

SOCIAL SUPPORT

The time after transplant can be scary and daunting. You may feel burdened, stressed or have anxiety about the various responsibilities and costs that come with having a transplant. The recommendation of the transplant team is that you wait 6 months after transplant before returning to work, to allow for a full recovery.

To thrive after transplant, you should rely on the help and support of friends and family. If you or your family need additional support, contact the lung transplant team or the transplant social worker at **(443)-287-2986**.

Concerns that can be addressed include:

- Difficulty adjusting to the responsibilities of managing your transplant
- Inability to pay your medical bills or to fund daily needs
- Lack of reliable transportation to & from your appointments
- Anxiety, depression, or other mental health issues

How Do I Get Through on an Emotional Level?

Everyone has their own unique ways of navigating through difficult situations. You might like to speak openly about your feelings with friends, family, and caregivers or you might prefer to participate in individual activities such as journaling or going fishing. Wherever you are with coping is ok. The transplant team will work with you to identify healthy ways of coping and self-expression. If you are unsure about how you tend to cope, consider taking this online Coping & Stress Management Skills Test from Psychology Today:

http://psychologytoday.tests.psychtests.com/take_test.php?idRegTest=3200. This might help you become more familiar with your coping style. **Be careful not to order the full report as it costs money.**

If you're having trouble working through this transitional time or if you feel "stuck", feel free to reach out to your transplant team, social worker or psychiatrist/counselor.

Here are some activities to consider to manage stress:

- Meditating
- Going for a walk
- Petting your dog or cat, or other animal
- Journaling
- Making a list of things for which you feel grateful
- Calling a friend or family member
- Yelling into a pillow

- Allowing yourself to cry
- Going to see a movie
- Enjoying a healthy meal
- Participating in exercise
- Progressive muscle relaxation

Social Media

We neither encourage nor discourage the use of social media for transplant related issues. However, please bear in mind that news stories and social media sites may only represent one aspect of a patient's experience, and may not always represent a "typical experience". If you have any questions or concerns regarding any transplant related topic that you may see on social media or news coverage, please reach out to your transplant coordinator or physician.

YOUR EMOTIONAL WELL-BEING

Depression & Anxiety

The transplant journey can be overwhelming for many people at various times in the process. Depression and anxiety are very common in patients with lung disease. Signs of depression include a combination of the following: low mood, minimal interest in activities, irritability, poor energy, poor appetite, low motivation, poor concentration, feelings of hopelessness or guilt, thoughts that life is not worth living, and suicidal thoughts. Anxiety symptoms can include panic attacks and generalized worries. Depression and anxiety are treatable medical conditions. Patients have better outcomes post-transplant when depression and anxiety are well-managed.

If you are currently have depression or anxiety, a medical provider, such as a psychiatrist or mental health counselor may be helpful. Sometimes medications can be helpful. In general, antidepressants are safe and effective for both anxiety, panic, and depression. For anxiety, we try to avoid medications that are in the benzodiazepine family such as lorazepam (Ativan), clonazepam (Klonopin), and alprazolam (Xanax), as these can be harmful to your health. Benzodiazepines can be addictive, worsen confusion post-operatively and cause dementia later in life. If you are currently taking benzodiazepines, we may ask you to reduce your dose prior to transplant and find safer alternatives to treat anxiety. In addition to medications, we may recommend therapy to work on coping skills and techniques to adjust to stressful situation given the unique life changes you are experiencing.

After transplant, some of the anti-rejection medications, such as prednisone, can cause side effects, such as increased anxiety, agitation, irritability, or depression. Although anti-rejection medications cannot be stopped, side effects can be managed with guidance from our psychiatry team.

At any point during the transplant process, please reach out to us if you:

- **Need to speak to someone about your emotional well being**
- **Are feeling overwhelmed**
- **Are concerned about alcohol, drug dependence or pain medication addiction**



Alcohol and Drug use

Although many healthy adults drink alcohol, transplant patients should minimize or limit alcohol intake because it can interact with your transplant medicines and cause serious organ damage. Similarly, no drug use should occur after transplant. Since alcohol and recreational drugs are habit forming, they must be addressed before transplant so that you can be successful at avoiding them after transplant. If you have had a history of alcohol or drug abuse, including marijuana, cocaine, and opioids, you will need to stop completely, and may need to complete a counseling program.

