



# LifeChoice

## A guide to living kidney donation



# *Giving the Gift of Life—*

## **What You Need to Know**

*If you are reading this booklet, you are probably a relative or a friend of a person in need of a kidney transplant, and you are looking to find out more about kidney donation and what happens next.*

*Here, you will find information about an important option you may want to consider—that of **living** kidney donation. A living donation is provided when a person (while alive) gives one of his or her own kidneys to someone who needs one.*

*Choosing to donate a kidney and give the gift of life is one of the most meaningful things anyone can do. Becoming a living donor offers a loved one or friend an alternative to remaining on the national transplant waiting list to receive an organ from a deceased donor. While living donation is not for everyone, it can be the closest thing to a miracle that anyone will ever experience.*

*This guide explains certain issues and answers many common questions about living donation. By knowing the facts, you and your family can make an educated decision—one that you can feel comfortable with, now and in the future.*

# Important Information for an Important Decision

## Where do donated kidneys come from?

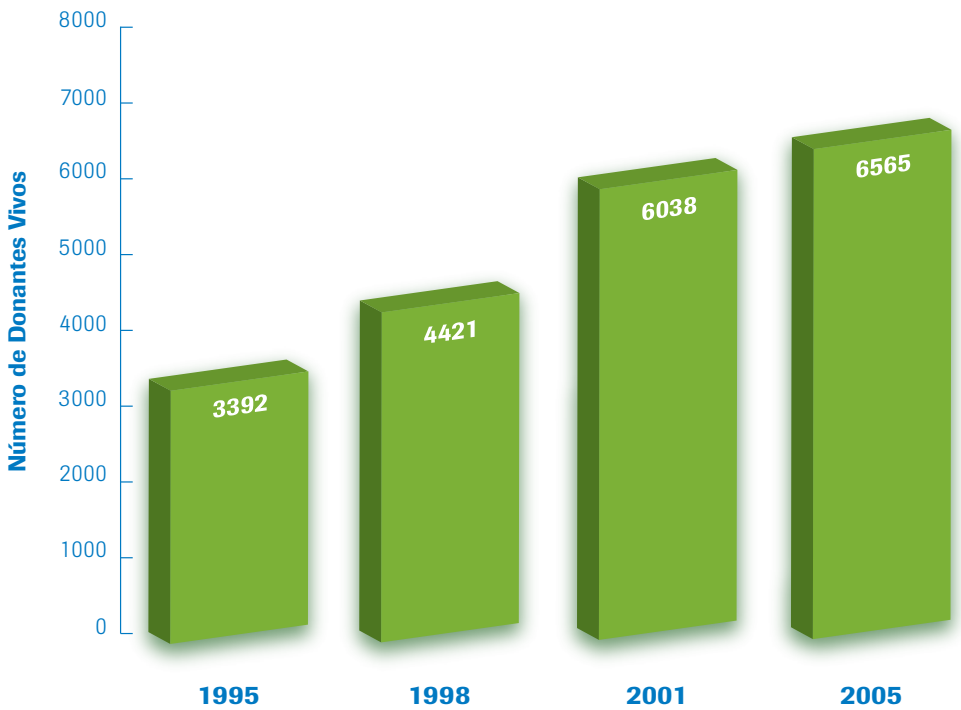
In 2005, there were 16,477 kidney transplants. Most of these organs—9914—came from deceased donors. However, about 6500 of the transplanted kidneys came from living donors.

Receiving a living donation means getting a kidney for a transplant from a living person instead of from someone who has died. Usually this person is a relative, although sometimes it can be a friend, or even someone who is not known to the recipient. A donated kidney from a living donor typically works better and lasts longer than a kidney from a donor who has died.

## Can a person live with only one kidney?

Yes. Most people are born with 2 kidneys. After donating a kidney, a person can live a long and healthy life with just one. The remaining kidney simply grows bigger and takes over the work of both kidneys. However, there are some risks to donating a kidney, which will be discussed later in this booklet. Please see the section titled “What are the surgical risks for the donor?” on page 22.

# Living Kidney Donations by Year



Source: Organ Procurement and Transplantation Network, based on data as of November 3, 2006.





