we often recommend that they remain in the hospital, under continuous observation, until transplant or until their condition stabilizes further.

**Status II:**
Patients who
- are sick enough to be listed for transplant and well enough to wait at home, and do not require continuous intravenous medication or other types of life support.

**Status 7:**
Temporary inactivation on the transplant list for patients for whom transplant is not in their best interest because
- their condition has worsened and they are too sick to undergo transplant,
- their condition has temporarily changed (i.e., a complication such as an infection),
- their compliance with medications or appointments is in bad standing (if behavior does not change, the patient will be de-listed), or
- they are traveling out of the area.

Note: Wait time is neither lost nor accrued while in Status 7. You will be informed if you are ever made inactive.

Being listed in a category does not guarantee continued listing at the original status. During the course of waiting, you will be reevaluated periodically and your circumstances may change (for example, if your condition stabilizes, your status may be lowered). These changes may ultimately affect your suitability as a candidate, and the transplant team might decide to remove you from the list, temporarily or permanently. If that should happen, you will of course be informed as to why and how your care will be affected.

These categories are meant to provide guidelines for the team, and while they are usually appropriate, sometimes they don’t perfectly represent an individual’s situation. In most cases, we can simply modify your treatment accordingly (for example, suggesting you wait in the hospital even though you are a Status IB). Every so often, special circumstances warrant actual exceptions to these categories. If your case requires special attention, we will submit an appeal to the Regional Review Board, which consists of representatives of transplant centers around the region, and help you get listed in the most appropriate category.

These categories are part of a fair and equitable system that ensures well-matched donor organs for as many people as possible. It is important to understand that your name goes on a list with patients from all over the country and from many other transplant programs. Donor organs also become available in all states, often quite far from Philadelphia. Therefore, it is not possible for us to tell you “where you stand” on the waiting list, since as each specific donor is identified, a list is
created with those potential recipients who might be a good match for that specific organ.

**Multiple Listing**

Multiple listing means that you register on the waiting list at more than one transplant center. It is possible that multiple listing may increase your chances of getting an organ offer earlier.

You should know that ultimately, it’s up to those additional transplant centers to decide whether or not to accept you for multiple listing, and it will most likely involve another full evaluation by their team. You may want to check with your insurance first to be sure that they will cover the additional testing.

UNOS provides a booklet that explains this option thoroughly. Your Transplant Nurse Coordinator will give you a copy.

**Status-Specific Information**

Some of the guidelines you will follow as you wait for your donor heart will be specific to your condition (represented broadly by your listing category). Please read both Status I and Status II sections, as your Status may change over time, but sign and date your current category.

**Status I Candidates**

If you are listed as either a Status IA or IB patient at your evaluation, you likely will need to wait for your heart transplant in the hospital at Temple ("inpatient"), unless you have a mechanical assist device such as an LVAD that allows you to comfortably wait at home. Most patients in this Status will be on intravenous infusions on a continuous basis while waiting, and your heart will be monitored by a portable monitor pack 24 hours a day. The typical waiting period is variable and may be as short as a few days or as long as many months.

**Exercise**

During your time as a Status I candidate, you will need to keep your body in the best shape possible before going in to the operating room for your transplant. The better shape you are in when you receive the call for transplant, the shorter and easier your recovery after transplant will be.

A Cardiac Rehabilitation Nurse will meet with you and prescribe a program of exercises. Initially, you’ll be escorted to and from the gym and monitored to ensure that you are doing everything correctly. Once you are comfortable with your routine, you will exercise on your own.
Lifestyle

Modifications to your diet and exercise routines should be considered lifelong behavioral changes. Your meals will be provided while you are in the hospital, but you will also be allowed to order food in. In order to make healthy choices, now and in the future, dietary counseling is available to you. We recommend that you meet with the counselor periodically during your stay.

Emotional Well-Being

The effort to maximize your health is both physical and emotional, and will be an ongoing process even after transplant.

Often, patients waiting in the hospital experience a range of (very normal) feelings, including stress or loneliness. For some, the transition of moving back home after transplant is intimidating.

A staff member from the psychology department is available to help you through this challenging time and to make the transition between pre-transplant and post-transplant as smooth as possible. Contact your Transplant Nurse Coordinator to schedule a confidential appointment.

Note: Even if you feel perfectly calm and content throughout your stay, we recommend you meet with the psychologist at least once (after your initial evaluation) to touch base.

Education

Support groups. You are expected to attend and participate in Temple’s Second Chance Heart Transplantation Support Group, which meets the first Wednesday of each month at 11 a.m. in the conference room on the seventh (7th) floor of the Patient Tower. Here, you can meet and ask questions of other people going through the same experience. Learning as much as you can about transplantation will help you. If you know what to expect, you will feel better throughout the process.

Ongoing education. Your Transplant Nurse Coordinator will be providing information relevant to your transplant and post-transplant experience throughout your stay in the hospital.

These education and support systems are valuable resources, available to help prepare you for success until, during, and after transplant. It is the expectation of the transplant team that you will take advantage of the time and the expertise of our team members to ensure that success.

Ongoing Health Screenings and Appointments

While in the hospital, you will undergo routine examinations (blood work, physical exams, review of medications) and receive certain immunizations and
vaccines’ that will help keep you healthy. Any changes in your clinical status will be assessed, and plans for customized laboratory testing and medical therapy will be made.

Approximately every four-to-six weeks you will have a right-heart catheterization. Every 12 months, you will undergo a full re-evaluation, including all the tests you took to get listed originally.

* Vaccines may include chicken pox, pneumonia, flu (in season), and the Hepatitis B series.
STATUS I CANDIDATE: RESPONSIBILITIES AGREEMENT

As part of my responsibilities as a member of the transplant team, I, ________________________, am expected to do everything possible to ensure that my transplant is a success. Adherence to these expectations will demonstrate my commitment to transplant as my transplant team is committed to me.

