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## **What is living donation?**

Living donation takes place when a living person donates an organ (or part of an organ) for transplantation to another person. The living donor can be a family member, such as a parent, child, brother or sister (living related donation).

Living donation can also come from someone who is emotionally related to the recipient, such as a good friend, spouse or an in-law (living unrelated donation).

In some cases, living donation may even be from a stranger, which is called nondirected donation.

## **What organs can come from living donors?**

The organ most commonly given by a living donor is the kidney. Parts of other organs including the lung, liver and pancreas are now being transplanted from living donors.

## **What are the advantages of living donation over deceased donation?**

Transplants performed from living donors may have several advantages compared to transplants performed from deceased donors:

1. Some living donor transplants are done between family members who are genetically similar. A better genetic match lessens the risk of rejection.
2. A kidney from a living donor usually functions immediately, making it easier to monitor. Some deceased donor kidneys do not function immediately, and as a result, the patient may require dialysis until the kidney starts to function.
3. Potential donors can be tested ahead of time to find the donor who is most compatible with the recipient. The transplant can take place at a time convenient for both the donor and recipient.

## **Are transplants from living donors always successful?**

Although transplantation is highly successful, and success rates continue to improve, problems may occur. Sometimes, the kidney is lost to rejection, surgical complications or the original disease that caused the recipient's kidney to fail. Talk to the transplant center staff about their success rates and the national success rates.

## **Where can I find statistics related to living donation?**

You can find some statistics on the United Network for Organ Sharing (UNOS) web site. UNOS compiles statistics on every transplant center in the United States. To view all UNOS data, go to

<http://optn.transplant.hrsa.gov/latestData/viewDataReports.asp>. You can find statistics on the number of non-living and living donor transplants performed at that particular center, respectively, and the graft survival rates for the transplant recipient.

The best source of information on expected donor outcomes is from your transplant team. See the list of "Elements of Disclosure" at [http://www.kidney.org/transplantation/livingDonors/pdf/jama\\_article.pdf](http://www.kidney.org/transplantation/livingDonors/pdf/jama_article.pdf) (page 3) for a list of issues to discuss with your transplant team.

### **How does liver donation work?**

Some transplant centers perform living donor liver transplants. If you are considering donating a part of your liver to a friend or family member, contact the person's transplant center for more information. If the transplant candidate does not yet have a transplant center, contact centers in the candidate's area for information.

Donating a section of a liver is riskier than kidney donation, and much less common. Transplanting a piece of the liver works because the liver regenerates itself in both the donor and recipient after transplantation.

Besides being in excellent physical and psychological health, the liver donor must undergo extensive examinations and testing. A radiological imaging of the liver is done to assess the anatomy, liver volume and size. A liver biopsy may be performed.

Most often parents donate a piece of a liver to a child. Adult to adult live liver transplant is still relatively rare.

We recommend talking to your transplant center about their experience and success rates, which can give you critical information to help you make a decision. You can find statistics and information about living donation on the United Network for Organ Sharing (UNOS) web site at [www.transplantliving.org](http://www.transplantliving.org).

### **How does lung donation work?**

Living lung donation involves two adults giving the right and left lower lobes from each respectively to an adult or pediatric recipient.

The potential donors' lungs must be the right size and volume. For adult recipients, the donors should be at least as tall as the recipient. Ideally, donors should not be overweight and should be non-smokers.

Potential donors receive a series of exams and tests including chest radiography, pulmonary function testing, ventilation-perfusion scanning and computed tomography, cardiac stress test.

Again, donating a lung is riskier than live kidney donation and the risks and benefits will be discussed with the transplant team.

Contact transplant centers for additional information about lung donation. You can find statistics and information about living donation on the United Network for Organ Sharing (UNOS) web site at [www.transplantliving.org](http://www.transplantliving.org).

### **What about blood and bone marrow donation?**

Blood and bone marrow donations save lives every day. For more information about blood donation, call the American Red Cross at (800) GIVE LIFE, or visit [www.redcross.org](http://www.redcross.org).

For information about bone marrow or blood stem cell donation, contact the National Marrow Donor Program at (800) MARROW2 or at [www.marrow.org](http://www.marrow.org).

### **How can I be a living kidney donor to someone I know?**

To donate a kidney, you must be in good health and have normal kidney function and anatomy.

If the donor meets the criteria for donation, additional testing will be required to check for further compatibility (cross matching and tissue typing) as well as physical examinations and psychological evaluation. More information on testing and surgery procedures can be found in this booklet.

The donor should make the decision voluntarily and free from internal or family pressure. The decision to donate needs to be made with all the information necessary to make an informed, educated choice.

Immunosuppressive medications, which keep the recipient's body from rejecting the donor kidney, have improved greatly over the last few years. Now, a genetic link between the donor and recipient does not appear to be necessary to ensure a successful transplant.

