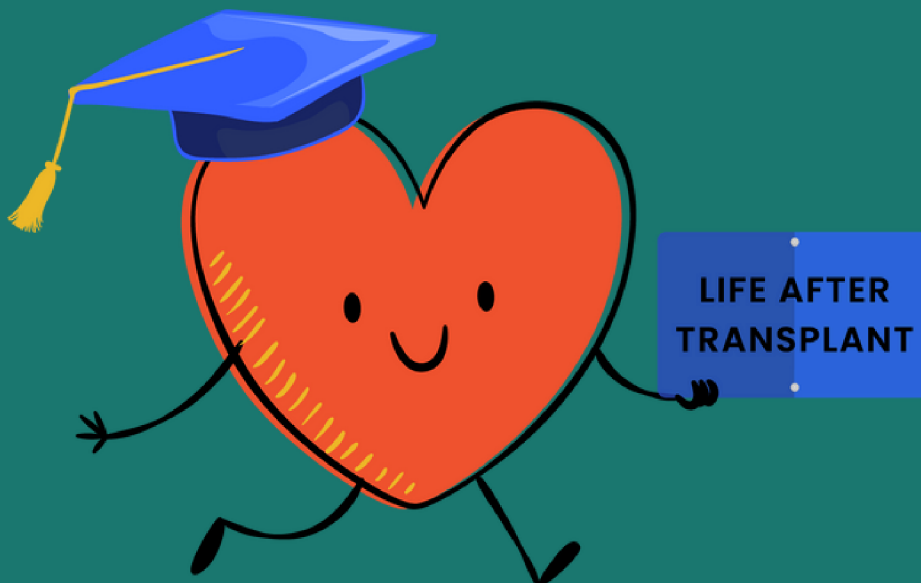




HEART TRANSPLANT 101

An easy-to-use manual for families of heart transplant candidates, written by heart transplant recipients

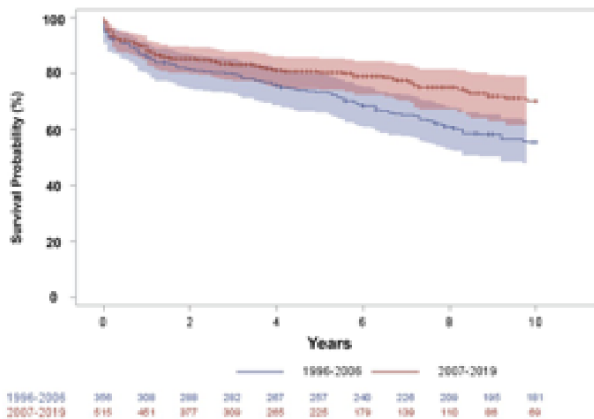
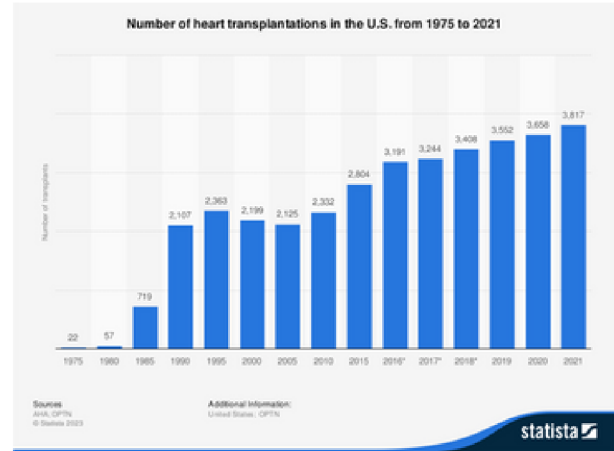
Heart Transplant Guides is a 501(C)3
Non-profit, Charitable Corporation



THIS IS A GREAT TIME TO BE GETTING A HEART TRANSPLANT

HUGE ADVANCES ON THE SCIENCE FRONT

Heart transplant, the “last resort” for heart failure treatment, has “come a long way, baby”. One aspect is the sheer number of transplants done in the U.S. (Source: Statista 2023)



Another measure is survival statistics, where results are also positive, as shown in this report on Stanford survival rates:

This guidebook is available for the first time:
written BY transplant recipients FOR transplant candidates.

