Living: A Giving
ACTS Act

About
Choices in
Transplantation
&
Sharing

Another option…

Although African Americans make up only about 13% of the national population, they comprise nearly 35% of national kidney waiting list candidates.

The average African American kidney transplant recipient waits 5 years for a deceased donor after being placed on the waiting list.

But there is another option:
Living Donor Transplant

On average, kidneys received from living donors can last up to 8 years longer, and wait times can be as short as a few months.

Emory Transplant Center

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Living ACTS

About Living Donation

There are over 111,000* patients on the United Network for Organ Sharing (UNOS) national transplant waiting list. Because of the gift of organ donation, around 28,000* patients receive a transplant every year. However, the need for transplantation far outweighs the demand. Organ donation and transplantation not only save lives, they enhance lives and give people a better quality of life. People can choose to become an organ donor after death or decide to make a living donation to enhance the life of a loved one. Family members, friends, and even strangers can serve as living donors and give a normal, healthy life to another.

The choice of living donation is a personal one. This booklet will help provide you with some basic information about living donation and transplantation. It also includes comments from kidney experts, actual donors, and recipients about their experiences with living donor transplant. We hope that it is informative and addresses any questions that you may have as a transplant candidate or a potential organ donor.

**Source: OPTN.transplant.hrsa.gov, as of 7/7/11*

> *"Transplantation is the best option because it affords the patient…the opportunity to have as close to a normal and healthy lifestyle as they enjoyed before they had kidney problems."*
>
> *—Dr. Janice Lea, Nephrologist*

Why is it important for African Americans to talk about donation?

Because organ donation saves lives!

Today, in the U.S., African Americans are especially hard hit by the shortage of organs.

- About 35%* of patients on the kidney transplant waiting list are African Americans.
- Of all of the African Americans on the national transplant waiting list, 93%* are waiting for a kidney.

Because each day African Americans die waiting for an organ transplant!

- More than 111,000* people are waiting for organ transplants.
- Every 10 minutes a new name is added to the national waiting list.

Because education is the key to saving a life!

*Source: OPTN.transplant.hrsa.gov, as of 7/7/11

Types of Organ Donation

There are two common types of organ and tissue donors:

Living Donors: A family member, friend, or unknown donor who gives a kidney, or part of a liver, lung, or pancreas; bone marrow, or blood to another person.

Deceased Donors: A person who has suffered "brain death" or "cardiac death" and who has donated their organs for transplantation.

What Organs Can be Donated?

Deceased Donation	Living Donation
Heart	- - - - - - - - -
Liver	Segment of the liver
Lungs	Lobe of a lung
Kidney	Kidney
Pancreas	Portion of the pancreas
Intestines	Portion of the intestine

> *"{My sister} decided to be a living donor. She was tired of me being sick all the time."*
>
> *—Sofia, kidney recipient*

Who can be a Living Donor?

Becoming a living donor is a voluntary decision that involves careful consideration. It is important to educate yourself about the donation process.

Making the Decision

While many people are willing, not everyone can be a living donor. Potential donors must be:

(1) over the age of 18,

(2) willing to donate,

(3) physically fit,

(4) in good general health; and

(5) free of diabetes, cancer, kidney disease & heart disease.

Testing

The potential living donor must undergo a blood test to determine if blood type is a match to the recipient. If blood type is compatible, the next steps are a medical history review, followed by a complete medical and psychosocial examination.

Living ACTS

Steps for Becoming a Living Donor

1. Potential Donor Calls the Transplant Center

A Medical-Social Interview is done over the telephone to find out more about the potential donor's own medical history, as well as the donor's family medical history and the donor's social history. This is to see if there are any issues that might prevent him/her from donating.

2. Packet with Questionnaires is Sent to the Donor

A Follow-up packet is sent to the donor's home to get more information about the person's medical history. Some questions from the Medical-Social Interview may be repeated to make sure the center has the correct medical information.

3. Transplant Center Sends a Blood Kit to the Donor

A Blood Kit will be sent to the interested donor after the packet has been received by the center. This is done to see what the donor's blood type is and if it is compatible with the intended recipient. A second test, called a **cross-match**, will also be done, to determine if the recipient will be able to receive the kidney from this person.