## Who can become a donor?

Not surprisingly, those who are related to the transplant recipient make the best donors. This is because their blood and tissues are usually similar (this is called “matching”). Living donors can be:

- Brothers and sisters
- Parents
- Aunts and uncles
- Children (must be 18 or 21 years of age or older, depending on the transplant center’s requirements)
- Cousins

Living donors who are not blood relatives but have a compatible blood type can also match, including:

- Spouses
- Close friends
- Coworkers
- Altruistic individuals (sometimes known as “Good Samaritans”)

## Nonrelated living donors

### **Altruistic Living Donor**

**Programs** match potential donors who believe in acting for the good of others (also known as “Good Samaritans”) with recipients awaiting transplantation. There are 2 types of altruistic donation: directed and nondirected. In directed altruistic donation, the potential donor may know of someone who needs a kidney, possibly through their community. In nondirected altruistic donation, a donor offers a kidney to a person on the waiting list whom he or she does not know.

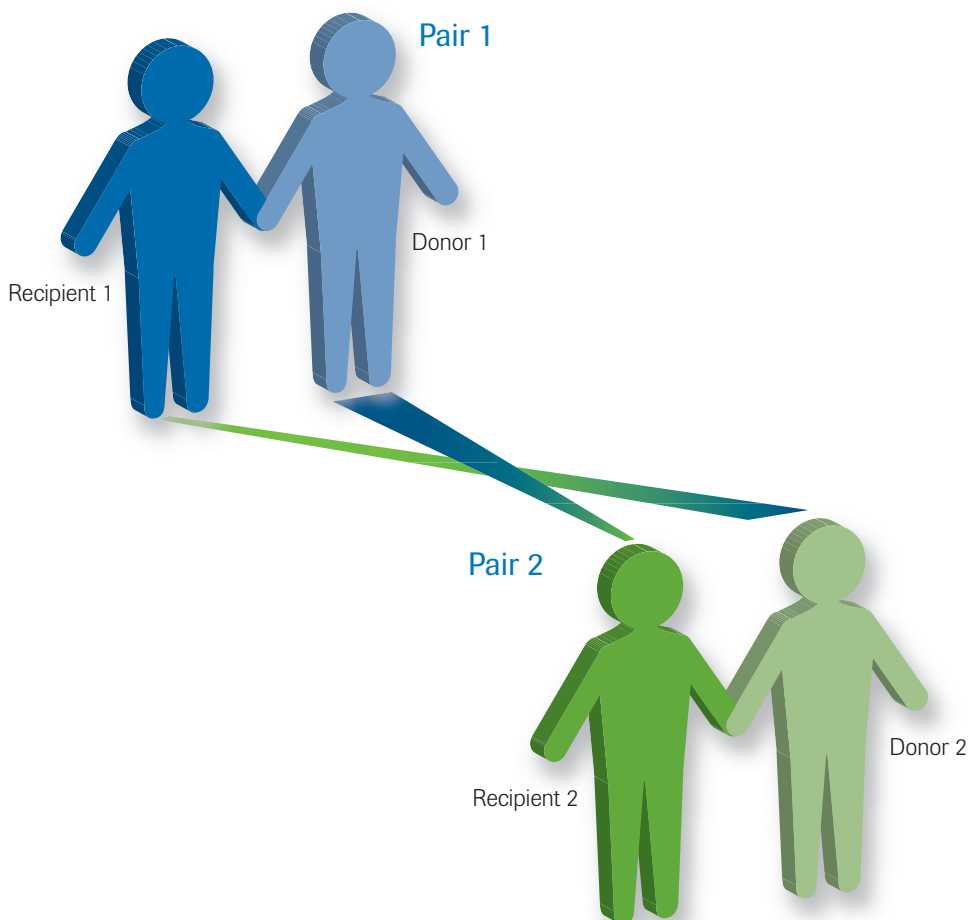
Many people consider altruistic living donation to be a unique and special gift. More information about becoming a donor is available at [www.LivingOrganDonor.org](http://www.LivingOrganDonor.org) and [www.LivingDonorsOnline.org](http://www.LivingDonorsOnline.org).

If the donor’s blood type doesn’t match, or isn’t compatible with, the blood type of the potential kidney transplant recipient, there are other options. There are programs called **Paired Donation** or **Paired Exchange** that help patients get a kidney even though the blood type of their prospective donor is incompatible. It is important to check if this is an option at your center.

In a paired kidney exchange, a kidney from such a donor is matched and transplanted into the recipient of a second donor-recipient pair (also whose blood type is incompatible), and vice versa. The transplants are performed simultaneously.