Before surgery, the donor will receive education and counseling to help prepare mentally and emotionally for the donation and recovery. If the donor has questions, the transplant team can help. The decision to donate will affect all members of the person's family and should not be taken lightly.

Your first step is to contact the potential recipient's transplant center. (Transplant centers are hospitals that perform transplant operations-and donor operations, if there is a living donor). You should ask to speak with the Kidney Transplant Coordinator, who can give you additional information about living donation, and help you get started. If you live far away from the transplant center, you'll be referred to a center in your area for initial testing.

### **I want to be a donor to a friend or family member, but they won't let me. What can I do?**

Some individuals with kidney failure may decide they do not want the transplant or choose not to consider a living donor. The person with kidney failure can choose to accept or reject your offer to donate. He or she has the right to decide against a transplant (though you may feel it would help). The patient, who must live with the disease, has the right to decide what is to be done. That decision, as well as yours, must be respected.

### **What are the long-term risks of donation?**

You will also have a scar from the donor operation- the size and location of the scar will depend on the type of operation you have.

Some donors have reported long-term problems with pain, nerve damage, hernia or intestinal obstruction. There are not currently any national statistics on the frequency of these problems.

In addition, people with one kidney may be at a greater risk of:

- High blood pressure
- Proteinuria
- Reduced kidney function

For more information, visit the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) website at <http://kidney.niddk.nih.gov/kudiseases/pubs/solitarykidney>

You should discuss these risks with your transplant team, and ask for the hospital for any statistics related to these problems.

### **What else can I do?**

You may not be able to be a living donor- or you may decide that living donation isn't right for you. You can still help those awaiting life-saving organ transplants. Here are a few ways you can make a difference.

1. **Be a Donor after Death:** Learn more at <http://www.donatelife.org>

2. **Donate blood or bone marrow:** Blood and bone marrow donations save lives every day. For more information about blood donation, call the American Red Cross at (800) GIVE LIFE, or visit [www.redcross.org](http://www.redcross.org).

For information about bone marrow or blood stem cell donation, contact the National Marrow Donor Program at (800) MARROW2 or at [www.marrow.org](http://www.marrow.org).

3. **Volunteer or make a donation:** Contact the NKF at (800) 999-9697 to make a donation, or for information about NeKF programs in your area.

### Who pays for living donation?

The cost of the living donor's evaluation, testing and surgery are generally paid for by the recipient's Medicare or private health insurance, if the donation is to a family member or friend. Donors should always coordinate their tests with the transplant coordinator at the hospital in case there are any exceptions.

Time off from work and travel expenses are not covered by Medicare or private insurance. However, donors may be eligible for sick leave, state disability and the Family and Medical Leave Act (FMLA). Some follow-up expenses may also not be covered, so it's important to discuss these matters with the transplant center. The financial counselor at the transplant center can answer any questions you have about the cost of donation.

You can also request a free Q&A from the United Network for Organ Sharing entitled "What Every Patient Needs to Know." The booklet has an extensive section on financial issues for both donors and recipients, including social services, insurance coverage, Medicare and Medicaid coverage, fund raising campaigns and other possible sources of assistance. Call UNOS toll-free at 888-894-6361 to request a copy.

### What tests are used to determine if someone can be a kidney donor?

Potential donors will have blood, urine and radiology tests to determine suitability for donation. A full physical examination will be done, and psychology evaluation may also be required. Time will be allotted for asking questions and addressing any concerns the donor may have.

Before surgery, special x-rays will be taken of the donor's kidneys, including either a renal arteriogram or spiral CT scan to check the anatomy of the kidney. Additional blood tests called tissue or HLA typing may also be done to determine the quality of matching between the donor and the recipient. The closer the match, the lower the likelihood of rejection of the transplanted kidney.

The following process is used to determine if someone can be a donor. This is a general description of the testing process, and may vary from center to center:

1. **A financial consultation** will be used to determine financial and insurance coverage for the testing process and the donation itself. Generally, if the donation is to a family member or friend, the recipient's insurance will pay for testing and surgery expenses. However, the donor might be responsible for travel expenses (if the donor and recipient live in different towns/states) and follow-up care, in addition to lost wages. Since donors are never financially compensated, be sure to ask the financial counselor and/or social worker at the transplant center for assistance with these issues.
2. **Immunological Tests:** A blood sample is taken for the following tests:

- ABO test to determine the donor's blood type: O, A, B, or AB

In living donation,

Donors with: Blood type A

Can give to: Blood types A & AB

Donors with: Blood type B

Can give to: Blood types B & AB

Donors with: Blood type AB

Can give to: Blood type AB only

Donors with: Blood type O

Can give to: Blood types A, B, AB and O

\* O is the universal donor; that is, it can be given to A,B,AB, and O blood types.

