

the ultimate gift:
sharing life

A Guide to Living
Donor Kidney
Transplantation

UK Transplant Center



UKHealthCare



UK Transplant Center

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..... **The purpose of this booklet** is to help you and your family understand what it means to be a living donor for a kidney transplant. We will discuss this with you personally, but we also want you to have something you can take with you and read. Please keep this as a reference.

Thank you for considering becoming an organ donor. Donating a kidney is a **voluntary** decision by a family member or friend of the potential recipient. It may also be the choice of a caring stranger.

A living donor advocate will work with you through each step of the process. The living donor advocate will promote your best interests regarding living donation and assist you in obtaining and understanding information regarding the evaluation process, surgical procedure and follow-up. The donor advocate is not involved with the potential recipient evaluation and remains independent of the decision to transplant the potential recipient.

introduction

to **KIDNEY** transplantation

- 1. Deceased donor kidney transplant.** In this case, a kidney is removed from a person who has died suddenly and who has told family members that he or she wants to be an organ donor after death. Deceased donors usually have died as a result of an accident or stroke. After the person has been declared brain dead, the kidneys are surgically removed and kept in a cold, sterile fluid until a suitable recipient (a patient who needs a kidney) is found—preferably within 24 hours.

The United Network for Organ Sharing (UNOS) computer registry chooses a recipient based on the length of time the person has been on the waiting list and how closely the person's proteins (antigens) match the donor's. Patients waiting for a deceased donor transplant may have to wait several years for a kidney because there are not enough deceased donor organs to meet the growing need. A person may be moved to the top of the list if the recipient and donor are a "Six Antigen Match," now called a "zero mismatch." It is rare that a "zero mismatch" kidney becomes available for anyone.

There are two types of kidney transplants. The difference is based on the source of the donor kidney.

2. Living donor kidney transplant. In this type of transplant, a person chooses to donate a kidney to the recipient while the donor is still alive. Living donation can reduce a recipient's waiting time to weeks rather than years. The donor is usually a brother, sister, parent, spouse, adult child or a very close friend of the recipient. This type of transplant requires planning. The procedure is scheduled when both people are in good health and at a convenient time for both.

About half of the transplants performed in the United States come from living donors. Living donation has become the gold standard for kidney transplantation in the United States.

Markita Hodge recently graduated from high school and wants to pursue a degree in physical therapy. She received her transplant from her father Tim in 2006.



What are the advantages of a living donor transplant?

Kidney donations from a living donor tend to be more successful than those from a person who has died. Some of the reasons are:

- **Shorter waiting time.** The waiting time to receive a deceased donor kidney transplant is getting longer. A patient may wait one to three years or longer before receiving a deceased donor kidney at our program and much longer at other programs. Once the donor and recipient evaluations are complete, we can usually schedule a living donor transplant operation within just six to eight weeks.
- **Living donation is elective surgery.** Living donation can take place at a convenient time for both the donor and recipient. The transplant surgery is scheduled for a time when both the donor and recipient are in the best health for surgery.
- **Living donor kidneys work better.** A kidney from a living donor normally starts working sooner and continues to work better and longer than a kidney from a deceased donor.
- **The donor surgery has improved over the years.** The laparoscopic kidney donor operation is less painful to the donor, and the recovery time for returning to normal activities is much shorter.



“ To live my life without my wife, there would be no life to live. Thank you for giving us the opportunity to enjoy life together.” – Dan Adams

Potential living donors

The living donor kidney transplant is usually performed between close blood relatives. However, a living donor does not have to be a blood relative. A spouse, friend, co-worker or anyone else who is willing to help may be able to donate.

Sometimes a recipient has a willing donor, but the initial screening tests (blood typing and tissue crossmatch) show that they are not compatible. In these situations, the hospital works with an organization called the Paired Donation Network (PDN). By being in this program, you have a chance to match with recipients and donors at other transplant programs. This involves two donors and two recipients. If the recipient from one pair is compatible with the donor from the other pair and vice versa, we can work with the other transplant center to see if you are a match. Simply put, two living donor/recipient pairs will undergo kidney transplants with the donated kidneys being transplanted into the paired recipient rather than the original intended recipient. Please discuss this option with your living donor nurse coordinator.

Teri Adams received a kidney from her husband Dan in June 2007. Both Teri and Dan are working full time and enjoy traveling once again in their spare time.

..... Making the choice to donate

The choice to donate a kidney is *voluntary*. It is normal to have mixed feelings at first. You may not know what to expect. Learn the facts and talk about it with your doctors and family.