Although it is available in legal forms, marijuana use can worsen mental health and should be avoided entirely. Patients should not use other drugs, including cocaine or non-prescribed opioids. Although some patients are prescribed pain medicine in the “opiate” class, these medications can be habit forming, worsen your breathing and have a risk of overdose death. If you are prescribed opioids, the transplant team may ask you to wean off of these medications before transplant if possible. We will work with a pain management team after transplant to find the safest and most effective way to manage surgical pain.

THE ROLE OF THE CAREGIVER

Caregivers are Key to Transplant Success

An organ transplant is major surgery and caregivers play a crucial role in providing physical and mental support before, during, and after transplantation. To help patients have successful transplant outcomes, caregivers will be needed to provide quality care at home and support throughout the transplant process. The job of a caregiver can be a rewarding experience, but it can also be a very challenging one. It is important during this time that the caregivers remember to take care of themselves and if necessary seek help for themselves.

- The role of a caregiver is vital to the success of a transplant recipient.
- Patients need 2 designated caregivers to work with the transplant team and help meet the needs of the patient.
- You may be asked to sign a written document from the transplant team that outlines your commitment to these responsibilities.

The Role of Transplant Caregivers:

- ✓ Stay Organized
 - Create a checklist to keep track of
 - Appointments
 - Medications and when they should be taken
 - Diet
 - Exercise
 - Keep a schedule to help track milestones, goals and progress
 - Report all changes (good and bad) to the care team
- ✓ Stay Positive
 - There will be times during the transplant process both before and after that your loved one may feel discouraged. Providing encouragement could help your loved one through challenges.
 - Staying positive can help your loved one take small steps toward recovery.
- ✓ Remain Patient
 - During the transplant process your loved one may experience mood swings or outbursts during moments of frustration, stress, or sadness.
 - These behavior changes may be a reaction to certain medications.
 - Try to remain calm, patient, and understanding through these difficult times.
 - Consult a professional if these emotional outbursts become violent or don't improve.
- ✓ Provide Transportation
 - After transplant your loved one will need you to drive them to pulmonary rehab, appointments, procedures and possible emergency visits.
- ✓ Attend All Hospital Teaching
 - You will need to learn how to care for your loved one when you leave the hospital after surgery so we ask that you:
 - Be present at the hospital and be able to participate in discharge teachings.
 - Be available for transplant coordinators to contact and meet with you.
 - Be available for other members of the care team to contact and meet with you.
 - Case manager
 - Pharmacist

✓ Help at Home

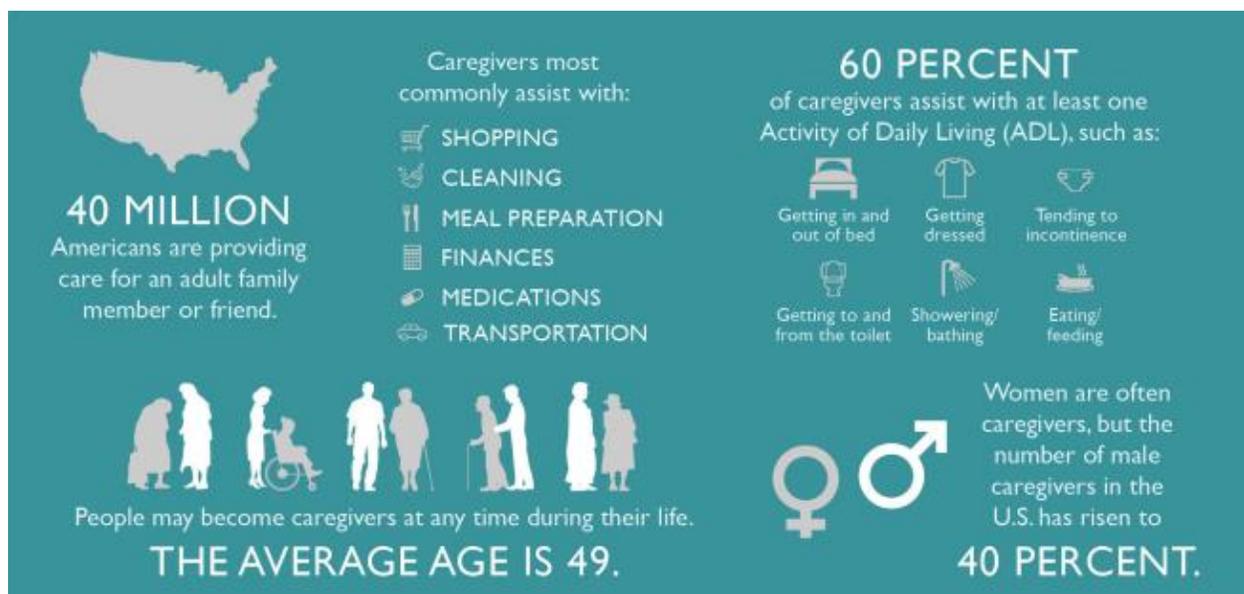
- A caregiver will need to be able to stay with the patient at home after surgery.
- At home your duties may include:
 - Taking care of family members and/or pets that typically rely on your loved one
 - Help changes bandages etc.
 - Help keep track of your loved ones health.
 - Vital sign records
 - Appetite
 - Weight
 - Mood
 - Medication
 - Finances
 - Food and household chores

