# What Every Patient Needs to Know

















United Network for Organ Sharing (UNOS) is the mission-driven non-profit serving as the nation's transplant system under contract with the federal government. We lead the network of transplant hospitals, organ procurement organizations, and thousands of volunteers who are dedicated to honoring the gifts of life entrusted to us and to making lifesaving transplants possible for patients in need. Working together, we leverage data and advances in science and technology to continuously strengthen the system, increase the number of organs recovered and the number of transplants performed, and ensure patients across the nation have equitable access to transplant.

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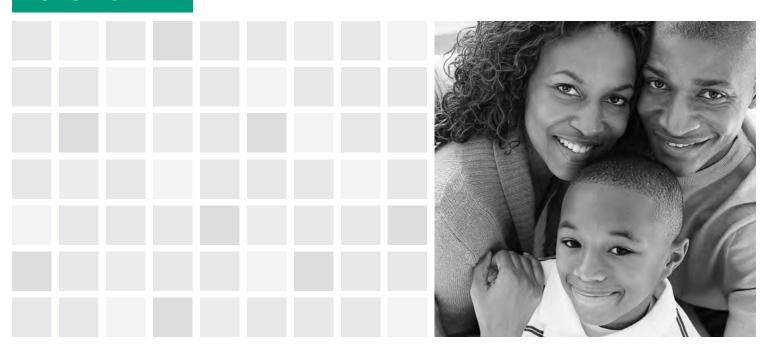
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### **SECTION 1**



## **Introduction to the Transplant Network:** The Big Picture

### **Introduction to the Transplant Network:** The Big Picture

If an organ transplant is in the future for you or a loved one, you are not alone. Patients and transplant professionals wrote this booklet to help you learn the process.

If you are reading this for the first time, you may feel scared and confused. With so much to absorb, it may help to read this booklet with someone close to you. Keep a pen and paper handy to write down questions to ask your health care team.

#### This section covers:

- the history of transplantation
- how the organ transplant network is managed in the U.S.
- the process for matching patients with donated organs

#### Later sections will cover:

- how to prepare for a transplant
- what happens while you are on the transplant waiting list
- how a loved one can become a living donor
- transplant finance issues
- what to expect after your transplant



### **Understanding Transplantation A Brief History**

In 1954, a kidney was the first human organ to be transplanted. Liver, heart, and pancreas transplants were performed in the late 1960s, while lung and intestinal organ transplants began in the 1980s.

Until the early 1980s, organ rejection issues limited the number of transplants performed. Advances in treating rejection led to more transplants with better outcomes for patients, and an increase in demand.

More than 800,000 people have received transplants in the U.S. More than 35,000 people receive the gift of life each year.

#### **National Organ Transplant Act**

In 1984, Congress passed the National Organ Transplant Act, which prohibited the sale of human organs and called for a national network to manage organ recovery and placement. The act created the Organ Procurement and Transplantation Network (OPTN) and assigned it the task of developing equitable organ distribution policies.

### The Organ Procurement and Transplantation Network

The OPTN (optn.transplant.hrsa.gov) helps to ensure the success and efficiency of the U.S. organ transplant system. Under federal law, all U.S. transplant centers and organ procurement organizations (OPOs) must be members of the OPTN. Other members include:

- tissue typing labs
- medical, scientific, and professional organizations
- health and patient advocacy groups
- members of the general public with an interest in organ donation and transplantation

### The United Network for Organ Sharing

UNOS (www.unos.org) is a private, nonprofit organization that coordinates the nation's organ transplant system under contract with the federal government. UNOS was first awarded the OPTN contract in 1986, and it continues as the only organization ever to manage the OPTN.

UNOS members include 57 local OPOs that manage recovery and placement in the 50 states, D.C., and Puerto Rico. UNOS links the organ donor, the transplant center, and the waiting patient.

The UNOS mission is to advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology, and policy development.

Learn from yesterday, live for today, hope for tomorrow.

- Albert Einstein

#### What We Do

- manage the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year.
- monitor every organ match to ensure that organ allocation policies are followed.
- bring together OPTN members to develop policies that make the best use of the limited supply
  of organs and give all patients a fair chance of getting the organs they need based on medical
  criteria—regardless of age, sex, ethnicity, religion, lifestyle, financial or social status.
- maintain the database that contains all organ transplant data for every transplant that occurs in the U.S. This data is used to improve transplantation, develop organ-sharing policies, support patient care, and help patients make informed health care choices.
- provide a toll-free patient services line: (888) 894-6361. Transplant candidates, recipients, living donors, family members, and the general public can call to obtain general information, the process to request transplant data, organ allocation policy information, or to discuss concerns about transplant centers.
- provide a website, www.transplantliving.org, with patient-focused information for transplant candidates and patients, and loved ones.
- educate professional groups about their important roles in the donation process.

### **Introduction to the Transplant Network:** The Big Picture

### Deceased Donor Organ Donation, Matching, and Allocation The Five Steps in Matching Deceased Donor Organs

- 1. An organ is donated. Organ Procurement Organizations (OPOs) are responsible for identifying potential organs for transplant and coordinating with the national network to allocate organs. When a deceased donor organ becomes available, the OPO managing the donor enters medical information about the donor including organ size and condition, blood type, and tissue type into the UNOS computer system.
- **2. A match run is generated.** The UNOS computer system generates a match run, which is a list of candidates who have medical profiles compatible with the donor's. Each organ follows different criteria for allocation. The computer prioritizes candidates based on the allocation policy for the organ and on how closely the candidate's characteristics match the donor's.
- **3. Transplant centers are notified.** Organ placement specialists at the OPO or the UNOS Organ Center electronically contact the transplant centers whose patients appear on the match run.
- **4.** The transplant team considers the organ for the patient. When an organ is offered, the transplant team considers many factors to determine what's best for each patient. Sometimes the team turns down an offer for an organ. This is a normal part of the process.
- **5. The organ is accepted or declined.** If an organ is turned down for one patient, it is offered to the next patient on the match run list for that organ. These offers continue until the organ is placed.

It is common for patients to be called about an organ offer (one patient will be the primary candidate and the others will be backups in case the primary is not available or eligible). Sometimes a patient reports to a transplant center for a potential offer, but then does not receive the transplant.

### **How Organ Allocation Policies Are Made**

Organ matching and distribution policies are developed by committees and a board of directors comprised of organ procurement and transplant professionals, patients, donor families, and the public. As the transplant field continues to advance, organ allocation policies evolve. Goals are to make the best use of every donated organ and give every transplant candidate a fair chance to receive the organ he or she needs. Organ transplantation is unique in U.S. medicine because patients have a formal role in policy making. The public can provide feedback on policy proposals by visiting optn.transplant.hrsa.gov/governance/public-comment/. Call the patient services line at (888) 894-6361 for more information.

You must do the thing you think you cannot do.