• Exercise and diet
  o Physical activity and modifications to your diet to maximize your health

• Emotional well-being
  o Utilizing resources available to ensure good emotional health throughout the transplant process

• Education
  o Participation in the Second Chance Heart Transplantation Support Group

_________________________________________________________
SIGNATURE

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DATE
Status II Candidates

Status II candidates are permitted to live at home, and as such are “outpatients.” This allows for additional freedoms AND additional responsibilities on your part.

When a patient is selected to receive a donor heart, he or she must be available, healthy enough to undergo major surgery, and willing to be transplanted immediately. That means you must be responsible for ensuring we can find you at any time, and that you maintain (or improve) your health, which includes diet and exercise as well as keeping up with your schedule of office visits.

Beepers

When a donor heart becomes available, the physicians have a few precious hours to keep it healthy and get it to you. Because time is such a critical factor, we will provide you with a beeper (free of charge – our secretary will make the arrangements), so we can reach you immediately should an appropriate donor organ becomes available. It is very important that you keep your beeper with you at all times, and call (215) 707-3782 anytime you are paged or called. Periodically, a member of our team will call you to ensure that the beeper is functioning properly. The beeper should be used ONLY for Temple University Hospital contact, and not for personal pages.

We advise that you change the batteries in the beeper monthly. If we cannot reach you by beeper, the Transplant Nurse Coordinator will try to reach you by phone, so if you have CALLER INTERCEPT, you must provide our office with the code to bypass it. Failure to do so limits our ability to care for you, and therefore can jeopardize your status on the national waiting list.

WHEN YOU ARE PAGED OR CALLED, CALL (215) 707-3782 IMMEDIATELY.

Staying Connected

If you are sick and want to report symptoms, or have a question for the Transplant Nurse Coordinator, call (215) 707-3782. This is a 24-hour number. After hours and on weekends and holidays, all calls are answered by an answering service and are forwarded to the appropriate on-call physician or coordinator. During business hours (from 8 a.m. – 5 p.m., Monday through Friday, when calling you will access the voicemail system, directing you to either the prescription line, the Transplant Nurse Coordinator, or Scheduling Coordinator lines. Select the Transplant Nurse Coordinator and leave a message. Phone messages will be returned in a reasonable time. Please keep in mind that these calls will be addressed based on the nature of the call.

If it is urgent (including returning a page), you will be able to speak to someone who will direct your call by pressing zero (“0”). Please keep in mind that this should be used for emergencies only – otherwise we expect you to leave a message.
It is critical that you stay accessible so the team knows how to contact you at all times. This is your responsibility: if you go on vacation, if you leave the area for any reason, you must contact the Transplant Nurse Coordinator with phone numbers where you can be reached and when you will be back. When you return from any trip, you must call the Transplant Nurse Coordinator with the update that you are home. Keep in mind that travel outside of a two to three hour radius of the hospital will require us to list you as a Status 7 candidate, which will be switched back when you return (all the more reason to contact us immediately when you get back).

If you are hospitalized for ANY reason during your time on the waiting list, you must let the transplant team know right away. If you are hospitalized at Temple University Hospital, tell the doctor treating you to notify the Heart Transplant Team. If you are at a different hospital, ask a member of your family to call the Transplant Nurse Coordinator if you cannot. Ideally, you should then be transferred to Temple University Hospital. If that is not possible, at least have the physician call our offices.

If, during any hospitalization, a physician feels you need a blood transfusion, you should tell them that you are waiting for a transplant, and to contact your transplant team to discuss the transfusion. Under these circumstances, please come to our offices for a special blood test as soon as you are able.

**Cardiac Rehabilitation Program**

We recommend that you enroll in a specialized exercise program. The overall goals of this program are to reduce your shortness of breath and improve your ability to perform activities of daily living. Improved conditioning prior to transplantation will also improve your ability to recover after surgery. To that end, you will be prescribed individualized exercises designed to improve cardiovascular conditioning and strengthen respiratory muscles.

We offer this program at Temple, or we can help you find one closer to your home if you prefer. Once you choose a facility, please have the Cardiac Rehabilitation Nurse contact us so we can help prescribe a personalized program for you. We will stay in contact with the Nurse to monitor your progress.

**Ongoing Health Screenings and Appointments**

You will stay connected with your transplant team while you are waiting for your donor heart on an outpatient basis through regular visits at the Advanced Heart Failure and Transplant Center. You will come in to the hospital every four weeks for office visits. This will help keep you healthy. Your Transplant Nurse Coordinator will provide you with a schedule of appointments. It is very important that you follow this schedule. If you are between visits, you should call in to your
Coordinator to report any illness or changes in your health, most importantly if you are hospitalized.

Monthly office visits with the Transplant Nurse Coordinators and physicians are scheduled on Mondays or Wednesdays, between 9 a.m. and 12 noon. At these visits, you’ll undergo routine blood work, a physical examination, and review of medications. Any changes in your clinical status will be assessed, and plans for testing and medical therapy will be made.

At regular intervals, right-heart catheterizations/echocardiograms/exercise VO2 (exercise stress tests) will be done. Every 12 months, you will undergo a full re-evaluation, including all the tests you took to get listed originally.

The coordinators and physicians review your condition and lab results within 24 business hours of your visit. They will then contact you to discuss your test results and schedule your next follow-up appointment. Please be advised that the coordinators will leave a phone message regarding the results of testing and plan of care as well as follow-up appointment date. If you do not wish for the coordinator to leave a message, please discuss this promptly with the Coordinator. We will indicate your wishes on your chart and messages will not be left thereafter.

If at some point the cardiologist determines you are not well enough to continue to wait at home, we will admit you to the hospital and upgrade you to Status 1, awaiting heart transplantation.

Parking Passes

As a patient listed for transplant, you are entitled to parking passes for your visits to Temple, or for immediate family members visiting while you wait for transplant in the hospital. These can be obtained at the Patient Relations office off the main lobby.
Being Prepared

The good news about your organ may arrive at any time. Because you never know when or where you will be when you get the call, it’s a good idea to be ready.

