Giving Your Kidney

New Facts for the Living Donor

Giving a kidney to a family member or friend can be one of life's greatest experiences. For many, this gift has meant restored health for the person receiving the transplant and closer ties among everyone involved. The decision to donate a kidney is an important one, however, and it helps to know as much as possible about the potential benefits and problems.

This brochure presents basic facts about donation and describes the experience of 220 persons throughout the United States who donated their kidneys between 1973 and 1995. These individuals are of all ages and incomes, are men and women, white, black, and Hispanic, married and single, and differ widely in their occupations and religious preferences. Nevertheless, their experiences as kidney donors were remarkably similar.

You can use the information in this brochure to discuss donation with your family, with the person needing the kidney, and with your friends. It might also give you ideas for questions to ask the transplant surgeon, social worker, transplant nurse coordinator, and other health professionals. Learning as much as possible about kidney donation will help you make the decision that is right for you.

Here are some questions commonly asked by people who are considering kidney donation:

Are there different kinds of kidney donations?

Kidneys for transplantation may come from either an unrelated person who has recently died (cadaver), a living unrelated person (spouse, or friend) or from a living-related donor. Generally, a relative's kidney will match the recipient's body tissue more closely than a cadaver kidney. A close match between the tissues of the donor and recipient increases the chance that the recipient's body will accept the donated kidney.

Do kidneys from living donors last longer than those from cadavers?

Each person's situation is unique. However, national statistics indicate that 96% of the kidneys from living (related and non-related) donors are still working at the end of one year, compared to 91% of cadaver kidneys. Three year survivor rates overall, for both cadaveric and living related donors, hover at 69% nationwide. The success of both kinds of transplants is continuing to improve with the development of more effective procedures and drugs to prevent the rejection of a transplanted kidney.

What factors are considered in becoming a donor?

Most important, the donation of a kidney must be a voluntary act. Family members, spouses and friends generally come forward as potential donors. Then, the individual circumstances of each of the possible donors is evaluated by the transplant team. For example, can the person take the time from work necessary for the surgery and recovery at home? After the situations of each of the potential donors have been carefully considered, the specific person for donation is determined by a series of blood tests. These reveal whether the kidney of the potential donor is likely to match the body tissue of the recipient: the closer the match, the lower the chances that the kidney will be rejected and fail to function. In addition, the psychological readiness of the donor is evaluated; is the potential donor very fearful or worried?

What makes a good match between a kidney donor and recipient?

A good match is obtained when the donor and recipient share similar genes. The more closely related two people are, the more their blood and body tissues will be alike. If the tissues of a donor and recipient are similar, the recipient's immune system is less likely to reject the new kidney. 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 foreign "intruders" and tries to destroy anything that is different from its own tissue, whether a virus, germ, or a new kidney.

To decrease the chance of rejection as much as possible, the vast majority of living donor transplants are done

between members of an immediate family. People receive half of their genetic characteristics from their father and half from their mother. Thus, a kidney patient's brothers and sisters are likely to be a better match than his or her parents or children. There have, however, been many successful transplants made between living unrelated individuals, and the success in this area continues to grow. From national data, 50% of the donors were the brother or sister of the recipient, 27% were the parent of the recipient, 11% were the children of the recipient and 3% were spouses. 4% of the donors were friends of the recipient, while the relationship of the donor to the recipient was unknown in the remaining 5%.

What tests determine who can be a donor?

Potential donors and recipients have a number of blood tests to determine how similar their tissues are. These tests determine who will be the best match. The number and the type of tests may vary from center to center, but may include ABO (blood type) testing and HLA typing and crossmatching. These tests will tell the transplant team whether the donor and recipient have compatible blood types, whether their white blood cells will react against each other, and the similarity of their body tissues. HLA typing specifically shows whether the donor's antigens match those of the recipient. Antigens are inherited substances on the surface of all cells that cause the immune system to fight a foreign substance which enters the body, in this case a new kidney. The more antigens the donor and recipient have in common, the lower the likelihood the kidney will be rejected.

