Living Donor Kidney Transplant Education Manual

Texas Transplant Institute
A Department of Methodist Hospital
On the Campus of Methodist Specialty and Transplant Hospital
A Campus of Methodist Hospital

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About Methodist Healthcare

Methodist Healthcare is the most preferred health care provider in South Texas, according to consumers surveyed by the National Research Corporation. Methodist Healthcare has also won the Top Gold Award in the San Antonio Express-News’ Readers’ Choice Awards for the past three years.

Methodist Healthcares’ kidney transplant program at the Texas Transplant Institute, a department of Methodist Hospital, has built an outstanding reputation as a leading transplant center in the United States. The Texas Transplant Institute was created over 10 years ago to combine both the solid organ transplant program along with the adult and pediatric blood and marrow stem cell transplant program.

Our kidney transplant program began in 1984 at what is now Methodist Specialty and Transplant Hospital, a campus of Methodist Hospital. Since then we have performed over 3,000 transplants. Our dedicated transplant team focuses on providing the highest quality care to our patients and their families. The Texas Transplant Institute is committed to excellence in transplant patient care, education, and research. Our kidney transplant team puts nearly 30 years of experience to work each day as they evaluate patients from all over the United States.

At the Texas Transplant Institute, our team is devoted to improving life and making transplants happen for many patients who may have been told they would never find a suitable donor. Patients tell us that they chose Texas Transplant Institute because of the team approach to transplantation and the compassionate care they received. Our team approach has allowed us to give individualized attention to ensure recipients and donors have the best possible outcomes.

You and your family become part of the transplant team by taking an active part in your health care. As a member of the transplant team, you will be responsible for learning as much as you can about the transplant process. The first step in your journey is learning about the donation process and all that is involved. Since you are part of our team, you will not go through this process alone.

We are committed to quality patient care and encourage you and your family to contact us with any questions. We are truly grateful for the giving spirit of organ donors, both living and deceased, and their families.
Kidney, or Renal, failure occurs when the kidneys are unable to perform their normal function of filtering out waste and excess water from the body. When a patient loses 90-95 percent of their kidney function, life-saving treatment becomes necessary. Currently, the treatment options available include hemodialysis, peritoneal dialysis, and kidney transplantation.

Many patients with renal failure choose transplantation. Patients with renal failure can receive a kidney in one of two ways: from a deceased donor (a person who has died from an injury or accident or from a living donor. We ask each kidney transplant recipient to ask their family and friends to see if any of them are willing to donate one of their two kidneys. A living kidney donor is an ideal option because:

- In general, kidney transplants from living donors last longer than those from deceased donors;
- If a suitable living donor is not identified, the recipient may wait many years for the transplant from a deceased donor who is a match.
- With a living donor transplant, the surgery can be scheduled at a convenient time; once the evaluation process for the donor and the recipient has been completed and approved by the transplant team.
- With more modern transplant medications, a person receiving a living donor kidney may require fewer medications after a transplant which reduces potential side effects from those drugs.

The donation of a kidney to an identified recipient is a serious decision that must be made by a consenting adult (18 years or older). A living donor must understand the risks as well as the benefits involved in donating a kidney to another person. As with any surgery there are potential risks involved with donating. Possible risks include infection, bleeding, pain, as well as other complications including death in very rare circumstances.
Introduction to Transplantation

This Education Manual was developed specifically for anyone who wants to become a living donor. Please read the manual thoroughly and share it with interested family and friends. If you decide to pursue giving the gift of life by donating your kidney, you will need to review this information before your transplant. Please keep this manual readily available.

The decision to donate a kidney is a serious one for the donor and the recipient. Both are likely to have mixed feelings, which is normal. The recipient may find it difficult to ask a family member or a friend to donate a kidney. At the same time, the donor may be hesitant to offer because they don’t know what’s involved. That’s why we are providing this manual to help educate those who are considering kidney donation so they can fully understand all that’s involved in the process.