Once again, the transplant team should have a list of contact phone numbers so they can reach you 24 hours a day. You should be carrying your beeper with you at all times, updating your transplant team if you do any traveling. Again, it is your responsibility to be available, otherwise your place on the waiting list may be jeopardized.

You should have a plan for getting to the hospital, especially if you will need a ride or other assistance. You may also want to have someone designated to alert the rest of your family that you have gone to the hospital.

Education

You are expected to attend and participate in Temple’s Second Chance Heart Transplantation Support Group, which meets the first Wednesday of each month, at 11 a.m. in the conference room on the seventh (7th) floor of the Patient Tower. Here, you can meet and ask questions of other people going through the same experience. Learning as much as you can about transplantation will help you. If you know what to expect, you will feel better throughout the process.
STATUS II CANDIDATE: RESPONSIBILITIES AGREEMENT

As part of my responsibilities as a member of the transplant team, I, ____________________________, am expected to do everything possible to ensure that my transplant is a success. Adherence to these expectations will demonstrate my commitment to transplant as my transplant team is committed to me.

- **Accessibility**
  - Responsible use of your pager
  - Maintaining good contact with team, especially if you go out of town or become hospitalized

- **Compliance**
  - Coming to your office visits as scheduled
  - Following the prescribed treatment plan
  - Accurately reporting any change in your condition

- **Exercise and diet**
  - Physical activity and modifications to your diet to maximize your health

- **Education**
  - Participation in the Second Chance Heart Transplantation Support Group

________________________________________________________
SIGNATURE

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DATE
How Long Will I Wait?

The major limiting factor for heart transplantation is the availability of donor organs. Currently, average waiting times vary primarily based on blood type and the status of other waiting recipients in your geographical area. You can contact your team for more information concerning your place on the list.

Of all the stages in the transplant process, the waiting period is perhaps the most difficult.

Now is a good time to get your finances in order and perhaps get involved in some stress-reducing activities and hobbies.

Financial Considerations

Your insurance company has approved you for the transplant along with medication coverage necessary following the transplant. Any changes to your insurance coverage must be reported to the financial coordinator at (215) 707 – 2518. As you will be relying heavily on your health insurance benefits, it is critical that you become very familiar with your policy and that you keep up with your monthly payments (premiums) to ensure you don’t lose your coverage. If your insurance requires referrals for service, it is your responsibility to obtain them prior to your visit and/or testing. Any insurance questions you have may be referred to the above number.

See the General section of this notebook for more detailed information regarding finances.

Stress and Stress Management Suggestions

We know that this is an extremely stressful time for you and your family, but stress can further aggravate your health condition. Do things that keep you physically and mentally active, social, and happy. There are many ways to manage stress and control anxiety. It is important that you find a method that works for you.

*Physical activity.* Stay as active as your condition will permit and attend your Cardiac Rehabilitation classes. This will not only help take your mind off things, but it will help you recover from your operation more quickly. Stay involved with your normal activities to the best of your ability, keeping up with work, studies, or leisure activities. Start a new project or hobby, something “you’ve always wanted to do.” Don’t put your life on hold!

*Support groups.* You are expected to attend and participate in Temple’s Second Chance Heart Transplantation Support Group. Here, you can meet and ask questions of other people going through the same experience. Learning as much
as you can about transplantation will help you; if you know what to expect, you will feel better throughout the process. Lean on your family and friends to keep you company and distract you.

Stay healthy! No smoking, no drinking, and maintain a healthy body weight. Keep up with all routine doctor visits like dental cleanings and gynecological exams. Keep your scheduled appointments with your personal physician and also with your cardiologist in the Heart Transplant clinic. Talk to them or any member of your transplant team about any emotional or physical stresses you are feeling.

Remain hopeful and optimistic. Learn relaxation techniques that can help keep you feeling positive.
WHERE TO GO, WHAT TO DO

After a donor has been identified as compatible to you as determined by the cardiac transplant team, you and your family will be notified as soon as possible. As a Status I or II patient waiting for transplant at home, the Transplant Nurse Coordinator will notify you, first at home, by telephone. If we are unable to reach you by phone, we will contact you by cell phone, then beeper. When your beeper activates, call the number you are paged to. If you have any difficulty, call: (215) 707 - 3782. We will make every effort to give you as much notice as possible, but you should be prepared to come to the hospital as soon as possible (within two to three hours) after you have been notified. If you have been waiting for your transplant as a Status I patient in the hospital, you will be notified by the Transplant Nurse Coordinator.

Do not eat or drink anything after receiving this call. You can take your breathing medication ( inhalers, nebulizers), but no pills. Call the Transplant Nurse Coordinator if you have any questions about what you can and cannot take at (215) 707 - 3782.

The Transplant Nurse Coordinator will have given you directions on exactly which door to enter and where to go, but you can always call back if you are unsure.

Any family that will be with you at the hospital may want to have a bag already packed with toiletries, a pillow, comfortable clothes, spare glasses, books, or cross-word puzzles. You won’t need anything until you come out of Intensive Care (see below), at which time your family can start bringing you your personal items. If your family is from out-of-town, call our concierge service for a listing of hotels and transportation options in the area. The number is (215) 707 - CARE (2273).

Your family is encouraged to accompany you to the hospital, however, we don’t recommend that young children come along until after the operation is over since the process can be very long. The operation itself generally lasts between 6-10 hours, from the time the patient leaves the floor to the time the patient returns to the Intensive Care Unit.