- Eleanor Roosevelt

### Common Questions about Transplantation

### How are patients added to the national organ transplant waiting list?

If your physician decides that you need an organ transplant, you will be referred to a transplant center for evaluation. The medical team at the transplant center will consider your medical condition and situation. They also will consider your financial situation, including insurance or other resources you have to pay for the surgery and medications afterwards. Another consideration is whether you have family and friends to care for and support you. If the transplant team decides that you are a good candidate, you will be added to the waiting list and the transplant center will send you a letter to let you know.

### Can patients list at more than one transplant center?

Yes. This is called "multiple listing." OPTN policy permits patients to be considered for organs that become available in other areas by being registered at more than one center. This may reduce your waiting time in some cases, but not always. There may or may not be an advantage in listing at more than one transplant center in the same OPO's local service area. Discuss this with the individual centers so you can be counseled appropriately. Each center has its own criteria for listing transplant candidates, and each center can refuse to evaluate patients seeking to list at multiple centers. Your insurance may also have certain restrictions. Confirm your coverage before beginning a transplant evaluation at a new center.

### How long does it take to receive an organ?

Once you are added to the national organ transplant waiting list, you may receive an organ that day, or you may wait many years. Factors affecting how long you wait include how well you match with the recipient, how sick you are, and how many donors are available in your local area compared to the number of patients waiting.

### How can I access data on organ transplantation and donation?

You can obtain national, regional, state, and center data by visiting optn.transplant.hrsa.gov (Data>View Data Reports>Center Data). You can find survival data at the Scientific Registry of Transplant Recipients website at www.srtr.org. If you need help accessing data reports, please call patient services at (888) 894-6361.

For more information, call the Organ Procurement and Transplantation Network (OPTN) patient services department (888) 894-6361, email Patient.Services@unos.org or visit www.transplantliving.org.

### Is living donation a possibility for me?

Kidneys and parts of livers, lungs, intestines, and pancreata can be donated from one living person to another. Medical personnel at transplant centers determine who is a candidate for living donation. Living donors have historically been a close relative (such as a spouse, sibling, or parent) or friend of the recipient. Living non-directed (stranger-to-stranger) donation is newer. Other types of living donation are paired donation, positive crossmatch, and blood type—incompatible donation. Contact your transplant center to discuss living donation. See section 3 of this booklet for more details.

### Does UNOS oversee donation and transplantation around the world?

No. UNOS only oversees transplantation in the U.S. and Puerto Rico.

### **Introduction to the Transplant Network:** The Big Picture

### Can a patient from another country receive a transplant in the United States?

Yes. Patients can travel from other countries to the U.S. to receive transplants. Once a transplant center lists them, non-residents are considered based on the same factors as U.S. citizens. Non-residents comprise roughly 1.2% of the U.S. waiting list. They also comprised 0.3% of deceased donors and 1.4% of living donors in the U.S. during 2020. Transplantation for non-U.S. citizens is at the discretion of each transplant center.

### How can I find out about organ allocation policy changes that affect organ transplantation and donation?

Information on policy proposals can be found at optn.transplant.hrsa.gov/governance and in various UNOS publications. To request these resources, contact UNOS at (888) 894-6361.

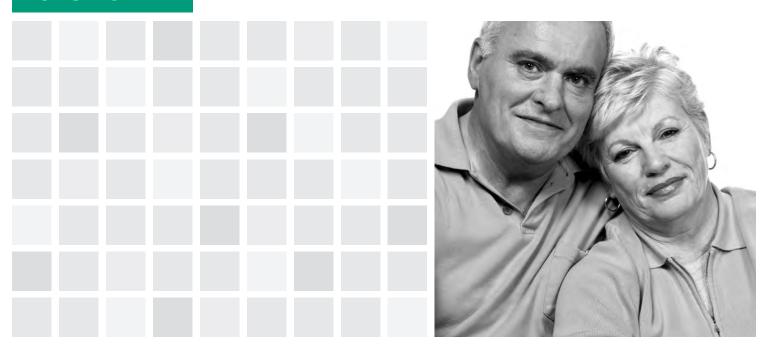
### What does UNOS do to increase the supply of organs?

Due to the shortage of organs, about half of those on the waiting list receive a transplant within five years of listing. The OPTN has 19 committees with healthcare professionals, scientists, statisticians, patients and the public who meet regularly to create policies to increase the number of patients who receive transplants and reduce deaths on the waiting list. They come up with creative ideas to use all viable organs from deceased donors and reduce geographic disparities in order to encourage living donation.

# Heroism...is endurance for one moment more.

– George F. Kennan

### **SECTION 2**



**Preparing for Your Transplant** 

### **Preparing for Your Transplant**

Each person's journey to transplant is unique. Some people wait for extended periods of time, hoping for the day when they will be called for a transplant. Others come to transplant with compatible living donor candidates and move quickly to surgery and life with their new organ. No matter the circumstances, nearly everyone finds it difficult to completely absorb the fact that they have an end-stage disease that can best be treated with a transplant.

The fear and anxiety that nearly every transplant candidate feels is further compounded by the complex system for transplant evaluation and organ matching. To make the process easier to understand, here's what you can expect when your doctor recommends that you be evaluated for a transplant and refers you to a transplant center.

Practice selfadvocacy by stating, 'I think, I feel, I need, I want.'

- Transplant Social Worker

### **The Transplant Process**

- 1. You are evaluated for a transplant by the medical team at a transplant center.
- 2. If accepted as a transplant candidate, you are registered on the national organ transplant waiting list. A living donor may also be identified and evaluated for living donation.
- 3. You begin organizing your support system.
- 4. You begin developing your financial strategy.
- 5. Your waiting period begins.
- 6. Your transplant takes place.
- 7. Your medical team manages your post-transplant care.

In the following sections, we'll present step-by-step instructions to get you started, based on experiences of transplant recipients and their donors.

### **Transplant Centers**

A transplant center is a hospital with staff that specializes in transplant medicine.

Your primary doctor or organ specialist can refer you to a transplant center that:

- is near your home
- specializes in your medical situation
- accepts your insurance

You can also contact a transplant center yourself. A referral from a doctor is not necessary, but your doctor may have test results and medical history that will make it easier for the transplant center to start the evaluation process.

### **Choosing a Transplant Center**

One of the biggest decisions you will make as a transplant candidate is choosing a transplant center. There are more than 250 transplant centers in the U.S. and all of them must meet strict professional standards. Go to optn.transplant.hrsa.gov (Members>Find a Member) to access transplant center listings and links. Many patients simply choose the facility closest to them, but there are several questions to ask when choosing a transplant center:

- Can you easily reach the transplant center for all appointments before and after the transplant?
- Can you easily reach the transplant center when called to receive an organ?
- If the center is a distance from your home, can your caregivers stay near the transplant center without causing an undue burden?
- Is the center within your healthcare network?
- Do you feel comfortable with the transplant team?

For more information, call UNOS patient services at (888) 894-6361 or go to www.transplantliving.org.

#### **For More Information**

When choosing a transplant center, you may want to compare the number of transplants performed, waiting list size and survival rates at the centers you are considering.