Kidney donation will not change your lifestyle in any major way. It does not change the length of your life. It does not increase your risk of getting kidney disease in your remaining kidney. Woman can still have children. In fact, 2 to 4 percent of people are born with only one kidney and can expect to live a completely normal life.

You can change your mind and decide not to donate your kidney at any time during the evaluation process. The transplant team will fully support you, no matter what your decision. If you choose not to donate, we will inform the recipient of your decision, but we will not share the reasons for your choice.

“ If I could give again, I would. Being a donor is the easy part. How great to be able to give someone another chance in life.” – Paula Carrington



“ Six weeks of discomfort and inconvenience is a small price to pay to save a life. My decision to donate a kidney was more about common sense than anything else. The reward-to-risk ratio was a no-brainer.” – Larry Smiley

Medical expenses

All medical expenses related to the evaluation of a potential donor, the transplant surgery and hospitalization, and the immediate follow-up care of the potential donor are paid completely by the potential recipient’s insurance.

As a potential donor, you should not see any bills related to your medical evaluation or hospitalization for this possible transplant procedure. If you are incorrectly billed, call the living donor coordinator and we will correct this immediately. Please provide the original bills to the living donor coordinator. Other costs (such as travel expenses, time off from work and nonmedical bills) are usually not covered by the recipient’s insurance company or by the hospital.

Erik Roby (left) received a living unrelated kidney transplant from Larry Smiley in October 2007. Larry learned of Erik’s needed transplant from Erik’s father, who is a regular at a restaurant in Larry’s management district. Erik is pursuing a philosophy degree and enjoys spending time with his 9-month-old daughter.



the **LIVING DONOR** transplant evaluation

You will have several tests and consultations before donating a kidney. These are done to make sure you are a good donor candidate and that the donation will not harm you. Everything is done on an outpatient basis.

Family conference: During the recipient's transplant evaluation, the recipient and his or her family members will meet with a member of the transplant team. Kidney transplantation in general, and specifics concerning the recipient's history, will be discussed at this time. Both living donor and deceased donor transplants will be discussed in order to inform the recipient of all options available to them. If a potential living donor or donors is/are identified, the *potential donor(s) must call the living donor coordinator*. A brief medical history will be conducted over the phone and a comprehensive medical questionnaire will be mailed to the donor. It is preferable to have the potential donor and recipient come together on the first clinic visit. We will usually be able to interview all people at this initial visit and often make some decisions as to whether to start initial tissue typing right away.

Initial tissue typing tests: After the family conference, the potential recipient and donor(s) will have their blood tested. The initial tissue typing tests are:

- **Blood type:** O, A, B, or AB.
- **HLA crossmatch:** to check for preformed antibodies.
- **Tissue type:** also called "HLA Type."

Blood type: A potential donor MUST have a blood type compatible with the recipient. The following chart illustrates which blood types are compatible:

Recipient blood group	Donor blood group
O	O
A	A or O
B	B or O
AB	A, B, AB or O

For example, if a recipient has blood type “O” and the potential donor has blood type “AB,” then their blood types are INCOMPATIBLE and a transplant between these two will not be performed. If a recipient has blood type “A” and the potential donor has blood type “A” or “O,” then their blood types are deemed COMPATIBLE and they can move to the next stage of testing.

HLA crossmatch: The second initial tissue typing test is called an HLA Crossmatch. In this test, blood from the recipient is combined with blood from the potential donor to check for the presence of preformed antibodies. If these antibodies are present in the recipient’s blood they can immediately destroy the donated kidney. These proteins may develop after blood transfusions, pregnancies or a previous transplant. A “positive” crossmatch test indicates the presence of these antibodies and predicts a rapid rejection of the kidney from that particular donor by that particular recipient. A “positive” crossmatch prevents a transplant from that potential donor. A negative crossmatch is a predictor of a successful transplant, but not a 100 percent guarantee of success. Every potential living donor or deceased donor kidney transplant is checked first by a crossmatch test.

Tissue type (HLA type): The tissue type or HLA type is performed using white cells that are found in your blood. These cells have proteins on them that are the same as those on your kidney cells. Therefore, all that is needed to find out your kidney type is to test a blood sample drawn from your arm.

..... the evaluation, continued

The lab tests the recipient's blood and the donor's blood for six proteins called HLA antigens. These antigens are inherited in sets of three from each parent. In any given family, there are several types of matches that can be found.

If at this point a potential donor is found to be both blood type compatible and HLA crossmatch compatible, then the donor evaluation process can continue. If either of these tests is incompatible, then another person who wishes to donate may be evaluated. If there are no other potential living donors, the recipient will be placed on the deceased donor waiting list.