How does the transplant staff determine if the donor is healthy enough to undergo surgery?

To determine the general health of the donor, as well as the condition of his or her kidneys, several routine tests are conducted. Typically, these include: a complete medical history and physical examination, a chest x-ray, an electrocardiogram (EKG) to check the donor's heart, and blood and urine tests. Special x-rays of the donor's kidneys are also taken: an IVP (intravenous pyelogram) and a renal arteriogram. In each of these tests, dye is injected into the bloodstream and travels through the kidneys. This enables the transplant team to determine whether there are any abnormalities in the kidneys or the blood vessels leading to them.

Whether the donor needs to be hospitalized for these tests or have them performed on an outpatient basis varies from center to center. In either case, this occasion provides a good opportunity to ask additional questions about donation and to resolve any problems or concerns which may have arisen.

Do some donors have trouble making the decision to give a kidney?

Some people make the decision instantly, with few worries or problems. Others must go through some soul-searching before deciding. 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 own reluctance. Most importantly, it must be remembered that the only "right" decision is the one with which the person considering donation feels most comfortable.

Do potential donors feel pressure from family members, friends, or the transplant staff?

In some families, everyone wants to be the donor, while in others there is a general unwillingness to consider donation. Sometimes the spouse, the children, or the parents of a potential donor express reservations or even strongly oppose the whole idea. In our study, 86% of the donors stated that they experienced no pressure from members of their family, 6% were pressured to donate, and 8% were discouraged from donating.

The donor's friends appear to encourage donation. For example, 95% of our sample of donors reported that they received support from their friends to donate. With friends, as well as family members, it generally helps if the donor can share his or her feelings about and reasons for the decision and can describe the procedures involved. These percentages are virtually unchanged from the previous studies.

The primary role of the transplant staff is to assist potential donors in making their own decisions. Not surprisingly, therefore, 91% of the donors in our study felt no pressure from the hospital and transplant staff. Again, the ability of the donor to communicate his or her feelings about the decision is essential to building a relationship in which the transplant staff can be of the most help.

What happens when the donor enters the hospital for the transplant operation?

Generally, the donor is admitted to the hospital one day before the operation. At this time, a physical examination and several routine tests are performed to ensure that the donor is healthy and that his or her kidneys are functioning well. If it has not occurred before, the surgeon who will be removing the donor's kidney will be introduced and will discuss any final questions or concerns the donor may have.

What happens to the donor during the surgery?

Shortly before going to the operating room, 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 the surgery. The surgeon usually makes an incision in the lower back on the side from which the kidney is to be removed. The incision extends from that side to the front of the donor's waist. Next, the kidney is removed and taken to an adjoining operating room where the recipient is waiting. Immediately, the donor's one remaining kidney begins to take over the work that was previously done by two kidneys. While the donor's incision is being closed and stitched, the donated kidney is placed into an abdominal incision in the recipient. In most instances, the transplanted kidney begins to function right away. Sometimes, it takes several hours or days. In a few cases, however, the transplanted kidney fails to work at all.

Typically, the preparation for the surgery and the operation itself take from 3 to 4 hours. After the surgery, the donor is moved to the recovery room for observation while the anesthesia wears off and is then returned to his or her room in the hospital.

How risky is the operation for the donor?

The operation involves the same level of risk for the donor as any other major surgery. The risk of death in a major surgery in which a general anesthetic is used is less than 1 in 10,000 cases. Actual experience is likely to be lower than this rate since donors are in very good to excellent health prior to the surgery.

Although the risk of death from the operation is low, donors may experience some complications following the surgery. In our study, 80% of the donors experienced no medical complication as a direct result of the surgery. Fourteen percent reported medical problems requiring a doctor's visit post hospitalization.

The majority of complications were relatively minor but 6% reported problems requiring longer hospital stays or rehospitalization. Everyone fully recovered and no one died.

How do donors feel during the recovery period after the surgery?