Once you have been taken to the operating room, your family should go to the Cardiac Intensive Care Unit (CICU) Waiting Room, which is located on the second floor of the patient tower building. There are other areas for waiting in the tower, but the CICU Waiting Room is the ONLY location that the operating room staff, intensive care unit staff, and surgeons will come to locate families for communication during and after the procedure. The Transplant Nurse Coordinator or a member of the CICU can provide you with updates most often throughout the procedure.
The Cardiothoracic Surgeon will have spoken to you about the specifics of your individual surgery, but may not be there when you are being readied for surgery. The surgeon will have gone to the location of the donor to evaluate and hopefully bring back your organ. So, if you are arriving from home, you may “beat” the arrival of your donor organ. You will be “prepped” so that you are ready to go when the organ arrives, but this may take a few hours depending on the location and condition of the donor. You will be in a sterile environment, so your family will not be able to keep you company, but many members of your transplant team will be with you to keep you comfortable.

FALSE ALARMS

Unfortunately, when the surgeon evaluates the donor organ, it may be determined that it is not a good match for you. This can be based on many factors, such as the condition of the organ or the levels of antibodies in your bloodstream at the time (making it more likely that your body will reject the organ). Remember, the transplant team is dedicated to obtaining the best possible organ for you, but they are fragile and their condition can degrade significantly in just minutes. The surgeon will not “trade down” for you – we would rather wait for the best possible heart.

Because time is so critical, you will already have been brought to the hospital and probably “prepped” for surgery. At this point, you will be sent home or back to your hospital room to wait for a future offer. This can lead to significant disappointment and stress for you and your family; therefore, we will always do our best to avoid these situations. Rest assured, your place on the national waiting list will remain the same.
POST-TRANSPLANT PLAN

POSTOPERATIVE PERIOD

Once your operation has been completed, the surgeon will go to the CICU Waiting Room and speak with your family. Again, if your family wishes to speak directly with the surgeon, they should be there when the surgeon arrives. Usually, the patient arrives in the Unit approximately 30 minutes to one hour after the surgeon speaks with the family. The CICU staff will allow your family to come visit you for a few moments after you have been settled into your room and assessed by the nurse assigned to you.

You will arrive in the CICU with many tubes, wires, pumps, and monitors, as is common in any open-heart surgical procedure. Patients are generally unresponsive for the first six to eight hours, due to the effects of anesthesia. The nursing and physician staff in the Intensive Care Unit will work to wake you gradually and remove tubing and wires steadily over the first eight to 24 hours.

Regular visiting hours are from 11 a.m. to 8:30 p.m. Your family must use proper precautions, including hand washing, while you are in the CICU. You are not required to wear a mask, and it’s up to you whether you ask your visitors to wear one. We would certainly recommend the use of masks by visitors if they believe they have an active infection or feel they have experienced close exposure to someone with an infection, but it would be better if they didn’t visit you in the hospital at all, under those circumstances. Recommendations for using masks and other precautions once you return home is outlined in a later section.

Next, you will be transferred to a “step-down” unit, with staff experienced in caring for patients after heart surgery. You will remain here until the team feels you are safe to be discharged. This basically means when your condition has stabilized and you are strong enough to drink and eat on your own, and walk short distances.

The average length of stay in the CICU is between two and four days. Total average hospital stay after transplantation is usually 7 to 12 days.

GOING HOME

Going home following your transplant can be exciting as well as frightening. As wonderful as it is to return to your home, assuming responsibility for your own well-being may be worrisome. We will help you with the entire transition.

The first thing you will do to prepare for returning home is assign a primary support person to be home with you, 24 hours a day. You can choose a family member or close friend, but it should be someone you trust to help you with your personal care. You will also need to have a digital scale for reading your weight,
a digital thermometer for taking your temperature, and a digital blood pressure
cuff to measure your blood pressure.

Patient’s family members and caregivers must make themselves available for
two meetings, before you go home:

The first is an overview of everything you will need, EXCEPT your medications.
The Transplant Nurse Coordinator will take this time to educate you and your
caretakers on the essentials of your care at home, including guidelines for
exercising and returning to other day-to-day activities, and how to perform your
new routine of daily self-monitoring (see sections below). They will also provide an
overview of your follow-up visits after your discharge. All this will be summarized
on a Discharge Guide (see back pocket of booklet).

The second meeting occurs on your last day in the hospital, when we review the
organization and administration of your medications. Your new regimen of
medication is fairly complex (see sample Medication Chart), and because taking them
properly is so critical, we will provide you with a few tools to help keep it straight.

First, we will have ordered your first round of medications from your pharmacy.
Family members will need to bring these medications to your hospital room,
where the Transplant Nurse Coordinator will review the medications with you
and your “support” person (this ensures you have a “second set of eyes” taking
all the information in). We feel so strongly about this that we’ve made it part of
the official process of discharging you (in other words, you’re not allowed to go
home until you do it!).

Secondly, we will provide you with a helpful list of tips (see Tips for Taking
Medication), as well as a chart to help you organize and record everything once
you get home.

We understand that your caretakers may be taking valuable time off of work to
stay home with you during the first days after you are discharged, and therefore
they may be apprehensive about taking this additional time off while you’re still
in the hospital to hold these meetings with us. The Heart Transplant Nurse
Coordinators will make every effort to be flexible in scheduling these meetings,
but this information is critical to your comfortable and safe return home, so it
needs to happen before you leave the hospital.

The Transplant Nurse Coordinator will be available, via phone, to answer any
questions you may have. This phone number and many other important contact
numbers are listed on your Discharge Guide. Feel free to call them at any time;
there is no such thing as a “silly” or “dumb” question. Remember, if you thought
to ask it, someone else probably did too.
RECOVERY AND REHABILITATION

You are now officially in the longest phase of your transplant – the recovery and rehabilitation that will last for the duration of your life.

This will include physical activity, home testing/monitoring of certain cardiac functions, a strict regimen of medication, a series of routine follow-up appointments with your transplant team, and ongoing attention to your body's "signals," to ensure that you stay healthy and your new heart continues to work with your body.