So,

Recipients with: Blood type O

Can receive from: Blood type O only

Recipients with: Blood type A

Can receive from: Blood types A and O

Recipients with: Blood type B

Can receive from: Blood types B and O

Recipients with: Blood type AB

Can receive from: Blood types A, B, AB and O

\* AB is the universal recipient; that is, it can receive O, A, B, or AB blood types.

**Please note that there are some programs that may help donor/recipient pairs with blood types that are incompatible: paired exchange and plasmapheresis. [Click here for more information.](#)**

- Tissue typing is used to identify the donor's particular HLA antigens and determine if the donor and recipient are compatible.
- Family analysis: If an entire family is being tested, blood samples will be taken of all potential donors to determine compatibility. This takes approximately one week before the results are known.

Some transplant centers use a Skin Crossmatch to determine compatibility. A small piece of skin is removed from the potential donor's arm under local anesthesia. This is an outpatient procedure.

The cells of the skin are closer to the genetic composition of the cells in the kidney. The process takes the skin cells of the donor and incubates them against the sera of the recipient. If the skin cells are destroyed, resulting in a "positive crossmatch", the transplant cannot take place.

### 3. **Laboratory Tests:** A blood sample is taken to:

- Assess the hematological system
- Assess clotting mechanism
- Assess baseline kidney function
- Screen for abnormal electrolyte balance

- Screen for unsuspected tendency toward glucose intolerance which might occur post transplant with steroids
- Screen for venereal disease
- Screen for pancreatitis
- Screen for liver abnormalities, which might delay the transplant until the cause is found (fluid overload, acute or chronic hepatitis)
- Determine whether or not the patient has Hepatitis B
- If HbsAB is positive (and the HbsAg is negative), the patient has developed antibodies to Hepatitis B either through vaccination or exposure
- Look for past or present viral activity
- If the donor is CMV positive, the recipient may need to receive Cytogam and gancyclovir post transplant to prevent reactivation of the disease
- Screen for the HIV virus

4. **An EKG will be performed** to assess heart function. A chest x-ray will be used to assess the lungs for the presence of any abnormalities.
5. **A medical history review and physical examination.** An extensive review of all systems, including previous illnesses and surgeries and past family medical history. Any abnormalities found are investigated further before invasive tests are performed.
6. **A psychological evaluation will be used to:**

- Provide emotional support and information to the donor
- Assess the donor's motivation. If the potential donor does not want to donate, the transplant team can help the donor decline in a way that preserves the family relationships.
- Evaluate if there is family pressure or financial incentive to donate.
- Give the donor an opportunity to express himself or herself more fully than she might to the physician, or with the recipient or family present.
- Help the staff work with the donor and family prior to, and after surgery.

7. Female donor candidates may undergo a gynecological exam and mammography.
8. **Kidney Function Tests:** Urine samples are taken to:

- Screen for kidney disease or any abnormalities
- Determine the absence or presence of a urinary tract infection.
- Assess the amount of protein excreted in a 24-hour period. An increased secretion of protein would need to be evaluated before resuming the evaluation; the creatinine clearance is to determine adequate kidney function and to ensure that the 24 hour collection is an adequate one.
- Determine glomerular filtration rate (GFR) which measures "how fast" the kidney can clear a known substance.

9. An intravenous pyelography test may be used. This test involves an injection of dye into a vein in your arm. The dye circulates through your body, into your kidneys, and then into your urinary tract. X-rays are taken to identify the structure of the kidney, veins, arteries, the ureter, and other anatomy.
10. A Helical CT Scan is done in some transplant centers. The helical CT scan is used to evaluate the internal structure of the kidney and look for the presence of cysts, tumors, etc.
11. Some transplant centers will perform a renal arteriogram if there is a question of an abnormal finding on the Helical CT Scan. The renal arteriogram is an x-ray which looks at the vasculature of each kidney: the number of blood vessels to and from each kidney, or any evidence of vascular disease that might rule out donation. This test requires an observation period post-exam of 6-8 hours and in some instances may require hospitalization. This is the last test done.
12. When the tests are completed, the results are presented to the transplant team (surgeons, nurses, social workers, financial counselors, etc.) to determine if the person is a suitable candidate for donation. The length of the testing process depends upon the availability of the donor for testing, the results of the completed tests, and the individual policies and procedures of the transplant center involved.

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### Can I get tested as a donor without the recipient knowing?

It may not be possible to be tested anonymously. You will need to ask the "Kidney Transplant Coordinator" or "Kidney Transplant Social Worker" at the recipient's hospital about this issue.

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### Can smokers be living donors?

Smoking is considered a risk to the potential donor. Because smoking damages the lungs, it may put the donor at a higher risk of developing pneumonia after surgery. Potential donors should be honest with the transplant center about smoking habits to ensure that the donation and transplant are successful.