Although each situation is unique, donors typically have a rapid and uneventful recovery. Immediately following the operation, the donor feels very tired, a natural bodily reaction to surgery and the general anesthetic. Certainly, there is pain lasting from several days to several weeks as the muscles around the incision heal. In fact, the donors in the national study often stated that the amount of pain was greater than they had expected. The discomfort generally decreases, however, as the donor becomes more physically active.

How long do donors remain in the hospital?

The length of the hospital stay varies depending on the individual donor's rate of recovery and how well he or she feels. In our study, 80% of the donors were hospitalized for 1 week or less following the operation, while 18% were in the hospital for 8 to 14 days after the surgery. The remaining 2% were hospitalized for greater than 2 weeks to resolve specific complications which had developed.

When can the donor return to normal activity?

The donor's individual rate of recovery and his or her surgeon will determine how rapidly normal activities can be resumed. After leaving the hospital and returning home, donors typically experience tenderness, itching, and stretching problems as the incision continues to heal. Generally, they are advised to avoid heavy lifting for bout 6 weeks following hospitalization. It may also be suggested that the donor avoid participating in such activities as football and ice hockey, sports which might injure the one remaining kidney. It is particularly important that the donor talk with the transplant staff about the best ways to return as quickly as possible to feeling physically fit.

Seventy-seven percent of the donors studied returned to their usual level of physical activity following recovery from the surgery, 9% increased their level of activity, and 14% described the themselves as less physically active.

Of the 220 donors included in our study, 90% returned to the work they were doing before the surgery, almost all of whom did so within 4 to 6 weeks; several were actually back at work by the third week after the operation. Six percent had improved work status because

of improved physical conditioning gained from pre-donation exercise. The remaining donors (4%) had to move to less physically strenuous jobs because they con tined to experience pain and had difficulty with stretching and lifting.

Will giving a kidney affect the ability of a donor to become pregnant or father a child?

There is no evidence from our study that donating a kidney had any effect on the ability of the donors to have children. Among these donors, 87% made no attempt to have children, while 12% tried and were successful. Only 8 persons attempted to have children and were unsuccessful, but appear to be for reasons that were unrelated to having been a donor.

Is a donor more likely to develop kidney disease or other health problems later in life?

This question is being carefully examined by several research groups in the United States, but at present, it does not appear that kidney donation places an individual at risk for future health problems. Although 20% of the donors in our study have had some type of illness since the operation, none of these individuals have developed kidney disease. The illnesses which the donors did describe seem to reflect the natural process of aging rather than anything caused by having only one kidney.

Equally as important was the finding that 93% of the donors believed that donation had not changed their health status, or had improved it, while 7% reported negative health changes since donation.

Are there any emotional problems which result from kidney donation?

Some researchers have reported that a small minority of kidney donors have negative or mixed feelings after the surgery. However, there is no evidence from the study that kidney donation causes major emotional problems. None of the 220 donors reported experiencing problems since the time of the operation which required psychiatric hospitalization.

This is not to suggest that kidney donors do not have feelings and concerns regarding the surgery. It is important, therefore, that the potential donor obtain as much information as possible, discuss it, and evaluate it before making the decision to give a kidney.

Who pays for the donor's medical expenses?

Medicare, which pays part of the treatment costs for kidney patients, pays all of the donor's medical expenses if they recipient is eligible for Medicare's end-stage renal disease (ESRD) program. According to a handbook from the Social Security Administration, Medicare will pay "all reasonable preparatory, operation, and post-operative recovery expenses connected with the donation." Since the medical payment policies of the federal Medicare program are subject to change, individuals who are considering donation are encouraged to discuss the issue with the transplant social worker to learn details of the current policy. The social worker will also be able to provide information about sources of financial assistance for individuals who are not covered by the Medicare program.

Does a donor have expenses which are not paid by Medicare or other sources?

