

LIVING KIDNEY DONATION

**Information for Potential
Living Donors**



Atrium Health

INTRODUCTION

This booklet is intended to provide some answers for you as you consider donating one of your kidneys to a loved one who has lost his/her kidney function and is facing dialysis.

Presently, a kidney transplant is the best chance for your recipient's long-term survival. For some, a new kidney means a chance to spend more time with their family, for others it may mean a chance to return to work, a chance to travel, or perhaps a chance to start a new way of life.

Unfortunately, there are more people waiting for a kidney transplant than there are available donors. As of 2018, there are over 100,000 people in the USA waiting for a kidney transplant; of these, approximately 15,000 will be transplanted this year of which 6,500 will be a result of living donation.

The first successful kidney transplant was done in 1954 between brothers and since then living donation has always been an option. Several research studies have been done with previous kidney donors which show that over 90% overwhelmingly report that the experience was positive and worthwhile. Furthermore, many report that having gone through it, they would do it all again.

We feel that donating a kidney is a major decision and you should know as much as possible about the risks and benefits to both the recipient and to you before proceeding. Hopefully, the information in this booklet will assist you in making your decision. During this process, your donor team can also arrange for you to talk with a prior kidney donor if you would like their thoughts on the experience.

WHO CAN BE A DONOR

There are three sources of kidneys available for transplantation: a deceased donor, a living related donor, and an unrelated living donor.

DECEASED DONORS

More than 50% of all transplants performed each year are from deceased donors. The age of these donors range from young children to 65 plus years who have died as a result of trauma, or a neurologic/vascular incident. Deceased donors must have consent from their next of kin, be free of all infection and have good kidney function. Patients in need of a deceased donor kidney must be placed on a waiting list until an organ becomes available for them. The waiting time for a deceased donor kidney is likely to be at least 3-4 years. The success rate of kidneys transplanted from a deceased donor is approximately 90% for the first year. Kidneys from a deceased donor are used when no living donor is available.

LIVING DONORS (related and unrelated)

Any healthy family member or friend who has a compatible blood type and negative crossmatch testing may be considered as a possible kidney donor. A related donor is considered to be parents, children, siblings, half-siblings, aunts, uncles and cousins. Another possible option is Kidney Paired Donation if you have a healthy living donor but are not a match.

Living donor kidney transplants have a success rate of approximately 95%. This increased success rate is a result of several factors including shared genetic markers (DNA) not shared with a deceased donor, and decreased injury to the kidney that can occur during the kidney recovery and before it is transplanted. In fact, research studies show that a kidney from a living donor without any DNA match can work as well or better than the best matched kidney from a deceased donor. Related and unrelated living donor kidney transplants offer important advantages over deceased donor kidney transplants. The rejection rate is significantly lower and the living donor transplant surgery is scheduled when convenient, possibly shortening the time on dialysis for the recipient who might otherwise wait years for a suitable deceased donor transplant.

The ideal living donor is between 18-65 years of age.

You may qualify as a living kidney donor if you are in good general health, do not suffer from high blood pressure, cancer, or diabetes and have good kidney function. Your overall health and emotional wellbeing are very important to the donor team.

In the event that a person decides to begin the donor evaluation, the donor team will refer him or her to a Transplant Nephrologist (kidney doctor) after a series of blood work and urine test have been completed. A thorough evaluation will be performed by the donor team to be sure that the donor is not only healthy enough but truly motivated to become a donor. We will make certain each patients information and decision to donate is confidential and provide the potential donor with an advocate who is free of conflict of interest and has the donors' best interests in mind.

Most importantly, the donation of a kidney must be a voluntary act. In the case of multiple potential donors, the individual circumstances of each potential donor are evaluated. After the situation of each potential donor has been carefully considered, the specific person for donation is selected by a series of lab work along with cardiac and radiology testing.

INITIAL EVALUATION

The first step in the donor evaluation is to determine whether you have a compatible blood type. This is called ABO testing. Blood is typed as A, B, O or AB. Even though some blood types are not the same, they may still be compatible with others. (Figure 1) If your blood type is not compatible with the recipient, then other options may be considered, in certain situations, where you could still be able to donate.

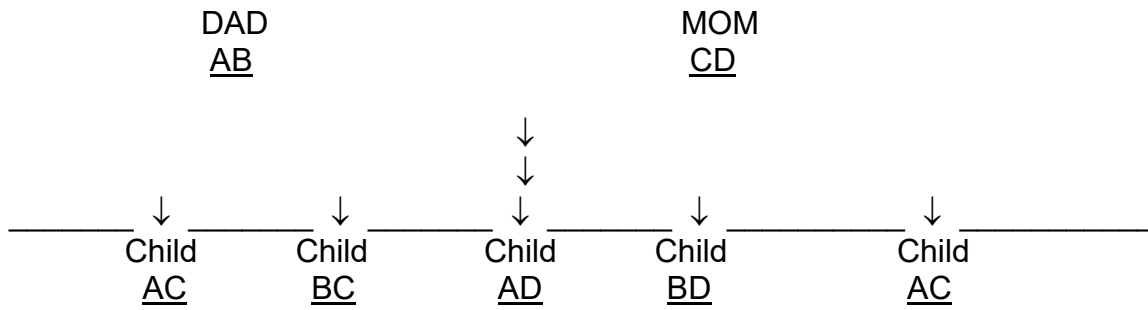
| <i>Blood Type</i> | Can Receive From | Can Donate To Type |
|-------------------|---------------------|-----------------------|
| O | O | O, A, B, AB |
| A | A, O | A, AB |
| B | B, O | B, AB |
| AB | O, A, B, AB | AB |

The second test performed on the blood is called a crossmatch. The crossmatch is a test that mixes the blood cells of the potential donor with the blood of the recipient to see if they are compatible. If the recipient's blood attacks the cells of the donor it is called a **POSITIVE CROSSMATCH** and means that the immune system of the recipient reacts unfavorably to the particular donor. If the crossmatch is positive, other options may be considered in certain situations. When there is no reaction between donor and recipient cells this is called a **NEGATIVE CROSSMATCH**.