✓ Attend Medical Appointments

- The clinic visit is a time to bring up concerns and address questions. We ask that the primary caregiver attend the transplant patient's clinic and social work appointments.
- We encourage your secondary caregivers to also attend these appointments.
- **Someone must attend all appointments** with the patient until they are cleared after transplant to come alone (usually at least 4 months).

✓ Bereavement and Grief

- Grief is a unique process and is a natural part of life.
- Feelings of grief may be experienced throughout the time you care for someone who is ill, not just at the time of your loved ones death. Facing ongoing loss is one of the many challenges that you may encounter as you adjust to changes in your loved ones health. With each change, you may experience feelings of loss.
- For example you may experience feelings of loss as your loved one loses the ability to be independent and take care of themselves
- It is important to note that everyone will grieve in their own way and in their own time. There is no right or wrong way to grieve.



UNOS and Mayo Clinic Stress Management



Coping ABC's for Caregivers

- ✓ **A**sk the transplant team to explain any aspect of care you do not understand.
- ✓ **B**e realistic. Determine what is most important.
- ✓ **C**onsult experts if you need help.
- ✓ **D**on't overprotect your loved one.
- ✓ **E**at right and exercise safely.
- ✓ **F**ind a good listener - someone with whom you can share your thought, feelings, and concerns.
- ✓ **G**et enough rest.
- ✓ **H**ave patients with your loved one.
- ✓ **I**nsist on having some time for yourself each day.
- ✓ **J**oin a support group.
- ✓ **K**eep life as normal as possible.
- ✓ **L**et your loved one resume former roles and responsibilities after the transplant.
- ✓ **M**aintain your sense of humor.
- ✓ **N**urture yourself.
- ✓ **O**btain help when you need it.
- ✓ **P**ost important phone numbers in a prominent place.
- ✓ **Q**uell the temptation to accept responsibility for your loved one's decisions and behaviors.
- ✓ **R**emain optimistic and think positively.
- ✓ **S**et limits.
- ✓ **T**ake care of yourself first.
- ✓ **U**se a variety of positive coping mechanisms.
- ✓ **V**anquish guilt.
- ✓ **W**atch out for signs of caregiver burden.
- ✓ **X**erox your loved one's medication list and other important medical information.
- ✓ **Y**ell if you have to, when alone.
- ✓ **Z**oom in on what is really important in your life.

Additional Caregiver Resources

Caregiver

<http://caregiver.com/>

Caregiver Media Group provides information, support, and guidance for family and professional caregivers. Founded in 1995, they produce Today's Caregiver magazine, the first national magazine dedicated to caregivers, caregiving books, and custom publications.

The Gift of Life Family House: Caregiver

<https://www.gifttolifefamilyhouse.org/>

The Gift of Life Family House Caregiver Lifeline Program provides services specifically tailored to the needs of organ transplant patients, family members, and caregivers. Their programs integrate in-person, email-based, phone, online support services, educational recourses, and community-bases outreach activities in the Gift of Life service area.

