

PATIENT INFORMATION

YOUR KIDNEY DONATION DECISION: WHAT YOU NEED TO KNOW



Beaumont®

**Beaumont transplant office
and Clinic directory**

Transplant Services
Medical Office Building
3535 W. Thirteen Mile Road, Suite 644
Royal Oak, MI 48073
248-551-1033
800-253-5592, then press #1
The office is open Monday – Friday

Pre-transplant nurse coordinators

Renautta Wojtylo, R.N.
Sharon Berman, R.N.
Jesse Syring, R.N.
Joan Rappley, R.N.
Kelley Kulikowski, R.N.
Carolyn Wolan, R.N.
Jennifer Fogarty, R.N., outreach coordinator

Inpatient nurse practitioner

Patty Sills, R.N., M.S.N., ANP-BC, CCRN

Transplant social workers

Susan Walker, L.M.S.W.
248-551-9897
Maria Munoz, L.M.S.W.
248-551-1201

Renal transplant dietitian

Jill Jensen, R.D., C.N.S.C.
248-898-6978

Transplant assistants

Erica Hyman
Dawn Beltowski
248-551-1033

Transplant financial coordinator and representative

Julius Eason
248-551-0077
Angelia Harris
248-551-0771

Independent living donor advocate

Kathy Swartz, R.N.
248-898-5024

Transplant pharmacist

Maxine Ng, Pharm.D., BCPS
248-898-2661

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THE BEAUMONT TRANSPLANT PROGRAM

The Beaumont Transplant Program is committed to providing comprehensive medical care to patients with chronic kidney disease and to guide them in choosing the best possible individualized treatment options for their end-stage renal (kidney) disease.

More than 40 years of excellence

Since the first kidney transplant performed here in 1972, the Transplant Program at Beaumont Hospitals has performed more than 2,100 adult kidney transplants. We routinely perform high-risk transplants, even for patients with viral hepatitis, repeat transplants and transplants in highly sensitized individuals. We have also offered desensitization protocols for transplants across the barrier of a positive cross match for the appropriate individual. We specially tailor immunosuppression to the individual needs of our patients.

We also have some of the most extensive experience in the state in performing the technically challenging pediatric en-bloc kidney transplants.

The Beaumont Transplant Program is a Medicare approved transplant center. In order for patients to receive full Medicare benefits for a transplant, they must go to a Medicare approved facility. These programs meet Medicare criteria for the number of transplants they perform and the overall quality of patient outcomes.

Patients at a Medicare approved facility may have to meet certain selection requirements to be eligible for Medicare coverage. This criterion may include a patient's age, and the medical condition for which they may need a transplant.

Patients transplanted at Medicare approved facilities, which have Medicare Part A at the time of transplant, are eligible for immunosuppressant medication coverage at a reimbursement rate of 80 percent. Patients must have Medicare Part B at the time they purchase medications.

Non-approved Medicare facilities are unable to provide neither transplantation, nor immunosuppressant medication benefit coverage for Medicare patients.

Kidney donor financial responsibility

The transplant donor carries no financial responsibility for services rendered as related to the kidney transplant donation.

From the donor's perspective all services related to transplant donation are covered either under the recipient's insurance coverage or by Medicare. Services rendered for predetermination of donor candidacy such as laboratory work up, outpatient procedures, inpatient services such as surgery and hospitalization, as well as post surgical aftercare is all covered under Medicare. Your required post-donation follow-up visits for health/social screening at six months, one year and two year intervals will be coordinated by the transplant program where you have your donor surgery and also will be covered by Medicare. If you choose to have these post-donation health follow-up visits completed by your local/family physician due to distance from the recovery hospital, you will be provided information on how and what testing is required and covered as part of your follow-up care during the two years after donation. You will be expected to provide this information to the transplant program when they send you a reminder letter as this information is required to be reported to the Organ Procurement and Transplant Network (OPTN) and the United Network for Organ Sharing (UNOS). Physician fees related to the transplant donation are covered under the recipient's insurance.

In the event of unforeseen complications directly related to the transplant donation, these services would also be reviewed for possible payment under the recipient's insurance coverage.

We have transplant financial coordinators available to discuss and address any questions or concerns potential donors may have concerning potential costs or expenses.

Data for the Beaumont Transplant Program outcomes is available for national comparison at www.unos.org. This information includes comparisons of patient and kidney survival as well as other data and will be provided in a handout with the most recently available data.

Multidisciplinary team

The specialized multidisciplinary team includes highly skilled transplant surgeons, transplant nephrologists and immunologists, a transplant pharmacist, as well as transplant nurse coordinators, transplant financial coordinators, a transplant social worker, independent living donor advocate and transplant dietitian. We work very closely with our patients and their families, their referring physicians and other outstanding hospital disciplines and staff members to provide all the support, guidance and state-of-the-art medical care needed in the preparation for their journey through the transplant process.

Beaumont has a multi-physician and surgeon Transplant Team available 24-hours/7 days/week to respond when an organ is made available (deceased donor or Kidney Paired Donation donor) for transplant and to provide transplant program coverage.