- Visit optn.transplant.hrsa.gov (Data> View Data Reports>Center Data) for the number of transplants and waiting list size by transplant center.
- Visit www.srtr.org for median wait time and survival rates by transplant center.

### **The Transplant Evaluation**

The transplant evaluation process can be stressful and involve long days of tests and clinic visits. The transplant team will test every major system in your body. Tests could find other medical conditions that could complicate your transplant or make it less likely to succeed.

It's perfectly normal to feel anxious or vulnerable, like your life is in the hands of the medical team. They understand and can help. Below are some questions to ask as you go through the process:

### **Questions for the Transplant Center** and Team

- Do I have choices other than transplantation?
- What are the benefits and risks of transplantation?
- What are your criteria for accepting organs for transplant?
- Who are the members of the transplant team, and what do they do?
- How many surgeons are available here to do my type of transplant?
- How do I find out about the transplant process?
- Is there a special hospital unit for transplant patients?
- May I tour the transplant center's units?
- Will I be asked to take part in research studies?
- What are the organ and patient survival rates for my type of transplant at this hospital?
- How many of my type of transplant do you perform each year? How long have you been doing these transplants?



### **Preparing for Your Transplant**

#### **Questions about Your Evaluation**

- What should I bring with me?
- What should I do to prepare for the appointment?
- Does your center offer parking permits or overnight accommodations?
- What does the evaluation and testing process include? How does it affect whether I am put on the list?

### **Financial Questions**

- What part of the transplant cost is covered by my insurance?
- What if my insurance does not pay for medications?
- What financial coverage is accepted by this hospital?
- What happens if my financial coverage runs out?
- How much will I have to pay in the end?

### **Questions about Living Donation**

- What types of living donor transplants does the center do? Is a living donor transplant a choice in my case? If so, where can the living donor evaluation occur?
- What are the costs if I have a living donor?

Write your questions down and bring them to the appointment. You might also want to bring a trusted friend or family member with you and ask them to take notes.



### The Standard Transplant Evaluation

The standard transplant evaluation usually includes the following tests:

- blood typing
- tissue typing
- dental exam
- chest x-ray
- cardiac work-up
- pulmonary work-up
- infectious disease testing
- cancer screening
- gender-specific testing
- psychological evaluation to determine emotional preparedness
- evaluation of social and financial supports and ability to care for yourself and your new organ after transplant

Other testing may be required depending on the organ you need and your health history.

Life is 10% what you make it and 90% how you take it.

- Irving Berlin

## It's always too early to quit.

Norman Vincent Peale

#### **After the Evaluation**

You will likely receive a huge amount of information during your evaluation. Afterward, spend some time alone to let it all sink in. It may also be helpful to talk with others who have had a transplant. Ask your transplant social worker to refer you to a peer mentoring program or transplant candidate support group, either at your center or in the community. This is a good way to spend your time as you wait for insurance approval and test results.

It is normal to feel unsure whether transplant is for you. You may doubt your ability to get through the process. Or you may be frozen with fear. Your transplant team is there for you. It is okay if you decide that a transplant is not for you — it is your decision to make.

### **The Waiting List**

The waiting list is a computer system that stores the medical information for every person waiting for an organ transplant in the U.S. and Puerto Rico. When a deceased donor organ becomes available, information about that organ is entered into the computer system. The system then generates a match run, which is a list of candidates who might be a good match for that organ. To determine a potential match, the system looks at factors like blood and tissue type, medical urgency, body size and distance between the donor hospital and your transplant hospital.

Each organ has different criteria for allocation, but wealth, social status and citizenship are never factors. To learn more about OPTN policies, visit optn.transplant.hrsa.gov (Governance>Policies).

- **Livers:** Medical test results and geography determine priority for transplant.
- Hearts, lungs, intestines: Priority is based on clinical or medical status and geography.
- Kidneys and pancreata: Waiting time is a factor, but other factors like tissue type matching are also considered.

#### You're on the List

Congratulations! The evaluation is over and you're on the organ transplant waiting list. Your transplant center will confirm your registration in writing and will also notify you in writing if you are ever removed from the waiting list. It is normal to feel relief and hope, and also fear and regret.

Now the waiting begins. Waiting for a donor organ can be stressful, since you don't know how long that wait will be. Factors affecting how long you wait include how well you match with the donor, how sick you are, and how many donors are available in your local area compared to the number of patients waiting. Now is the time to mobilize your resources so you're ready when the call comes.

Remember, transplant is not a first-come, first-served process. Organ allocation is based on many criteria. While you wait, there may be others who get their transplant before you. Being on the waiting list simply means that your transplant team found you to be a good candidate for transplant and you're being considered for organs.

### **Preparing for Your Transplant**

You want to be sick enough to be listed, but well enough to survive the transplant.

– Heart recipient

### **Multiple Listing**

After talking with staff and other patients and doing your own research, you may decide to be on the waiting list at more than one center. Listing at more than one center can provide advantages:

- You will have access to multiple donor pools.
- There may be different rules in other regions (pilot projects or other agreements).
- Average wait times for your organ may be shorter in another region.

Each center decides who it accepts as a candidate and a center can refuse patients who are listed elsewhere. Every center can require that tests be redone at their own center. Insurance may not pay for duplicate tests so confirm your health plan's coverage before going forward.

Inform both your primary center and any other centers you contact of your plans. There may or may not be an advantage in listing at more than one transplant center in the same OPO's local service area. Discuss this with the individual centers so you can be counseled appropriately. Waiting time for a kidney candidate starts at the time dialysis was started or when the candidate was added to the waiting list with a qualifying GFR, whichever occurs first. For all other organs, waiting time starts after a center adds you to the list.

### **Transferring Waiting Time**

If you choose to change centers or register at multiple centers, you can transfer your waiting time. Tell your new center that you want to transfer time from another center. You will have to sign a request for the waiting time transfer.

Confirm your insurance coverage before you transfer centers. To avoid gaps in waiting time and the chance that you might miss organ offers, remain listed at your old center until you are on the waiting list at your new center.

### What if the transplant center does not accept me as a transplant candidate?

Ask your transplant team about your options. You may need to manage other medical conditions first. You may be too healthy for a transplant now but might need one in the future. You may still be a candidate at another transplant center. If a transplant is not an option, you should commend yourself on putting forth your best effort to survive. This may now be a time for personal, spiritual, and emotional reflection.

For more information, see Section 3
of this booklet or visit
www.transplantliving.org (Living Donation).

### What If I Have a Living Donor?

If your transplant center identifies you as a good candidate and you also have a compatible living donor, the center will work with you and your donor to coordinate surgery. The timing of your transplant depends on your and your donor's health, the schedules of all involved and administrative factors like the availability of operating rooms.