The crossmatch is performed before ALL kidney transplants. For living donors, it is performed at the initial evaluation and again prior to the scheduled transplant to ensure that the recipient has not developed antibodies to the donor since the initial evaluation. The crossmatch may be done a third time if it has been longer than six months between the initial blood testing and the evaluation with the donor.

If your blood type is compatible with the recipient's and you have a negative crossmatch, the transplant coordinator will arrange for blood testing for HLA Tissue Typing prior to surgery. Tissue typing determines how well the DNA of the donor will match with the recipient.

The HLA typing is a blood test that involves having a tube of blood drawn from both the potential donors and potential recipient. This test identifies small proteins on our body cells called antigens(DNA). All of us are born with a specific set of antigens that we have inherited from our parents. We inherit half from our mother and half from our father (Figure 2).



It is possible that a donor has some, all, or none of the same antigens that the recipient as.

The immune system is the body’s means of fighting germs, viruses, and other foreign material, even a kidney transplant. The immune system can’t tell the difference among various kinds of “intruders” and tries to destroy anything that is different from its own tissue, whether a virus or a new kidney. The body will never accept the transplanted kidney as its own. The recipient will take medications to prevent rejection for the rest of his/her life or as long as the kidney functions.

All these tests are done at Carolinas Medical Center’s Laboratory. The blood samples can be drawn at Carolinas Medical Center. For potential donors outside of the Charlotte area, special arrangements can be made for having blood drawn at a LabCorp near your home and then shipped to Carolinas Medical Center via UPS.

These initial screening tests DO NOT commit a person to become a living kidney donor.

EFFECTS OF DONATION

The advantages to the recipient of a living kidney transplant have to be weighed against the potential risk to the donor. Living donation is the only operation with no planned benefit to the donor.

The person donating a kidney will undergo a purely elective operation. The surgical risk to the donor is no greater than the risks associated with any surgical procedure, that of an anesthetic and an incision.

Results from studies encompassing all donors in the USA from 1980 to present calculated the preoperative mortality to be 0.03% or 3 in 10,000 and is less than the risk of a woman during pregnancy.

Post operative complications must also be considered. Data compiled from 16 studies showed a major complication rate (pulmonary embolus, severe infection, heart attack) of 1.8% and a minor complication (urinary tract infection, upper respiratory infection, wound infection) rate 10%.

A donor can lead an active, normal, healthy life with only one kidney. A potential donor should not worry about an increased risk of developing renal disease as a result of only having one kidney remaining. Kidney disease affects both kidneys, not just one. The second kidney should not be thought of as a "spare". When chronic kidney failure is present, dialysis or transplantation is necessary whether the person has one kidney or two. The one remaining kidney enlarges and is able to do approximately 75-80% of the work that the two kidneys had done previously.

The side effects of donating a kidney on future development of kidney (renal) failure have been studied extensively in humans as well as experimental animals. The longest follow up study of 23 years showed no progressive loss of renal function, no rise in serum creatinine or clinically important elevated blood pressure or urine protein. The blood pressure reading and risk of developing high blood pressure are not higher than that of the general population or from readings in non-donating healthy siblings or in persons unrelated to the donor but of similar age, sex, or race. A recent study, however, shows that certain racial groups, particularly African Americans have an overall increased incidence of kidney disease, hypertension and diabetes. However, there is no evidence to support that donating a kidney increases the chances of developing these problems. For this reason, it is **essential** that living donors maintain good healthy lifestyle practices such as weight management, a healthy diet, regular exercise, and yearly physician visits to include labs and blood pressure monitoring.

Although there is no data to suggest decreased fertility or peri-natal complications, women of child bearing age should discuss the risk of having one kidney with their physicians should they decide to get pregnant. Although isolated cases of renal failure have occurred after donation, it is rare.

Of note, there have also been cases in which the donor evaluation has led to the diagnosis and treatment of medical conditions and potentially life threatening diseases. Thus there is a possible small benefit to being a potential donor.

MAKING THE DECISION

Some people make the decision on whether to donate a kidney instantly, with few worries or problems. Others must go through some soul searching before deciding. There are some families where everyone wants to be a donor, while in others there is a general unwillingness to consider donation. It is quite normal for a potential donor to be afraid of the idea of giving a kidney or to feel guilty about his or her reluctance. The primary role of the donor team is to assist potential donors in making their own decisions. Most importantly, the only right decision is the one with which the person considering donation feels more comfortable.

The decision to donate an organ is always a voluntary decision. Private, confidential discussions with the donor coordinator, donor advocate, transplant social worker, and transplant nephrologist and surgeon allows prospective donors to ask questions without any obligation to donate.

Even after the decision to donate has been made the donor has the opportunity to change his or her mind up to the time of surgery. In each case, the donor's feelings are kept in the strictest confidence.

THE DONOR EVALUATION

A potential donor will be seen and evaluated by a donor advocate team, that is separate from the recipient team, to determine their candidacy for living donation.