Objectives

This booklet will help you understand the following information:

- kidney (renal) failure
- three major forms of treatment
- the interview processes prior to donation
- diagnostic studies during the evaluation phase
- time it takes to complete the evaluation phase
- admission to the hospital and your stay
- expectations before and after surgery
- life after donating a kidney

Donating a kidney is one of the most important personal decisions you can make. It is a decision that requires a great deal of information and thought.

During the evaluation phase, you will have the chance to talk with members of the transplant team, other kidney donors (living related or living non-related) and your family. This is the time to ask questions and share any concerns you might have.

Please keep in mind that this booklet is for general information only. Your individual treatment and experience may vary.

Initial consent for kidney donation

You have chosen to donate your kidney to someone whose kidneys are failing or have failed. This means that without a kidney transplant, that person will die unless they go on peritoneal dialysis or chronic hemodialysis, a mechanical method of filtering a patient's blood, which their own kidneys can no longer do. Usually the person donating the kidney is a relative or a close friend. Donation of your kidney will not improve your health and has a potential of harming it; that potential is rare and will be discussed in the education process prior to transplant.

Donating a kidney does have potential emotional benefits because you have helped someone survive and improved their quality of life. Regardless of whom you are donating to, all of your medical information will be kept confidential.

If, during the process of your work-up, you are found to have a previously undetected health problem, you will be counseled regarding it. Please note that health information obtained during your donor evaluation will be subject to the same regulations as all records and could reveal conditions that the transplant program must report to local, state or federal public health authorities. Presuming your blood type and serum factors are compatible, the recipient will only know that it is medically unsafe to receive your kidney.

Criteria for live donor candidacy

1. Living kidney donor candidates are generally between the ages of 18 and 60. Being both under 18 years of age and mentally incapable of making an informed decision are exclusion criteria for kidney donation. Individuals older than 60 can be considered on a case-by-case basis if they are highly motivated and do not exhibit prohibitive comorbidities.
2. The candidate must possess decision-making capacity to understand kidney donation including its risks, benefits, and alternative treatments available to the recipient. Agreeing to be a kidney donor is a very personal decision. The only “right” decision is the one that is right for you. You can change your mind about being a donor at any time. Talk to your transplant nurse coordinator, independent donor advocate or transplant social worker about your concerns or decision. All information will be kept confidential.
3. Each candidate presenting for evaluation to be a living donor to a transplant candidate must be reasonably healthy without evidence of kidney disease. Candidates undergo a detailed evaluation by transplant nephrologists, donor surgeon, transplant nurse coordinator and social worker. This process is conducted to obtain a comprehensive medical and psychological assessment of the patient. Additional testing to clarify acceptability (including kidney function, risk factors for or details of established medical conditions) may be required. In the event that medical, anatomic, psychological or other factors that preclude donation are identified, he or she will be advised that they are not candidates to donate their kidney.

If any of the following criteria exists, you cannot be considered as a kidney donor:

- uncontrollable hypertension or history of hypertension with evidence of end stage organ damage
- HIV
- diabetes
- active malignancy, or incompletely treated malignancy
- evidence of acute symptomatic infection (until resolved)
- diagnosable psychiatric conditions requiring treatment before donation including any evidence of suicidality

4. Candidates must be voluntary, altruistic donors.

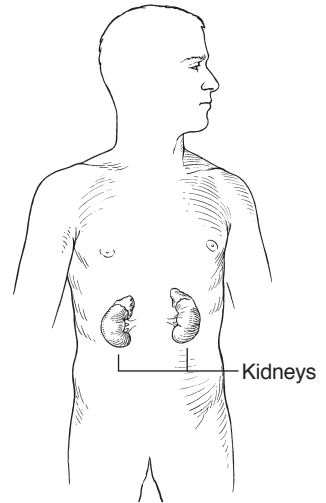
Those donors with any substantiated or unsubstantiated evidence of coercion to donate a kidney will be excluded from donation. If there is high suspicion of illegal financial exchange between the donor and the recipient for valuable consideration (i.e., for anything of value such as cash, property, vacations), the donor cannot be considered as a kidney donor.

5. Determination for live kidney donor candidate eligibility has been developed within the framework of the hospital's mission for the care of persons without regard to race, national origin, religion, gender and sexual orientation.

GENERAL INFORMATION

Where are the kidneys?

The kidneys are bean-shaped organs that are below your ribs in the back of your abdomen. They lie on either side of the spine. An adult's kidneys weigh four to six ounces each and are about the size of a fist. Normally, everyone has two kidneys. Occasionally people are born with only one kidney and still live entirely normal lives.



What do kidneys do?

Kidneys filter and remove waste products from the blood and help control blood pressure.

Kidneys also control the balance of fluid, acid, electrolytes and minerals in the body. Electrolytes and minerals include calcium, phosphorus, sodium, chloride and potassium. The sodium and chloride play a role in your body's fluid balance. The calcium and phosphorus help bones grow and keep them strong and healthy. Potassium regulates the heart beat. These electrolytes and minerals are very important in maintaining good physical health. Kidneys make hormones such as erythropoetin, which stimulates red blood cell growth.

KIDNEY FAILURE

What is kidney failure?