This manual will help answer any questions you may have about donating a kidney. Any questions not covered in this education manual can be discussed with a transplant coordinator, transplant surgeon, nephrologist, social worker, or independent living donor advocate.
Who Can Be a Living Donor?

You may be very excited about the prospect of donating a kidney to your loved one. First, let’s explore those who can actually be considered for a living kidney donation:

- Members of the recipient’s family: parents, siblings, aunts, uncles, cousins, grandparents, nieces, and nephews.
- Unrelated donors or “emotionally related” donors will be considered: spouse, in-laws, and close friends. These types of donors work just as well as “related” donors.
- All donors must be at least 18 years of age.
- All donors must be in great health. Each identified donor will have a complete physical and psychosocial evaluation. We will look for potential medical issues such as diabetes, high blood pressure, heart disease, as well as family and financial support.
- Compatible donors will be considered by the transplant team.

If you chose to become a living donor, it can be a very rewarding experience. You are giving the gift of life to someone you care about. This choice, however, is one that only you can make. At anytime during the evaluation, you change your mind to donate, your wishes will be respected. The transplant team is available to assist you with any questions or concerns you may have.
Expanded Live Donor Program

In 2009 and 2010, the Texas Transplant Institute in San Antonio performed the most living donor kidney transplants in the nation. We have developed new opportunities for kidney patients who typically had to wait a long time for a kidney or who were told that finding a match would be impossible. New, innovative alternatives for a living donor kidney transplant are now offered to candidates, such as:

A) Blood - Type Incompatible Program
B) Sensitized Patient Program
C) Kidney Paired Exchange Program
   - Incompatible Exchange Program
   - Compatible Exchange Program

Blood - Type Incompatible Transplant Program

At one time, patients who had living donors with a blood type that was not compatible, were not considered for a living donor kidney transplant. Now with the Blood - Type Incompatible Program, patients can receive a kidney from a living donor through a treatment process to remove antibodies that could cause rejection or through the Kidney Paired Exchange Program.
Sensitized Patient Program

About 30% of patients who are waiting for a transplant have high antibody levels. This is usually caused by a previous transplant, blood transfusion and/or pregnancy. These antibodies can make it very difficult to find a donor match, resulting in a long wait on the transplant list. Other antibodies not related to blood type may cause incompatibility between the donor and recipient. Although some recipients have someone willing to donate a kidney to them, they may not be able to use them because of their high antibody levels and how their body reacts to the donor’s cells.

Through the Sensitized Patient Program, the person in need of a kidney transplant can receive a treatment called plasmapheresis along with an intravenous (IV) medication to help remove these antibodies. The candidate may require several IV treatments. Antibody levels are checked throughout this treatment. In order to schedule the living donor kidney transplant, the antibody levels must be within a certain range.

Another option for sensitized patients with living donors is the Kidney Paired Exchange Program. The recipient/donor pair will be placed in the Kidney Exchange Program database to find a suitable exchange pair which is an acceptable match.
Kidney Paired Exchange Program

INCOMPATIBLE EXCHANGE PROGRAM

The Texas Transplant Institute is a national leader in exchange transplantation. We have a team dedicated to transplanting patients with living donors who are not a match. We have a very large database with hundreds of incompatible recipient/donor pairs, recipients who have a willing living donor who cannot donate because they are not a match due to incompatible blood types or due to the recipient antibodies.

A recipient/donor pair who wish to participate in this program are placed in the database to see if they are a match with another incompatible recipient/donor pair. It can sometimes be difficult to find a suitable exchange pair and the wait may be long. You will be contacted by the exchange team when a potential match is found.
Kidney Paired Exchange Program

**COMPATIBLE EXCHANGE PROGRAM**

Another type of exchange program involves exchanging recipient/donor pairs that are “compatible”. This means that they are not sensitized and have compatible blood types. Research has shown that the age of the donor kidney is a strong predictor of long-term kidney function. The Kidney Paired Exchange Program offers patients with older compatible kidney donors the opportunity to exchange donors with recipients who have a younger donor who is not compatible with them. An example is:

In this example, a recipient has a chance to receive a kidney from a younger donor while the other recipient with an incompatible donor is able to receive a living donor kidney transplant from a compatible donor.
Kidney Removal Techniques

The donated kidney can be removed by using one of two surgical techniques, these are:

- Laparoscopic Donor Nephrectomy
- Open Donor Nephrectomy

**Laparoscopic Donor Nephrectomy**

Nearly all living donor operations performed at the Texas Transplant Institute are performed laparoscopically. Laparoscopic nephrectomy is a minimally invasive surgery that uses small incisions to remove the kidney. The small incisions allow a special camera called a laparoscope to view inside the abdominal cavity.

The kidney, which is about the size of your hand, is removed from a 3-4 inch incision around the belly button.

Using small incisions, this type of surgery results in less blood loss, less pain, faster recovery and quicker discharge from the hospital. The operation typically takes one to two hours and most donors are in the hospital two to three days, and usually return to normal activities in 3 to 4 weeks.

Rarely, the laparoscopic surgery may need to change to the open nephrectomy procedure if the surgeon decides it is necessary. This does not keep you from donating the kidney; it only changes how the kidney is removed.

Not everyone can have their kidney removed laparoscopically. Some patients may not qualify for this type of kidney removal if:

- The anatomy of the kidney does not allow it.
- The donor has had multiple abdominal surgeries in the past.
**Open Donor Nephrectomy**

Open donor nephrectomy is reserved for living donors who do not qualify for the laparoscopic technique. This type of surgery involves a 5-7 inch incision on one side of the abdomen. Sometimes it is necessary to remove part of the rib to get more room to remove the kidney.

The operation typically lasts two to three hours and recovery in the hospital is four to five days. Donors could return to normal activity within 8-12 weeks.

Your transplant surgeon will discuss each of the techniques with you and go over the risks involved. The transplant surgeon will determine which surgery would be most suitable for you and answer any questions you may have.
Financial Considerations

A major concern among those who wish to be a kidney donor is how medical costs and hospitalization will be paid. Most patients with kidney failure are eligible for benefits covered by Medicare. They may also have additional insurance from their employer. These benefits are extended to their potential donors. The donor evaluation, transplant surgery, hospitalization, and follow-up medical care are, in most instances, paid for by the recipient’s insurance. If the recipient’s insurance does not cover those items, the transplant center assumes responsibility.

However, the recipient’s insurance does not pay for the following expenses: loss of income during hospitalization and recovery, transportation costs to and from the hospital, or any other non-medical costs that would arise as a result of not being able to work for that period of time. If there are any problems regarding any of these issues, the transplant team will work with you to address these concerns.

If any complications related to the donation occur, the recipient’s insurance or the transplant center will pay for the medical treatment (See table on next page).

All donor complications **MUST** be reported immediately to the transplant team before any medical treatment is given.

After donation, there is a chance you could be denied insurance coverage. This is a potential risk that you should fully understand prior to donation. You may want to consult with your insurance provider ahead of time.
The following table will clarify exactly how bills will be paid throughout your evaluation and following your surgery.

<table>
<thead>
<tr>
<th>Donor Coverage Categories</th>
<th>Donor Evaluation</th>
<th>Surgery</th>
<th>Surgical Follow Up (routine)</th>
<th>Complication(s) Hospital</th>
<th>Complication(s) Physician</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coverage Related to Donation</td>
<td>Texas Transplant Institute</td>
<td>Recipient Insurance</td>
<td>Recipient Insurance</td>
<td>Texas Transplant Institute</td>
<td>Recipient Insurance</td>
</tr>
<tr>
<td>Healthcare issues NOT related to donation</td>
<td>Donor Responsibility</td>
<td>Donor Responsibility</td>
<td>Donor Responsibility</td>
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*If the recipient did not apply for a policy with coverage, he/she will be responsible for donor bills.