The evaluation includes the following:

1. 2 - 24 hour urine collections (to help detect high levels of protein and calculate clearances), and blood work.
2. Chest x-ray (to evaluate lungs).
3. EKG (to evaluate the heart). If abnormal further testing may be required.
4. Meeting with the living donor coordinator and a medical social worker.
5. Complete history and physical exam by a transplant nephrologist (kidney specialist).
6. Meeting and evaluation with the transplant surgeon.
7. Radiology tests; CT Scan to assess anatomy of both kidneys. A Glofil study may be necessary, and will be at the discretion of the MD evaluating you.
8. Once the tests are completed and if you are a candidate for the laparoscopic procedure, you will meet with a laparoscopic surgeon as well. Rarely, a renal arteriogram is needed but if anatomy is not seen well on the CT Scan, it may be required.
9. Once you complete the evaluation, the Transplant Team will review all the information and make a decision as to whether you are a suitable candidate for donation. Only after the Team has made a decision, will potential dates for surgery be discussed.
10. Any further tests depend upon the donor's medical history
11. Final crossmatch with recipient to check antibodies will be scheduled within the final week prior to the actual transplant.

All of the potential donor's testing can be performed as an outpatient at Carolinas Medical Center.

GLOFIL STUDY

PURPOSE

Evaluate true measurement of glomerular filtration rate

CONTRAINDICATIONS

- I-125 Glofil should not be administered via a central venous line.
- Patients that are allergic to iodine will not be able to have this procedure.
- Prior procedures where radioactive material was administered to the patient.

PATIENT PREP

- Lugol's solution; 3 drops by mouth, 3 times a day for 1 to 2 days prior to the test.
- Patient will start drinking a large amount of water starting 1 hour before the test. The amount of water is determined by your weight (20ml water/kg).
- A foley catheter is required, as accurate measurement of urine production is essential to the calculation of GFR.

THE PRE-OP WORKUP FOR DONATION SURGERY

The donor is admitted to Carolinas Medical Center very early on the day of surgery. Prior to this, usually within one week of surgery, you will have several appointments for final testing. These appointments include:

1. Physical Exam with surgeon and possibly the nephrologist
2. Blood Tests – required for surgery and final crossmatch.
3. Chest x-ray (if not performed recently)
4. EKG if indicated
5. Pre-operative Anesthesia appointment. The anesthesiologist will meet with the donor to review his or her health and medical history. Any questions about the anesthesia to be used during the surgery can be discussed at this time.

The donor will re-visit with the transplant team to discuss any final questions or concerns.

The day before the surgery, the donor will be drink a liquid bowel prep (mild laxative) and your diet will consists of clear liquids after 2:00 pm, then nothing after midnight. He/she will be asked to shower the morning of surgery using antibacterial soap at the site where the incision is to be.

Upon arrival to the Pre-Operative Holding area, final paperwork will be completed, IV fluids will be started, and the surgical team will introduce themselves to the patient and family. Shortly before going to the operating room a medication is given to the donor to help him or her relax. A general anesthetic is administered in the operating room to put the donor to sleep during surgery.

RECOVERY

After the surgery, the donor will be monitored closely. He/she will have a Foley catheter in the bladder to measure urine output; this is removed 1-2 days post operatively. The donor will also have an IV for 1-2 days to provide nourishment and medication until the stomach and intestines recover from the effects of anesthesia and the donor is able to eat and drink without difficulty. Diet will progress from ice chips to liquids to easily digested solid foods. The urinary catheter and other tubes will be inserted during surgery while the donor is asleep.

Medication is available for the discomfort of pain and nausea that accompanies such major surgical procedures.

The nurses immediately encourage the donor to turn, cough and deep breathe to help clear the lungs of secretions. The process is repeated every two hours to prevent pneumonia and other respiratory difficulties associated with the use of anesthesia during surgery. In addition, the donor is helped to walk several hours after surgery and is encouraged daily to increase his or her physical activity. These exercises may cause some discomfort around the incision while coughing and moving. This is uncomfortable for the first 2-3 days, but becomes much easier as activity increases.

Smoking greatly increases the chances of lung infection and other surgical complications as well as potential long term health issues we would like to avoid such as heart disease. If you are seriously considering donation we recommend you quit smoking. Of note, smoking is not allowed anywhere at Carolinas Medical Center.

The total hospital stay is usually three to four days, depending on the individual's strength and healing of the incision. Friends and relatives are welcome to visit the donor during the hospital stay. The stated Carolinas Medical Center visiting hours are 12:30 pm until 8:30 pm, but are quite flexible. It is best to coordinate times other than these with the primary nurse.

Although each situation is unique, the donors typically have a rapid and uneventful recovery. Following the operation, the donor feels very tired, a natural bodily reaction to surgery and general anesthetic. Certainly there is pain lasting from several days to several weeks as the muscles around the incision heal. There may also be itching at the incision site and difficulty in stretching. During the first few days to weeks after surgery frequent rest periods are needed. Light housework, driving, sexual activity, and mild exercise may be done when it feels comfortable, usually within 3-4 weeks. Heavy lifting and strenuous exercise such as jogging should be avoided for six to eight weeks.

When the donor returns to work depends on the kind of work involved, jobs that involve heavy physical activity require 6-8 weeks before returning, whereas less physical jobs are usually 3-4 weeks. After recovery, the donor should expect to return to all the normal activities that were enjoyed before kidney donation. There should be no restrictions of any kind on the donor's lifestyle.

Some donors have expressed a let down feeling just before discharge from the hospital or during the first few days at home. This is not uncommon and may be due to the pain medication side effects or to a change from the excitement of surgery to the slower pace of recovery. Anyone who undergoes any type of surgery that requires a general anesthetic should expect to feel emotionally and physically tired for a short period. If you have any concerns please discuss this with your donor coordinator who is there to help you.