### What does it mean to be inactive on the waiting list?

Sometimes a transplant center has to inactivate a patient on the waiting list. If you are inactive on the waiting list, it means you are not eligible to receive organ offers. For some organs, you also do not accrue waiting time while inactive. There are reasons why you may have to be inactive for a period of time, including a change in your health or social support. Make sure you understand your transplant center's policies regarding inactivity. It's up to you to communicate with your transplant team to ensure your status is active. If you have any concerns regarding your inactive status on the waiting list, discuss this with your transplant team. If possible, they can help you determine steps to take to become active again.

### **Preparing for Your Transplant**

Wait times for transplants vary. Not everyone who needs a transplant will get one. Because of the shortage of organs that are suitable for donation, about 50% of people on the waiting list will receive an organ within five years.

After your evaluation, it's important to prepare for your transplant while you are waiting. Work closely with your transplant team. Keep all scheduled appointments. Build a solid support system of family, friends, clergy and medical professionals. Let people know what's going on in your life. They can be a tremendous source of support and information. Taking these steps puts you in control.

Prepare yourself for your transplant:

- medically
- practically
- emotionally
- educationally
- financially
- spiritually

### **Preparing Yourself Medically**

While you are on the waiting list, your transplant team will monitor you continuously to make sure you remain suitable for transplant. If your condition improves or complications arise, you may be taken off of the waiting list. Always discuss any concerns with your transplant team. If you need to make lifestyle changes before getting a transplant, you should continue with them after your transplant to ensure the best outcome. Remaining healthy and active before the transplant will make recovery easier.

- Take care of your health. Take your prescribed medicines. Notify your transplant coordinator about all of your health issues and any other prescriptions.
- Keep your scheduled appointments with your physicians. Until your transplant, you will need to meet with the transplant team so that they can evaluate your overall health.
- Follow diet and exercise guidelines. Weight
  management is important while waiting for
  your transplant. Transplant team staff, including
  a dietician, can help you develop a program
  that will give you the best results. Ask about
  ways to reduce the use of painkillers and how to
  manage issues with alcohol, tobacco, or drugs.
- Make sure you are available. Your transplant team needs to know how to reach you at all times. Cell phones, pagers, or answering machines may be required by your transplant center. Your transplant coordinator may ask you to stay within a certain geographic range.
- Complete medical tests and procedures.

  Ask your transplant team about other elective or required surgeries (not related to your organ failure) before your transplant.
- Women of childbearing age: Ask your medical team about birth control and pregnancy and what precautions you should take before and after your transplant.
- Stay organized. Keep a notebook of your records to help you manage your medical information. Stay in contact with your transplant team to learn about your waiting list status.

### **Preparing for Your Transplant**

### **Preparing Yourself Practically**

- **Select your primary support person.**Choose someone you feel close to who has the time, health and flexibility to be your caregiver. You need to know you are a not a burden to this person.
- Prepare a phone/email tree. This will make
  it easier for your caregiver to update friends
  and family and also cut down on phone or
  email volume. There are also online options
  that you can use to update friends and family.
- Organize your personal affairs. Consider filling out an advanced directive, writing a will, and sharing access to bank accounts, email or blogs. You may also need to fill out Family Medical Leave Act (FMLA), insurance or loan deferment paperwork.
- Consider dependent care. Find someone you trust and set up a plan to take care of your children and/or pets. Ask your doctor when you can expect to see your children and pets after your transplant.
- Arrange transportation. When you are on the organ waiting list, your first responsibility is to plan how to get to the transplant center quickly when you get the call that an organ is available. Make arrangements well in advance. Plan the driving route and think about traffic conditions. If you are relocating, make housing arrangements in advance.
- Pack your bags. You'll need to be ready to leave as soon as you get the call that an organ is available. Include insurance information, a list of medications, an extra 24-hour supply of medication and other necessities.

I made sure I had my glasses, Chapstick<sup>™</sup>, and a box of chocolates packed for after surgery.

- Pancreas recipient

### **Preparing Yourself Emotionally**

Many portrayals of the transplant process in the media are inaccurate or sensationalized. In the real world you get sick, you wait, and hopefully, you get a transplant. Your transplant team should be the main source of information about your care. You can also find a wealth of information on www.transplantliving.org, a UNOS Web site designed for transplant candidates, patients, and loved ones.



#### **Preparing Yourself Educationally**

Transplantation is a whole new world with a whole new language to learn — one filled with medical terms, abbreviations and acronyms. The best way to navigate this world is to choose to become a lifelong learner. Carefully review any educational materials provided by your transplant center. Many organor disease-specific organizations provide patient education. This book is just one example of the patient-focused resources available through UNOS. Join a transplant support group, either in person or online, for information and support. As you learn about the transplant and what to expect, you will gain control of your transplant experience and your life. Education leads to empowerment!

Need more information?
Visit www.transplantliving.org or www.unos.
org (Donation & Transplantation>Patient
Education), or call (888)894-6361 to request
printed materials.

### **Preparing Yourself Financially**

Major health problems can impact your finances. Success in transplant includes having a realistic financial plan. It can be scary to face concerns about loss of income, employment or insurance; high medical bills; and the need to apply for financial help. Yet facing these possibilities helps you gain a degree of control over the unimaginable. A good financial plan begins by talking with your loved ones about your situation. Also inform your transplant team about financial issues. See Section 4 for details.

### **Preparing Yourself Spiritually**

Spiritual challenges and growth await many transplant candidates and recipients. Some find that a life-threatening illness makes them question their faith; others find their faith strengthened through the transplant process. Your second chance at a healthy life may come with the knowledge that another life was lost. Receiving a donor organ may create a sense of spiritual rebirth. This may create a profound change in your beliefs, and spiritual guidance and counseling can help you deal with these issues. Just as every patient has different medical issues, spiritual needs vary as well. Talking to your pastor, your rabbi, or the hospital chaplain may help.

### **Preparing for Your Loved One's Transplant**

A caregiver may be a family member or friend. Some caregivers have been supporting a medically fragile loved one for years. While the transplant team social worker may be able to suggest resources for caregivers, here are some basic tips:

- Physical health. Ask the transplant team and your own doctor what you need to do to stay healthy in your care-giving role, such as using medications or vaccinations. Make sure you are in good physical condition.
- Mental health. Spending time with one person can be the best of times and the worst of times. Make sure you arrange some respite time to take a walk, call friends, or do something for yourself. This can keep you from feeling burned out.
- Living arrangements. Where will you stay
  while the patient is in the hospital? If you are
  away from home, be sure that your mail and
  phone calls are forwarded and you've packed
  necessities.
- Support network. Caregivers need support too! Find people to help you with respite care, errands or meals. The best resource for caregivers may be other caregivers who have "survived" a transplant. Ask your social worker if your transplant center offers these types of support groups.

### **Preparing for Your Transplant**

- Financial arrangements. Make financial and insurance plans or take leave from work or other duties.
- Manage expectations. To avoid questions and stress later, find out the hospital's visiting hours, limits on visitation, storage, parking, hygiene requirements and cafeteria hours.
- **Saying no.** Being a caregiver is a great reason to cut back on other responsibilities and de-stress your life. You have enough on your plate.