Please discuss any questions about potential complications with the transplant financial coordinator and transplant nurse.
The donor evaluation testing can be completed at the Texas Transplant Institute clinic. If you live outside San Antonio, arrangements can be made with your transplant coordinator to have these tests done in your hometown. We strongly recommend having the testing done at our center to expedite the evaluation process and to take advantage of the clinical expertise available at the Texas Transplant Institute that deals specifically with transplant surgery and evaluations.

As a potential living donor, you will go through a complete evaluation to see if you can be a donor. This includes the following tests:

1. **Donor Screen to evaluate for possible risks**  
   *(Questions will be asked to evaluate your ability to safely donate a kidney.)*

2. **Laboratory studies:**
   - Blood type  
   - Genetic type  
   - Urine testing  
   - Crossmatch *(Test done to see if the recipient’s blood will react to your blood)*  
   - Routine laboratory testing

3. **Diagnostic testing:**
   - Chest X-ray  
   - Electrocardiogram (EKG)  
   - Other tests that may be needed

4. **Medical:**
   - Provide a complete list of any medication you are taking: prescription, over the counter, vitamins, herbal supplements  
   - Physical exam by the transplant coordinator, transplant surgeon, and transplant nephrologist  
   - Evaluation by a social worker  
   - Evaluation by an independent living donor advocate  
   - Evaluation by a transplant psychologist or psychiatrist, as needed  
   - Evaluation by a nutritionist, if needed
5. Final Medical:

- Radiology imaging of the kidneys (Spiral Cat Scan, X-ray, Ultrasound)

The Spiral CT is a detailed imaging procedure that allows the surgeon to see the kidneys and their blood supply. This test takes approximately 20-30 minutes to complete. Before the imaging, you must not eat or drink anything for at least four hours before the test. You will be positioned on your back and an IV inserted in your arm. The CT scanner will take images of your abdomen. A dye may be injected into the IV in your arm and the CT scanner will record more images so doctors can see how the dye passes through your kidneys blood supply. Once the final pictures are taken, you will need to stay for a short time to make sure there is no allergic reaction to the dye.
6. Independent Living Donor Advocate:

After the medical and psychosocial evaluation, an independent living donor advocate will be assigned to you as a resource. The purpose of the advocate will be to protect and promote your interests. The advocate will assist you in making informed decisions, while balancing external pressures involved in the donation process. The advocate will be a representative of the transplant program but is not a part of the kidney recipient’s evaluation team. The advocate will work only with you and will keep your welfare as their primary concern.

An independent living donor advocate assessment will be performed. Once the assessment is completed, any concerns or need for information will be addressed. When a decision has been made about whether you are ready to proceed, the case will be presented to the patient selection committee and the multi-disciplinary team for evaluation.

The independent living donor advocate is part of YOUR team. Please feel free to request him/her at any time during your evaluation or following your surgery.
7. **Final Step:**

After completing your evaluation, your case will be presented to the patient selection committee. Your medical and psychosocial data will be reviewed by the committee. Upon approval from this group of professionals consisting of transplant surgeons, nephrologists, transplant nursing staff, nutritionist, social workers, psychologist, psychiatrist, and the independent living donor advocate, the surgery may be scheduled.

If at any point during the evaluation you are ruled out, the next available living donor (if any) will begin the process, or the recipient will remain on the waiting list.
You and the recipient will arrive at the transplant clinic the day before the scheduled transplant. At this point, both of you will undergo a final medical evaluation. If either of you show any abnormalities, the transplant surgery will likely be postponed or cancelled.

Pre-operative teaching takes place during this clinic visit and allows you time to discuss any last minute questions with your transplant surgeon or the transplant staff. Expect to spend most of the day at the clinic. The next day will be an important one and we do not want to rush any of the last minute details. After the clinic visit, you and the recipient will be free to leave. Sometimes, the recipient might need to be admitted directly to the transplant unit and spend the night in the hospital.