"And so the good news is that when people went in and tried to help me, they found out things that they didn't know about themselves. And now they're taking care of things that they might have not known about for a long, long time … because they were willing to give the gift of life…"

—Caroline (CJ), kidney recipient

4. Pre-Evaluation Testing

A 24-hour urine collection will be done to test the donor's kidney function.

Depending on the donor and family medical history, a second test may be needed. For example, if the donor has a family history of diabetes, a test will be done to make sure the donor does not have diabetes. If s/he does, the person cannot be a donor because diabetes is the leading cause of kidney disease.

5. Evaluation

The donor will be brought into the Transplant Center to do more blood work to see if s/he can be a donor, as well as a chest x-ray, EKG, and a scan of the person's abdomen to see if everything is normal with the shape and structure of the kidney. The donor and patients can also ask transplant staff questions about the donation process and transplant admission.

Final tests are done to make sure the donor has enough kidney function to be able to live with a single kidney, and to make sure the risk is low for kidney rejection by the recipient.

6. Transplant

The donor and patient transplant is scheduled after final clearance.

Types of Living Donor Transplants

Living Donation includes many types, but the three most common are:

1. **Directed Donation** is a donation between a donor and recipient who know each other. There are usually two types of donors:

   A. Biologically related donors can be siblings, parents, and adult children.

   B. Unrelated (or non-biological) donors can be persons who share a connection with the recipient such as a spouse, or distant family member. They can also be friends, neighbors, in-laws or co-workers who've learned of the need of a transplant candidate.

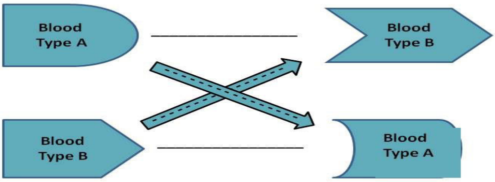
2. **Non-directed donors** are persons who make a living donation to someone they do not know. This is also referred to as "altruistic donation".

"Our lives have been so much better...I got my sister back!"

—Pam, kidney donor

3. **Conventional Paired Donation** is an exchange between two kidney donor/recipient pairs whose blood types are not a match for their intended recipient. Instead, the two recipients trade donors so that each can receive a kidney from a donor with a matching blood type:

Matching Blood Types



Donor Candidate Blood Type	Potential Recipient Blood Type
O	O
A or O	A
B or O	B
A, B, AB, O	AB

The Transplant Process

While not a cure, organ transplantation is a therapy that could save or enhance a person's life after disease or accidental situations have caused end-organ failure.
The transplant process has multiple phases:

Phase 1: Evaluation and Referral

Evaluation: The transplant team's evaluation includes a medical, psychiatric, psychosocial and financial assessment.

Insurance Coverage: In most cases, the patient is covered for the majority of transplant costs. Insurance benefit plans can vary. Depending on coverage, private insurance may or may not pay the total cost for transplantation. For those who qualify, Medicare and State Medicaid pay for kidney transplants.

For those patients in need of financial assistance, the transplant program social worker or financial coordinator can assist the patient and his or her family with resource information.

Referral: Once the evaluation is complete and the patient is determined to be a transplant candidate, the transplant staff will place the patient's name and medical information into the UNOS national transplant waiting list database. At the time of the evaluation and again at listing, the patient is told about living donation as an option.

Phase 2: Waiting

Each transplant candidate is unique. For a recipient from a deceased donor, depending on how sick the candidate is and the availability of a suitable organ, s/he may wait a few days or several years for an organ transplant. With living donation, wait time is eliminated, as the donor is already available, pending the outcome of the donor's evaluation.

> *"By educating ourselves about living donor transplant, we are able to make informed decisions about whether living donor transplant is right for our particular situation …"*
>
> *—Erica Henderson, Living Donor Coordinator*

Phase 3: The Transplant

Donor matching: When a donor organ matches a candidate on the wait list, the transplant surgeon and the patient's local physician talk to make sure the patient is in good health to receive the transplant. If so, the organ is accepted and the patient is called to the hospital. For living donation, the compatibility of donor organ to the recipient is determined during the evaluation process for both the donor and the recipient.