Twenty-six million American adults have chronic kidney disease, or CKD, and millions of others are at increased risk. CKD or kidney failure occurs when the overall function of the kidneys declines to less than 10 percent of normal. When this happens, treatment, such as dialysis or a transplant, is needed to support life. There are two types of kidney failure: acute and chronic.

- Acute kidney failure occurs when the kidneys lose function very rapidly. This may occur within a few hours or days. Kidney function may return to normal or progress to CKD.
- Chronic kidney failure occurs when the kidney tissue is slowly and permanently destroyed. Often, no symptoms occur until less than 25 percent of kidney function remains. When the kidney function declines to less than 20 percent of normal, planning for dialysis or a kidney transplant becomes necessary. The patient's nephrologist (kidney doctor) will monitor the patient's kidney function and make the appropriate recommendations.

TREATING KIDNEY FAILURE

Dialysis

When the kidneys do not function, fluids and waste products accumulate in the body. One method used to remove the build up of fluid and waste products from the body is dialysis. However, dialysis cannot perform many of the other functions of a normal kidney. At best, dialysis only provides the equivalent of eight to nine percent of kidney function.

Hemodialysis

Hemodialysis uses a machine to remove the fluids and waste products from the blood stream. Patients may have a catheter in their upper shoulder area for hemodialysis access. This is usually a temporary access. Most hemodialysis patients have a connection called a fistula or graft. This connection is made between an artery and a vein in the patient's arm. The fistula or graft provides a large blood vessel (or tube) through which blood can easily be removed and replaced.

Blood flows from the patient's artery through a special filter called a dialyzer. While the blood is in the dialyzer, waste products and excess water are removed and washed away in a solution called dialysate. Blood is then returned to the patient through a vein. Hemodialysis is usually needed three times each week for two to four hours per treatment. Most patients go to outpatient dialysis centers for their treatments. The nephrologist monitors the labs and physical health of the patient during the dialysis sessions. Nurses and technicians are always present. Hemodialysis can also be done at home.

Peritoneal dialysis

Peritoneal dialysis also removes waste products from the body. To prepare for peritoneal dialysis (also called continuous ambulatory peritoneal dialysis, or CAPD), a catheter (a soft plastic tube) is surgically placed into the abdomen just below the navel. A solution called peritoneal dialysate flows through the catheter into the abdominal cavity. Waste products and excess water move from the body fluids into the dialysate. The dialysate is then drained out of the body. Peritoneal dialysis is repeated four times per day, every day of the week. Patients are taught how to perform peritoneal dialysis for themselves. This method of dialysis allows the patient to be more mobile and independent. Some patients are candidates for the cyclor, which is an automated way to perform peritoneal dialysis.

ORGAN TRANSPLANTS

Deceased donor organ transplants may be done for individuals with end-stage organ failure. The list of organs that can be transplanted continues to grow with improved technology. Examples of organs that can be transplanted include heart, lung(s), kidney(s), liver and pancreas. Tissues can also be transplanted, such as cornea, heart valves, skin and bone. One organ donor can provide more than 10 individuals with a much-needed, life-saving organ or tissue transplant.

Living donor kidney transplants have been performed since 1954. Currently, living donor surgery comprise approximately 35 percent of kidney transplants in the United States.

Kidney paired donation (KPD) may be an option; additional information will be provided about this program by the transplant team.

A well-functioning transplant can last 20 years or more. Many kidney transplants do not last the rest of the recipient's life. Reasons for losing the transplanted kidney can include: surgical problems, rejection, side effects of medications or recurrence of the original disease. Also, any transplant candidate/recipient might have risk factors for increased morbidity (complications and/or loss of kidney transplant) or mortality (death) that are not disclosed to the potential donor. The recipients must do their part, take proper medications as prescribed and be diligent in follow-up office appointments.

KIDNEY TRANSPLANT

Kidney transplants are a widely accepted treatment for end-stage kidney failure. Transplantation is not a cure, but is an alternative to dialysis. More than 13,000 kidney transplants are successfully performed each year in the United States. But while those individuals are receiving their new kidney, more than 100,000 people wait for kidney transplants.

Kidneys can be donated by a living donor (living-related or living non-related) or a deceased donor (a deceased person whose family has consented to organ and tissue donation). Success rates vary depending on each recipient's situation.

Living-related kidney transplant

A living-related kidney can be donated by a blood relative such as a mother, father, sister, brother, son, daughter, cousin, aunt or uncle. Patients who have the option of a living-related kidney transplant have certain advantages.

Generally, a living-related kidney provides a closer genetic match than a deceased donor kidney. This increases the chance that the recipient's body will accept the kidney. Typically, a closer matched kidney will function for a longer time, and the recipient may be treated with lower doses of immunosuppression medicine. And thanks to your potential donation, the recipient will not need to wait on the deceased-donor kidney list, where the average wait is five years. Early donation may eliminate the need for dialysis. The longer an individual needs to stay on dialysis, the more negative its impact on their survival and health.

Success rates for the transplanted kidney (graft) at one year, for persons receiving a living related kidney transplant, may reach 95 percent. The average living-related kidney lasts 25 years.

