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 2014, 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.

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.

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)
- 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 if necessary

The Transplant Center will <u>not</u> be financially responsible for: <u>Routine Health Maintenance</u>

- 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)

If you have questions, please feel free to call:

The Living Donor Office

704-355-3602 or 800-562-5752.

Revised: 1/12, 6/14

(N:Kidney-Pancreas/Donor Info Packet/The following are services...)

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 donors ages range from young children to 70 plus years and who have died as a result of trauma, or a neurologic/vascular incident. Donors must have consent from the 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 wait for a deceased 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 a negative crossmatch may be considered as a possible kidney donor. A related donor is considered to be parents, children, siblings, half-siblings, aunts, uncles and cousins.

Living donor transplants have a success rate of approximately 95%. This increased success rate stems from several factors including shared genetic markers not shared with a deceased donor, and decreased injury to the kidney that can occur during preservation before being transplanted. In fact, recent studies have shown that a kidney from a living donor who shows no genetic markers lasts as well or better than the best matched kidney from a deceased donor hence the rationale for living unrelated transplants. This type of transplant offers important advantages over deceased kidneys: the rejection rate is significantly lower and a living donor transplant can be scheduled when convenient, possibly shortening the dialysis period for the recipient who might otherwise wait years for a suitable deceased donor transplant.

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

You may qualify as a donor if you are in good general health, do not suffer from high blood pressure, cancer, diabetes, and have good kidney function. You are not necessarily excluded as a donor if you have a medical condition; it may have no effect on your ability to donate a kidney. Your overall health and emotional well being are of primary concern to the donor team.

In the event that a person decides to pursue donation, the donor team will refer him or her to a Transplant Nephrologist. A thorough evaluation will be performed to be sure that the donor is not only healthy enough but truly motivated to become a donor. We will ensure confidentially and provide the potential donor with an advocate who is free of conflict of interest who has your 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 situations of each of the potential donors have 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.

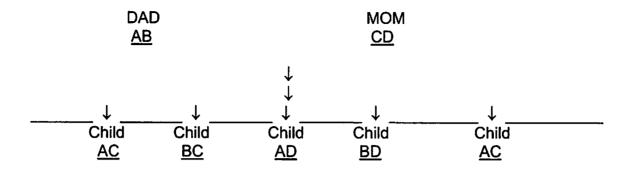
Blood Type	Can Receive From	Can Donate To Type	
0	0	O, A, B, AB	
Α	A, O	A, AB	
В	B, O	B, AB	
AB	O, A, B, AB	AB	

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, that 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 you match with the recipient.

The HLA typing is a scheduled test that involves having several tubes of blood drawn from the potential donors and potential recipient. This test identifies small proteins on our body cells called antigens. 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 it 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, would 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 consequences of donating a kidney on future development of 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 incidence of hypertension 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 causes 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 prospect 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, transplant social worker, and transplant nephrologist allows perspective 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.
- 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 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 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 given a 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 using antibacterial soap at the site where the incision is to be.

Shortly before going to the operating room IV fluids and 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 bowels 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 solid foods. The urinary catheter and other tubes will be inserted during surgery while the donor is asleep.

Medication is available for the discomfort 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 five 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 your Donor Transplant Coordinator at 704-355-6649 or 800-562-5752