Medical evaluation: Once the initial tissue typing has been completed and a compatible potential donor is identified, the medical evaluation of that potential donor can continue. This evaluation can take place at the University of Kentucky or, if the person lives far away, many of the tests can be performed closer to the potential donor's home.

The potential donor's outpatient medical evaluation consists of:

1. Additional blood tests.
2. Urine tests, which may include urine cultures, routine urinalysis performed twice.
3. Chest X-ray and ultrasound of the kidneys.
4. EKG (and a stress test if EKG is abnormal).
5. Psychosocial evaluation.
6. Transplant surgeon consultation, including a history and physical exam.
7. Spiral CT.
8. Urologist consultation, including consent for the donor surgery.

.....Types of living kidney **donation** surgery

There are three types of surgery for a living kidney donation: laparoscopic assisted, anterior subcostal approach and the traditional flank.

The latest approach is surgery with the help of laparoscopic instruments (tube-like video cameras), which is also called laparoscopic donor nephrectomy. This surgery has been performed at UK since 1998. The use of laparoscopic instruments allows the incision where the kidney is removed to be smaller and less painful. By using the laparoscopic approach, the left kidney can be removed from an incision below your belly button or the right kidney by an incision below your right front ribs, lower than a typical subcostal (below the ribs) incision. The major benefits from the laparoscopic approach are faster recovery time and less discomfort for the donor.

The second approach is making a 6-8-inch incision below the front of your ribs on either the right or left side. This is called the subcostal approach. Both the skin and muscle need to be cut in order to reach your kidney. This usually heals faster than the traditional flank incision and has less risk of forming a hernia and/or bulge.

The third approach is the traditional flank incision, a 6-8-inch opening on either your right or left side. Both the skin and muscle need to be cut in order to reach your kidney. Sometimes, the bottom rib on that side may be partially removed. Loss of this rib does not cause any disability or additional discomfort.

“ Every time I see the recipient, I think of how good she looks, how she is able to travel freely through life without the concern of dialysis. It is truly a miracle and a blessing.” – Anonymous

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Risks for donors

There are some risks and complications associated with donating a kidney. Most complications are rare, but we feel it is important that you be aware of them.

- ***Numbness around the incision area*** (and down toward your lower abdomen if the traditional flank incision is used).
- ***Lung, wound and urine infections.*** The chance of developing a lung infection is decreased by deep breathing and moving around as much as possible.
- ***A tear or hole in an organ (lung, intestine, spleen or liver).*** These are not dangerous situations when treated properly. The presence and treatment of these do not necessarily make your hospital stay any longer.
- ***Hernia near the incision.*** You should not do heavy lifting for four to six weeks after surgery to avoid this problem. A hernia is more common with the flank incisional approach.
- ***Blood clots in your leg or pelvis, possibly traveling to your lungs.*** Wearing sequential compression stockings and walking early after the surgery help keep this from happening.
- ***Bleeding requiring a blood transfusion.*** This is very uncommon. It normally occurs when the kidney's blood vessels are not in their usual location.



“ I was more than happy to donate a kidney to my son to give him a normal life. It has brought the whole family closer together. If I had another kidney to give, I would.”

– Danny Martin

A kidney donor usually stays in the hospital for two or three days after surgery. The stay will vary depending on each donor's particular case. You can usually return to work in two to four weeks, unless your job requires heavy lifting.

Within a month of the surgery, a donor's remaining kidney takes over 60 percent of the missing kidney's work by growing larger. Research on kidney donors indicates no serious long-term effects from having only one kidney. In fact, there is a small percentage of the population born with only one kidney who live long, happy lives without any ill effects. The most important factors in making sure your remaining kidney keeps working well are to check your blood pressure at least once a year and to keep your weight down to a healthy level to decrease your chances of adult-onset diabetes.

Danny Martin donated a kidney to his son Doug in January 2007. Both Danny and Doug stay busy fishing, working and watching car races. Doug now has the energy to keep up with his children, while Danny stays busy spoiling his grandchildren.



the SURGERY process

Before the surgery

You, as the donor, will be admitted to the hospital on the day of surgery; the kidney recipient will be admitted one day before the surgery. Both you and the recipient will need to come to the hospital approximately seven days before surgery to repeat the crossmatch test. The donor may need to be seen in the preoperative anesthesia clinic on the same day as the additional blood tests are done.

The day before surgery you will be placed on a clear liquid diet as well as a bowel prep. Do not eat or drink anything after midnight the night before surgery. In a clinic visit before surgery, the urologist will explain the surgical procedure and its risks. Any questions you have will be answered at this time. You will then sign the operative consent form.