CONCLUSION

The decision to donate is not always an easy one. Donation is not right for everyone. There are emotional, physical, and financial matters to think about. Potential donors should discuss these matters with their families, since they will also be affected by the decision.

Talking to others who have been through the donor process is usually helpful for those who are considering the idea of donation. This can be arranged by the donor coordinator.

Hopefully, many of your questions and concerns have been answered after reading through this informational booklet. In the end, it is your personal decision to make. Whatever you decide, it needs to be the right choice for you.

WEBSITES:

<http://transplantliving.org/>

www.optn.org

www.livingdonors.org

www.ustransplant.org

24 HOUR URINE COLLECTION

For each collection:

1. Obtain a jug from hospital laboratory or outpatient facility. Write your name, social security number and date of birth on jug.
2. Determine the day you are going to collect 24 hour urine. Pick a day when you can stay home the entire 24 hours. Saturdays or Sundays are usually easiest.
 - When you wake up, urinate as usual in toilet and flush toilet.
 - **The collection starts now.**
 - Write the date and time you start collection on the jug.
3. Collect **ALL** urine for the next **24 hours**. The collection ends with your first urine the next morning being placed in the jug.
4. Bring collection jug to lab the next day after completion as instructed.
5. The day you bring in the jug, a small blood test will also be performed.

IMPORTANT:

- Urine jug(s) must be kept in refrigerator or in a cooler on ice at all times.
- **ALL urine must be placed in jug. If not, this test will have to be repeated.**
- Drink lots of fluids.
- Do not collect urine immediately before, during, or immediately after your menstrual period.

QUESTIONS???

- Call the Living Donor Office at 704-355-3602 or 800-562-5752

LAPAROSCOPIC DONOR NEPHRECTOMY

◆ *What Is Minimally Invasive Surgery?*

In the past, most major abdominal operations required a large incision, which often resulted in a long period of recovery for the patient. However today, surgeons are using newer, “less invasive” methods for performing a wide variety of operations. One of these techniques (called *Laparoscopic Surgery*) allows surgeons to perform well-established surgical procedures through much smaller incisions. For the patient, this can mean less pain, a shorter stay in the hospital, a more rapid return to regular activities, and smaller scars.

◆ *How Are Kidney Transplants Performed Using Laparoscopic Surgery?*

Kidney transplantation is one form of treatment for patients with kidney failure. A successful transplant eliminates the need for dialysis and allows the recipient to lead a more normal life. Live donor kidney donation is a process that allows a healthy individual (the donor) to donate one of his/her kidneys to another person (the recipient). In most cases, the donor and recipient are related by blood, but organs can also be transplanted between unrelated individuals. In the past, removal of the healthy kidney from the donor required a large incision along the patient’s flank and removal of the lowest rib. After the operation, the donor would usually spend 4 to 6 days in the hospital and recuperate at home for 6 to 8 weeks.

Surgeons are now able to remove the kidney from the donor using laparoscopic surgery. The operation is called “*Laparoscopic Donor Nephrectomy*”. By using smaller incisions, patients have less pain and can recover from surgery much more quickly. Most patients spend 3 to 4 days in the hospital and are able to return to work in 3 to 4 weeks.

◆ *How Is Laparoscopic Donor Nephrectomy Performed?*

Since the first laparoscopic donor nephrectomy was performed in 1995, this procedure has become the method of choice for performing live kidney donation at transplant centers across the country. As with any major operation, the procedure is performed in an operating room using general anesthesia (the patient is asleep during the entire operation). Instead of using one large incision, laparoscopic removal of the kidney requires three small incisions. Two of these are less than one-half inch in size. The third

incision measures about 4 inches and is used for removal of the kidney. Laparoscopic surgical tools (trocars) are passed through each of these small incisions and allow for specially-designed long, thin instruments to be placed into the abdomen during surgery. These instruments may vary in size from 5 to 10 millimeters in diameter.

At the beginning of the procedure, the patient's abdominal cavity is inflated with carbon dioxide (CO₂) – a harmless gas – to provide more space for the surgeon to see and work. A small telescope (laparoscope) is inserted through one incision. It shines a light into the abdomen and has a camera attached to it. This allows the surgeon to see the internal organs by projecting the laparoscopic image onto a video screen. The operation usually lasts about 3 hours. The carbon dioxide is removed at the end of surgery and the incisions are closed with internal stitches. A few patients may experience left shoulder pain associated with retained gas in the abdomen which moves to this area.

◆ ***What Can Kidney Donors Expect After Laparoscopic Surgery?***

After surgery, kidney donors should expect to spend 3 to 5 days in the hospital. The patient begins drinking liquids the morning after surgery and should return to eating soft regular foods within 2-3 days. Pain medications are given intravenous (IV) for the first 2 days then changed to pain pills. After laparoscopic surgery, most patients require occasional pain medications for about one week following surgery. While patients may experience mild, occasional discomfort for several weeks after the operation, most patients are able to return to light activities within 7 to 10 days, and can usually return to work within 3 to 4 weeks. For jobs that require heavy physical labor, patients are limited to "light duties" (lifting no more than 10-15 pounds) for the first 6 to 8 weeks after the operation. Light exercise (walking) is permitted as soon as discomfort allows, but strenuous activity such as sit-ups, weight lifting and contact sports should be avoided for 8 weeks.

◆ ***Why Consider A Living Related Donation?***

Kidneys used for transplantation may be donated by a living friend or relative, or they may be donated by the family of an individual who has suffered irreversible brain damage (deceased donor). Since there are several thousands of patients who need a kidney transplant and only a limited number of potential deceased donors, patients may have to wait 3 to 5 years for a deceased donor kidney. The waiting time for a live donation may be as short as a few months.