Recovery:
After the transplant procedure, the patient will usually stay in the hospital about 3-5 days. For living donor transplant, the donor is typically out of the hospital within 1-3 days.

Phase 4: Follow-up

Therapy:
Patients must take anti-rejection drugs everyday. This therapy begins immediately prior to transplant and continues for the rest of their lives to prevent the body from rejecting or destroying the new organ. Annual cost of these drugs range from $15,000-$20,000. For the donor, pain medication is prescribed after the surgery, and donors vary on their need to take the medication. The need is also short-term, and donors typically need no further pain medication after the first few days.

Additional care: Follow-up visits by the recipient with the transplant program are required. During the first month the patient must have blood work done and be seen by the transplant team 2–3 times/week. Eventually return visits and lab testing will decrease to 1/month, then once a quarter, once every six months and finally, once a year. Donors do not typically need additional care beyond the first month.

Donor Health Effects

Unlike most surgeries, the donor candidate will be in excellent health when undergoing transplant surgery, so the risks that are associated with living donation are mostly due to the surgery itself. Overall, the risks of living donation are low, and the majority of living donors have recovered completely within a few months of the operation. However, this process is considered major surgery, involves the use of anesthesia, and does have associated risks.

Pain

Post-transplant pain and discomfort are normal and very likely for most donors. Fortunately, this pain can be managed through medication.

Surgical Complications

The donor is at risk for temporary problems related to the surgical incision and the possibility of blood clots following the operation. Complications related to the transplant may include infection at the incision site, minor bleeding, allergic reactions to anesthesia, and injury to surrounding organs or tissues.

Reoperation

Some complications may be serious enough to need to go back into surgery; however this occurs less than 2% of the time. Examples include hernia, bleeding, bowel obstruction, and bowel injury.

Readmission

About 2% of donors return to the hospital because of symptoms of nausea, vomiting, bleeding, constipation, diarrhea, and/or infection. Unfortunately death is also a possibility, occurring .03% of the time (that's 3 out of every 10,000 procedures).

"Words cannot express how I feel after this. It was a gift for me as well. I can't describe to you to see her and to see how well she is what it's done for me. I mean it gives your life meaning."

—Kim, kidney donor

Psychological Health

- Mood can often be affected by the relationship between the donor and recipient and what happens to the recipient post-donation.
- Donors often report feeling a sense of happiness, reward, satisfaction and relief because most recipients have significant health improvements.
- Post-donation the relationship between the donor and recipient may change. In some cases, the donor/recipient have feelings of guilt or regret, but most often, living donors report an improvement in their relationship with the recipient.

Long-term Consequences to Health

- The general health and kidney function of living kidney donors is as good as the general population.
- To date, the life expectancy of living donors is better than the general population, likely because prior to donation, they tend to be in excellent health.
- Some living donors may experience a slightly elevated blood pressure and protein in the urine without other symptoms.

Later Need for a Kidney

Research has shown that within 5 years of donation, less than 1% of donors experience end-stage renal disease themselves. If a living donor does need a transplant, the United Network for Organ Sharing (UNOS) gives them an additional 4 points, which places them higher on the waiting list and shortens their wait time for a deceased organ donation.

Potential Risks to the Recipient

Like the donor, recipients of a transplanted kidney face the usual risks of surgery, including the possibility of pain, complications, reoperation, and readmission. However, as a potential recipient, there are a few additional risks to consider.

Kidney Rejection

Sometimes, the recipient's body won't accept a kidney from a donor. This is called ***rejection***. The body is trying to protect itself from something foreign that did not belong to the body. To limit rejection, doctors do several tests to make sure the donor kidney is a good match for the recipient well before transplant surgery occurs. In addition, the recipient takes anti-rejection medication for life, further lowering the risk of kidney rejection.

Returning To/Being Placed on Dialysis

If the kidney is rejected after the transplant, a person may need to return to or be placed on dialysis for some time. Fortunately, this rarely happens, as over 90% of living donor transplant surgeries are successful.

Potential Loss of Healthcare Benefits

Some potential recipients may worry that they will lose disability benefits because they are now able to work. The good news is that the vast majority of people who seek living donor transplant are covered for surgery and medication after the surgery through either private insurance or Medicaid or Medicare. For those who are not already covered, there are resources available to provide financial assistance.