Living non-related kidney transplant

Living non-related kidney transplant (sometimes called "emotionally related kidney transplant" or "living unrelated kidney transplant") includes anyone who is living, but not blood related, such as the spouse or a friend. The advantages to a living non-related kidney transplant are the same as the living-related kidney transplant. Statistically, a living non-related transplant recipient has a higher success rate than a deceased-donor kidney recipient.

Success rates for the transplanted kidney, at one year, for someone receiving a living non-related kidney transplant, may reach 95 percent. The average living non-related kidney lasts 18 to 20 years.

Kidney paired donation

Imagine this situation: Someone wants to donate a kidney to you, but your blood type does not match or there is some other incompatibility. Imagine a second pair in the same situation, but the kidney from the potential donor in that pair is able to donate to your transplant recipient candidate. By swapping the donors and the recipients in these two pairs, two transplants are made possible. Usually, an exchange transplant involves two recipient/donor pairs; however, sometimes, exchanges include more than two recipient/donor pairs.

Beaumont transplant is participating in the KPD Pilot Program a part of the OPTN. The OPTN is managed by UNOS through a contract with the Health Resources and Services Administration (HRSA) and agency of the U.S. Department of Health and Human Services. The OPTN registers and tracks everyone who chooses to participate in the Pilot Program throughout the country. This database is part of a computerized system that allows transplant centers and organ recovery agencies throughout the United States to search for cases where the donor in each pair is compatible with the recipient in another pair (or multiple pairs). By exchanging the donors, a compatible match for multiple recipients can be found.

As a potential donor, you must also be willing to take part in an exchange in addition to your transplant recipient candidate. Like any living donation program, all potential donors are required to complete an extensive medical and psychological evaluation and consent process to decide if you may donate.

Deceased-donor kidney transplants

Typically, deceased donors are individuals who have been declared brain dead. They are often in an intensive care unit. The individual's family has been offered the option of organ and tissue donation and has consented to the donation. When a person is on the waiting list for a kidney, they are waiting for a deceased donor kidney. Unlike living-related and living non-related kidney transplants, the deceased-donor kidney transplant surgery cannot be scheduled ahead of time.

It is most likely that your intended transplant recipient is on or is in the process of completing their evaluation to be placed on the deceased donor waiting list. They will remain on the deceased donor waiting list even though you are in the process of your donor evaluation, so a deceased donor kidney offer may become available before your evaluation is completed or the living donor transplant occurs.

Success rates for the transplanted kidney, at one year, for persons receiving a deceased-donor kidney transplant, are about 88 percent. The average deceased-donor kidney is expected to last 10 to 12 years.

DONOR EVALUATION

A thorough medical and psychosocial evaluation prior to becoming eligible to donate a kidney begins with a telephone interview to screen your medical history. This is followed by physician interviews, physical examination and blood tests. If testing shows there is a reason why it would not be good for you to donate your kidney, the person you wish to donate your kidney to will have alternative therapies available. They could receive a kidney from another person who wishes to donate, from someone who has died and been able to donate their kidneys, or be able to continue living with the use of dialysis.

Donors should be volunteers. You should feel good about making a generous gift to a person who can benefit from your gift. If you are being coerced to donate, it is important to share this information during the donor work-up. It is a federal crime for the potential donor to knowingly acquire, obtain or otherwise transfer any human organ for valuable consideration (i.e., for anything of value such as cash, property, vacations).

Personal expenses of travel, housing, childcare costs, loss of wages related to donation, telephone and television while in the hospital are not covered. However, resources might be available to defray some donation-related costs. If the donor needs assistance or lives out of the area/state, please contact the transplant social worker or financial coordinator who will provide assistance in accessing this information and application process.

You will be educated about the potential success of kidney donation both for you and the recipient. National statistics and our program's success rate (transplant recipient outcomes) from the most recent Scientific Registry for Transplant Recipients (SRTR) and notification about all CMS outcomes requirements not being met by the transplant hospital if applicable will be made available to you in print form. Donating a kidney should not increase your personal risk for kidney failure or shorten your life expectancy. Nevertheless, you will be left with only one kidney and should that kidney be injured or develop a disease process such as a kidney stone, you would then have risk to the function of your only remaining kidney. This risk should be no greater than people who are born with only one kidney, and people born with only one kidney tend to have normal life expectancies. With that being said, there is the possibility that future health problems related to donation may develop and if they do they may not be

covered by your insurance. Donation may have a negative impact on the ability of the donor to obtain future employment. This may also impact the ability to subsequently obtain health, life and disability insurance. If at any time during the process of your evaluation you are uncomfortable considering donation, you have the right to opt out of donating and your reason for this will be kept confidential.