Called to Care

www.hopkinsmedicine.org/jhbmc/c2c

A program at Johns Hopkins Bayview Medical Center, prepares and supports individual Is caring for loved ones with health-related needs or limitations. Supportive services include individualized consultations to guide caregivers, training, educational sessions, and referrals for direct services through a network of community partners.

National Alliance for Caregiving

<http://www.caregiving.org/>

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

Healthcare Hospitality Network

<http://www.hhnetwork.org/>

The Healthcare Hospitality Network, Inc. (HHN) is a nationwide professional association of nearly 200 unique, nonprofit organization that provide lodging and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities. The mission of HHN is to support homes that help and heal to be more effective in their service to patients and families.

PREPARING FOR TRANSPLANT

Prior to transplant, planning ahead is essential. Below are some things you will need to think about.

- ✓ Financial Planning:
 - Ask your team about and prepare for out-of-pocket costs related to surgery, hospitalization, medications and transplant follow-up.
 - Prepare for costs related to hospitalization, such as telephone services, parking for visitors, meals, and other miscellaneous small items.
 - Plan for transportation and temporary housing costs (if needed). You will need to manage costs of travel to Johns Hopkins for multiple visits.
 - Think about your living expenses: how will you cover expenses while you are recovering and unable to work?
- ✓ Transportation:
 - To and from the hospital (admission and discharge): You may need to come to the hospital at any time of the day or night and will need to plan accordingly. **If you are unable to get to the hospital on time, you might lose the opportunity for a transplant.**
 - To appointments: you will be required to come to Johns Hopkins East Baltimore Campus for follow-up appointments and bloodwork after transplant.
 - To run errands locally.

You will be restricted from driving for about twelve weeks after surgery.
The Johns Hopkins Hospital and the Comprehensive Transplant Center do NOT provide or pay for transportation.

Local Housing/Hotel Options

Guest Services & Accommodations: Johns Hopkins Guest Services and the Johns Hopkins Accommodations Office can help locate and reserve hotel rooms & extended-stay accommodations at a reduced Johns Hopkins rate. Some hotels or apartments have shuttle service to the hospital.

**Please remember, anyone living more than 3-hours from Baltimore will need to relocate for a minimum of 3-months post-transplant.



Johns Hopkins Guest Services
410-614-5100

Check with your health insurance provider to see if there is any coverage through your policy for local housing related to your transplant.

Other Things to Consider:

- ✓ Speaking to your employer about taking time off from work and applying for Family and Medical Leave Act (FMLA) benefits, gaining support from employer or supervisor.
- ✓ Identifying caregivers or people to assist you after surgery. You will need to plan for 24-hour supervision for at least 2 weeks after discharge for support and assistance at home. You will also need to plan for caregiver(s) who can provide transportation to/from your follow-up appointments after discharge.
- ✓ Identifying caregiver(s) for others for whom you are responsible such as children, elderly parents, and/or your pets.
- ✓ Identifying temporary housing (if needed). Housing is costly and is not usually covered by insurance. **Temporary housing is not covered by Medicare, Medicaid, the hospital or the Comprehensive Transplant Center.** You may need time to save money or raise funds to pay for local housing.
- ✓ Identifying where you will fill your prescriptions: Which pharmacy will you use? Is this the best one to use with your health insurance?
- ✓ Gathering information: Don't be afraid to contact your health care team with questions.
- ✓ Request a case manager through your insurance company. A case manager can help you navigate the ins-and-outs of your insurance policy.

FINANCES AND FUNDRAISING

Developing a financial plan is part of preparing for transplant. Fundraising is an option if you are in need of additional financial assistance for transplant. Fundraising can assist with expenses such as:

- ✓ Medical bills
- ✓ Medications
- ✓ Travel
- ✓ Accommodations

Fundraising organizations:

- ✓ Provide education and guidance to get your fundraising campaign going
- ✓ Manage accounts
- ✓ Work directly with transplant centers, hotels, airlines, etc. to arrange payments

The following organizations can help you decide if fundraising is for you. Please be aware that with some of the organizations the funds raised might count towards your assets, which could affect your eligibility for needs-based programs. However, some of the organizations allow for family and friends to make tax-deductible contributions to your fund.