ALL YOU NEED TO KNOW



A NOTE FROM OUR FOUNDERS

Dear Heart Transplant Candidate Family:

A very warm welcome to **Heart Transplant Guides!** We are an all-volunteer group of heart transplant recipients and their carepartners who have joined together to make your transplant simpler and more successful.

Our Guides bring their own experiences, both as transplant recipients and in helping others. It's this rich and extensive background that makes this manual possible.

We regard the transplant **surgery as the commencement**, not the end point: we will spend the time before surgery **preparing you for surgery** and the **reality of life after transplant**.

We know that receiving a heart transplant can be an overwhelming experience filled with uncertainty, anxiety, and many questions. It can be difficult to navigate the sea of information thrown at you. We're here to help make the process a little less daunting by helping you **FOCUS on those elements of the process that are critical to, and controllable by, you.**

To that end, we use a simple "**A**," "**B**," "**C**" approach:

Adaptability: Be **resilient**

Behavior: **5** simple actions

Care-Partner: A **mutual** support relationship

We honor the crucial dependency that exists between **you and your carepartner**. You will both need one another many times during this process.

Your carepartner and your transplant team are your most important support mechanisms, both before and after transplant. Your main responsibility to them is to be open, honest, and timely about how you are doing.

We are truly honored to be a part of your support network: let us bring our personal experiences to bear for you

With warm regards,

Jim Bischoff + Frank Andrews



Your carepartner and your transplant team are your most important support mechanisms, both before and after transplant.



HOW TO USE THIS MANUAL: YOU HAVE 2 OPTIONS



1 DO IT YOURSELF

We have written this to be clear and concise..easy to follow for you, your carepartner, and in consultation with your transplant team

2 GET A GUIDE

Contact us @ hearttransplantguides.org and we will set you up with your own personal guide to:

- walk you through the manual
- answer additional questions you might have
- Be a companion on your journey



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OUR BELIEFS: TWO CONCEPTS DRIVE OUR THINKING

IT REALLY CAN BE AS SIMPLE AS ABC: While you will be drenched in information, and have many, many questions, you can make the whole journey much simpler by focusing on our **ABC** approach:

- **ADAPTABILITY**
 - Life after the transplant will be full of **unexpected surprises**
 - How you **react** will determine your **reality**
 - The challenge is **mental and physical**
- **BEHAVIOR:** 5 simple behavior guidelines:
 - **G:** Groceries; you are what you eat
 - **U:** Update: keep daily logs of vitals
 - **I:** Inform: talk to transplant team and carepartner
 - **D:** Drugs: take as prescribed without fail
 - **E:** Exercise; Move as much as you can
- **CAREPARTNER**
 - Your carepartner is your most important ally
 - You have a mutual dependency

COMPLIANCE IS FUNDAMENTAL TO SUCCESS: When you embark on the transplant journey you are committing to **take care** of the heart you might be gifted. Part of “taking care” means **heeding** the advice and recommendations of your transplant team; doing so is called “**compliance**”, and compliance is important both **before and after** you get your new heart:

- **PRE-TRANSPLANT** you and your carepartner are being watched carefully and constantly to insure that you will be good custodians of the new heart. Be especially mindful of:
 - Following instructions regarding alcohol, tobacco, and non-prescription drugs;
 - Taking meds on schedule;
 - Keeping logs as requested;
 - Demonstrating a solid support relationship;
 - Being a reliable participant at clinic visits;
 - Being reachable and responsive.
- **POST-TRANSPLANT** you will have learned and be practicing the components of “GUIDE”, so compliance will be simply a matter of staying focused on the 5 simple behaviors you need to practice (“**GUIDE**”)



AN OVERVIEW- RULES OF THE ROAD



Just as there are “rules of the road” for car travel, there are also some “rules” to follow, to make your transplant journey safe and easy..

You can make your transplant experience better by:

- **Minimizing uncertainty:**

Uncertainty = anxiety = sub-optimal experience
Use Guide discussions, this manual, and your transplant team to reduce anxiety and uncertainty.

- **Being adaptable** physically and psychologically.

- **Being true carepartners:** Taking care of one another
Watching out for stress and depression (Appendix A).
Avoiding care-partner burnout (Appendix B).

- Knowing when to **ask for help.**

- **Getting enough sleep** since this is when your body heals (medical help is available).

- **Maximizing your clinic visit** experience (Appendix C).

- **Preparing for your transplant** call (Appendix D).