## Paired Donation



In living kidney paired donation, there are 2 pairs of donors and recipients. In the first pair, Donor 1 is not compatible with Recipient 1, and in the second pair, Donor 2 is not compatible with Recipient 2. However, the good news is that Donor 1 is compatible with Recipient 2 and Donor 2 is compatible with Recipient 1. At this point, complete evaluations are done by the transplant team for a matched exchange with each willing donor-recipient pair, and the surgeries are scheduled to take place at the same time.



## Why would someone want to consider living donation?

There are several important reasons why living donation may be a good option for certain people.

**Better success rates**—A kidney donated by a blood relative is usually a better match, with a better chance for success. Both the donation of a living kidney and the actual transplantation can happen almost simultaneously with very little loss of vitality to the organ, because it has not been outside the body for long.

These kidneys usually have a longer life span, and begin to function while the recipient is still on the operating table. Furthermore, when well-matched to the donor organ, the recipient is often able to take lower doses of antirejection medication.

**Shorter waiting time**—For some transplant candidates, a living donation can be lifesaving. Typically, there is about a 3- to 5-year wait for a deceased donor kidney. Recent

data show that approximately 1 out of 20 patients die each year from kidney disease as they wait for a donor kidney.

**More time to prepare**—While on the waiting list for a deceased donor kidney, one never knows when an organ will become available or when the surgery will happen. With a living donation, surgery can be scheduled ahead of time, avoiding the stress and uncertainty of being on the waiting list. Living donation also helps to avoid the potential complications of prolonged dialysis. Being able to schedule surgery in advance means both the recipient and the donor can prepare to be in the best of health, both physically and mentally.

**Free up the kidney waiting list**—As not all transplant patients are candidates to receive a living kidney, living donation allows more people on the waiting list (who need a deceased donor) to receive an organ and to have their kidney transplant sooner.



## Why don't more people consider living donation?

Most transplant candidates don't explore the possibility of living donation for the following reasons:

- They don't know it is an option
- It seems too complicated
- They are afraid to ask someone they care about to donate a kidney

- They are concerned that it would affect their loved one's health

Once you learn more about it, living donation will probably seem like a very good idea to consider.

*Choosing to donate a kidney and give the gift of life is one of the most meaningful things anyone can do. While living donation is not for everyone, it can be the closest thing to a miracle that anyone will ever experience.*

# The Facts for Potential Living Donors

## What are some of the first steps?

If you are being considered a candidate for living donation, the transplant team will evaluate the following:

**Matching tests**—These tests make sure that the donor’s blood and kidney will be compatible with those of the recipient’s. Blood-typing, tissue-matching and cross-matching will be performed. Blood types need to be compatible, but not necessarily an exact blood type match. Compatible blood types are listed in the table below.

**Health exams**—A number of tests will be done to determine whether the donor is in good health, which may include certain blood tests, kidney function tests, an ultrasound, a urine test, chest x-ray, an electrocardiogram (EKG) and routine screenings, such as a mammogram or a Pap smear (for women); colonoscopy may be performed as well.

**Counseling**—Donors need to understand the surgery and the risks involved and are evaluated for psychological suitability to be a donor.

Compatible Blood Types	
Recipient’s Blood Type	Donor’s Blood Type
O	O
A	A or O
B	B or O
AB	A, B, AB or O







### Availability of time and resources

—A kidney donor will need to take off about 3 to 4 weeks from work if he or she has a desk job, and approximately 6 weeks if he or she performs physical labor. Prospective donors will also need to take some time off from work for pre-transplant screening tests and evaluations. The time needed to recover from surgery will also depend on the surgical procedure that is used to remove the donated kidney. It is important that donors have the proper emotional and physical support to help them recover from surgery.

Finances are a major issue for most kidney donors. Donors need to make financial arrangements that ensure they have adequate funds to cover any unpaid time off from work. This is especially important if they are not covered by an employer who will help them with the needed time off. While potential donor testing and evaluations may be covered by Medicare or insurance, the donor

is responsible for lost wages from time out of work (this may be covered by sick leave), travel and lodging and child care costs.

Check with your healthcare insurance, as many medical plans cover donors' costs for surgery or hospitalization, and sometimes the donor's medical expenses and hospitalization are covered by the recipient's insurance plan. You may want to look into whether your short-term disability insurance covers kidney donation or whether your state is one that provides a tax credit for donors. These issues can be explored with the help of the person on the transplant team who knows a great deal about these matters, the financial planner/coordinator.