A small flexible tube (an IV) will be inserted into a vein in your hand or forearm. This is used to give you fluids and pain medicine. The IV stays in place for a short time after surgery until you are able to drink. Your physician will determine when the IV can be removed.

The day of surgery you will be given special socks to wear called sequential compression stockings. These stockings help the blood flow in your legs.

After you are put to sleep in the operating room, a small tube called a Foley catheter will be inserted into your bladder. This stays in place one or two days after surgery. This allows us to watch your urine output. A small tube will also be placed through your nose into your stomach to suction out stomach fluid; this is often removed before you are fully awake.

After the surgery

Once you return to your room after surgery you will still be very sleepy. The IV and catheter will still be in place. Your nurse will frequently take your blood pressure, pulse, temperature and measurements of urine output.

- You will need to cough and do deep breathing exercises at least every hour that you are awake. A side effect of the anesthesia is an increase of fluid in your lungs. If this fluid remains in your lungs, the risk of pneumonia is greater. Deep-breathing and coughing will help to prevent the development of pneumonia. A small plastic tool called an incentive spirometer will be used to help you take deep breaths.
- Pain medicine will be ordered for you to reduce incisional pain. Walking and deep breathing will be easier and more effective when the pain medication is working. Once you are able to eat, you will begin taking your pain medication by mouth rather than by an injection or in your IV.
- Walking after surgery will begin as soon as possible and is essential in preventing many of the complications that can occur after surgery, including pneumonia, blood clots and bowel problems.
- Your urine will be measured by means of the catheter. When the catheter is removed, we will continue to measure your urine output each time you go to the bathroom. This helps us to make sure your remaining kidney is working well.
- The surgery and pain medications will slow your bowel function for a short time. As bowel function returns and you start to pass gas, you will be allowed to have liquids and then work up to regular food. Walking as early as possible will speed up the return of your bowel function.

Preparing to go home

You should be able to go home from the hospital two or three days after surgery. You will be given specific instructions before you leave, including activity restrictions and your follow-up clinic appointments. You will also be given a prescription for pain medication.

You will need to restrict your activity for the first two to four weeks after surgery, depending on the type of surgery used to remove your kidney. After this, you can return to your normal routine. You may exercise with moderation after four to six weeks and gradually increase your activity level. Walking is a good exercise. Do **not** do any heavy lifting within the first six weeks; driving during this time is not recommended. In most cases you may return to work after two to four weeks following laparoscopic donation.

A clinic appointment will be made before you leave the hospital. The transplant clinic is located on the fourth floor of UK Chandler Hospital. Further activity and guidelines will be discussed at your clinic visit. **If any questions or problems arise before your clinic visit (or at any other time), call your living donor coordinator toll free at 866-474-6544, option 3, then option 3 again. Locally, call 859-323-5737.**

“ I want to thank the University of Kentucky and their staff for their dedication to this wonderful program that gives so many people a second chance at a ‘normal’ life. You can be a donor and still live as normal a life as you did before. I am living proof.” –Lesla Hopson

Conclusion

In general, if a donated kidney is working well one year after the transplant, then the long-term outlook for the transplant is considered good. It is important to know that even well-matched living donor kidneys may not continue to function for the recipient's entire lifespan. If that happens, the patient will need to either return to dialysis or have another transplant. However, the chances are good that a kidney transplant will be successful!

Donating a kidney can be very rewarding and satisfying. Feeling anxiety and fear are very normal and common. It is our hope that this booklet helps you put the donation process into perspective. We also hope it stimulates more questions. The entire staff will be happy to answer any questions you may have. It may even be helpful to talk to someone who has already donated a kidney. We want your experience to be special and very satisfying for you.

Robert Purnell was diagnosed with chronic renal disease in 1984 and received his transplant from his sister Lesa in 2006. Robert has returned to normal activity, enjoying fishing and hunting. Lesa has also returned to normal activity, enjoying walking, biking and mission work.



..... Questions answered

Q: What things might rule me out as a potential donor?

A: To qualify as a living donor, you must be willing to donate, be in good general health and have a blood type that is compatible with the recipient's blood type. You will be ruled out as a donor if you have a disease or health condition that affects your kidney function, such as high blood pressure or diabetes. Other health conditions that would exclude you from donating include heart disease or any other serious medical condition.

Q: Who should I talk to as I make my decision or if I have concerns about donation?

A: Your transplant team, living donor advocate team and social worker are available to discuss any concerns or questions you have throughout the entire process. They will not reveal any of the concerns that you share with them to the recipient, your family or anyone else who is not on the transplant or living donor teams without your permission. It is important that you wait until you know that you are ready and comfortable to make the decision.