THE TRANSPLANT PROCESS- WHAT TO EXPECT AND WHEN

SHIFTING THE PARADIGM: SURGERY IS COMMENCEMENT

Surgery is only a brief moment in your life. While it is easy to see why transplant surgery captures your attention, we urge you to regard it as a single step in the transplant journey. In fact, it's fair to say that the surgery is when the transplant journey really starts.

DO NOT OBSESS OVER SURGERY:

- It has a high success rate
- The surgical team are all "pros"
- It only takes up a tiny percentage of your overall time
- You will be asleep during the procedure

FOCUS ON:

- Staying on the wait list
- Preparing for surgery
- Getting to surgery
- Preparing for life after surgery

TRANSPLANT:

- Solves one big immediate problem
- May cause some challenges later on



THE 4 PHASE TRANSPLANT JOURNEY

The traditional way of thinking about transplants includes four steps:
WE think about them a little differently.

1. Pre-wait list:

Qualifying to "get listed"

3. Surgery:

The commencement exercise

2. Waitlist:

Preparing for life after surgery

4. Life after surgery:

Quality and quantity of life

1. Pre-wait list: Qualifying to get listed

These are the steps on the way to being listed with UNOS.

- **Tests:**
 - Blood/labs
 - Diagnostics
- **Transplant Committee:**
 - Cardiologist/Surgeon/RN
 - Psych/social worker/coordinator
 - Registered Dieticians
- **Insurance/payments:**
 - Discuss high cost of immunosuppressant drugs with team
- **Learning:**
 - Transplant team
 - Heart Transplant Guides
 - Internet (be very careful with sources)

2. Wait list: Prearing for life after surgery

- It's difficult to know how long you will be on the waitlist
- It's over when the **right heart for you** becomes available
- You will have frequent visits with the transplant team/clinic (Appendix C) You need to focus on your priorities
- Stay on the waitlist
- **Start practicing "GUIDE" behaviors** (to be introduced soon)



THE 4 PHASE TRANSPLANT JOURNEY CONTINUED

3. **Surgery: The commencement exercise**

A brief but important time.

- **Typical timelines (average)**
 - Surgery: 6-8 hours
 - ICU: 3-4 days
 - Hospital stay; 7-10 days
- **Surgery risks**
 - Infection
 - Rejection
 - Blood clots
 - Nerve damage
- **Next steps**
 - ICU
 - Cardiac care

4. **Life After Surgery: Quality and quantity of life**

- **Frequent clinic visits (Appendix C)**
 - Check-ups
 - Blood draws
 - RX changes
 - Biopsies (**Appendix E**)
- **Daily at-home monitoring (see Appendix G)**
 - 6-8 measurements
 - 1st sign of potential problems
- **Possible issues**
 - Dealing with heavy med load (esp. Prednisone)
 - Rejection (short- and long-term)
 - BP issues
 - Type 2 Diabetes
 - Fluid retention
- **Lifestyle Adaptations**
 - Vagus nerve
 - Anxiety
 - "Bumps in the Road"
- **Continuous improvement: In waves**
- **Annual Comprehensive Cardiac Exam**
 - (out-patient; in hospital)



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POSSIBLE SIDE EFFECTS OF TRANSPLANT

Transplant is a last resort solution for a specific problem: to prevent imminent death. As a transplant recipient, it is important for you to understand that there are potential risks and side effects that may occur, largely (but not exclusively) due to the regimen of immunosuppressant drugs you will need to take. In the short-term, you may experience 3 very common problems:

- Type 2 Diabetes: Immunosuppressants inhibit insulin production
- Skin Cancers
- Edema (swelling, usually ankles)

There are other potential issues:

- Talk to your team and/or go to clevelandclinic.org or mayoclinic.org for a more detailed discussion (Two renowned transplant leaders)

YOUR DERMATOLOGIST MAY BECOME YOUR NEW BEST FRIEND

Skin cancer is a frequent issue post-transplant. It sounds scary; skin cancer is the most “opportunistic” cancer, especially when your immune system is reduced. But remember, there are steps you can take to detect it early and receive prompt and effective treatment. By being vigilant and taking action, you can ensure that you stay on top of your health and address any issues as soon as possible.