As you can see, organ donation is not a spontaneous event, but a process. The purpose is to make absolutely certain that the donor will not be harmed by donating, and that he or she is healthy and will remain healthy after donation.



It also allows time for the donor to make sure he or she is fully aware of what will be required.

Remember, the donor has the right to change his or her mind at any time, even on the day of the surgery. If the donor should reconsider

the offer to donate a kidney, the healthcare team will respect that decision, and is trained to manage how it is communicated. This also leaves the door open for a change of heart in the future.

## What happens during the donor surgery?

The donor may be asked to come to the hospital 1 or more days before the surgery, and some routine tests are performed to make sure that the donor is still healthy. On the designated day, the donor and recipient will report to the pre-operative area. The donor will be prepared for surgery just as any patient would be, including having his or her temperature and blood pressure taken, and having an intravenous (IV) line started.

During the donor's surgery, the following will happen:

- The donor is given anesthesia and “put to sleep”
- The healthy kidney is removed along with the artery, vein and ureter (arteries and veins carry blood to and from the kidney, and the ureter carries urine from the kidney to the bladder)
- The surgery may last 2 to 3 hours

## What are the surgical options?

Laparoscopic surgery is being performed at many transplant centers. Laparoscopic nephrectomy is a specialized, high-tech, less invasive procedure in which the surgeon makes a few small incisions (also called “ports”) around a central incision near the belly button. A scope with a tiny camera on the end is inserted through one of the ports and transmits an enlarged microscopic image to a video screen to guide the surgeon.

The left kidney is usually removed for anatomical reasons. The opening through which the kidney is removed is less than one third the size needed in a conventional “open” nephrectomy (see the section on Conventional nephrectomy on page 21). The laparoscopic procedure may vary from center to center.







## What are the advantages of a laparoscopic nephrectomy?

- A shorter hospital stay
- A quicker recovery period, and less time off from work
- Usually, pain relievers are needed for a shorter duration
- Better cosmetic results

## What happens after a laparoscopic nephrectomy?

The average hospital stay for a donor is 2 to 4 days. Donors should understand that there will be pain right after the surgery, for which medication will be available. Over time, the pain will ease and become less severe, but it may linger for several weeks after the surgery.

Donors may be able to eat right after the procedure, but some people may experience a temporary loss of appetite. Donors will not

be able to do any heavy lifting or physically demanding activities for several weeks. In fact, donors should be prepared to “take it easy” for a few weeks.

## Conventional nephrectomy

The other, older technique, called conventional or “open” donation surgery, requires a single incision of about 2 to 10 inches on the side and abdomen, or the side and back. As in most conventional open operations, the incision requires cutting through 3 layers of muscle, and therefore may leave the donor in more pain, with a larger scar and with more recovery time than a laparoscopic procedure would.

The donor should discuss his or her surgical options with the surgeon and transplant team to become aware of the potential advantages and drawbacks of the particular procedure offered to him or her.

## What are the surgical risks to the donor?

Living donors should fully understand the important risks involved in donating an organ. Even though they have to be in good health, there are always some risks as with any surgery. Some of these may include:

- An allergic reaction to the anesthesia
- Pneumonia
- Blood clots in the lung
- Infection of the wound or urinary tract
- Bleeding—rarely a blood transfusion is needed
- Death—the rate of this is extremely low, 0.03% (that is, 3 out of every 10,000 procedures)

## What are the benefits of being a living donor?

Donating an organ so that another person can live is in itself a very rewarding experience. It's one of the few chances that most people ever get to be a real hero. Even with the risks and sacrifice involved, most living donors are positive about their decision and say it is one of the most important things they have ever done.

Many living donors, for example, say that they feel better about themselves after donating. Some say that they feel that their life has a higher purpose and that they benefit from the improved health of the recipient. Donating can also create stronger ties between family members. Most spouses say donating an organ to their partner is just a natural response to the love they share.





## Issues to discuss with the transplant team

The risk of dying from the donation surgical procedure is extremely low, but if you are concerned, talk about it.

Rarely, a donor may need a blood transfusion. You may want to talk about this with your surgeon.

During a laparoscopy, it is sometimes necessary to change to an open nephrectomy procedure,

usually because of a complication that could not be determined in advance. The rate of this happening is typically very low, about 2% to 3%, but you may want to discuss this with the team.

As always, the transplant team is there for you and will answer any questions you may have.

## Life after donation

Before the surgery, most of the focus is on the living donor. He or she receives a lot of attention and is treated very well. After the surgery, however, the focus changes to the kidney recipient—helping them recover and making sure his or her body doesn't reject the new organ.