On the day of the surgery you will go to the registration area designated by your transplant coordinator. The donor operation usually lasts one to two hours. Family members can wait in the waiting room where a member of the surgical team will come and talk to them after the operation.
After surgery you will go to the recovery room. You will be transferred to your hospital room when you wake up from the anesthesia. You may have an IV in your arm and you may also have a catheter in your bladder that is inserted when you are under anesthesia; this is a tube that empties urine out of your bladder.

You will be able to start drinking clear liquids once you go to your hospital room. Your diet will gradually be increased to a regular diet by the transplant surgeon.

We encourage activity starting on the first day after your surgery to include breathing exercises and walking. Your pain will be managed through your IV. Before you are discharged from the hospital, your medication will be changed to pills or liquid. The catheter in your bladder will likely be removed the first morning after the operation.

Although very rare, there are always potential complications with any major surgery. These complications may include infection, collapsed lung, pneumonia, bowel obstruction and/or painful scar. These can be treated but, may result in a longer hospital stay. Most donors do not experience any complications. The average length of stay in the hospital for a donor is two to three days.

The discharge instructions on how to take care of yourself at home will be reviewed with you by a transplant coordinator. The coordinator will also schedule your follow-up visit. You will be discharged with medications as ordered by your transplant surgeon.
Once you are discharged from the hospital, a follow-up appointment with your transplant surgeon should be scheduled for two weeks after surgery. You may return to moderate activities such as walking, light housework and driving, as directed by your doctor. Sexual activities can return to normal once you feel comfortable to do so, and if there is no direct pressure on the incision. Your diet or fluid intake will not change, but a well balanced diet is recommended for six to eight weeks post-transplant to help the incision(s) heal and to prevent constipation.

You should not lift anything over 15 lbs. for at least four weeks after the surgery; this includes pets and small children. This will allow your incision enough time to heal. You may also experience a bloated feeling in your abdomen for one to two weeks after surgery. This will gradually go away. You can usually return to work within two to four weeks depending on your occupation and how much lifting is required. By the sixth week, you should be able to return completely to your normal activities of daily living.
Follow-Up

Because your health is important to us and we want to continually improve the experience of our living donors, at no cost to you, the transplant center will do health monitoring exams for two years at the intervals listed below:

• 6 months
• 1 year
• 2 years

The transplant staff at the Texas Transplant Institute hopes that this Education Manual serves as an introduction to living donation. This is only an overview, and we encourage you to ask the transplant team questions at any time during the process.
**Frequently Asked Questions**

**What happens if my blood tests show that I am compatible?**

You will usually be informed of your blood test results (within five to seven days) after a blood sample is drawn. Discussion regarding further testing will begin.

**What if a recipient has several compatible donors?**

We will check for compatibility for up to four potential living donors per recipient. Once we determine who is compatible, it will be the family’s decision to choose the primary person to go through the full evaluation to become a living donor.

**Will I be the only one contacted with my compatibility results?**

Yes, you will be the only person contacted with any medical results.

**How long will it take for the transplant to happen?**

The time varies for each patient (recipient and donor) due to the amount of testing that is required. The goal for completing the evaluation is four to six weeks. Once both the recipient and donor evaluations are completed and approved for transplant surgery, a surgical date can be planned.

**Who decides on whether the recipient and donor are good candidates?**

The transplant team is composed of transplant surgeons, nephrologists, transplant nurses, social workers, dietitians, psychologist, psychiatrist, and an independent living donor advocate. This team meets every Monday to discuss patient evaluation results and whether individuals are suitable candidates for transplant or donation.
**Frequently Asked Questions**

**Will young female donors be able to have children in the future?**
Yes. Females of childbearing age can have children following kidney donation. They will need to inform their doctors of their history of kidney donation and be followed closely by their obstetrician. Sexual capabilities will not be affected in either men or women.