Different transplant centers have different policies regarding smoking and living donation. Living donors may be asked to quit smoking prior to the donation, and if the person is a heavy smoker, he or she might be asked to see a pulmonary doctor to check breathing.

#### 4. Making the Decision

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- a. [What do I need to think about before donating?](#)
  - b. [What if I decide against being a living donor?](#)
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### What do I need to think about before donating?

Living donation is a big decision, so you should make sure you're comfortable with your choice. Consider all the information in this booklet carefully, as well as information from your transplant center. Talk to your family members and friends. Some donors also find it helpful to consult with co-workers, a psychologist, social worker, or spiritual advisor.

You can also connect with other living donors through the National Kidney Foundation. If you'd like to talk with other donors about their experience, please visit our [Sharing & Support](#) section. Your transplant center may also be able to refer you to other donors.

Your transplant center will have a social worker who can help you with the process. The social worker is there to assist you, and will keep your discussions confidential.

Potential donors should consider the following questions:

1. How do you feel about organ donation in general? How much education and information do you have about the process?
2. What are the benefits and risks of donation to you personally?
3. How would living donation affect you financially? Would you lose wages during your recovery? Are you able to get paid leave from your employer? Are you retired or currently unemployed, so that lost wages wouldn't be a factor?
4. Who else can be considered as a donor? Other potential donors should consider these issues, as well.
5. Are you physically active? It's recommended that kidney donors avoid sports that involve high risks of collision, to avoid damaging the remaining kidney (such as boxing, field hockey, martial arts....). Do you have a physically demanding job?
6. How is your relationship with the recipient? If the donor and recipient have a difficult relationship, some donors may have unrealistic expectations that the relationship might improve.

How will you feel if the organ fails? How will you feel if the recipient is not grateful in the way you imagined? If the relationship becomes strained or difficult, can you cope?

7. Are you able to handle post-operative pain, a bout of depression, anxiety? Are you prepared emotionally and financially to seek psychological counseling or help if you need it? Can you handle a complication that may delay your recovery?
8. Do you live near the recipient and the transplant center where the donation would take place? If the donor lives near the transplant center, the donation will be logistically easier-- and save travel, lodging and other expenses.
9. What other obligations do you have (such as a demanding job, volunteer commitments, young children, etc.)? How will you manage these obligations during your recovery?
10. Do you smoke? If so, you might have to quit smoking prior to the donation.
11. Are you overweight? If so, you might need to lose weight prior to the donation.
12. Do you have plans to change occupations soon? If so, how would donation affect your health insurance coverage? Life insurance? Some branches of the military, police and fire departments won't accept individuals with one kidney. If any of you are in these fields (or considering these fields), you should think carefully about how living donation might affect you.
13. Who can support you (both in emotional and practical ways) during this process?

Potential donors will need to consider their overall health, any medical problems such as high blood pressure or diabetes, level of activity, the effects of donation on children or other family members, financial considerations, time lost from work, travel expenses, and the donor's distance from the transplant center.

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### **What if I decide against being a living donor?**

The decision to become a living donor must be made voluntarily and free from pressure. Individuals have the right to decide that kidney donation is not for them. Likewise, some individuals with kidney failure may decide they do not want a transplant or choose not to consider a living donor. The decision of the potential donor and recipient must be respected. Living donors may change their minds at any time during the evaluation process without fear of embarrassment or repercussions:

*There may be instances... in which the potential donor seeks the support of the transplant team to decline donation. For example, if the potential donor anticipates being ostracized from the family by saying "no" to the recipient, the transplant team could assist the potential donor in developing an appropriate medical disclaimer, enabling the potential donor to decline gracefully...*

*-- The Authors for the Live Organ Donor Consensus Group, "Consensus Statement on the Live Organ Donor", JAMA, December 13, 2000- Vol 284, No. 22 (Reprinted)*

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### **5. Financial and Insurance Issues**

- a. [Who pays for living donation?](#)
- b. [Will my health or life insurance coverage be affected by donation?](#)
- c. [Is there any assistance available for lost wages, travel and lodging?](#)
- d. [Resources and Additional Information](#)

### **Who pays for living donation?**

Potential donors should talk with their transplant hospital about financial and insurance issues. The hospital will have a "Transplant Social Worker" and/or "Transplant Financial Counselor" who can advise potential donors about their options, along with what expenses will be incurred by the recipient's insurance, the donor or the hospital.