A transplant is a life-saving gift for both the recipient and the caregiver. It is what you have hoped for during the long wait and time of illness. Transplant is not only life-saving; it is life-altering.

A transplant will help the patient become more independent so he or she can return to work and other activities. For the caregiver, transplant may mean a big change in roles. This can bring on feelings of sadness, resentment, and stress. All of this is perfectly normal and can be resolved with open communication and a little adjustment time. If more is required, talk to your transplant social worker about counseling and support groups.

I'm ready for the right lungs at the right time.

Lung candidate

### Receiving "The Call"

Answer your phone at all times of day and night, especially if it's from the hospital. If they call to tell you that an organ is available, you will likely have to stop eating and drinking to get ready for surgery. You may wish to shower or bathe. You may be asked whether you have a cold, cough, fever or other infection. Your doctor will explain which medications and treatments to stop or continue.

You will be asked to go to the hospital within a certain window of time. Plan ahead and have directions to the hospital handy, and find out where to park. Ask where your caregiver will stay during the surgery. Bring the bag you packed and your insurance card. Your caregiver should also bring his or her packed bag. When you arrive at the hospital, be ready for medical tests and possibly a long wait for surgery.

You may feel a surge of adrenalin, excitement, eagerness, a peaceful state of readiness, or a sense of dread, shock and disbelief. You may also feel sadness for the family members who lost a loved one at the same moment you are thrilled to receive the gift of life. All of these feelings are normal.

After receiving the call, contact your support person to make sure he or she can be with you. Your support person can help you contact other close family or friends and take care of children, pets and other matters such as paying bills.

#### A "Dry Run"

Sometimes an organ may be evaluated more closely after you've arrived at the hospital, and it is found to be in poor condition for transplant. You could be told that you will not receive a transplant and must go home. This can be very disappointing after a long wait. Your transplant team is looking out for your best interests and outcome, and maybe this organ just wasn't right for you. *Be patient*.

One patient suggested thinking of this waiting time as a sort of *sabbatical* during which you get to consider your plans and goals for the potentially "very long and reasonably healthy life" you will have after transplant.

### The Surgery

Transplant surgery can last from four to nine hours, but each transplant is unique. Most patients are placed on a breathing machine. You will likely spend some time in intensive care or intermediate care. It is normal to go through some challenges, which your medical team will manage. Everyone adjusts to surgery and medications differently. Ask your transplant team when you can expect to eat, walk, use the bathroom and go home after transplant.

See Section 5, Life after Transplant, for details on how to live your best life after transplant surgery.



20

### **Preparing for Your Transplant**

### **Going Home**

Going home after a transplant is something to celebrate! You made it through the hardest part, and now you can start to recover and live again. Make sure you and your caregiver know your medication routine, clinic visit schedule and diet and exercise restrictions. Ask your medical team what your caregiver needs to do to prepare your home for your arrival for your health and safety.

Most patients feel more like themselves within six months of transplant, although this varies by age, health and the organ they receive.



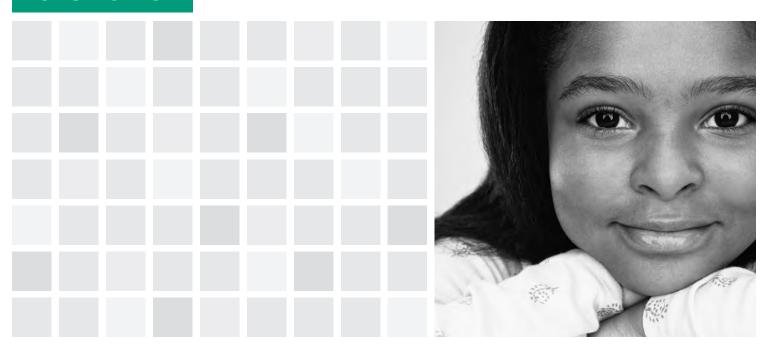
I was there for my one-year posttransplant treadmill stress test. I had completed the required health history forms before the test. Of course, I included my heart health history from before the transplant. Much to my amazement, the technician excitedly stated, "Oh, not with this heart, you didn't!" as she crossed out that entire section. That section related my old heart's history! What a revelation! That old heart history, with all its problems, didn't apply to my NEW heart!

– Heart recipient

Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.

– Helen Keller

### SECTION 3



**Living Donation** 

### **Living Donation**

Living donation offers another choice for transplant candidates. In 2020 there were more than 39,000 organ transplants performed in the U.S. More than 6,500 of these were living donor transplants. Approximately 100,000 people are waiting for transplants in the United States, the demand for organs far exceeds the supply. Living donation extends the supply of organs.

Need more information? Visit www.transplantliving.org (Living Donation).

### **History**

- The first successful living-donor transplant was done between 23-year-old identical twins in 1954.
- Living donor kidney transplants did not become routine until the development of modern immunosuppressive medications to prevent rejection.
- The first successful living-donor liver transplant was performed in 1989.
- The first successful living-donor lung transplant was performed in 1990.

I trusted what I felt in my gut. I trusted my decision to do what I chose to do. I chose to donate a kidney.

Non-directed living donor

### Facts about Living Donation Who can be a Living Donor

Parents, children, husbands, wives, friends, co-workers—even total strangers—can be living-donor candidates.

### **Living Donor Criteria**

Living donor candidates should be:

- in good physical and mental health.
- free from high blood pressure, diabetes, cancer, HIV, hepatitis, or organ-specific diseases.
- in most cases at least 18 years old.

These medical/physical criteria are very important for organ donation. They play a critical role in finding good candidates for transplant. A good donor should also:

- **be willing to donate:** No one should feel that they MUST donate.
- be well informed: A good donor candidate has a solid grasp of the risks, benefits, and potential outcomes, both good and bad, for both the donor and recipient.
- **have good support:** Significant others should support your decision.
- have no alcohol or substance abuse problems.
- have psychiatric diagnoses well controlled over an extended period of time.

### Organs a Living Donor may Give

- one kidney
- segment of the liver
- lobe of a lung
- portion of the pancreas
- portion of the intestine

### Donor Relationship with Transplant Candidate

#### **Directed Donation**

- related: healthy blood relatives of the transplant candidate.
- unrelated: healthy people who are not blood relatives of the candidate and who may or may not have a social connection to the transplant candidate.

#### **Non-Directed Donation**

Non-directed living donors are not related to or known by the recipient, but donate purely from selfless motives. This type of donation is also called anonymous, altruistic, altruistic stranger and stranger-to-stranger living donation.

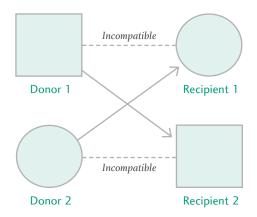
I am a living donor from Rhode Island. In 2002 my good friend, Bonnie, confided over coffee that she had been sick with kidney disease for a long time. She needed a kidney. Her relatives were not viable donors. I privately thought about her predicament and a few days later told Bonnie that I would give it a shot.