**Will the donor have to pay for anything?**
The donor evaluation and surgery will be covered by the recipient’s insurance in most cases. The only areas NOT COVERED would be travel, lost wages from time away from work, or any non-medical costs related to time away from home or work. There are some organizations that can help with some of the costs. Your transplant coordinator can help you identify resources you may need.

**Does a living donor have to be related or be the same blood type?**
Donors do not have to be related. Many of our living donors are spouses or friends. The living donors do not have to be the same blood type, but they must be “compatible”. The transplant center can determine whether a potential living donor is “compatible” and will discuss this with you.

**What if a donor is not compatible to their recipient?**
The Texas Transplant Institute has performed more incompatible exchange transplants than any other transplant center in the nation. Your transplant coordinator can provide you with more information about the Kidney Paired Exchange Program.
Frequently Asked Questions

Can donors with diabetes or high blood pressure donate?

Donors with diabetes cannot donate due to the effect diabetes has on the kidneys. Donors with high blood pressure may or may not be able to donate. The transplant physicians will perform tests to determine if you can be a donor or not.

Will I feel different following donation?

Following donation and recovery you should feel no different than you did prior to your surgery. Sometimes the recovery process can take time, but you will be able to resume all your regular activities in time. There should be no changes in frequency of urination. A small number of donors have experienced some emotional effects after donation (anxiety, depression, tearfulness, and uncontrolled emotions). If you experience any of these, please contact us at (210) 575-8425.

What happens if I have a problem related to the kidney donation?

At any point, if you have a medical problem directly related to the kidney donation, immediately contact the transplant center. Regardless of the amount of time since your donation, the transplant center staff is available to help you.

How does this change affect me?

Donation does not restrict or interfere with your lifestyle. After a period of recovery, you may gradually return to your normal activities and work. There are limited lifestyle restrictions for people who perform full contact sports or are pilots. Your life expectancy does not change and kidney donation does not increase your risk of kidney disease. Your remaining kidney will grow and maintain daily function.

Do donors have trouble keeping or getting insurance following donation?

Donors should not have difficulty maintaining or obtaining life, health or disability insurance following kidney donation. A survey of insurance companies indicated that the cost of insurance does not increase, and another survey of donors found that roughly 98 percent encountered no problems with insurance. However, donors are encouraged to check with their insurance companies to verify the details of their policy prior to donation.
If you decide to donate, it should be a voluntary gift without financial gain. Your decision will be respected and you should never feel pressured to donate. The recipient may also reject your offer and his/her decision must also be respected. All feelings can be expressed to the transplant team and will be kept completely confidential.

If at any time you change your mind, the team will help you make a confidential withdrawal from the procedure.

If you have any further questions please contact the Live Donor Hotline

(210) 575-GIVE (4483)
Toll Free: (800) 888-0402
## Important Phone Numbers

**Texas Transplant Institute**  
*At Methodist Specialty and Transplant Hospital*  
8201 Ewing Halsell Drive, 2nd Floor  
San Antonio, TX 78229

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<tr>
<th>Transplant Clinic - San Antonio</th>
<th>Transplant Clinic - Corpus Christi</th>
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<tbody>
<tr>
<td>Telephone: (210) 575-8425</td>
<td>Telephone: (361) 884-2809</td>
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<tr>
<td>Fax: (210) 575-8435</td>
<td>Fax: (361) 884-2781</td>
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**Live Donor Hotline:**  
(210) 575-GIVE (4483)  
Toll Free: (800) 888-0402  
Fax: (210) 575-8648

My Transplant Surgeon: ________________________________________________

My Transplant Nurse: _________________________________________________

My Transplant Scheduler: _____________________________________________

My Social Worker: ___________________________________________________

My Pharmacy: _________________________________________________________
Texas Transplant Institute
Texas Transplant Institute
8201 Ewing Halsell Drive
San Antonio, Texas 78229
(210) 575-8400 – (800) 888-0402
Thank you for your consideration on becoming a kidney donor and providing the “Gift of Life”!

Continuing the Legacy of Hope
Through Patient Care, Research and Education