The shift in attention may be hard for the donor and the donor's family, causing a feeling of abandonment. This is natural—but donors need to remember that they made the most selfless gesture anyone can make, and possibly saved a life.

Living with 1 kidney should not cause long-term problems for a donor. There are some considerations, however, which all living donors should be aware of, which may include:

- A slightly increased risk of high blood pressure
- A slightly increased incidence of kidney failure
- A slight risk of developing a disease in the remaining kidney
- A risk that you may become depressed after the surgery, requiring the use of prescription antidepressants for a period of time

You may be advised not to engage in contact sports to reduce the chance that the remaining kidney could become seriously injured. Please talk to your transplant team regarding any questions you may have.

Donating a kidney does not affect a woman's ability to have a normal pregnancy and childbirth, and, in most cases, has almost no effect on the long-term health of the donor.



## *The Other Perspective—*

# What a Potential Kidney Recipient Might Be Thinking

### How can I ask someone for a kidney?

There's no question about it, asking a relative or friend for a kidney isn't easy. Donating a kidney does involve a sacrifice, but the recipient will probably be pleasantly surprised at how many people are willing to donate once they understand what's involved.

### What if my potential donor feels uncomfortable?

This is a big concern for many recipients. They worry about their donor, especially if it is a friend or relative. For most living donors, there is no question that they want to donate, particularly when it comes to family. It is important to reassure the recipient of your commitment to donating.

### What if my potential donor feels he or she just can't go through with the donation?

No one should feel pressured to donate a kidney. The recipient should be aware that it is a potential donor's right to say "no," no matter what the circumstances. This just needs to be shared with the transplant team, who can make it easier for possible donors to decline by protecting their privacy. All anyone has to know is that certain people are good candidates to be living donors and others are not. The reasons why can be kept a private matter between the potential donor and the transplant team.



## What if the transplant doesn't work?

This is probably one of the biggest fears that everyone, both donors and recipients, have about living donation. There is always a possibility that this may happen, even though all the tests were done to ensure a successful transplant. Should this be the case, it is important to know that the recipient

may still be a candidate for another transplant, either from a living or deceased kidney donor.

When a transplant does not turn out as expected, both the donor and recipient may feel bad and blame themselves. However, donors should remember that they did the best they could do, and recipients should know that it's not their fault.

# The Next Steps for You

It is helpful to communicate with the transplant team as well as with your family doctor. The transplant team is experienced in this area and can help you as a potential donor make a decision based on the most complete and accurate information possible. Your family doctor is a great asset because he or she knows you best and will have good advice to share with you.

Remember—be positive and take care of yourself. Make sure you

and your family explore all the possibilities as you make important choices about becoming a living kidney donor.

For more information, the Transplant Patient *Partnering Program*™ consists of educational materials available for you and your family, to help at each stage of the transplant process. Ask your transplant coordinator about these valuable brochures.







# Important Resources

The following is a partial list of where you can turn for support, information and education.

## American Transplant Association (ATA)

1-800-494-4527

[www.americantransplant.org](http://www.americantransplant.org)

## National Foundation for Transplants (NFT)

1-800-489-3863

[www.transplants.org](http://www.transplants.org)

## Children's Organ Transplant Association (COTA)

1-800-366-2682

[www.cota.org](http://www.cota.org)

## National Kidney Foundation

1-800-622-9010

[www.kidney.org](http://www.kidney.org)

## Donate Life

[www.organdonor.gov](http://www.organdonor.gov)

## Transplant Living

1-888-894-6361

[www.transplantliving.org](http://www.transplantliving.org)

## Living Donors Online!

[www.livingdonorsonline.org](http://www.livingdonorsonline.org)

## Transplant Recipients International Organization (TRIO)

1-800-874-6386

[www.trioweb.org](http://www.trioweb.org)

## Living Organ Donor.org

[www.livingorgandonor.org](http://www.livingorgandonor.org)

## Medline Plus

[www.nlm.nih.gov](http://www.nlm.nih.gov)

## TransWeb

1-734-998-7314

[www.transweb.org](http://www.transweb.org)

## United Network for Organ Sharing (UNOS)

1-888-894-6361

[www.unos.org](http://www.unos.org)



# THE TRANSPLANT PATIENT



## *Partnering Program™*

The Transplant Patient *Partnering Program™*  
consists of educational materials provided by  
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