Directed unrelated living donor

### When the Living Donor and Candidate Don't Match

Paired exchange donation consists of two (or more) kidney donor/recipient pairs whose blood types are not compatible. The two recipients trade donors so that each recipient can receive a kidney with a compatible blood type. Once all donors and recipients have been tested, the kidney transplant surgeries can be scheduled. There are several paired exchange programs available in the U.S. It is important to ask your transplant coordinator which programs your transplant center participates in and how they work.

#### **Paired Exchange Donation**



Blood type incompatible donation allows a transplant candidate to receive a kidney from a living donor who has an incompatible blood type. To prevent immediate rejection of the kidney, recipients undergo specialized medical treatments before and after the transplant to remove harmful antibodies (a protein substance) from the blood.

#### **Blood Type Compatibility Chart**

Candidate's Blood Type	Donor's Blood Type
0	0
Α	A or O
В	B or O
AB	A, B, AB or O

Positive crossmatch donation involves a living donor and a transplant candidate who are incompatible because antibodies in the candidate will immediately react to the donor's cells, causing loss of the organ. The candidate will receive specialized treatment to prevent rejection.

### **Living Donation**

### **Getting Started**

If you want to donate to someone you know, contact their transplant center. If you want to donate to anyone who needs an organ, contact the transplant center of your choice. Consult the OPTN member directory page at optn.transplant.hrsa.gov (Members>Find a Member) for a list of transplant centers by state. Once you find a transplant center, call to let them know you want to be a living donor. To find out more about being a living donor, go to www.transplantliving.org (Living Donation>Being a Living Donor).

### **Moving Forward**

If you still want to go forward after your first contact with the transplant team, you will begin an extensive series of tests to determine whether you can donate an organ without harming your own health, and in order to provide the best outcome for the candidate.

As part of the process you will be asked to talk about:

- Why you want to donate
- Your current relationship with the recipient
- How you believe donation will impact (change) your relationship with the transplant candidate
- Who will provide support for you (financial, physical, social and emotional) during the transplant process
- Plans with your employer while you recover from donation
- Plans for childcare or other responsibilities during your recovery period
- Your emotional preparation for a less-thanoptimal transplant outcome
- How you handle stress and disappointment
- Future plans for having children
- Future plans for schooling or employment

Every donor should have someone other than the transplant candidate to rely on for support during the process.

### **Things to Remember**

- You should receive the same quality of care and attention that the recipient receives.
- Your donor work-up is confidential. Information cannot be shared with the transplant candidate or anyone else.
- You may choose to stop the donor work-up at any time and the transplant program will help to identify a blameless reason for not continuing.
- It's important to have your own support person.

### What You Should Know about Living Donation

#### **Risks**

Living donation is major surgery. All complications of major surgery apply. These include:

- pain
- infection at the incision site
- incisional hernia
- pneumonia
- blood clots
- hemorrhaging
- potential need for blood transfusions
- side effects associated with allergic reactions to the anesthesia
- death

You may also have negative psychological symptoms right after donation or at a later time. You and/or your recipient may face surgical complications. The transplanted organ may not work right away. There is also the chance it will not work at all.

Donors may feel sad, anxious, angry or resentful after surgery. Donation may change the relationship you have with the recipient.

#### **Positive Aspects of Donation**

Living donation provides an unparalleled opportunity to give someone a second chance at life. Through donation, many recipients may be able to resume many of their normal activities: working, playing sports, self-care and living life to the fullest. Not only do you impact the life of one person or one family, but by taking a single person off the waiting list, you open the door for others who don't have a living donor.

#### **Legal Aspects**

In 1984 Congress passed the National Organ Transplant Act (NOTA), which prohibits the sale of human organs. However, the payment of "the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ" is expressly permitted by section 301 of the NOTA.

#### **Financial Aspects**

Living donor medical costs are generally covered by the recipient's insurance. This includes customary costs associated with the donor evaluation and follow-up. However, some post-operative costs, especially those incurred after the initial post-surgical visit, may not be covered. Living donation may also impact health insurance options in the future.

Here are some expenses that may not be covered by the recipient or his/her insurance:

- annual physicals
- lodging
- travel costs
- lost income from work
- health problems identified as part of the donor evaluation
- non-medical expenses

Your health insurance may not cover these expenses either. Talk to the transplant center's financial counselor about any of your financial concerns before the transplant. You may also call the National Living Donor Assistance Center toll free at (888) 870-5002 or check their Web site at www.livingdonorassistance.org. They help qualifying donors with uncovered expenses.



### **Living Donation**

#### **Questions to Ask**

Questions to think about as you give careful consideration to becoming a living donor include the following:

- How do I feel about organ donation?
- Can I afford to be a living donor?
- What will my insurance cover?
- Do I know enough to make an informed decision?
- Am I being psychologically pressured to be a living donor?
- Is there someone else who could donate?
- If there is more than one possible donor, how will the living donor be chosen?
- Will donation impact my relationship with the recipient?
- What are the medical risks involved?
- How does my religion view organ donation?
- Am I up to it physically? Are there aspects of my health that might keep me from donating?
- Do I have a "support network" to help me through this process?
- How will I feel if I am rejected as a result of the screening process?
- Am I prepared to deal with the possible rejection of the transplanted organ?

I donated a kidney to my son, Tyler, in 1993 after an accident destroyed his kidneys. The nephrologist encouraged me to consider donating a kidney. My biggest concern during my transplant work-up was, 'What if I can't donate?' I feared, 'Who else could we find to donate? What if they find something wrong with me?'

Living donor mom

When you give yourself, you receive more than you give.

- Antoine de Saint-Exupery

### **SECTION 4**



**Developing a Financial Plan** 

### **Developing a Financial Plan**

Transplants are expensive. Patients and families are understandably concerned about how the cost of transplant will affect them. Your concerns are valid, but there are many tools available to help you develop a financial plan for your care, both before and after the transplant. Your transplant team will share these resources with you.

### **Support Services**

Most transplant centers have social workers and financial coordinators on staff who can help you with the financial details of your transplant. Depending on the structure at your center, one or both will help you develop a strategy.

### **Transplant Social Workers**

There are two types of financial challenges in transplant. There are the obvious issues, such as paying for the surgery and medications necessary after transplant. Also, there are unexpected financial issues, such as:

- inability to pay your medical bills
- lack of funds to meet daily needs
- lack of transportation to and from the transplant facility
- lack of housing for out-of-town patients and family members
- re-employment issues

Your social worker can help you find resources to manage your issues and decrease your anxiety. Information you share with your social worker will remain confidential, as long as it is not vital to your medical care.



#### **Financial Coordinators**

Your transplant financial coordinator focuses on insurance issues related to the transplant surgery and medical follow-up. They are experts in insurance and hospital and physician billing issues who can help with insurance requirements and will coordinate benefits. They might also suggest other ways to manage the costs of your care.