The confidential donor evaluation phase begins when you contact the Beaumont Transplant program office. You will be mailed a donor booklet, an outpatient general consent to treatment form, Beaumont's notice of privacy practices and a donor questionnaire, which asks questions about your medical history. It is essential that you answer all of the information completely and accurately on this questionnaire, sign the forms and return them in the envelope provided. The transplant team will review the information and make the decision to test you as a possible donor. If any one of the following criteria exists you cannot be considered as a kidney donor:

- being both under 18 years old and mentally incapable of making an informed decision
- uncontrollable hypertension or history of hypertension with evidence of end stage organ damage
- HIV
- diabetes
- active malignancy, or incompletely treated malignancy
- high suspicion of donor coercion
- high suspicion of illegal financial exchange between donor and recipient
- evidence of acute symptomatic infection (until resolved)
- diagnosable psychiatric conditions requiring treatment before donation including any evidence of suicidality

In general, donors need to be in excellent health, apart from a few conditions that may be of little or no significance. Please note that health information obtained during your donor evaluation will be subject to the same regulations as all records and could reveal conditions that the Transplant Program must report to local, state or federal public health authorities.

The transplant nurse coordinator will contact you after receiving your donor questionnaire. An appointment will be made for the initial blood work. This blood work includes blood typing (ABO), non A1 subtyping (if applicable), tissue typing (a blood test for genetics) and a cross match (compatibility test). There are no diet or fluid restrictions prior to this test.

If you do not live in the Beaumont Hospital, Royal Oak or lower Michigan area, the transplant nurse coordinator will help arrange to have the blood drawn where you live. Your blood will need to be delivered by next-day mail service to our laboratory for testing. Our office will provide all the necessary blood tubes, instructions and pre-paid mailing envelopes.

Who will I see?

During your transplant evaluation, you will meet the following members of the transplant team:

Transplant nurse coordinator

The transplant nurse coordinator's role is to provide continuity of care while you are being evaluated for donating a kidney. The transplant nurse coordinator will work closely with you to be sure that tests are being scheduled and completed, results are being sent to the transplant office for review, communication lines are staying open and questions are being answered. It is very important that you keep in touch with your transplant nurse coordinator. Any test results that you might have from other hospitals should be sent directly to your transplant nurse coordinator.

Your transplant nurse coordinator is a liaison between the nephrologist and you to be sure that accurate information is being shared and recorded in your medical record. Your work-up is successfully completed when all of the necessary medical information has been reviewed and approved by the transplant team.

Transplant social worker

The transplant social worker's role is to make sure you have adequate emotional support and resources to help in your decision to donate a kidney. At the time of your evaluation, the transplant social worker will meet with you, and possibly your support person.

Transplant dietitian

The transplant dietitian will participate in your donor evaluation by completing a nutritional assessment prior to donation to help determine if there are any nutritional contraindications to your kidney donation. Diet education will be completed as needed prior to donation.

The transplant dietitian will also participate in your care during the donation and discharge phases of care by completing another nutritional assessment at the time of donation, and by providing weight management diet education to donors with BMI \geq 30.

Transplant financial representative

The transplant financial representative will participate in your donor evaluation by discussing any financial concerns you may have and counsel you regarding available resources. The financial representative is also available by phone to answer your questions.

Transplant surgeon

The surgeon/urologist will ask you about your medical history and discuss the kidney donation operation. This is also the doctor who will do the surgery on the living kidney donor and care for you after surgery.

Transplant nephrologist

The transplant nephrologist will complete a medical evaluation including a physical exam. It is vital to know everything about your health history, any medical problems, hospitalizations and test results.

Transplant pharmacist

The transplant pharmacist will participate in your donor evaluation by reviewing all pertinent medical history, medication use and laboratory data to determine if there are any contraindications to your kidney donation.

The transplant pharmacist will also participate in your medication management as needed after your kidney donation surgery while you are in the hospital as needed.

Transplant assistant

The transplant assistant schedules your evaluation appointment with the transplant team. The day of your evaluation appointment, the transplant assistant collects medical records you have brought with you or that have been sent and coordinates your appointments with the individual members of the transplant team. The transplant assistant is available to help you schedule the tests that will be part of your kidney donation work-up.

LIVING KIDNEY DONOR EVALUATION CONSENT

Outlined below are some of the potential risks associated with the donor evaluation process and donation.

The following are inherent risk associated with evaluation for living donation:

- allergic reaction to contrast
- discovery of reportable infections
- discovery of serious medical conditions
- discovery of adverse genetic findings unknown to the donor, and discovery of certain abnormalities that will require more testing at the donor's expense or create the need for unexpected decisions on the part of the transplant team

The following surgical, medical, psychosocial and financial risks are associated with living kidney donation. These risks may be transient or permanent and include, but are not limited to the following:

- potential medical or surgical risks
 - death
 - scars, pains, fatigue and other consequences typical of any surgical procedure
 - decreased kidney function
 - abdominal or bowel symptoms such as bloating, nausea and/or developing bowel obstruction
 - kidney failure and the need for dialysis or kidney transplant for the donor
 - impact of obesity, hypertension or other donor-specific medical conditions on the potential donor's morbidity and mortality

- potential psychosocial risks
 - problems with body image
 - post-surgery depression or anxiety
 - feelings of emotional distress or bereavement if the transplant recipient experiences any recurrent disease or in the event of the transplant recipient's death
 - impact of donation on the donor's lifestyle
- potential financial impacts
 - personal expenses of travel, housing, child care costs and lost wages related to donation might not be reimbursed; however, resources might be available to defray some donation-related costs
 - need for life-long follow-up at the donor's expense
 - loss of employment or income
 - negative impact on the ability to obtain future employment
 - negative impact on the ability to obtain, maintain or afford health, disability and life insurance
 - future health problems experienced by living donors following donation may not be covered by the recipient's insurance