"She gave me the gift of life. I mean, she gave me a second chance at living"

—CJ, recipient

Benefits to the Recipient

While there are risks to living donor transplant, there are also many benefits:

Better Kidney Functioning

A kidney from a living donor provides better kidney function than one from a deceased donor. A donated kidney from a living donor does between 50-80% of the work of two normally functioning kidneys. Dialysis only does between 10-15% of the work of a normally functioning kidney.

Ability to Return to Work

Kidney recipients are also usually able to return to work after transplant. Many recipients report this as being a HUGE benefit of transplant surgery, because they can now earn their own money and not have to adjust their work schedules due to dialysis.

Improved Quality of Life

After the transplant, the recipient will not have to worry about going to dialysis several times a week, or locating nearby dialysis centers before going out of town. S/he will be able to live a relatively normal life, like someone without kidney disease: More energy, improved skin color, and a "second chance at life. "

Living Donation VS.

Living Donation

- Living donation eliminates the recipient's need to wait for a kidney.
- Kidneys from living donors last an average of 21.6 years.
- Living donor kidneys almost always start functioning immediately.
- The transplant surgery can be scheduled at a mutually-agreed upon time.
- Better genetic matches between living related donors and recipients may decrease the risk of organ rejection episodes.
- The recipient has the psychological benefit of knowing the organ came from a loved one or caring stranger.

"The benefit of a living donor...is that living donors are more prepared to be donors. We can find those donors or have those donors come to the hospital at their healthiest state. That makes it more likely that, that organ will be a healthy donated organ and have its best chance of survival."

—Dr. Allen Pickens, Transplant Surgeon

Deceased Donation

Deceased Donation

- The UNOS transplant waiting list includes more than 111,000 people, but only approximately 11% receive a kidney within a year.
- Kidneys from deceased donors last an average of 13.8 years.
- Deceased donor kidneys may not work immediately and could take from a few days to a few weeks to start functioning.
- The time of transplant surgery is dependent on when an organ becomes available, which can occur at any time, day or night, without much advance notice.
- There may be an increased chance of rejection with deceased donor kidneys.
- At the time of surgery, the recipient will not know the donor's identity because of confidentiality policies.

Financing a Kidney Transplant (Potential Recipients)

One question a lot of people have is, "How am I going to be able to afford a transplant?" Below are some ways potential recipients can finance living donor transplant surgery:

Medicare

The good news is that the majority of patients interested in a kidney transplant qualify for Medicare through the End-Stage Renal Disease (ESRD) program or Medicare for seniors. Both types of Medicare cover kidney transplantation when the transplant is being performed at a Medicare approved transplant center.

Other Financing

Private Insurance: Patients who continue to work after being diagnosed with ESRD may have transplant coverage through their employer's health plan. The recipient will need to check with his/her insurance to see if any additional expense are covered.
State Medicaid: For those who are eligible, most state Medicaid program have coverage for kidney transplantation. Coverage, however, is not usually 100% and is dependent on the individual plans. There are deductibles and co-pays. Additionally, coverage for the anti-rejection medications that must be taken may be limited in either the amount of coverage and/or the number of years the medicines are covered.

Finally, agencies are available to teach you the art of fundraising, and assist with setting up fund-raising accounts, provide matching funds, and building resources to support your needs. For more information, check with the transplant center social worker or coordinator for details, and talk to the financial coordinator in the transplant center to help you learn what your out-of-pocket expenses are projected to be.

" For a person who says, 'I can't afford it,' I would say that you know, it will take some work, but putting together all of the resources that are available, if you want to have a transplant, you CAN."

—Sandy McMath, Director of Patient Services

Costs for Living Donation (Potential Donors)

Another concern many people have is the costs to the donor for the transplant. The sections below discuss how donors deal with this concern.

Living Donor Evaluation and Surgery

Medical costs related to the potential living donor's evaluation, the donation surgery and hospitalization are billed to the intended recipient's insurance plan (federal, state, or private insurance). There are living donor assistance funds through the federal government and community resources available to those who qualify to assist with lodging, travel, and in some cases, child-care and other expenses related to the donation. Check with the kidney transplant program's social worker and living donor advocate to learn more.