### **Financial Questions to Ask**

- If I have questions or problems, how can I contact you?
- What is the average cost for a pre-transplant evaluation?
- What is the average cost for the transplant I need?
- What is the average cost of follow-up care?
- How much will my insurance cover and what portion do I have to pay?
- When and how will I get billed?
- Do you require a deposit or a down payment for my pre-transplant evaluation or transplant?
   If so, how much?
- What if I have no resources? What are my options for community assistance?
- If I run out of funds before I get a transplant, what actions will you take? Will I be made inactive on the patient waiting list or removed from it completely?
- When can I expect to be billed? What kinds of payment options do I have? Does your hospital have a payment plan?
- Do you know of any local organizations that can assist us with transportation or lodging?

# Hope is patience with the lamp lit. - Tertuillian

### **Transplant Costs**

You, the transplant recipient, are responsible for the following charges (along with your insurance or other coverage):

- candidate testing and evaluation for transplant
- transplant surgery (transplant surgeons, anesthesia, and operating room personnel)
- follow-up care, lab tests and medication

**Note:** The recipient is NOT personally responsible for any costs related to the recovery of deceased donor organs and the donor's medical expenses.

### **Donor Expenses**

All costs associated with the recovery of deceased donor organs or tissue are assumed by the OPO. These charges are then paid by the recipient's insurance. Living-donor medical costs and immediate follow-up also are paid by the recipient's insurance. Non-medical expenses (housing, transportation, etc.) are not covered.

#### **Other Costs**

- food, lodging and transportation near the transplant center if required for the transplant, patient evaluation and other checkups
- lab tests
- physical or occupational therapy and other treatment
- the cost of anti-rejection drugs and other medications, which can easily exceed \$10,000 per year for the lifetime of the transplanted organ
- non-covered medical costs (for example, blood pressure monitors)
- loss of income while out of work
- insurance or Medicare premiums, copays and deductibles

### **Developing a Financial Plan**

### **Financing your Transplant**

The first step in developing a financial strategy is to figure out how much of your costs insurance will cover. Your financial coordinator or social worker can help. Then you can begin to explore other funding sources. Most patients use a combination of sources.

#### **Private Health Insurance**

Even if you have health insurance, the terms and extent of coverage vary widely. Read your insurance policy carefully to see what types of transplant costs (lab tests, medications and follow-up appointments) are covered. If you have questions, contact your employer's human resources department or contact your insurance company directly.

Some insurance questions to consider:

- Is my transplant center in-network with my insurance company?
  - o If my transplant center is out-ofnetwork, do I have an out-of-network benefit for transplant?
- What deductibles will apply?
- What are my co-payments for
  - o doctor visits?
  - o hospitalizations?
  - o medications?
- Does my plan require prior authorization?
- Who needs to get prior authorization?
- Does my plan have a lifetime maximum or "cap" for transplant services?
- Do any pre-existing-condition requirements apply to coverage for a transplant?

Regardless of how much your insurance covers, you are responsible for any unpaid costs, unless you have made other plans. Keep up with your insurance premiums so that you do not lose your coverage. Include these costs in your financial strategy.

#### Medicare

Medicare is a federal health insurance program available to people:

- age 65 or older and those under age 65 with certain disabilities
- of any age with permanent kidney failure ("end-stage renal disease" or ESRD)

Medicare, like most private insurance plans, does not pay 100% of your costs. In most cases, it pays hospitals and health providers according to a fixed fee schedule, which may be less than the actual cost. You must pay deductibles and other expenses.

To receive full Medicare benefits for a transplant, you must go to a Medicare-approved transplant program.

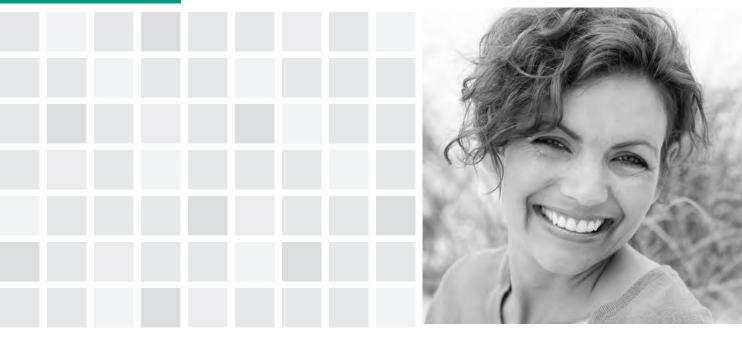
If you have questions about Medicare eligibility, benefits, or transplant programs, contact your local Social Security office, visit www.medicare. gov, or call 1-800-MEDICARE (1-800-633-4227 / TTY: 1-877-486-2048).

For more resources, visit www.transplantliving.org (Before the Transplant>Financing a Transplant>Financial Resources Directory).

First we make our habits; then our habits make us.

- Charles C. Noble

### SECTION 5



**Life after Transplant** 

### **Life After Transplant**

Every transplant candidate has a dream of what life will be like on the day after transplant surgery. Those dreams can be both thrilling and frightening, so it helps to know what you might expect.

Transplant recipients will tell you two truths: no two transplants are alike, and a transplant is not a cure. Even after your transplant, you may still have a serious chronic illness that must be closely managed.

### **After Transplant Surgery**

After dealing with the effects of long-term illness (lack of energy, shortness of breath), you may feel euphoric when you awake after surgery to find those symptoms gone. Anesthesia often protects you from post-surgical pain for a short time. Follow your team's pain management instructions to make the overall experience as comfortable as possible.

Transplant is major surgery. It may take time to get back to eating normally, moving around and managing your own care. Don't be discouraged. Most recipients report feeling much better just after transplant. Others take longer to feel better, move around and manage their care. Remember that you now have a functioning organ, which gives you a new lease on life.

### **Going Home**

There is no set time for people to go home after transplant. Here are some factors that can affect how soon you will be able to go home:

- The organ that you received (kidney, liver, lung, etc.); recovery for each organ is different
- Your overall health and ability to take care of yourself before your transplant
- Your lab results and overall health status
- Other chronic health problems
- Availability of support at home

After you are discharged from the hospital, here are a few things to expect.

#### **Medications**

Immunosuppressants, or anti-rejection medications, "hide" your new transplanted organ from your body's immune system to protect it from being attacked and destroyed. Take these and other medications just as your doctor prescribes. Talk to your transplant team before making any changes. You will take immunosuppressants for the lifetime of your transplanted organ. Visit www.transplantliving.org (After the Transplant>Medications) for more information.

You also will take other medications to help the immunosuppressants to do their job, or to control side effects. You may need medications for other chronic health problems. In the beginning it seems like you are taking lots and lots of medications, but this likely will change as you recover.

### Every day holds the possibility of a miracle.

– Elizabeth David

#### **Doctors and Wellness Visits**

In the first few months after transplant, you will visit with your transplant team frequently to be sure that your new organ is functioning well and to help you develop good health habits. A big part of keeping your new organ healthy is keeping your body as healthy as possible. Keeping all wellness appointments will help you meet this goal.