Generally, the recipient's Medicare or private health insurance will pay for the following for the donor (if the donation is to a family member or friend). Donors should always coordinate their tests with the transplant coordinator at the hospital in case there are any exceptions:

- Evaluation to determine if the person is a good candidate for living donation
- Donation surgery
- Post-operative care

However, the following expenses generally wouldn't be paid by either the recipient or the donor's insurance:

- Lost wages during the donor's recovery. Time off from work is **not** covered by Medicare or private insurance. However, donors may be eligible for sick leave, state disability and the Family and Medical Leave Act (FMLA).
- Travel expenses. If you are traveling to a transplant hospital away from home, you can incur expenses for travel, lodging expenses during evaluation and recovery, phone calls to home, childcare, etc. Some transplant hospitals offer free or low-cost hospitality houses for you and your family—be sure to ask about your options.
- Expenses for treatment of unrelated conditions that are discovered during the evaluation process
- Some follow-up expenses may also not be covered, so it's important to discuss these matters with the transplant center. The financial counselor and/or transplant social worker at the hospital can answer any questions you have about the cost of donation.

Again, potential donors should talk to the transplant hospital about their unique situation.

You can also request a free booklet from the United Network for Organ Sharing entitled "What Every Patient Needs to Know." The booklet has an extensive section on financial issues for both donors and recipients, including social services, insurance coverage, Medicare and Medicaid coverage, fund raising campaigns and other possible sources of assistance. Contact UNOS at <http://www.unos.org/contact/index.php> to request a copy.

### **Will my health or life insurance coverage be affected by donation?**

There have been some instances in which living donors had difficulty changing insurance carriers after the donation, due to higher premiums or a pre-existing waiting period. It is not known how commonly these issues have arisen.

If you are considering donation, talk to the financial counselor and social worker at the transplant center to find out if donation will affect your health or life insurance coverage.

If you already have insurance, check your insurance contracts carefully to see if living donation would affect your current policies. You might also want to consult with a lawyer who is knowledgeable about insurance law.

In December 2000, a group of transplant professionals (surgeons, physicians, transplant coordinators, social workers) published recommendations related to the care of living donors. You can find their published recommendations at [http://www.kidney.org/transplantation/livingDonors/pdf/jama\\_article.pdf](http://www.kidney.org/transplantation/livingDonors/pdf/jama_article.pdf). The article does address life and health insurance coverage under the section on "Psychosocial Suitability". Here is the excerpt:

*In addition, the psychosocial evaluation can address a variety of other issues including the ability of the potential donor and family to cope effectively with stresses associated with transplantation (before and after donation)..... [including] the ability of the donor to subsequently obtain life insurance without additional cost.*

*For example, with regard to obtaining insurance, a survey of health insurance companies conducted by Spital and Kokmen<sup>10</sup> found that the majority of health care organizations did not consider healthy kidney donors to be at increased risk for medical problems and would not raise their premiums. To guarantee that a factual basis supports this contention of future insurability, more relevant prospective data are needed that would include live organ donation of the lung, liver, intestine, and pancreas.*

*Since the Spital and Kokmen report, some of the conference participants have been told by potential donors that their life insurance options would be limited if they became an organ donor. In such cases, it may be necessary for transplant centers to inform the insurance carrier of existing data that report that the patient is not at increased risk of death because of donation. Some organizations are attempting to offer insurance options specific to live organ donors (i.e., life, health, and disability insurance).*

Again, it is important for potential donors to carefully consider these issues before proceeding with donation.

### **Is there any assistance available for lost wages, travel and lodging?**

Living donors often lose wages during their recovery period, which can be a big expense. Living donors are typically responsible for any time lost from work, unless their employer is able to provide paid leave or allow the donor to use short-term disability. Some donors use a combination of vacation time, sick leave and/or short term disability during their recovery period. The NKF suggests that you discuss these issues with:

- Your transplant center (Financial Counselor and/or Transplant Social Worker)
- Your employer's Human Resources department

### **Donor Leave Laws**

#### **Employees of the Federal Government**

Employees of the federal government receive 30 days paid leave for organ donation and 7 days for bone marrow donation. The leave is over and above the employee's sick and annual leave.

#### **Employees of State Governments**

Modeled after federal law (for federal employees), many states have begun to offer state employees up to 30 days leave (paid or unpaid) for serving as a living organ donor. This leave is considered separate from any annual or sick leave already accrued by an employee. Usually, the period of leave is 30 days for organ donors or 7 days for bone marrow donors. [Click here](#) for detailed state-by-state information.

#### **Private Sector Employees**

Eight states (Arkansas, Connecticut, Illinois, Louisiana, Maine, Minnesota, Nebraska and Oregon) allow a leave of absence for private sector employees but in many cases, it only applies to marrow (not organ) donors. [Click here](#) for detailed state-by-state information.

#### **Tax Deductions or Credits**

There is pending federal legislation that would provide a federal tax credit of up to \$5,000 for unreimbursed expenses, including lost wages, for living donors of kidney, liver, lung, pancreas, intestine or bone marrow.