After the Donation and Transplant

Some employers provide living donor benefit leave that allows donors time off work to donate, without fear of lost wages or loss of employment. Unlike the transplant recipient, donors do not take medications post-donation. The one exception would be pain medication immediately post-transplant to manage any post-surgical pain or discomfort. Most donors are able to function normally within a few days of the donation surgery and over the course of a few weeks are able to return to their pre-donation lifestyle.

After the first post-donation visit with the donor surgeon and team, donors rare released back to their primary care physician for routine healthcare and health maintenance. Depending on the transplant program, there may or may not be out-of pocket expenses to the donor. For more information, check with your transplant center.

> *"I would say for the person that is considering giving up themselves to help someone, the reward is greater than you could ever imagine. ..It's a lot better for the person that is giving of the organ and the one receiving the organ."*
>
> *—Greg, kidney recipient*

Starting the Conversation

For a patient considering living donor transplant as an option:

1. **Gather information**. Find out as much as you can about your condition, options available to you, and the pros and cons of each option. It may be helpful to look at materials online to see what others say about managing their kidney disease. You can also contact the transplant center to find other resources for information.
2. **Know yourself and what is important to you.** Think about how you would like your life to be, and determine if getting a transplant is the best decision for *you*.
3. **Work past the fear of telling someone of your need for a transplant.** It is important the other person understands that a kidney transplant is a life-changing *need* that will dramatically improve your quality of life.
4. **Tell as many people as you can of your need.** By telling a large number of people, you greatly increase your chances of finding someone both willing and able to donate a kidney.
5. **Encourage a potential donor to have an open and honest conversation.** Let him/her know what you are going through, present all the information that you have, and encourage the potential donor to lay out every concern he/she may have about donating. By addressing concerns upfront, you can help the person make an informed decision.
6. **If questions or concerns remain, point the potential donor to other sources of information.** However, *do not* pressure the person as it is a very personal decision, and you do not want him/her to feel obligated to donate.

"Really deep down in the back of my mind, I had two, he needed one, we were a match. That was a sign, I mean, you got to go for that sign ...Plus, I've reaped multitudes of rewards by...just donating a kidney to him."

—Paul, kidney donor

For a person considering serving as a donor:

1. **Make an effort to understand what the potential recipient has been going through.** If he or she is on dialysis, try to go to an appointment with them to see the process. It not only helps you better understand their need, but also helps the potential recipient feel you are making an informed decision.

2. **Review information online about different types of treatment, including living donor transplant.** You can also contact the Transplant Center for additional sources of information.

3. **Have an open and honest conversation with the intended recipient.** Talk to him/her about any potential concerns both of you might have, and try to find ways to address them.

4. **Set up an appointment to be evaluated.** Make sure that both of you are making an informed decision (regardless of the outcome). If you are still thinking about donating, contact the Transplant Center to set up an appointment to be evaluated. The staff will be happy to answer any remaining questions you might have, and you can decide whether donating would be the right choice for you.

Important Dates

January

National Volunteer Blood Donor Month

February 14th

National Donor Day

April

National Organ and Tissue Donation/Donate Life Month

August 1st

National Minority Donor Awareness Day

November

National Marrow Awareness Month

National Donor Sabbath: A weekend devoted to encouraging faith communities to spread the word about the importance of organ and tissue donation.

National Give Thanks, Give Life Day (Thanksgiving Day)

Additional Resources

African American Community Health Advisory Committee
www.aachac.org

American Society of Multicultural Health and Transplant Professionals
www.asmhtp.org

Coalition on Donation
www.donatelife.net

Department of Health & Human Services Health Resources and Services Administration, Division of Transplantation
www.organdonor.gov

Department of Health & Human Services, Office of Minority Health
www.omhrc.gov

Gift of Hope Organ and Tissue Donor Network
www.giftofhope.org

National Institutes of Health, Health Information
www.health.nih.gov

LifeLink Foundation
www.lifelinkfound.org

National Minority Organ Tissue Transplant Education Program
www.nationalmottep.org

The Organ Procurement & Transplantation Network
www.optn.org

United Network for Organ Sharing: Organ Donation & Transplantation
www.unos.org

Project Living ACTS:

“About Choices in Transplantation & Sharing”

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