- **Skin cancer is easily**
 - **a. Detectable**
 - Visual exam by a dermatologist
 - Biopsy/pathology
 - **b. Treatable**
 - Freezing
 - Surgery (in-office; site numbing)
- **Take preventative measures:**
 - Use sunscreen liberally
 - Wear broad-brimmed hats
 - Wear long-sleeved shirts/blouses
 - Avoid mid-day sun
- **Visit your dermatologist 6-12 mo. after surgery**
 - Treat current issues (if any)
 - including sternum itch cream
 - May prescribe supplements
 - Get a recommendation on follow-up visit frequency
- **In selecting a dermatologist:**
 - Experience with other transplant patients is highly desirable
 - A MOHS-qualified doctor is best.
- **Find someone:**
 - You trust and are comfortable with (they may become your new BFF)
 - Who’s close (you may be going frequently)



**We have never encountered a transplant recipient who has said they would not do it all over again.*



PREPARING FOR YOUR TRANSPLANT

CRITICAL AND CONTROLLABLE

Although much of the transplant process is out of your control, **there are “critical and controllable” factors that you can focus on.** These important aspects can optimize your journey and it’s helpful psychologically to know that you have some control over them. Therefore, these are some things that you must do to optimize your journey.

A simple acronym we use is **“GUIDE.”**

- **Groceries**
- **Update**
- **Interact**
- **Drugs**
- **Exercise**

Practice before the transplant and continue practicing after the transplant.

i. GUIDE Discussion

- **Groceries:**
 - You are what you eat.
 - Heart-healthy diet: It is important to follow a heart-healthy diet according to a registered dietitian's recommendations.
 - Build a plan around foods you enjoy
 - Small incremental changes can make a big difference.
 - Take special care in the months immediately following the transplant.
- **Update:**
 - **Maintain and update a daily log of your vital signs and personal thoughts.** This helps you to identify the first warning signs of any potential health issues. Form available as Appendix G
- **Interact: Communicate regularly and honestly with:**
 - Transplant Team/ Guide
 - Care partner
- **Drugs:**
 - Take as prescribed every day.
 - NEVER stop simply because you “feel better.”
- **Exercise:**
 - Move!!!!



CARE PARTNER'S RESPONSIBILITIES

Care partner's responsibilities are heaviest in the 3-6 months immediately following surgery. Their responsibilities will grow in part from our GUIDE program, assisting, reminding, and encouraging the patient. In addition the Carepartner will probably also:

- Communicate with the transplant team
- Manage the scheduling and transportation for of clinic visits
- Place and order medication changes
- Notify others of these changes
- Handle grocery purchases and prepare meals
- Participate in the patient's exercise routine
- Provide emotional support

IMPLEMENTATION PLAN

Since "GUIDE" involves shared responsibilities, it is helpful to create a written plan for **"Roles and Responsibilities."** (Appendix F)

- You can fill out and add to the plan with the help of your guide



LIFE AFTER TRANSPLANT

Year 1: Recovery and Adaptation

We previously provided you with a timeline of events during the first year post-transplant.

- It's crucial to **stay vigilant** during this time since your immune system is at its weakest.
 - Avoid crowded areas and wear a mask to prevent infections.
 - **Wash your hands frequently**
- **Eat healthy:** you are recovering from surgery and are de-conditioned
- **Be attentive to your medications** and keep track of your vital signs.
 - You will be the first to detect any potential issues.
- Good days and bad days are expected, here your adaptability will be tested.
- Your doctor will advise you on **cardiac rehabilitation** (months 3-4) and **when to return to work.**

- **Attending transplant support groups and communicating** with your medical and personal teams is vital.
 - Utilize technology, especially when communicating with your medical team.
- **Write your donor family:** If/when the time is right, your transplant team can explain how to do this

- **Keep Heart Transplant Guides in mind:**

- Keep your guide involved
- Write us with suggestions for the next edition of this manual
- Consider a donation to help future candidates
- Consider volunteering to be a guide

- You will get an annual **Comprehensive Cardiac Exam** on transplant anniversary:
 - Left heart catheterization
 - EKG
 - Chest X-ray
 - Complete labs
 - Echocardiogram



APPENDIX

Signs of Stress and Depression **A**

Avoiding Care-Partner Burnout **B**

Maximizing Clinic Visits **C**

Prep for Transplant Call **D**

Typical Biopsy Schedule **E**

Roles and Responsibilities **F**

Daily Log **G**



APPENDIX A

STRESS AND DEPRESSION

(some may be caused by medications)