Physical Activity

Physical activity and progressive exercises are absolutely necessary for your complete recovery. Therefore, a full program of activity will begin while you are still in the hospital. The Physical Medicine and Rehabilitation Department (PMR) will visit you while you are still in the hospital to help plan an exercise program for you. As soon as you are able, you will be encouraged to walk on a daily basis, more and more frequently as you get stronger.

When you go home, you are to continue to walk daily, gradually increasing the distance covered. Many people find a stationary bike or treadmill to be a convenient adjunct to their walking schedule, especially in bad weather. Upper body exercise is limited to range of motion activities until the surgical incision is healed.

Shortly after discharge from the hospital, you will be expected to enter into a full rehabilitation program. This program is available five days a week at Temple. If you are too far from Temple to participate in our program, we will try to help you find one near your home.

For six to eight weeks after surgery, we ask that you refrain from driving. When riding as a passenger, you should not disable the passenger side airbag but move your seat all the way back (following the same guidelines as for a child). This is to avoid the serious impact an airbag deployment in the front seat would have on you, in the event of an accident. You may begin to drive in approximately eight weeks.

Sexual activity may be resumed at any time during your recovery. Occasionally, long periods of illness and complicated drug regimens impair sexual activity. If you find this to be an issue, please let the doctors know, as there are specialists and therapies that can help.

Please note that each stage of increased activity should begin only after a member of the transplant team gives approval for that particular activity.
Home Testing

Every day, you will be recording many measurements which will serve as indicators of your health. These include your weight, blood pressure, temperature, fluid intake, and, if necessary, blood sugar. Each of these tests tells us something important about your post-transplant condition. Ideally, all the data you collect will stay within safe ranges, but we will teach you how to perform the tests and recognize any dangerous changes that you should report to your transplant team.

General Guidelines

General guidelines for many day-to-day activities are outlined in the back of this notebook, as well as rules for traveling (see Post-Transplant Day-to-Day Guidelines in the back pocket of this binder). Please read these, as they answer many frequently asked questions about your daily life at home.

DETECTING ORGAN REJECTION AND INFECTION

Organ rejection and infection are the most common causes of transplant failure, particularly in the first year after surgery. We will help you learn to catch the signs of potential rejection and infection at the earliest possible stage.

Organ Rejection

Rejection is basically your body’s way of fighting off anything that is different from itself. When your body recognizes foreign tissue (i.e., a transplanted organ), it sets off an immune reaction, which releases specialized blood cells that travel through the blood stream and eventually reach the transplanted organ and try to destroy it. If allowed to continue, the transplanted organ would function poorly, eventually failing entirely.

After your transplant, you will be prescribed a number of medications (called immunosuppressives), many of which are designed to keep your immune system from rejecting the new organ.

Each of the drugs has a specific job designed to interrupt and/or prevent either the recognition or activation phase of the immune reaction, so you must remember to take each one exactly as prescribed.

Even though you will be on these immunosuppressives, it is expected that most heart transplantation recipients will experience at least one episode of rejection, which requires additional treatment, sometimes involving a trip to the hospital. This can occur at any time following transplantation but is most likely to happen early in the first year. Most rejection episodes have no symptoms. This is why...
biopsies are done - to find rejection before the heart function deteriorates to the point that you do have symptoms.

Rejection can be discovered in one of two ways: first, by a biopsy*, taken on one of your routine follow-up appointments (see Follow-Up Schedule), and secondly, by you, as you perform your home testing routine. You will be asked to keep a daily watch on your personal health, religiously keeping up with your home testing and hospital follow-up visits so that you can detect the symptoms or indicators of infection or rejection as early as possible.

Symptoms that should be reported include:

- Fever
  - 99.5F or higher
- Flu-like symptoms
  - Chills
  - Aches
  - Tiredness
  - Headache
  - Dizziness
  - Nausea
  - Vomiting
  - Diarrhea
- Change in heart rate
  - Increase or decrease from normal
  - Abnormal (irregular) rhythm
- Fluid retention
  - Swelling in feet, ankles, legs, hands, abdomen
- Shortness of breath
- Cough
- Weight gain (2 lbs. overnight, or 5 lbs. in 5 days)
- Blood pressure changes
  - Sudden increase in diastolic blood pressure (diastolic greater than 100)
    - Diastolic = bottom number (i.e., 160/105 – 105 is diastolic)
  - Sudden decrease in systolic blood pressure (systolic less than 100)
    - Systolic = top number (i.e., 160/105 – 160 is systolic)

If rejection is detected, treatment is begun immediately. Treatment consists of high dose steroids, usually administered over a three-day period. Adjustments may also be made to your other immunosuppression medications. This process may require hospitalization, but may be carried out at home. In the majority of cases, the steroids successfully stop the rejection, but in the unlikely case that you need further treatment, you may need to be hospitalized for more aggressive therapy.
Endomyocardial Biopsies, a method of identifying organ rejection, are considered the Gold Standard for detecting rejection and are routinely performed in our cardiac catheterization laboratory. A catheter (tube) is passed to the right ventricle (right lower chamber of the heart) from either the large vein in the neck (internal jugular vein) or from the groin (femoral vein). This special tube has “pincers” (small jaws) on its end that can be opened and closed by the physician (from outside of the patient). When the catheter is positioned properly, the jaws are opened and closed, taking a tiny “bite” of tissue from the heart muscle. This is usually repeated four to six times, allowing the muscle to be studied under the microscope by a pathologist.

Detecting Infections

The immunosuppressive medications you will be taking will protect your new heart by making your body's defense system weaker, which will also make you more prone to infection. To help protect you from infections during the first weeks after surgery, visitors and staff will need to wash their hands prior to entering your room. You are permitted to have flowers in your room after surgery, but you should change the water daily to avoid the growth of microorganisms. Family and friends can also brighten your room with pictures, cards, and/or balloons instead.

In the months and years that follow, infection will continue to be a concern, as the immunosuppressive medications that you will be taking actually put you at greater risk for developing infections.