National Foundation for Transplants	Children's Organ Transplant Association (COTA)
www.transplants.org	www.cota.org
1-800-489-3863	1-800-366-2682
HelpHOPELive	Compass
www.helpholive.org	(for Cystic Fibrosis Patients)
1-800-642-8399	compass@cff.org
	1-844-COMPASS (844-266-7277)

Medical costs include:

- Insurance deductibles
- Insurance co-pays
- Pre-transplant evaluation and testing
- Surgery
- Follow-up care and testing
- Additional hospital stays for complications
- Fees for surgeons, physicians, radiologist, anesthesiologist and recurrent lab testing
- Anti-rejection and other drugs, which can easily exceed \$2,500 per month
- Rehabilitation

Non-medical costs include:

- Food, lodging and long distance phone calls for you and your family
- Transportation to and from your transplant center, before and after your transplant (parking, gas, tolls, etc.)
- Air travel to get to your transplant hospital quickly
- Child care
- Lost wages if your employer does not pay for the time you or a family member spends away from work
- If your transplant center is not close to your home, lodging close to the center before and after your surgery. Ask your social worker about lodging options close to The Johns Hopkins Hospital.

Prescription Costs

It is very important to maintain a health insurance plan to cover costs of medications post-transplant.

Transplant medications can be very expensive. If you have no prescription coverage and had to pay “out-of-pocket” for medications, the cost could exceed \$3,000 a month during the first year after transplant. The cost of immunosuppressive medications alone can be over \$1,000- \$2,000 per month. You will also be prescribed additional medications (anti-infection, gastrointestinal, etc.), which will add to the monthly cost.

Remember, Medicare Part B assists with immunosuppressant medication only at 80%. You may have additional coverage for other medications if you choose to have Medicare Part D. Medicare will pay for your immunosuppressant medication even if you become eligible for Medicare following your transplant (www.medicare.gov).

If Medicare is your primary insurance, you will need to check with your pharmacy to see if they will bill Medicare Part B for immunosuppressant medications.

Medicaid from states other than Maryland: Only Maryland Medical Assistance/Medicaid will pay for medications at a pharmacy in Maryland. If your Medicaid is from another state, you will have to arrange to obtain medications from that state or from a participating mail order pharmacy. Many out-of-state Medicaid programs require that a physician licensed in their state write the prescription, so please plan for this with your health care team prior to transplantation.

Don't forget to contact your tax professional regarding deducting medical expenses such as co-pays, etc.

Social Security Disability

The Social Security Administration (SSA) administers two disability programs:

- ✓ Social Security Disability Insurance (SSDI)
 - Applicant is disabled based on medical definition of disability under Social Security
 - Eligibility based on an individual's work history
 - Financed through Social Security or payroll taxes and paid by workers and employees
 - Amount of the benefit is based on the individual's earnings

- ✓ Supplemental Security Income (SSI)
 - Applicant is disabled based on medical definition of disability under Social Security
 - Based on financial need
 - Amount of the benefit varies based on the total income of the individual

Disability Criteria:

Disability under Social Security is based on your inability to work. You may be considered disabled if you are unable to do any kind of work for which you are suited and your disability is expected to last for at least 12 months. Social Security does not have partial or short-term disability programs. Keep in mind, Social Security is able to review your case 1 year after transplant, and they may determine that you are no longer disabled.

Compassionate Allowances:

Social Security keeps a list of certain health conditions that will automatically enable you to be eligible to receive disability benefits. **If you have Idiopathic Pulmonary Fibrosis or another qualifying lung disease, you are eligible to receive disability benefits.**

To apply or for more information call Social Security at 1-800-772-1213 or www.ssa.gov

Veterans Administration

If you are a veteran, you may be entitled to medical care or financial benefits through two programs: Disability Pension Benefits or Disability Compensation Benefits.

Call the VA Eligibility Office in Baltimore at **410-605-7324** or go to www.va.gov to determine if you are eligible.