Please help us get this legislation passed! Visit [www.kidney.org/takeaction](http://www.kidney.org/takeaction) to join the NKF's "People Like Us" Take Action Network to advocate for legislation to help living donors, transplant recipients and kidney patients. Be sure to reply to ALL the featured alerts, including the "NKF Calls for Action in Organ Donation END THE WAIT!" Campaign" which includes a call to action on this federal tax credit.

Many states have already enacted tax deductions or credits to living donors for unreimbursed expenses associated with donation. [Click here](#) for detailed state-by-state information.

### **Additional Sources of Assistance**

The National Living Donor Assistance Center (NLDAC) may be able to pay for up to \$6,000 of the living donor's (and his or her companion's) travel and lodging expenses. The transplant center where the recipient is waiting will apply on the living donor's behalf. Visit the NLDAC Web site at [www.livingdonorassistance.org](http://www.livingdonorassistance.org) for more details and to read about general eligibility requirements and how the program works. [Click here](#) for a flyer about the program.

There are some other limited sources of financial assistance that might be available to you. Please click here for a list of possible options. You'll need to check with these organizations to determine if help is available for your particular situation and at what level. You can also check with the [NKF office in your area](#) to ask if any financial assistance is available.

### **Resources and Additional Information**

[Donor Leave Laws and Tax Deductions/Credits for Living Donors](#)

[National Living Donor Assistance Center \(NLDAC\) flyer](#)

[Financial Assistance for Living Donors and Transplant Recipients](#)

[NKF's "People Like Us" Take Action Network](#)

### **NKF's END THE WAIT! campaign**

The National Kidney Foundation has just unveiled a comprehensive action plan designed to increase the number of organs available for donation and transplantation by removing barriers and improving the transplant system. The NKF's "[END THE WAIT!](#)" campaign aims to eliminate the waiting list over the next 10 years by enacting programs that are proven and effective to increase organ donation.

With over 25 specific recommendations, it recognizes that no single solution will work. We must work with Congress, the Administration and medical professionals and organizations to transform the organ donation and transplantation system in this country.

You will play a vital role as we build consensus and support for elements of this campaign as they are introduced in Congress. Together, we can remove the barriers to organ donation and make the Gift of Life more available. Please be sure to visit [www.kidney.org/takeaction](http://www.kidney.org/takeaction) to join the NKF's "People Like Us" Take Action Network to advocate for legislation to help living donors, transplant recipients and kidney patients. Be sure to reply to ALL the featured alerts there!

END THE WAIT! recommendations fall into four key areas:

1. Improve outcomes of first transplants by extending coverage for immunosuppressive drug coverage and providing patient education about transplantation
2. Increase deceased donation with better hospital training to work with potential donors and expanding the use of Extended Criteria Donors.

3. Increase living donation by reimbursing all expenses associated with donation, including lost wages, guaranteeing access to health care and insurance coverage and more. [Read the full recommendations, including recommendations for living donors, here.](#)
4. Improve the system of donation and transplantation throughout the U.S. by eliminating regional variations and racial disparities.

[More detailed information on END THE WAIT! is available here.](#)

## 6. The Surgery

- a. [What are the different types of surgery?](#)
- b. [What are the risks of surgery?](#)

### What are the different types of surgery?

A kidney can be removed in either of two ways, the traditional open surgery or the laparoscopic technique. Your transplant team can provide you with information about the different types of surgery.

Some donors may not be able to have laparoscopic surgery because of previous surgeries or anatomical variations. These variations are generally detected during the testing process, in which the potential donor would be notified that they would not be a candidate for laparoscopic donation.

Some scheduled laparoscopic donations must be converted to the open technique during the surgery process.

Once all the testing has been successfully completed, the operation is scheduled. A general anesthetic is administered in the operating room. Generally, the donor and the recipient are in adjacent operating rooms. The kidney is carefully removed and transplanted into the recipient. Immediately, the donor's single kidney should take over the work previously done by the recipient's two kidneys. Typically, the surgery takes 3-5 hours with time in the recovery room recovery afterward for observation.

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### What are the risks of surgery?

It is quite normal for a donor and the donor's family to have fears and concerns about potential complications. This might be felt by some as a reluctance to donate, yet it is natural reaction to a major surgery. Potential donors should speak openly with the transplant team about these fears. All conversations between the living donor and the transplant team and the results of medical testing will be kept confidential.

Both laparoscopic and open surgery have different benefits and risks, which potential donors should discuss with the transplant team.