◆ ***Who May Donate A Kidney?***

Any person over the age of 18 may be considered as a living donor. A donor must be in excellent health and have no history of diabetes, high blood pressure, or kidney disease. Potential donors undergo an extensive medical evaluation before donating a kidney. This includes a complete medical history, physical examination, blood and urine tests, and x-rays. All potential donors are also evaluated by a kidney specialist (nephrologist) and a transplant surgeon.

◆ ***Other Considerations***

The decision to be a donor is a very personal one and our goal is to do no harm. You must carefully consider many things, including your relationship to the recipient, your family, and your time lost from work. Even up until the time of surgery, you may change your mind. All information is confidential and your decision will be supported and respected. Your donor coordinator will assist you in any way possible.

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Atrium Health
LIVING KIDNEY DONOR
SELECTION CRITERIA

The standard criteria for living kidney donor candidates are as follows:

1. Healthy adults, age \geq 18 years old.
2. Non-reactive HIV and Hepatitis.
3. Free of active infection. In certain infections, patient will be evaluated on an individual basis.
4. Malignancy (cancer) free. If there is a history of malignancy, each patient is evaluated on an individual basis.
5. Normal renal function with two kidneys.

Relative Contraindications: (possibly unable to donate)

1. Patients with a history of kidney stone(s) will be evaluated on an individual basis.
2. Patients with a BMI of >32 will be evaluated on an individual basis.
3. Proteinuria (goal is $<280\text{mg}/24\text{hrs}$)
4. Microscopic hematuria (blood in urine) will be evaluated on an individual basis.
5. Multiple renal vessels will be evaluated by surgical team.
6. History of thrombosis or thromboembolism will be evaluated on an individual basis.
7. Controlled HTN with 1 agent will be looked at on a case-by-case basis
8. Smokers will be asked to quit.

Absolute Contraindications: (unable to donate)

1. History of diabetes.
2. HIV infection
3. Uncontrolled hypertension or a history of with evidence of end stage organ damage.
4. Active/untreated substance (drug/alcohol) abuse.
5. GFR (kidney function) $< 80\text{ml}/\text{min}$
6. Multiple medical problems (ie: heart disease, sickle cell anemia)
7. Unstable psychiatric history, conditions actively being treated, including any evidence of suicidality.
8. High suspicion of donor coercion.
9. High suspicion of illegal financial exchange between donor and recipient.
10. Pregnancy or actively breast feeding.
11. Mentally incapable of making an informed decision.
12. Active malignancy or incomplete treatment of malignancy.

The Transplant program may exclude a donor with any conditions that, in the Transplant programs medical judgment, cause the donor to be unsuitable for organ donation.

Thinking about being a living donor? *This is what you need to know first.*

This paper explains what you need to know before you may agree to be a living organ donor. It is a patient version of the OPTN (Organ Procurement and Transplantation Network) informed consent policy. This paper explains:

- What it means to give your consent
- That only you can decide to donate
- You have the right to privacy as you get tested and make your decision
- The role of an Independent Living Donor Advocate
- What the transplant hospital staff must do before, during and after donation
- The risks of living organ donation, including the medical, mental, social, and financial risks
- How your health might be affected by donation
- What information you must be given about how well transplant recipients do after their transplants
- What information about your organ recipient you do not have the right to receive
- Your need for medical follow-up after donation

A living donor can donate a:

- Kidney
- Portion of their liver, pancreas, or intestine
- Lobe of their lung

Some words used in this paper and their meaning may be helpful.

- A person who needs an organ transplant is called a “**transplant candidate**”. A transplant candidate must be on the national waiting list to receive an organ transplant from a deceased donor or a living donor.
- After a transplant candidate receives an organ transplant they are called a “**transplant recipient**” or “**recipient**”.
- If the living donor knows the recipient it is “**directed donation**”.
- If the living donor does not know the recipient it is “**non-directed donation**”.

You will meet with the hospital staff who will help you decide if you can be a living donor. The hospital staff must get your informed consent. Through informed consent, the hospital staff gives you information so that you understand the benefits and risks of donor testing and organ donation, and that you agree to the testing and donation. Informed consent will include all the items below.

Consent for Living Donation

To become a living donor you must be able to state that:

- You want to donate.
- No one forced you to donate.

- No one said they would give you something of value for donating.
- You know that you can decide not to donate at any time.

The hospital staff will ask you to sign a paper for your medical record to show you understand these things.

Living Donation is Your Choice

You Have a Right to Privacy as You Get Tested and Make Your Choice

It is your choice to donate an organ. It is against the law for you to receive something like cash, property or a vacation for donating an organ.

If you become a living donor, the hospital staff must keep your personal and medical information private. The hospital staff must also keep the recipient's personal information private. If you want to be a non-directed donor, the hospital staff must keep your identity private. The hospital staff must also keep the identity of the recipient private.

If you decide not to donate, the hospital staff will keep your decision and reasons private.

The Independent Living Donor Advocate (ILDA)

The hospital staff will provide an independent living donor advocate (ILDA). An ILDA is a person who understands the organ donation process and who will:

1. Promote your best interests.
2. Check that you have received information about the following topics:
 - The informed consent process.
 - The tests needed to be a living donor, and the risks of these tests.
 - The surgery, and the care you will get after the surgery.
 - The need to have follow-up care after donation.
3. Help you get more information about these topics as needed

The ILDA should not be involved with the transplant candidate.

Hospital Staff Responsibilities

The hospital staff will tell you about the donation process. The staff must give you information using words that you understand so that you can ask questions.