Transplant Finance Office

The business office is a division within the transplant service focused specifically on obtaining authorizations for all organ transplants. The office is also responsible for verifying hospital facility transplant benefits, coordinating clinical information, securing reimbursement for the hospital, and ensuring that each patient is activated on the transplant list. The Transplant Finance Office would like to ensure smooth financial planning of all transplant procedures. Therefore, **it is extremely important that they be contacted with any insurance changes, questions or concerns.**

TRANSPLANT FINANCE OFFICE

Phone: 443-997-0707

Fax: 410-800-4087

BILLING QUESTIONS:

- | | |
|----------------------------------------------|----------------|
| • Billing Customer Service | 1-855-662-3017 |
| • Johns Hopkins Hospital Billing | 1-443-997-3370 |
| • Office of Johns Hopkins Physicians Billing | 1-410-933-1200 |
| • Johns Hopkins Home Care Group Billing | 1-410-288-8000 |

Parking Rates at Johns Hopkins Hospital

Regular parking:

- \$4.00 Up to 1 hour
- \$5.00 Up to 3 hours
- \$6.00 Up to 4 hours

- \$7.00 Up to 5 hours

- \$8.00 Up to 6 hours

- \$12.00 Maximum for 24 hours

Valet parking:

- \$11.50.....Up to 3 hours
- \$14.50Up to 6 hours
- \$18.50Maximum for 24 hour

The Comprehensive Transplant Center and Johns Hopkins Hospital do not validate parking or provide parking coupons.

Parking coupon books are available:

5 parking coupons for \$30.00 or 10 parking coupons for \$60.00.

Each coupon covers a 24-hour period. No refunds or expiration dates.

The Parking Office may be reached at 410-955-5333.

Where to Buy Parking Coupons	
Main Cashier's Office (Nelson Room 161)	Monday - Friday, 7:30 a.m. - 5:00 p.m.
Satellite Cashier - Zayed Lobby	Monday - Friday, 7:30 a.m. – 4:00 p.m.
Outpatient's Cashier's Office (1st floor of the Outpatient Center)	Monday - Friday, 6:30 a.m. - 4:00 p.m.
Weinberg Building (1st floor at Admitting & Registration)	Monday - Friday, 7:00 a.m. - 5:00 p.m. (open until 5:30 p.m. on Tuesdays)
McElderry Garage Manager's Office	Monday - Friday, 4:00 p.m. - 9:00 p.m.; Saturday, Sunday and holidays, 7:00 a.m. - 11:30 p.m.
Orleans Garage Manager's Office	Monday - Friday, 4:00 p.m. - 8:00 a.m.; all day Saturday, Sunday and holidays, 24 hours

WRITING YOUR DONOR FAMILY

For many, writing a letter to your donor's family is a helpful way to deal with the wide range of emotions experienced after receiving a transplant. The Living Legacy Foundation (LLF) facilitates all correspondence between donor families and recipients and our Family Service Coordinators are always available to assist you with the writing process. We can answer questions, discuss your feelings about taking this step, and help you write your card or letter. If you have questions or concerns, please call us at 410-242-7000 or email at familyservices@thellf.org.

Tips on Writing Your Letter

- Recipients may choose to write to their donor family to tell a little about themselves and the impact donation has had on their lives and the lives of their families. Donor families often welcome and appreciate these details.
- We recommend you do not disclose any identifying or direct contact information until you get a feel for your donor's family and how you feel about corresponding with them. While the Living Legacy Foundation does not restrict this information, we do want to make sure you have considered all of the potential outcomes of making such a disclosure.
- Due to increasing use of social media sites and other online search capabilities, the range of information making you “identifiable” has greatly increased. If you disclose the same information that you have written on a Facebook page or blog, your donor family may be able to locate you through the internet.
- Prior to sending your letter, LLF works closely with other donor programs and transplant centers to ensure donor families are ready for this next step. If we receive feedback the family is not ready to correspond, we will immediately contact you to let you know. Please be understanding of this decision, and know that we will do the same for you should you ever decide you are not ready for correspondence.
- After your initial letter is written and forwarded to the donor's family, you may feel anxious about what happens next. Although many recipients do hear back from their donor's family, there is no guarantee you will receive a response. Should your donor's family choose not to write to you at this time, please do not take this inaction personally.

To mail your letter:

Place your card/letter in a blank, unsealed envelope.

On a separate piece of paper, write your full name, the date you received the transplant, and your contact information.

To email your letter:

Attach your letter to the email as a word document or enter the text into the body of your email.

Please include your full name, the date you received the transplant, and your contact information.

Place the first envelope and the piece of paper in
a sealed envelope and mail your letter to:

The Living Legacy Foundation of Maryland

1730 Twin Springs Road Ste 200

Baltimore, MD 21227

Send your email to:

familyservices@thelf.org