The surgery involves the same level of risk for the donor as any other major surgery. The majority of complications following surgery are minor and may cause a longer hospitalization. The risks associated with surgery and donation should be discussed with your transplant team, and include:

1. Pain. You will receive medication for pain after the surgery.

2. Infection. If the wound from the surgical incision becomes infected, it will be treated with antibiotics. An infection can delay the healing process or cause scarring or other problems.
3. Pneumonia. Surgery increases the risk of developing pneumonia. You will be asked to cough and breathe deeply to decrease your risk of developing pneumonia.
4. Damage to the Kidney. There is a possibility of damaging the kidney during the surgical procedure. Every attempt will be made to minimize this risk. The surgeon may change a scheduled laparoscopic procedure to the open surgery in order to access the kidney safely.
5. Blood Clotting. You will be encouraged to move around as soon as you can after surgery. This will stimulate blood circulation to help prevent blood clots.
6. Collapsed lung. The kidney is close to the lung, and the pleura (the space around the lung) may be inadvertently opened during surgery. If this happens, the lung may collapse. The doctors would then insert a tube into the chest to expand the lung.
7. Allergic reaction to anesthesia. During the evaluation process, the transplant team will try to identify any allergies you might have. If you have an allergic reaction to anesthesia, the doctor will take immediate action to correct the problem.
8. Death. For living kidney donors, the risk of death is about 0.06% (about 1 death for every 1,700 procedures).

[Click here](#) for detailed statistics on short-term complications from living donation (as reported to the United Network for Organ Sharing).

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#### 7. What to Expect After Donation

- a. [What is the recovery period and when can the donor return to normal activities?](#)
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#### **What is the recovery period and when can the donor return to normal activities?**

The length of stay in the hospital will vary depending on the individual donor's rate of recovery and the type of procedure performed (traditional vs laparoscopic kidney removal) although the usual stay is 4 to 6 days. Since the rate of recovery varies greatly among individuals, be sure to ask the transplant center for their estimate of your particular recovery time.

After leaving the hospital, the donor will typically feel tenderness, itching and some pain as the incision continues to heal.

Generally, heavy lifting is not recommended for about six weeks following surgery. It is also recommended that donors avoid contact sports where the remaining kidney could be injured. It is important for the donor to speak with the transplant staff about the best ways to return as quickly as possible to being physically fit.

[Click here](#) for detailed statistics on short-term complications from living donation (as reported to the United Network for Organ Sharing).

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#### **How does living donation affect the donor?**

People can live normal lives with only one kidney. As long as the donor is evaluated thoroughly and cleared for donation, he or she can lead a normal life after the surgery.

When the kidney is removed, the single normal kidney will increase in size to compensate for the loss of the donated kidney.

The American Academy of Pediatrics, American Academy of Family Physicians and the Medical Society of Sports Medicine have suggested that people with one kidney **avoid sports that involve higher risks of heavy contact or collision**. This includes, but is not limited to, boxing, field hockey, football, ice hockey, Lacrosse, martial arts, rodeo, soccer and wrestling. This may also include extreme activities such as skydiving. 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 a single kidney are very serious.

Donors are encouraged to have good **long-term medical follow-up** with their primary care doctors. A urinalysis (urine test) and blood pressure check should be done every year, and kidney function should be checked every few years, or more often if an abnormal urinalysis or blood pressure is found. Click here for a fact sheet on "[Living With One Kidney](#)".

Living donation does not change life expectancy, and does not appear to increase the risk of kidney failure. In general, most people with a single normal kidney have few or no problems; however, you should always talk to your transplant team about the risks involved in donation. Some studies report that living donors may have a greater chance of developing **high blood pressure**. It is recommended that potential donors consult with their doctor about the risks of living donation.

**Pregnancy after donation** is possible but is usually not recommended for at least six months after the surgery. Living donors should talk to their physician about pregnancy and have good pre-natal care.

Some branches of **military service, police and fire departments** will not accept individuals with only one kidney (see [usmilitary.about.com/library/weekly/aa082701e.htm](http://usmilitary.about.com/library/weekly/aa082701e.htm)) for general information about Military Enlistment Standards). 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 for that particular field.

See also <http://kidney.niddk.nih.gov/kudiseases/pubs/solitarykidney/>

After donation, living donors often report a wide range of **mixed emotions**, from joy and relief to anxiety to depression. The process of getting through the evaluation and surgery can be so time-consuming that donors do not always have time to process everything they are feeling. It is normal for these emotions to come to the forefront after the donation and transplant take place.

Living donors generally rate their experience as positive. Different studies indicate that between 80-97% of donors say that in retrospect, they would have still made the decision to donate.

However, concerns about the recipient's outcome (as well as the donor's recovery) can contribute to feelings of anxiety, and may donors report a feeling of "let down" afterwards. Feelings of depression among living donors are not uncommon, even when both donor and recipient are doing well.

While extensive data on these issues is lacking, some studies have reported the following psychological outcomes:

- Less than 1% regretted the decision
- 3 to 10% reported depression
- 10% reported "family conflicts"
- 7% reported anxiety disorders

- 16% concerned about negative financial consequences of donation
- 3 to 15% concerned about a negative impact on their health

Living donors who are struggling with these issues are encouraged to:

1. talk to the transplant hospital's Transplant Social Worker for advice
2. seek professional counseling or other outside help to manage difficult emotions, and
3. talk with other living donors who can be particularly supportive if they have experienced the same feelings.