INITIAL BLOODWORK

ABO blood typing

This test determines your blood group: A, B, O or AB. Your ABO typing and non-A1 subtyping (if applicable) will be completed on two separate occasions prior to donation. It does not matter if you are Rh positive or negative (i.e. A+ or A-). Your blood type must be compatible with the recipient's blood type. You will notice that there is a category called A2. The blood type

A can be subtyped into A1 or A2. It may be possible for a person with an A2 blood type to donate a kidney to an O recipient. The transplant team will let you know if that may be possible.

You can use the following chart to determine whether your blood type is compatible with the recipient.

| If the recipient's blood type is: | then the donor's blood type must be: |
|-----------------------------------|--------------------------------------|
| O | O or A2 (This is a subtype of A) |
| B | B, O or A2 |
| A | A or O |
| AB | A, O, B or AB |

The donor and recipient blood types must be compatible, regardless of other results such as tissue typing or cross matching.

Tissue typing

Tissue typing is a blood test that uses DNA-based technology to identify genetic similarities (antigens) between the donor and the recipient. Tissue typing reveals how many antigens you and the person receiving your kidney (recipient) have in common. Antigens are molecules on cell surfaces that are important for transplant success.

The ideal match is an identical twin. Since few individuals have identical twins, the next best match is a living-related, six-antigen match. You received half of your chromosomes (genetic material, antigens) from each parent. Because of the way we inherit genes from our parents, it is possible for one sibling to match all six antigens (also referred to as HLA identical or a perfect match) with another sibling. It is also possible that among siblings, there might be either a three-antigen match (haplotype) or a zero-antigen match (complete mismatch). Parents and natural children will always match three antigens (haplotype).

Crossmatch

A crossmatch provides information about the risk of immediate, severe rejection if the kidney is transplanted. Two types of crossmatches may be done during the evaluation phase. In both cases, the recipient's blood is mixed with lymphocytes (white cells) from the donor's blood. There must be no reaction (in other words, a negative crossmatch) between the two samples for a kidney to be considered for transplant. The crossmatch is also done between potential deceased donors and recipient candidates prior to transplant.

If the blood test is reported as a positive crossmatch, despite your blood type compatibility and the genetic matching, you may not be considered as a living donor for this recipient.

CHOOSING THE DONOR

Decision to donate

When all interested parties have been tested as possible donors, one individual will be identified as the kidney donor of choice. This may be the person that has the closest genetic match to the recipient, but multiple factors are taken into account. If the identified donor is not able to continue the donor evaluation, another individual is chosen from those available.

Many things are considered beyond the initial blood testing. Your transplant nurse coordinator will discuss these issues with you when he or she calls with your results. Please write down questions you might have so they can be answered. Please tell your transplant nurse coordinator about any concerns you might have. Now is the perfect time to talk about any issues on your mind. The transplant nurse coordinator must know how you are feeling about being a kidney donor, so never hesitate to call. Be honest about your concerns, issues and questions. Your conversations with the transplant nurse coordinator will be strictly confidential.

If you do not live in Michigan and cannot come to Beaumont Hospital for the transplant team evaluation, your transplant nurse coordinator will make arrangements with the closest transplant facility in your area or your primary care physician. All testing will be done at that facility, with the exception of the computed tomography, or CT angiogram scan, the last test. You will be scheduled to meet the Beaumont transplant team members before the surgery date. You will receive details when you contact the transplant nurse coordinator.

Time of donor evaluation phase

The length of time to complete the diagnostic tests depends on you and your schedule. Testing is scheduled at your convenience, whenever possible. Work, family, and/or school schedules may have to be considered.

Because the tests need to be done in a certain sequence, we cannot group some of them together. Your transplant nurse coordinator will help you during this phase. It is essential that you stay in touch with your transplant nurse coordinator.

MEDICAL EVALUATION

To qualify as a potential kidney donor, you must be in good health. During the donor evaluation, each transplant team member will complete his or her part of a thorough physical and mental health history as well as a physical examination. The transplant team includes the transplant surgeon, transplant nephrologist physician, transplant social worker and transplant nurse coordinator.

The transplant team must be certain that you do not have any significant risk factors for this elective surgery. Any health conditions such as heart disease, high blood pressure (hypertension – blood pressure to be taken on at least two different occasions), obesity (height, weight and body mass index [BMI] will be measured), or diabetes may eliminate you as a candidate for live kidney donation. Kidney donors will not knowingly be placed at risk. If there are any concerns related to your health or your ability to serve as a kidney donor, the transplant team makes the final decision about whether you can continue as a kidney donor. Smokers are asked to stop smoking, not only for their own health, but to ensure a better surgical recovery and minimize the risk of blood clots.