Generally, public and private insurance programs will not pay the travel, meal, and lodging expenses which the donor incurs for testing before the surgery and for follow-up visits after the operation. For the donors in our study, these costs were typically less than $100 and were often paid by the recipient or another relative. However, "out-of-pocket" expenses exceeding $1,000 were incurred by 8% of the donors, emphasizing the importance of discussing the potential financial consequences of donation with the transplant social worker prior to the surgery.

It should also be noted that most insurance plans will not pay the wages or salary which are lost while the donor is in the hospital and recovering at home. Thee are many ways, however, which donors have used to cover the loss of income. In our study, for example, 41% used sick time from work, and an additional 16% used their vacation time. Twenty-six percent of the donors relied on their own support and the support of their spouse, while another 44% had financial assistance from the recipient or other family members. Personal loans and family savings were used by 7% and 20% of the donors, respectively.

Although most of the donors relied on several sources of support, a particularly important finding of the study was that 85% did not feel donation had caused a financial hardship. Thirteen percent felt it caused some hardship for their families, while the remaining 2% indicated that giving a kidney had been a great financial burden.

Do donors have difficulty keeping or obtaining insurance after the operation?

Among the 220 donors in our study, 2% had difficulty obtaining health insurance after the surgery, 2% had problems getting life insurance, and 1% experienced difficulty obtaining disability insurance. In each of these cases, a routine physical examination and a waiting period of from 1 to 3 years was required to satisfy the insurance companies.

How did kidney donors feel about their experiences?

In our survey of living-related donors, we asked, "If you could reconsider donating your kidney, would you make the same decision?" Ninety-seven percent said "Yes" without any reservations.

These donors were also questioned about their relationship with the recipient after the transplant surgery. Forty-one percent stated that they had always been close to the recipient and that this close relationship had continued. Fifty-nine percent felt their relationship with the recipient had improved since the operation.

What other sources of information about kidney donation and kidney diseases are available?

There are a variety of resources available to individuals who are considering giving a kidney to a relative. Certainly, the transplant surgeon, nephrologist, transplant nurse coordinator, and social worker are ideal sources of information. In addition, the donors in the national study indicated that the opportunity to discuss donation with people who had already been through the experience was particularly helpful.

Several national organizations also have materials which the person considering donation may find useful. These organizations include: National Kidney Foundation (30 E. 33rd Street, New York, NY 10016); American Association of Kidney Patients (100 S. Ashley Drive, Suite 280, Tampa, FL, 33602); and American Kidney Fund (6110 Executive Blvd., Suite 1010, Rockville, MD 20852).

The Missouri Kidney Program has a web site at: www.hsc.missouri.edu/~mokp that has several educational resources and links to Medicare documents. If your state has a Kidney Program, it is likely you can get more information there.

A Final Note to the Potential Living-Related Donor

This brochure was developed to give you basic information on living-related kidney donation and to share the experiences of donors from the Midwestern United States. This information should provide a good basis for discussing the possibility of becoming a kidney donor with your family and friends, as well as with the transplant staff. Most important, it must be remembered that when all is said and done the only "right" decision is the one that is best for you and with which you feel the most comfortable.

Glossary

ABO: a phrase used to describe blood types. The types are A, B, AB, and O.

Antigens: substances on the surface of all cells which signal the body's defense system to fight foreign materials, including a kidney transplant. Recipients whose antigens are similar to those of the donor are more likely to have a successful transplant.

Cadaver Kidney: a kidney taken from a person who has recently died.

Crossmatch: a test which determines whether there is a substance in the blood of the recipient which will react against the cells of the donor.

HLA Typing: a blood test which determines whether a donor and recipient have similar antigens.

Immune System: the body's defense against viruses, bacteria, and other foreign materials. Transplant recipients take special drugs to try to prevent the immune system from rejecting the new kidney.

Living-Related Donor Kidney: a kidney taken from a living, blood relative.

Mixed Lymphocyte Culture (MLC): a blood test which determines whether a donor's and recipient's white blood cells will react against each other.