The NKF's [Email Discussion Group](#) and [Message Board](#) are good places to find support from other living donors.

For more information about post-donation outcomes, visit [http://www.kidney.org/transplantation/livingdonors/my\\_donor.cfm](http://www.kidney.org/transplantation/livingdonors/my_donor.cfm)

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### **What are the long-term risks of donation?**

You will also have a scar from the donor operation- the size and location of the scar will depend on the type of operation you have.

Some donors have reported long-term problems with pain, nerve damage, hernia or intestinal obstruction. These risks seem to be rare, but there are not currently any national statistics on the frequency of these problems.

In addition, people with one kidney may be at a greater risk of:

- high blood pressure
- Proteinuria
- Reduced kidney function

For more information, visit the [National Kidney and Urologic Diseases Information Clearinghouse \(NKUDIC\) website](#)

You should discuss these risks with your transplant team, and ask for center-specific statistics related to these problems.

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### **Are there any dietary restrictions prior to, or after donation?**

If the donor is overweight, he or she may need to lose weight before the transplant. If the donor eats large quantities of protein, that could be an issue as well. But those are more general health issues, and not related to living donation per se.

Check with the transplant center to see if they recommend any dietary changes. If you are in good health, there will probably not be any specific dietary restrictions.

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### **Will I be able to obtain insurance coverage after donation?**

If your health remains stable, you shouldn't have problems in obtaining health or life insurance.

However, there have been some instances in which living donors had difficulty changing insurance carriers after the donation, due to higher premiums or a pre-existing waiting period.

Talk to the financial counselor and social worker at the transplant center to find out if donation will affect your health or life insurance coverage.

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### **What if I donate, and need a kidney later?**

This is something potential donors should discuss with the transplant team. Talk to your transplant team about any pre-existing condition or other factors that may put you at a higher risk of developing kidney disease, and consider this carefully before making a decision about donation.

There have been some cases in which living donors needed a kidney later- not necessarily due to the donation itself. It is considered a potential risk of donation. As of 1996, UNOS policy gives four extra points on the waiting list to living donors.

**Pregnancy after donation is possible but is usually not recommended for at least six months after the surgery. Living donors should talk to their physician about pregnancy and have good pre-natal care**

There have been two studies on pregnancy after kidney donation published by the American Journal of Transplantation.

Reisaeter AV, Røislien J, Henriksen T, Irgens LM, Hartmann A. Pregnancy and birth after kidney donation: the Norwegian experience. Am J Transplant. 2009; 9: 820-824. Epub 2008 Oct 6.

Available at: <http://www.medscape.com/medline/abstract/18853953>

This study in Norway compared post donation births to the general population. It showed that there were no dramatic differences between post donation births and those of the general public. However, the increase of blood pressure and loss of kidney function in donors may predispose for hypertensive pregnancy disorders, preeclampsia and other complications. Previous kidney donation is not detrimental to the course and outcome of future pregnancies, though pregnancies in kidney donors should be monitored carefully.

Ibrahim HN, Akkina SK, Leister E, et al. Pregnancy outcomes after kidney donation. Am J Transplant. 2009; 9: 825-834.

Available at: <http://www.medscape.com/medline/abstract/19353771>

This study compared post donation births to the predonation births of the living donors in the study. While the results showed that bad pregnancy outcomes post-donation were similar to the general population, they were not as good as predonation pregnancy outcomes of the same people. This particular study states that the outcomes of kidney donor pregnancies are generally favorable. However; postdonation pregnancies were associated with a lower likelihood of full-term deliveries and a higher likelihood of fetal loss. Postdonation pregnancies were also associated with a higher risk of gestational diabetes, gestational hypertension, proteinuria and preeclampsia.

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## **8. For Transplant Candidates**

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- a. [I need a transplant. How can I ask someone to be my living donor?](#)

b. [What if I don't have a living donor?](#)

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

This is a tough issue, and depends on you and your loved ones. All families are different. Many people found that their family members or friends brought up the subject of living donation. Others found asking someone they loved to donate too difficult - and didn't feel comfortable asking people directly, not wanting to pressure anyone to donate.

Others were able to overcome their fear of asking loved ones to risk surgery as 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 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 helps you and your family think about whether living donation is right for you. If you can, take your time, move slowly, and get all the information possible.

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**What if I don't have a living donor?**

You will need to work through your transplant center to discuss living donation. If you are trying to find a kidney donor, the best way to do this is to have interested family members and friends tested for a potential match. If you cannot find a donor this way, you should be placed on the transplant waiting list by your physician and transplant social worker.

You can also request a booklet on "Waiting for a Transplant" by contacting the NKF. The booklet addresses some of the practical and emotional considerations in waiting for a transplant.