To be a living donor, you must have medical tests to make sure you are healthy enough to donate an organ. The hospital staff will help you understand the medical tests that will be needed. The hospital staff will also make sure you are ready mentally to be a donor and have a plan for your recovery (for example, whether you can take time off from work and who will help you while you recover). This is called a psychosocial evaluation. Your ILDA will make sure you understand the steps in these evaluations. Your ILDA will get answers to any questions you have about testing, the use of personal information and any other questions you have about donating.

After the tests, the hospital staff may decide that you should not be a living donor. If this happens, the hospital staff should tell you that you could be evaluated at a different hospital. Another hospital might decide that you may donate because every hospital uses its own guidelines and judgment.

During the tests, the hospital staff may find that you have a medical condition that you did not know about. You could need to be treated for this condition. Also, the hospital staff could find that you have an infection or sexually-transmitted disease that you did not know about. It is the law that hospitals must report some of those conditions to local, state or federal public health authorities. They must report them privately, meaning that no one else will be told.

The hospital staff must tell you that transplant candidates have other options for treatment. A transplant candidate could get an organ from a deceased donor instead of from you. A transplant candidate who needs a kidney transplant could continue to get dialysis if they do not receive a transplant.

After you donate an organ, your hospital must continue to check on your health. Depending on the type of organ you donate, the hospital must report information about your health and personal status (e.g. ability to work) for two years after you donate. You must agree to take part in this follow-up. Ask the hospital staff how you will receive follow-up and who will pay for the follow-up.

A group called the Scientific Registry of Transplant Recipients (SRTR) collects and keeps information for every transplant hospital in this country. The information shows how well recipients do on average after getting transplants. The hospital staff must give you information about how well recipients do at the hospital performing the recipient's transplant, if the transplant hospital is known in advance. The information must include

- Percent of transplant recipients at that hospital still alive one year after transplant.
- Percent of transplanted organs at that hospital still functioning one year after transplant.
- Percent of transplant recipients alive and transplanted organs functioning after one year in the country overall

If the transplant center is not known, staff at your donation hospital must give you information about:

- the percent of transplant recipients across the country who are alive after one year
- the percent of transplanted organs functioning after one year across the country

Ask your ILDA if you need help understanding this information.

Information You Do Not Have a Right to Receive

The hospital staff can only give you some information about the transplant candidate if the candidate agrees. This information includes:

- Any reasons why the transplant candidate may have increased risk for a bad result after getting the transplant.

- Any personal health information about the candidate that the law says is private.

The transplant candidate could have a bad result after the transplant. A bad result could be, for example, that the organ transplant does not work, the recipient has new medical problems, or the recipient dies. The chance of one of these things happening to the recipient of your organ might be higher than it would be for other transplant candidates. The hospital might decide that the recipient would still benefit and that the transplant should happen anyway. The hospital staff is not allowed to tell you about the transplant candidate's chances of having a bad outcome unless the transplant candidate agrees to share the information. Each hospital chooses potential donors and transplant candidates based on the hospital's own guidelines, practices and judgment.

Risks of Donation

The hospital staff must make sure you know about the following risks. Ask your ILDA to explain any risks you do not understand.

Potential medical risks that could happen during the evaluation:

- Being allergic to a test and having a bad reaction.
- Discovery of an infection the hospital staff need to report.
- Discovery of a serious medical condition that could require more medical tests or treatment that you will have to pay for.
- Discovery of a genetic health risk factor or issue that you did not know about.

Potential surgical or medical risks that could happen if you donate an organ:

- Death or disease (being very overweight, older or having high blood pressure or other medical conditions could make you more likely to die or have a problem).
- Scars, hernia, infection, blood clots, pneumonia, nerve injury, pain, tiredness, and other symptoms that are common when people have surgery.
- Abdominal symptoms like bloating, nausea, or having a bowel obstruction.

Potential mental or social risks *after* donating:

- Problems with how you feel about your body or what it looks like.
- Problems with depression or fear and stress.
- Feeling sad if the transplant recipient becomes ill or dies.
- Changes in your lifestyle because you donated an organ.

Potential money problems after donating:

- Paying for travel, short-term housing, and child care, and not being paid while you were away or recovering from surgery. Some money may be available to help you with such non-medical donation-related costs.
- Having to pay for costs of lifelong follow-up visits.

- Losing your job or your income.
- Having a hard time finding a job in the future.
- Having a hard time getting, keeping, or paying for health insurance, disability insurance, and life insurance.
- Future health problems that may not be covered by the transplant recipient's insurance.

Effect on Your Future Health

Living Kidney Donors

If you donate a kidney, hospital staff must tell you about how living kidney donation relates to ongoing or chronic kidney disease and kidney failure. Your ILDA should help you understand these terms.

If you are thinking about donating a kidney, you should know that:

- On average, you will permanently lose 25-35% of your kidney function after donating.
- Your risk of having kidney failure later in your life is not any higher than it is for someone in the general population of a similar age, sex or race. However, you are more likely to have kidney failure than healthy people who are not donors.
- Chronic kidney disease most often starts in the middle of your life (40-50 years old). Kidney failure most often starts after age 60. If you get tested when you are young, doctors cannot predict how likely you are to have chronic kidney disease or kidney failure later in life.
- If you damage your other kidney (the one you did not donate), you may have a higher chance of having chronic kidney disease, which could go on to become kidney failure
- You will need medical treatment if you start to have kidney failure
- Current policy gives living donors priority on the national waiting list if they need to get a kidney transplant in the future. You can ask your ILDA or another transplant hospital staff member of about this policy.

These events and others could happen **during or after** surgery, and they could be **short-term or permanent**:

- You will lose some of your kidney function.
- You could have kidney failure and need dialysis.
- If you become pregnant after donating, you are more likely to have high blood pressure during pregnancy. This is called "preeclampsia".