Symptoms Can Include:

- Trouble concentrating, remembering details, and making decisions
- Fatigue or restlessness
- Feelings of guilt, worthlessness, and hopelessness
- Pessimism and hopelessness
- Insomnia, early-morning wakefulness, or sleeping too much
- Crankiness or irritability
- Loss of interest in things once pleasurable, including sex
- Overeating, or appetite loss
- Aches, pains, headaches, or cramps that won't go away
- Digestive problems that don't get better, even with treatment
- Persistent sad, anxious, or "empty" feelings
- Suicidal thoughts or suicide attempts

If you are experiencing these symptoms, please talk with your doctor, and/or the transplant team for additional support and resources as appropriate.



APPENDIX B

CAREGIVER BURNOUT

The symptoms of Caregiver burnout are similar to the symptoms of stress and depression.

They include:

- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to hurt yourself or the person for whom you are caring
- Emotional and physical exhaustion
- Irritability

If you are experiencing these symptoms, please talk with the transplant team for additional support and resources as appropriate. You may need additional support for yourself as well, which is okay.



APPENDIX C

MAXIMIZING CLINIC VISITS: THE BRIEF TIME YOU AND YOUR TEAM ARE ALL TOGETHER

- **Clinic visits are crucial to your transplant journey.**
 - During your visit, you will get to meet with your transplant team.
 - These visits provide an opportunity for you to ask any questions you may have.
- **Between clinic visits:**
 - Keep a written list of important topics that you want to discuss with your physician.
 - Whiteboard, the refrigerator door, or your phone
 - Keeping a log of your vital signs is also very important.
- **The day before the clinic visit:**
 - Prepare a list of questions you want to ask your doctor in priority order.
 - Don't forget to gather all of the necessary items you need to bring to your appointment.
- **On the day of your clinic visit:**
 - Take a recording device to capture important instructions and information from your doctor. (Ask for permission)
 - You should also bring your list of questions, your vital sign log, your current medication list, and something to entertain yourself if there is any delay.
- **The day after your visit:**
 - It is important to obtain and review the after-visit report.
 - Communicate medication changes with anyone who needs to know. (e.g. GP)



APPENDIX D

PREPARING FOR THE CALL

We may not know when the call will come, but we do know that when it comes, things will move quickly. So, there are several things that need to be dealt with / prepared for, such as:

1. **Create a communication tree**, so your care partner can make one call/text message to notify everyone.
2. **Making arrangements** for child and pet care.
3. **Creating legal documents**, like;
 - a. Power of Attorney (POA) for medical and legal purposes,
 - b. Do Not Resuscitate (DNR) order,
 - c. Will/trust.
4. **Planning for lodging** if center is in another city.
 - a. Your transplant social worker can help with local lodging resources if needed.
5. **Grooming (men especially)**: Get shaved and trimmed all over; tape sticks!
6. **Keep your phone charged** and your ringer on.
7. **Make sure your “voicemail box” is not full**, so if you miss a call, the team can leave you a voicemail.



APPENDIX E

TYPICAL BIOPSY SCHEDULE*

You got through the surgery; the biospies are a nuisance, but not much more. You will get a lydocane shot in the neck that stings, and you will have to sit with your neck at an uncomfortable angle for 15-20 minutes. After, you get up and go about your business

Month 1	1x per week
Month 2	Alternate weeks
Months 3-6	Monthly
Months 7-12	Alternate months 1x
Years 2-6	per year

*You should check with your own transplant center for their schedule and their position on AlloMap/AlloSure.



APPENDIX F

ROLES AND RESPONSIBILITIES:

For example only

	Patient	Carepartner	Frequency
GROCERIES			
Shop	X	X	
Prepare	X	X	
UPDATE			
Take Measures	X		
INFORM			
Carepartners	X	X	
Medical Team	X	X	
DRUGS			
Order	X	X	
Box	X	X	
Take	X		
Communicate	X	X	
EXERCISE	X	X	



APPENDIX G

DAILY MEASUREMENTS CHECKLIST:

All of these measures provide early signs of something wrong.

DAY/DATE	WEIGHT	TEMP	BP (AM:PM)	PULSE	O2	BLOOD SUGAR	PATIENT NOTES
SUN							
MON							
TUE							
WED							
THU							
FRI							
SAT							



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LET'S WORK TOGETHER

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