As we discussed in other sections, you’ll be monitoring your health very closely on a daily basis for the rest of your life. Some symptoms of infections are very similar to those of rejection. They include:

- Fever
  - 99.5F or greater
- Incision or insertion sites become
  - Red
  - Swollen
  - Warm
  - Tender
- Drainage from an incision or insertion site that changes in
  - Color (especially if color becomes green or yellow)
  - Amount (especially if amount increases)
  - Consistency (especially if drainage becomes thick)
- Development of
  - A productive cough
  - Sore throat
  - Cold or flu-like symptoms
  - Increased shortness of breath
MEDICATIONS

You’ll be taking several medications daily, each on a different schedule. Your Transplant Nurse Coordinator will walk you through each medicine and how and when to take it during your Discharge Training, and will provide you with a chart to help you keep it all straight (see Sample Medication Chart).

The medicines fall into three main categories: immunosuppressants, to help prevent rejection; antivirals/antibacterials, to help prevent infection; and various drugs to counter the side effects of the immunosuppressants.

Listed below are descriptions of the medicines you will most likely be taking and their side effects. Tell your doctor immediately if you start feeling these side effects, and he or she may be able to prescribe additional medicines to help alleviate those symptoms. Never make any changes to your medication regime (including stopping taking them) without calling your doctor first.

YOUR RESPONSE TO MEDICATIONS WILL BE HIGHLY INDIVIDUALIZED. REMEMBER THAT NOT ALL SIDE EFFECTS OCCUR IN ALL PEOPLE. IT IS IMPORTANT TO REPORT ANY UNUSUAL SYMPTOMS TO THE TRANSPLANT TEAM.

Cyclosporine (or Prograf)
This is a strong immunosuppressant medication taken twice a day, every day, to prevent rejection. It changes the immune system by inhibiting your T-cells, the blood cells that cause rejection. Cyclosporine and Prograf are available in a liquid or capsule form. You will take this drug for the rest of your life. The dosage will start out high and be reduced gradually over time; however, you will never be able to stop them altogether.

The most common side effects associated with these drugs are:

Hypertension (high blood pressure) – Approximately 80% of transplant patients treated with Cyclosporine develop high blood pressure. This cannot be corrected by changing the dose. You will be taught how to check your blood pressure at home. High blood pressure medication will be prescribed for you if necessary. Exercise and weight control are very helpful in controlling this form of hypertension.

Kidney dysfunction – The most serious potential side effect of Cyclosporine is kidney dysfunction. Kidney function is monitored at every outpatient visit by means of a blood test, and the dose of Cyclosporine is adjusted according to your biopsy results and your kidney tests.

Hand tremors – The “cyclo shakes” are related to high doses of Cyclosporine and will lessen over time as your Cyclosporine dose is reduced. This can also occur with Prograf, but it is less likely.
Excessive hair growth – Cyclosporine does not grow hair where it was never intended to be, but thickens and darkens existing hair. For female patients, this may be a cosmetic problem, easily managed with facial depilatories (hair removers).

Swollen and bleeding gums

Headaches

Burning and prickling sensation of hands and feet

Sinusitis (stuffy sinuses)

Prednisone
Prednisone is a steroid that functions as an immunosuppressant as well as an anti-inflammatory. It is used on a daily basis along with Cyclosporine to prevent rejection. Prednisone is available in tablet form.

The possible side effects of steroids include:

Diabetes mellitus – Prednisone may cause or worsen increased blood sugar or other symptoms of diabetes. Increased blood sugar is treatable. You may be placed on a calorie-restricted diet. Insulin or other medications may be prescribed.

Sodium retention and fluid retention – Prednisone may cause your body to retain water and to develop some fatty tissue in the cheeks, upper back, and abdomen resulting in weight gain. Weigh yourself daily. A diet and/or water pill may be prescribed to lessen your fluid retention.

Calcium loss from bones – A calcium supplement may be prescribed for you.

Fragile skin – Prednisone may cause your skin to bruise more easily and heal slowly. It may be more sensitive to the sun and be more prone to acne. Take care of your skin by washing it with soap and water and wear sunscreen.

Mood swings – While taking large doses of prednisone, you may notice that your moods become more intense. As your dosage is lowered, this side effect probably will decrease or disappear.

Stomach irritation – Always take prednisone with food or milk.
Cellcept (or Imuran)
Cellcept is another immunosuppressant medication, which is used with Cyclosporine and Prednisone to prevent rejection. It is available as a tablet or capsule.

The most common side effects are:

Stomach irritation – If it upsets your stomach, try taking it with food.

Liver damage – Liver function is monitored at outpatient visits by means of a blood test. Your dosage will be adjusted if any liver damage is found.

Low white blood cell count – Your blood tests will be monitored for this change, and your dosage will be adjusted if a drop is found.

Antivirals/antibacterials help prevent infection by viruses. This is particularly important right after surgery, when you need all your energy to recover. You will most likely be prescribed one of two antivirals: Acyclovir or Valganciclovir

You may also be prescribed vitamins, supplements or other medicines to help with the side effects of the various drugs in your regimen.
FOLLOW-UP SCHEDULE WITH THE HOSPITAL

After transplant, you’ll be going back to the hospital for a number of follow-up exams and tests. These visits will be fairly frequent in the beginning but less frequent as time goes on.

The routine lab and biopsy schedule for heart transplants is as follows:

- Once a week for six weeks
- Once every two weeks up to three months
- Once a month until six months
- Once every two months until one year
- Every three months until 18 months
- After 18 months, biopsies will be twice a year, until year three
- After year three, biopsies will only be done at annual testing

This schedule is subject to change, based on your individual rejection history and other factors.

You will also receive several vaccinations post-transplant, such as the flu and pneumonia vaccines.

Live immunizations such as varicella (chicken pox), mumps, measles, rubella, oral polio, yellow fever, oral typhoid, and BCG are contraindications for both the patient and their families.