Living Liver Donors

If you are thinking about donating part of your liver, you should know that these events and others could happen **during or after** surgery, and they could be **short-term or permanent**:

- You could have immediate liver failure and need a transplant.
- You could have temporary liver problems while you recover. This may depend on how much of your liver you donate.

- You may need a blood transfusion.
- Your liver may leak and you may need another operation to fix the leak.
- You may need more tests after you donate, which might also have risks.

After You Become a Living Donor

You must agree to give information about your health and general status to the hospital where you donated for two years after donation. The reason you need to have this medical follow-up is to check your health and to give you medical treatment as needed.

During this follow-up, like during any medical checkup, tests might show that you have a medical problem that could need to be treated, and the cost of the treatment might not be covered by the recipient's insurance. Also, if an infectious or sexually-transmitted disease is found, the hospital staff may need to report it, in confidence, to local, state or federal public health authorities, the transplant recipient's hospital and to the OPTN. The hospital staff will not share this information with your recipient, your family or any other person the staff is not required to tell by law.

If you have any questions or concerns about any step of living donor evaluation, donation or follow-up, ask your transplant hospital team or ILDA.

The United Network for Organ Sharing (UNOS) directs the nation's organ transplant system.

UNOS has a toll-free patient services phone number: 1-888-894-6361

Call this number to:

- Find a transplant center in your area that does living kidney or liver transplants.
- Learn more about organ donation and transplantation policies and data.
- Ask questions or talk about concerns or problems.



Presently, a kidney transplant is the best chance for your recipient's long-term survival. For some, a new kidney means a chance to spend more time with their family, for others it may mean a chance to return to work, a chance to travel, or perhaps a chance to start a new way of life.

Unfortunately, there are more people waiting for a kidney transplant than there are available donors. As of 2018, there are over 100,000 people in the USA waiting for a kidney transplant; of these, approximately 16,500 will be transplanted this year of which 5,700 will be a result of living donation.

We feel that donating a kidney is a major decision and you should know as much as possible about the risks and benefits to both the recipient and to you before proceeding.

Myths about Living Donation:

MYTH #1 DIALYSIS MUST COME BEFORE TRANSPLANT

Actually, people who receive a kidney transplant before going on dialysis do better than patients who went on dialysis before transplant! Both patient and kidney transplant survival are better when patients undergo pre-emptive transplantation (meaning transplant before needing dialysis)

MYTH #2 ONLY A CLOSE RELATIVE CAN DONATE?

Just about anyone can donate a kidney to someone in need of a transplant, as long as the donor is medically able to donate. With the medications available today, the genetic match of the transplant isn't as important as it used to be. In fact, even if you have a willing but incompatible donor (for example, incompatible blood type), you could enter a registry to "swap" donors with other incompatible pairs.

MYTH #3 LIVING DONORS FACE A LONG RECOVERY

With the availability of today's minimally invasive surgical procedures for living kidney donors, the majority of donors are in the hospital for just 3 to 4 days, and are recovered enough to return to work within about 4-6 weeks

Did you know that Carolinas Healthcare System offers Kidney Paired Exchange?

If you are found to be ABO incompatible (not the right blood type) or have a positive crossmatch with your intended recipient related to antibodies in their system, paired donation offers an option of finding another "pair" who are in your same situation. The hope is to then be able to "swap" kidneys so both pairs receive a healthy, compatible kidney.

Our Living Donor Coordinators are registered nurses and Certified Clinical Transplant Coordinators who will assist you in learning more about donation, as well as guide potential donors through the medical testing phases until donors are cleared to donate. Once cleared to donate, they will also assist organ donors in getting scheduled for pre-op and surgery and follow along with donors in the hospital. We are also mandated to follow up with organ donors for at least two years after organ donation.

Living Donor Office Contact Information

Please contact the Living Donor Office if you have questions about living donation or would like more information.

Yvonne Ellerbe, Program Assistant 704-355-3602
Tania Feemster, BSN, RN, CNN, CCTC-Donor Coordinator 704-355-8817
Lorrie Lockwood, BSN, RN, CCTC-Donor Coordinator 704-355-8093
Donor Office Fax: 704-355-4910
CMC Transplant Center: 704-355-6649, Option 4, Option 2

Could I Be a Living Kidney Donor?

By Jennifer Martin

Most living donors agree that their experience donating a kidney has been a good one. Some had more pain than they anticipated, some had complications, but most of them seem happy with their decision. However, there are no statistics on the long-term outcomes for donors, an area where study is needed. There are some serious risks in living donation, but the risks tend to be rare.

For most people, living donation doesn't change their lifestyle, or diet. There are a few things you should be aware of if you are considering living kidney donation.

When the donated kidney is removed, the single remaining kidney will grow and become larger than a normal kidney. As a result, the single kidney is more vulnerable to injury.

Once you have donated a kidney, it is important to be aware of the increased risk for injury with certain heavy contact and extreme sports. Careful decisions must be made regarding a potential donor's participation in various physical activities.

The American Academy of Pediatrics and the American Academy of Family Physicians have suggested that people with one kidney avoid sports and activities that involve higher risks of heavy contact, collision or risk of injury. These include boxing, field hockey, football, ice hockey, lacrosse, martial arts, rodeo, soccer, wrestling, and skydiving, among others. Anyone with a single kidney who decides to participate in these sports should be extra careful and wear protective padding. He or she should understand that the consequences of losing the single remaining kidney are very serious.


Donors are encouraged to have good long-term medical follow-up with their primary care doctor. A urinalysis (urine test) and blood pressure check should be done yearly, and kidney function should be checked every few years, or more often if the urinalysis shows abnormal results or blood pressure is elevated.