INDEPENDENT LIVING DONOR ADVOCATE

The living donor advocate is an individual who is independent of the transplant team, not involved with the potential recipient evaluation and is independent of the decision to transplant the potential recipient. This individual will be available to assist the donor during the donor evaluation, donation, post donation and follow-up phases of care.

The purpose of the living donor advocate is to:

1. focus on the donor's needs and questions
2. protect and promote the best interests of the potential living donor
3. ensure accountability of the protection of the rights of the living donor including the application of principles of medical ethics and the use of informed consent standards
4. respect the donor's decision and ensure that the donor's decision is informed and free from inducement and coercion
5. make recommendations to the transplant team regarding prospective donor's suitability for donation
6. assure the potential donor that a decision not to proceed with the donation will be protected and confidential and will only be disclosed with the consent of the potential donor
7. inform the donor that he/she may decline to donate at any time

The independent donor advocate is part of the independent donor advocate team, which includes transplant physicians, social workers, financial coordinators and transplant nurse coordinators. Together, they will assist the potential donor with understanding information regarding the:

- a. consent process
- b. evaluation process
- c. surgical procedure
- d. medical and psychosocial risks
- e. benefit and need for follow-up

TESTS

What tests will I have to do during the evaluation phase?

It is very important that we know a donor is in good health. The following tests will allow us to verify your current health status. If the transplant team feels that a test needs to be repeated, or clarified with an additional test, the transplant nurse coordinator will inform you. The tests are listed below in the order of scheduling.

Laboratory

Your health status will be checked with blood tests for general and metabolic function, organ specific function and transmissible diseases (such as hepatitis, AIDS, syphilis, etc.). These laboratory tests provide information about your general health and your kidney and liver function. Some of the blood work will require fasting (no food or drink for 12 hours before the laboratory tests are drawn).

General lab work gives us information about your kidney and liver function. A pregnancy test is also required for female patients. A 24-hour urine collection provides us with information about your kidney function. If you have excessive protein in your urine (proteinuria) or your kidneys are not able to clear waste products from your body (low creatinine clearance), then you will be ruled out as a living kidney donor.

Glucose tolerance test

This test is usually completed when there is a family history of diabetes. The transplant team will decide if this test is required based on your medical evaluation and family history.

Chest X-ray

A chest X-ray provides information on your lung status. If you have had this within the last six months, please bring the written report to your evaluation. You do not have to bring the actual X-ray films.

EKG

An EKG provides information on your heart function. If you have had this within the last six months, please bring the report to your evaluation.

Females:

Pap smear and pelvic

This is done as a routine cancer screen. All females must have a current pap and pelvic (within 12 months). If you have had this within the last 12 months, please bring the report to your evaluation. If you have had a hysterectomy, please see your doctor and have a pelvic examination.

Mammogram

This is done as a routine cancer screen. All female patients over age 40 must have a current mammogram. If you have had this within the last 12 months, please bring the paper report to your evaluation. We do not need the films.

Males:

PSA (prostate specific antigen)

Men should have this blood test as part of their annual screening for cancer. African American or patients with a family history of prostate cancer should have a PSA starting at age 40, otherwise starting at age 50.

Colonoscopy

This is done as a routine cancer screen. All donors over age 50 must have a current colonoscopy. If you have had this within the last 12 months, please bring the report to your evaluation.

Cardiac stress test

A cardiac stress test is done on a treadmill. This test gives us information about your current heart status. All donors over age 50 may need a current stress test. If you have had this within the last 12 months, please bring the report to your evaluation. If other risk factors are identified, you may need a stress test even if you are not yet 50 years of age.

CT angiogram scan

The CT (computed tomography) angiogram scan is an X-ray examination that produces a series of cross-sectional, 3-dimensional images of your kidneys. The CT angiogram confirms the presence of two kidneys, the structure of the kidneys, absence of stones, and the number of renal arteries, veins, and ureters. Wide variability in these structures may be found among different people.

This test determines which kidney will be used for donation. This test must be done at Beaumont Hospital.

An intravenous, or IV, contrast medium injection is used, which will highlight your kidneys. You may feel a warm flushing, but this soon passes. The test takes approximately 20 to 30 minutes. You do not need someone to come to this test with you. You are able to drive after it is completed. The only preparation for the CT angiogram is not to eat anything for three hours prior to the test, but you may have clear liquids.

Miscellaneous testing

Other testing may be required based on your medical and surgical history. Your transplant nurse coordinator will inform you of any further required testing as determined by the transplant team.

Testing review

It is essential that members of the Transplant Team review all diagnostic test results before a surgery date is set. If at any point during the evaluation phase the team is not comfortable with a test result, the donor's situation will be reviewed and recommendations will be made for further work-up based on the findings. These tests may not be covered because they are beyond the routine screening required for kidney donation.

The transplant hospital may refuse the potential donor. In such cases, the donor can choose to be evaluated by another transplant program that may have different selection criteria.

What happens when all the tests are completed satisfactorily?

When all of the required tests are successfully completed, your transplant nurse coordinator will schedule a mutually agreed upon date for the kidney transplant and living kidney donor surgery.

The recipient will have a few more items to complete as the surgery date draws near. A date is chosen that allows enough time to complete those items.