- Keep up with other check-ups—dental, gender specific, eye exams.
- Monitor your blood pressure, weight and cholesterol.
- Get all recommended health screenings on schedule.

### **Get Moving**

Every person is different. The amount and type of activity you can handle after your transplant depends on your age and health. The goal is to get moving. For one person, "moving" may mean sitting up in a chair. For another, it might mean walking several times a day.

If moving is challenging, your transplant team may prescribe physical rehabilitation to get you started in the safest manner possible. Rehabilitation may be done at home or at an outpatient facility. Sometimes a stay in a rehab facility is necessary. Don't be alarmed if you need rehab. It is one resource your transplant team uses to get you back to a more normal life. Once you have found your "new normal," keep exercising so that you stay as fit as possible.

### **Lifestyle Changes**

You may be able to return to activities you gave up because of your illness. Many people return to playing sports, gardening or hiking. Remember, don't start or resume any activity without getting approval from your transplant doctor first.

After transplant, you may need to change your diet. You may need to drink more water. You'll need to get laboratory tests done frequently. If you are a kidney recipient, you won't go to dialysis anymore. This is a good time to curb cigarette or alcohol use.

#### Back to Work or School

Many people go back to their jobs or classes, or even start new careers based on insights gained during their transplant journey. Vocational rehabilitation helps people who have been out of the workforce because of a disability by retraining them or providing adaptive equipment that allows them to go back to work. Ask your transplant social worker about vocational rehabilitation services in your state.

### **Physical Changes and Challenges**

It is common to have at least one episode of rejection, which is when your body attacks the newly transplanted organ. "Rejection" is a very scary word, but it doesn't always mean you are losing your transplanted organ. Your transplant team knows how to manage rejection with medication. After treatment, most people live normally with their transplanted organ.

Other complications may require re-hospitalization. Going back into the hospital allows you to be properly monitored and treated so that you can get healthy quickly.

### **Life After Transplant**

Many transplant patients experience annoying short-term side effects from the anti-rejection medications—hair growth, acne, mood swings and weight gain, to name a few. Symptoms diminish as the initial high dose of medications is tapered down in the early months after transplant. Talk with your transplant team about your concerns.

### **Relationship Changes**

While you were ill, family members and friends may have managed many things for you or helped you with your care. After your transplant, you may be able to handle more of these issues on your own. As you change and feel better, everyone will have to adapt their thoughts and behaviors to a new you.

Before your transplant, sexual activity may have been out of the question. Now that you feel better, you may be ready to reconsider. Talk to your transplant team before resuming sexual activity. Open communication will be important to maintaining good relationships.

#### Take It All In

It may be difficult to absorb all that has happened. If you received an organ from a deceased donor, you may feel sad or guilty because someone else died so that you could have a chance at a healthier life. Take advantage of available emotional and spiritual supports to help you understand how you feel about your transplant.

### Communicate with Your Donor or Donor Family

When you are ready, you may want to express your feelings to or about your donor. If you received your organ from an unknown deceased donor, you could write a letter to the donor's family. Your transplant team can help get your letter or other communication to a living donor or donor family.

### Pay It Forward

Your transplant is an awesome gift. You can never truly repay your donor, but you can honor the sacrifice that was made:

- Take good care of yourself and your new organ.
  - Take your medications.
  - o Exercise.
  - o Keep up with wellness checks.
- Get involved in promoting organ and tissue donation in your community so someone else can receive the same wonderful gift.

See Section 6 for more information about volunteering.

What lies behind us and what lies before us are small matters compared to what lies within us.

- Ralph Waldo Emerson

### **SECTION 6**



## **Promoting Organ and Tissue Donation in Your Community**

### **Promoting Organ and Tissue Donation in Your Community**

As you know, the organ shortage is the reason why patients must wait for transplants. Help promote the cause by urging others to sign up to become an organ and tissue donor and to share their decision with loved ones.

Taking these steps will help save more lives. Most states have a donor registry. In nearly every state, these decisions become binding after death.

Today, there are more than 100 million registered donors. Many of them signed up because people like you encouraged them to do so.

Contact your local organ procurement organization (OPO) to volunteer. Many OPO programs provide speaker training to help you learn how to tell your story, and to connect you with civic groups, health fairs or other opportunities. To find your local OPO, call UNOS at (888) 894-6361 or visit optn.transplant. hrsa.org (Members>Find a Member).

### **Donation Facts and Figures**

- People should never prejudge their ability to donate. Potential donors can be from any age and health status. Many factors are used to determine which organs & tissue can be donated.
- Donated organs (kidneys, livers, hearts, lungs, pancreas and intestines) save lives. Tissue is needed to replace bone, tendons, and ligaments. Corneas are needed to restore sight. Skin grafts help burn patients heal and can also save lives. Heart valves repair defects and damage. Today, hand and face transplants improve the lives of those in need.
- All major religions either support organ and tissue donation as an unselfish act of charity or leave it to each person to decide. Some even say it is a "sin" to not donate organs when possible.
- There is no cost to the donor's family or estate for organ and tissue donation. The donor family pays only for health care before death and funeral expenses.
- It is against the law to buy or sell organs and tissue in the U.S.
- People can donate one of their kidneys, or part of a liver. Visit www.donatelife.net for more information.
- More than 12,500 deceased donors made more than 39,000 organ transplants possible in 2020.

- In addition, there were more than 5,700 transplants in 2020 from living donors. There are about 39,000 tissue donors and 85,000 cornea donors annually, who make more than 2 million tissue and corneal transplants possible.
- More than 100,000 men, women, and children are waiting for lifesaving organ transplants. Sadly, an average of 17 people die each day because they didn't get a transplant in time.
- One organ and tissue donor can save and enhance the lives of up to 50 people.

### The Organ and Tissue Donation Process

- Organ and tissue donation becomes an option only after all lifesaving efforts have been made and death has been declared.
   Donation does not interfere with medical care.
- Consent for donation is confirmed by checking the state registry or when the donor's family provides written consent.
   Loved ones can participate in the process by providing a medical history.
- Surgery is used to recover donated organs and tissue. The body is always treated with great care and respect.
- Donation will not delay or change funeral arrangements, and will not prevent an open-casket viewing.

### **Who Receives Donated Organs and Tissue**

The UNOS national computer network matches organs by blood type, body size, tissue type, medical urgency and other factors. Tissue is distributed based on patient need, availability and medical criteria.

### **Tell Your Story**

When you talk about organ and tissue donation, here are four points to get across:

- 1. Transplantation works! Your own story is proof.
- 2. It is up to each person to decide to become an organ donor.
- 3. Urge people to take action and sign up with their states' donor registries.
- 4. Registration is legally binding, but telling family members is still a good idea.

# Want to Learn More About Organ Transplantion?

### Shop the UNOS online store

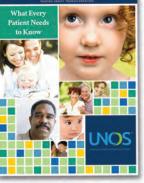
Many patient resources are free-of-charge, including customized transplant information kits and organ-specific brochures.

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