Q: How will my donation benefit my sick relative or friend?

A: Kidney transplants have helped thousands of people with kidney failure enjoy longer and healthier lives, free of the restrictions of dialysis. A living donor transplant typically works better and lasts longer than a kidney from a donor who has died. Also, the recipient may need to take less of the drugs that keep the body from rejecting the transplanted kidney, which means fewer drug-related side effects.

Q: What are the benefits to me of donating my kidney to a sick relative or friend?

A: Donating your kidney is a generous, selfless act. You are given the opportunity to enrich the quality of another person's life and to potentially extend that person's life.

Q: What if I feel pressured to donate or not donate?

A: The transplant team and living donor team will not pressure you to donate. They will respect and support your decision and help you throughout the process. It is normal

for family and friends to have many emotions about the situation. It is important for you to make your decision based on what is best for you and not based on others' motives for or against donation. All information about your evaluation will be kept confidential and will not be disclosed to the recipient.

Q: Is there a way to have the tests done without the potential recipient knowing?

A: No. The laboratory will need to crossmatch your blood with the recipient's blood. The transplant team cannot draw blood from the recipient or donor without explaining why.

Q: Are there any financial costs involved if I donate?

A: Donors will not be responsible for the medical costs of the tests, surgery, hospitalization or immediate follow-up care. You will need to manage your work schedule for time off, child-care expenses and any travel or lodging expenses. Your employer may provide sick or vacation leave to cover your time away from work. You can also see whether you are eligible for short-term disability insurance that may cover your time away from work.

It is important that you routinely, at least once per year, see your local physician for a health checkup.

Q: Will insurance companies turn me down for health, life or disability in the future if I donate?

A: It is very uncommon for a kidney donor to be turned down for insurance. If you have any concerns, please contact our financial counselor or living donor coordinator. They will help you work through your company to find the answers.

Q: Will I have any problems having children after I donate?

A: Medical studies have shown that there are no significant problems for females to become pregnant after becoming a kidney donor. It is advisable that you wait at least six months after your donation. If you do become pregnant, you should make sure that your obstetrician or gynecologist (OB/GYN) is aware of your donation so that your kidney can be monitored during the pregnancy. If you have more questions, please be sure to speak with your living donor coordinator.

Q: Will donating a kidney shorten my life expectancy?

A: Death from a donation is very rare and studies have shown that donation does not change the donor's life expectancy.

Q: What if I need a kidney transplant later in life?

A: Although this is rare, the United Network for Organ Sharing will assign the highest priority or status to a person who has donated a vital organ.

Q: Does my religion support donation?

A: Most religious denominations support and approve of organ and tissue donation. If you have more questions about how your specific religion views organ donation, talk to your living donor coordinator or chaplain.

Q: How do you decide what type of operation I will have?

A: Laparoscopic donor nephrectomy has been the standard procedure at UK since 1998. The advantage of laparoscopic surgery over the standard operation is that donors tend to have less pain, a smaller scar, a shorter hospital stay and a faster recovery.

Q: Is there anything I will be unable to do after I donate?

A: Your restrictions will be discussed with you by our urologist after your surgery. You should be able to do just about everything you do today once you have fully recovered.

Questions to consider in your decision to **donate**

- What are your basic feelings and beliefs about organ donation?
- What are the risks and benefits to you if you choose to donate?
- What impact will donation have on your relationships with the recipient or your other family members?
- How will you manage your work responsibilities while you are recovering?
- Who else might be considered as a donor? How will you all agree on who should be considered first?
- How will you feel if the evaluation process rules you out as a potential donor?
- Who will be your support network to help you through this process?

NOTE: It is highly unlikely, but possible, for a potential recipient and donor to go through the pretransplant workup and have the transplant canceled at the last minute due to a positive crossmatch or some other medical situation beyond our control. When this happens, the recipient is then placed or continued on our deceased donor transplant waiting list.

We hope this booklet helps answer many of your questions concerning living donation. Please feel free to call and ask us any additional questions you may have concerning any area of living donation or transplantation. **We strongly advise that you ask us to clarify any information you may obtain from sources outside of our transplant department.**

Again, thank you for considering becoming an organ donor. Your interest in sharing the “gift of life” is truly inspiring. The transplant program UK HealthCare is pledged to help you through this process.

“ *The whole experience from start to finish was made great due to the compassion, knowledge and professionalism of the team. I never felt alone, scared or uninformed before or after surgery. I felt the entire team wanted me to be comfortable and all strived to assist in that endeavor.*” – Sally Campbell

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