If you live with or care for infants and children, recommendations for what to do if the child develops chicken pox are as follows:

1. If you have been vaccinated for varicella or had the virus called chicken pox, no need to be isolated from the children
2. If you have not received the varicella vaccine and have never had the chicken pox, you need to remain separate for the duration that the child has the rash.
RESOURCES

At Temple University Hospital:
Temple Heart Center
Phone (215) 707 – 3782
Fax (215) 707 – 8191

The Temple Heart Center also has an Information Station with various materials from related organizations. Ask your Transplant Nurse Coordinator for access.

ORGANIZATIONS

One of the quickest and easiest ways to find the answers to your questions about organ transplantation and donation is by looking on the Internet. If you don’t have Internet access at home, try your public library. You can also ask your transplant team if you can access the Internet from the hospital.

The UNOS Patient Web Site
www.transplantliving.org
This site can help patients through the transplant process. It includes information about the waiting list, Organ Procurement and Transplantation Network (OPTN) policies, the matching process, patient and professional profiles, and resources for information.

The Scientific Registry of Transplant Recipients (SRTR) University Renal Research and Education Association (URREA) Web Site
www.ustransplant.org
This site contains information about the organization: what it does, transplant statistics, and research resources.

The OPTN Web Site
www.optn.org
This site has been created to educate, inform, and clarify some of the complexities of the organ transplant process for all those affected by and/or interested in organ donation and transplantation.

The Federal Government Organ Donation Web Site
www.organdonor.gov
This site was created by the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Patients can find answers to frequently asked questions, public affairs and legislative updates, links to other Web sites, and a glossary. There is also a section addressing myths about organ donation and information about various educational events and grant programs. You can download organ donation cards and brochures and order organ donation pins and bumper stickers to use as handouts for community activities to promote organ and tissue donation.
1. Medication Teaching
   - Use of pill box
   - Review of medication schedule
   - Medication uses and possible side effects
   - Notification of heart transplant office before taking any other prescribed or over the counter medications

2. Immunosuppression Precautions
   - Frequent hand washing
   - DO NOT clean cat litter box or dig in dirt
   - DO NOT fly in planes for the first 6 months
   - Avoid saunas and swimming pools for six months

3. General Precautions
   - No driving for eight weeks post transplant
   - Avoid anyone who may be sick
   - Avoid children who have recently received live vaccine (i.e. varivax or MMR2)

4. Daily Home Monitoring
   - Record daily temperature, blood pressure, heart rate and weight (same time of day) in log book
   - Record daily blood sugar, if applicable

5. Hydration
   - Drink ______ glasses of fluid per day

6. Daily Activity
   - Get up and get dressed every day!
   - Continue with home/outpatient rehabilitation as prescribed
   - Increase ADL’s as tolerated

7. Sexual Activity
   - Women of childbearing age must use contraceptives. The effects of many medicines on fetal growth are unknown

8. Contacting the Heart Transplant Team
   - (215) 707-3782. Office hours 8:00 AM to 5:30 PM Monday through Friday. Please leave message with your phone number. Follow instructions on voice mail if your problem is urgent. Calls are answered within one business day. Call (215) 707-3782 if a problem arises when the office is closed. Identify yourself as a Heart Transplant Patient and ask the answering service to page the Transplant Nurse Coordinator on call.

9. Response to learning – Verbalization Re demonstration
   PATIENT:____________________________________________ FAMILY MEMBER:________________________________________
   DATES OF TEACHING: __________/__________/__________/__________
   TRANSPLANT NURSE COORDINATOR:______________________________________________________________________
PREPARATION FOR GOING HOME:
You will need:

1. Digital scale
   • To measure weights

2. Digital thermometer
   • To measure temperature (initially 2x/day)

3. Digital blood pressure cuff
   • To measure blood pressure (2x/day)

4. Blood Glucose Monitor, if applicable

5. Medications
   • Prescriptions will be called/emailed to your pharmacy. Family members must pick them up and bring them to the hospital for review with the Transplant Nurse Coordinator prior to going home.

6. Support person
   • Must be home with you for the first 1-2 months, 24 hrs/day

7. Telephone
   • Always notify us of any telephone number changes (both temporary and permanent).

8. Common sense

WHEN TO CALL THE COORDINATOR/OFFICE:

Temperature: Higher than 99.5
• Remember to repeat temperature reading 30-45 minutes later if higher than 99.5. If temperature remains high, call the office.
• Do not take any acetaminophen (TYLENOL) or ibuprofen.

Blood Pressure: Higher than 150/90 OR lower than 90/50
• Remember to repeat blood pressure reading 30-45 minutes later. If reading continues to be above or below these guidelines, call the office.

Weight: Weight GAINS of 2 lbs overnight OR 5 lbs in 5 days, OR weight LOSS that is steady and not related to fluid loss.
• Remember to weigh yourself at the same time of the day.
• Morning weights should be done after emptying your bladder and with the same amount of clothing and similar shoes.
WARNING SIGNS OF REJECTION
Symptoms that should be reported include:

- Fever
  - 99.5F or higher
- Flu-like symptoms
  - Chills
  - Aches
  - Tiredness
  - Headache
  - Dizziness
  - Nausea
  - Vomiting
  - Diarrhea
- Change in heart rate
  - Increase or decrease from normal
  - Abnormal (irregular) rhythm
- Fluid retention
  - Swelling in feet, ankles, legs, hands, abdomen
- Shortness of breath
- Cough
- Weight gain (2 lbs. overnight, or 5 lbs. in 5 days)
- Blood pressure changes
  - Sudden increase in diastolic blood pressure (diastolic greater than 100)
    - Diastolic = bottom number (i.e., 160/105 – 105 is diastolic)
  - Sudden decrease in systolic blood pressure (systolic less than 100)
    - Systolic = top number (i.e., 160/105 – 160 is systolic)