In general, most people with a single normal kidney have reported few or no problems. However, there seems to be a greater chance of the donor developing high blood pressure. Again, because there have been no studies about the long-term effects of donation on the donor, it is not known how often this has occurred. Potential donors should consult with their doctor about the risks of living donation.

Pregnancy after donation is possible, but is not usually recommended for as least six months after the surgery.

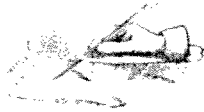
Some branches of military service, police and fire departments will not accept individuals with only one kidney. In addition, if you are already in military service, certain new service career options may not be available to you. If you are currently in one of these fields, or if your future plans include these career choices, you should check to see if living donation would affect your eligibility.

These are just a few things you should think about before you choose to donate a kidney. If

you would like additional information and support, you may find it on NKF's living donor Web site at www.livingdonors.org. 

Jennifer Martin is the transplant programs manager at the National Kidney Foundation.





The Gift

By Kim Johnson

Weak and tired
Life was a struggle
Somehow each day
Through life I would muddle

Thinking there must
Be a better way
To live without
This fight everyday

A gift of life
I needed from you
I didn't have to ask
You just came through

A huge sacrifice
You made for me
A life-changing difference
I can already see


After only one day
I feel brand new
A second chance at life
Thanks to you

There are no words
That can express
The feelings of love
That I possess

With my new life
I can do anything
I look forward to whatever
Tomorrow will bring

I plan right now
To live each day
To the very fullest
And I also pray

That I can give back
What you have given to me
A piece of the gift
Given so unselfishly

You are my Hero
My Brother and Friend
Thanks for the chance
To live again. 

Kim Johnson is a kidney recipient. She received a kidney from her brother, Kevin.

@ www.livingdonors.org

Your Questions Get Answers

Here's a commonly asked question. Visit our Web site for more Q&As.

Q: *I need a transplant. How can I ask someone to be my living donor?*

A: This is a tough issue and it depends on you and your loved ones. All families are different. Many individuals facing a need for a transplant found that their family members or friends asked them about living donation. Others found that asking someone they loved to donate to them was too difficult. They didn't feel comfortable asking people directly because they did not want to pressure anyone to donate.

Some transplant hopefuls were able to overcome the fear of asking loved ones to risk surgery, once they learned more about transplantation and donation. Taking the time to educate their families and friends about kidney transplantation and donation helped. You might want to ask your transplant center staff for brochures about donation, and share them with your friends or family members. Sharing as much factual information as you can, along with sharing your thoughts about your progress, your options, your hopes and dreams, can help you and your loved ones think about whether living donation is right for you. If you can, take your time, move slowly, and get all the information possible.

You can find a list of all U.S. transplant centers by state online at www.ltios.org

Because donors are never financially compensated, you may also want to meet with a financial counselor to discuss your situation as it relates to lost work time, testing expenses, etc. Most transplant centers have a financial counselor who can help you.

Living donation is not easy. You will have many questions and, while no one venue can provide all of the answers you seek,

www.livingdonors.org is designed to help you get some of them.



Atrium Health

Dear Sir or Madam,

My name is Jon Gee and I work closely with the Atrium Health Department of Transplant Nephrology fulfilling the role of the Living Donor Advocate. The position is a developing one in the transplant field, but one that is pivotal to your intentions and experience. As someone interested in living kidney donation, you are about to participate in a unique process. My job is to represent your interests within that process in a way that is energetic and unbiased.

Specific areas of focus for our meeting will include but are not limited to:

- Making sure you are here without undue pressure
- Making sure all of your questions are answered to your satisfaction
- Making sure your understanding of the risks involved is as full and clear as possible
- Promoting your choice to pursue donation...or choice not to if circumstances change

As well, the relationship we build will help to establish a link for you in the process to someone who does not work for or promote the interests for the Transplant team. Your rights and needs are important and visiting with someone in the Donor Advocate role has become a standard part of protecting them in the donation process.

In closing, I hope to meet you soon and know that it will be a pleasure to do so. Your coordinator will ideally schedule an appointment for us on a day when you are visiting the Transplant center for other reasons. Though you will be seated initially on your own, you may bring people that are important, to you to the visit as well, especially if you feel this will enrich our shared experience and understanding. Remember though, that this interview is for you, so I look forward to our completing it. Please do not hesitate to contact your coordinator or the department if you have questions at 704-355-3602 or 800-562-5752. Again, I look forward to meeting with you.

All the best,

Jonathan Gee, MD

Living Donor Advocate

Financial Responsibility of the Living Donor

The Transplant Center will be financially responsible for:
Basic Kidney Donor Transplant Evaluation

- **Labwork (both urine and blood work) May require 2-3 trips to lab to complete.**
- **Living Donor Coordinator (nurse)**
- **Medical Social Worker**
- **Dietician**
- **Transplant Surgeon**
- **Transplant Nephrologist (kidney doctor)**
- **CXR (chest x-ray)**
- **EKG (electrocardiogram)**
- **CT Scan of Abdomen and Pelvis**
- **Donor Advocate**
- **24hr Blood Pressure Monitor (if necessary)**
- **Other testing may be necessary based on individual health history.**

The Transplant Center will **not** be financially responsible for:
Routine Health Maintenance

- **Pap Smear females >18 years (within last 12 months)**
- **Mammogram >40 years (within last 12 months)**
- **Colonoscopy >50 years (within last 5 yrs)**
- **PSA males >50 years (within last 12 months)**
- **Vaccines if recommended.**

If you have questions, please feel free to call:
The Living Donor Office
704-355-3602 or 800-562-5752.