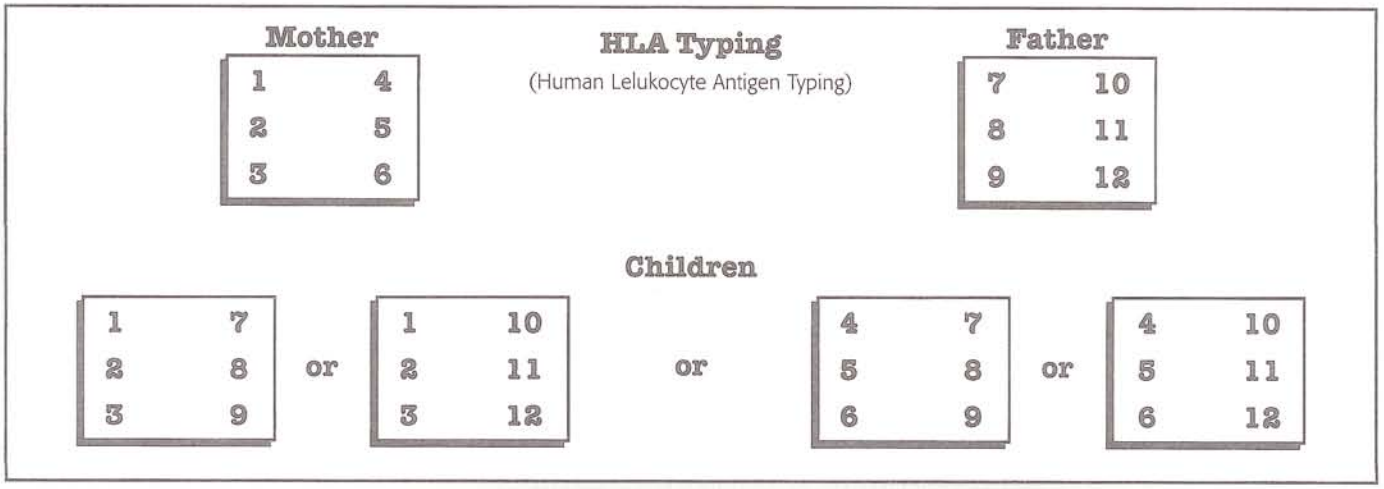
Rejection: the normal response of the body to a foreign substance, including a transplanted kidney. If the recipient's immune system rejects the new kidney and the special drugs given to the recipient do not work, the transplanted kidney will fail to function.

Tissue Typing: blood tests which determine how well the body tissues of a donor and recipient match.

HLA Typing (Human Leukocyte Antigen Typing:
In our bodies, we have proteins called antigens. Tissue typing involves identifying which antigens you and your relative have inherited. Antigens are classified by a numbering system and over 115 different antigens have been identified in the population. Each person has their own six unique antigens, or numbers, inherited from their parents - three from their mother and three from their father. Brothers and sisters born of the same parents will inherit various combinations or a different combination of antigens. The following diagram should help illustrate how antigens can be inherited.

In a family of brothers and sisters, there is approximately a 25 percent change of two children inheriting the same combination of antigens, and this is termed being "HLA identical" to your sibling. There is a 50 percent change of you sharing three of the six antigens and this is called a haplotype or a "half match". There is also a 25 percent chance of inheriting entirely different antigens and this is called a "complete mismatch". A parent and their child will always be a half match since the child inherits three numbers from each parent. Except for identical twins and some brothers and sisters, it is rare to get a six antigen match between two people, especially if they are unrelated.

There are many reasons why an HLA identical genetic "match" is preferred between donor and recipient. The likelihood of rejection decreases if you have the same antigens as your relative. The recipient's body recognizes the kidney as being "similar" to its own, and not a "foreign" object. Also, the amount of medication the recipient takes after transplant decreases faster if an identical kidney is transplanted. However, transplants can also be done if you are a half-match or a complete mismatch to your relative. Success rates of these type of matches are also very good.



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Additional copies of this brochure can be obtained from:

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