WARNING SIGNS OF INFECTION

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  - 99.5F or greater
- Incision or insertion sites become
  - Red
  - Swollen
  - Warm
  - Tender
- Drainage from an incision or insertion site that changes in
  - Color (especially if color becomes green or yellow)
  - Amount (especially if amount increases)
  - Consistency (especially if drainage becomes thick)
  - Foul odor
- Development of
  - A productive cough
  - Sore throat
  - Cold or flu-like symptoms
  - Increased shortness of breath
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- After year three, biopsies will only be done at annual testing

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POST-TRANSPLANT PROPHYLAXIS

Medicines that prevent infection include:

- Bactrim
  - Prevents PCP, Listeriosis, toxoplasmosis, community-acquired pneumonia
- Ganciclovir/Vanganciclovir
  - Prevents CMV (CMV can cause pneumonia, hepatitis, colitis, vision problems related to retinitis. CMV active infection is most common when immunosuppression medicines are at the highest, which is during the first few months post-transplant and during rejection episodes).
- Acyclovir
  - Treat or prevent recurrent Herpes Simplex Virus (shingles)
- Mycelex
  - Prevents oral fungus called thrush

Important points to remember about your medications:

1. After a rejection episode, immunosuppression meds are increased again for a short time, so infection prophylaxis should be restarted.
2. Patients who travel (national/international) should visit the travel clinic for specific precautions/immunizations. Call travel clinic at (215) 707-3807. Discuss any travel plans with your transplant cardiologist. We recommend no traveling for the first three to six months.
Tips for Taking Your Medicines

Temple Transplantation Program

Use this as a guide to organize and maintain your medication schedule.

Tips about your medicines

- Learn everything you can about your medicines. Your physician, Transplant Nurse Coordinator, pharmacist, support group and educational seminars can help.
- Some of your medications may be available as generics, which means from bottle to bottle, they may look different and go by a different name. Be sure you can read the label on your medication bottles to confirm you are taking what you are supposed to be taking, and that you understand the directions.
- Capsules and time-release tablets should be swallowed whole and never crushed, chewed or opened—otherwise, a large dose can be absorbed too quickly.
- Avoid grapefruit, pomegranate and papaya fruits and juices, as they may interfere with your medications. Ask your pharmacist for information about your medications’ interactions with other foods and other drugs.
- Do not change the dose, skip a dose, or stop taking your medications without your doctor’s approval.
- Some medications need to be refrigerated, especially liquid antibiotics. Check the directions on the bottle.
- Always check with your transplant team before taking any new medicines, even the ones you buy over the counter, including vitamins and herbal remedies.
- Wear a Medic Alert (or similar brand) bracelet or necklace that states you are a transplant recipient and you take steroids (if you do), in case you are ever in an accident and someone finds you unconscious. Some people may wish to engrave their bracelet with the Temple transplant center’s phone number.
- If any medicine changes odor or color, if it gets wet, or if it is soft, sticky, hard or cracked (and it shouldn’t be), it could have lost its effectiveness and should be replaced. Talk to your pharmacist about any changes in your medicines.
- If your insurance company does not require you to use a particular pharmacy, shop around. Prices can vary dramatically.
- Let your insurance company and transplant team know if you are having trouble paying for your medicines.
- Carry a list of your medicines and their doses in your wallet or purse. Share this list with your other doctors.
- Try to buy all your medicines from the same pharmacy. Many pharmacies keep a profile on their customers so that they can track whether or not a new drug will cause problems if taken with the patient’s other medications.
- Unwanted hair growth, caused by some medications, can be removed with shaving, waxing, or hair removal (depilatory) products.
- Limit your sun exposure and use a sunscreen.
• Do not take all your medicines at one time because it is more convenient. The doses are spread out to maintain the proper drug level in your body.

Tips about organizing your medications
To prevent your medicine regimen from interrupting your daily routine, plan ahead, organize your time and consider the following tips:

• Use tools to help organize your medicines, such as a pillbox that has individual compartments labeled with the days of the week. Please be aware, some medications cannot be put out ahead of time.
• If there are no children or grandchildren in the house, clear plastic Ziploc bags labeled with days of the week and times of the day can help, but they must be kept in a safe place—away from children and pets who may think the contents are snacks.
• Use an alarm clock, watch or charts to remind you of the times for medicines.
• Ask your transplant team to help set up your medicine times to fit your schedule.
• Set up a time each week to organize your medicines for the whole next week.
• Get into a routine. Take your medications at the same time each day.
• Keep track of how much medicine you have left. Don’t ever run out, even one dose.
• Mark your calendar so you remember to reorder your medications ahead of time.
• At first, you may want to have a family member or friend help you sort out and reorder your pills.
• Keep your medication in a cool dry place, out of the sun and extreme heat.

Tips on traveling
• Always keep extra doses of your medicine with you when you travel in case you are delayed or miss a plane, train or bus.
• Keep your pharmacy’s phone number with you.
• Never pack your medications in your luggage; always carry them with you or they may get lost or be exposed to temperatures that are too cold or too hot.
• Mail-order pharmacies can ship your medicines if you are away from home for an extended period of time.
• Carry a letter (or prescription) from your doctor about your medicines in case you have any problems with customs when traveling overseas. You may be able to fill your prescription in a pharmacy at your travel destination.
• Prevent infection. Wash your hands often and thoroughly, especially before eating. This is even more important the first few months after your transplant, when you are taking higher doses of anti-rejection medication.

What to do if you miss a dose:
Call your Lung Transplant Nurse Coordinator at (215) 707 – 1722
Call your Heart Transplant Nurse Coordinator at (215) 707 – 3782

Content is direct reprint from HRSA, pages 43-45, and UNOS, p 41.
# Home Monitoring Diary:

## TEMPLE HEART CENTER (215) 707-3782

<table>
<thead>
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<th>Date</th>
<th>AM Vital Signs</th>
<th>AM Blood Sugar</th>
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