BEFORE SURGERY

Your transplant nurse coordinator will review specific timetables with you prior to surgery. Specific blood tests are required at certain intervals, so there may be several appointments before surgery occurs. You will need to come in for an office visit immediately prior to the surgery date to meet with the doctor and transplant nurse coordinator for final instructions and blood tests for final cross matching and pre-surgical testing. They will review information regarding the surgery. Please make a list of questions to ask while you are at this appointment.

If you decide to donate you will have a donor nephrectomy, or the removal of a kidney for donation.

Your transplant surgeon will verbally explain the nature of open and laparoscopic donor nephrectomy to you, and answer any questions regarding each technique. Your transplant surgeon will determine which technique he or she is going to use, depending on the anatomic imaging that will be done prior to the operation. There is the possibility that a laparoscopic plan could be converted to an open plan depending on the findings during the operation.

Education regarding the actual operation, post-operative and potential complications for kidney donation will be discussed with you over the course of your evaluation.

You will be asked to drink a lot of water the day before surgery. This is done to keep your kidneys full of fluid (hydrated). The night before surgery do not eat or drink after midnight. It is important for your stomach to be empty.

For the laparoscopic kidney surgery you will be asked to take a bowel prep the day before surgery. This is an over-the-counter medication that will cause your bowels to move a number of times. This is important in laparoscopy to enhance the ease of surgery and reduce the risks to your intestines.

KIDNEY DONATION SURGERY

Laparoscopic donor surgery

At Beaumont, our surgeons perform virtually every living kidney donor surgery using the laparoscopic technique. Your transplant surgeon will be performing either an open operation involving a flank incision, which may or may not require removal of a portion of rib, or the surgeon will be performing a laparoscopic procedure. A laparoscopic procedure is performed with laparoscopic instruments viewed through a telescopic camera, in order for the kidney to be dissected and removed through a smaller abdominal incision in the midline. This technique uses two or three very small half-inch incisions through which a laparoscope

(small, lighted telescope) and other instruments are placed into the abdomen to perform surgery. To create a working space, the abdomen is filled with inert carbon dioxide gas. To remove the kidney from the body, a three-inch incision is used. People tolerate the small incisions better than an open surgery, shortening the hospital stay, significantly decreasing recovery time at home and producing a better cosmetic effect.

Other benefits of laparoscopy include greater magnification for the surgeon and lower blood loss due to the pressure of the gas in the abdominal cavity. Usually the left kidney is removed for transplant, but occasionally the anatomy of some donors dictates that the right kidney would need to be used.

Conversion of laparoscopic to open surgery

Rarely, if certain difficulties occur during laparoscopic surgery, the operation may need to be converted to an open operation. This would be done by creating a larger incision. Reasons for a conversion to open surgery may include difficult internal anatomy, bleeding or other complications. Fortunately, these circumstances are extremely rare, but a laparoscopic surgery might be converted to an open operation for your safety or to protect the donated kidney.

DAY OF SURGERY

You will be admitted to Beaumont Hospital early on the morning of surgery.

At the time of the procedure you will be asked to sign a formal hospital operative consent, which is required for all Beaumont patients undergoing surgery. You should read it carefully before signing.

The kidney donor goes to surgery before the kidney recipient. Your surgeon and anesthesiologist will meet you in the pre-op area and discuss the procedure and what to expect.

The pre-surgical nurses will place an IV in your arm and give you fluid. This keeps your kidneys hydrated.

You will receive general anesthesia and will not be awake during surgery. You will be intubated (a breathing tube is placed through your mouth into your trachea).

Once anesthesia is begun, a catheter tube is placed in the bladder to drain your urine. You will be carefully positioned on the operating table, a sterile prep solution will be applied to the surgical site, and sterile drapes applied to the area. The surgery will then begin. You will be positioned on one side or the other depending on which kidney is removed. Physicians are careful with positioning you under general anesthesia in order to avoid injury, yet despite best attempts, minor injury can occur. Skin or nerves can be damaged from pressure to small areas. These complications are typically very rare.

The kidney is removed from the donor and is flushed with a special cold solution and immersed in sterile ice slush to protect it from the lack of blood flow. The kidney is then taken by the recipient surgeon, who prepares it further for the actual transplantation.

In general, the operation will take between three and five hours. During the operation, the kidney to be donated will be removed, along with the important blood vessels, and the ureter, which drains the kidney to the bladder.

Once the kidney has been removed, your wounds will be closed and you will be transferred to the recovery room. The recipient operation is then performed. The kidney will be transplanted into the recipient.

Will I need a blood transfusion during surgery?

Kidney donation surgery usually involves minimal blood loss. It is highly unlikely that you will need a blood transfusion during or after your kidney donation. However, in the event that you would need a blood transfusion, please rest assured that the current blood supply meets the highest standards and is judged safe by the medical community. If you are still concerned, you can donate a unit of blood to yourself before surgery. This is called autologous donation. Your transplant nurse coordinator can help you arrange this. Autologous blood donation needs to be completed at least seven days prior to surgery, so if you are interested please let your transplant nurse coordinator know at least several weeks prior to surgery.

The blood you donate to yourself will only be used for you. If you do not need a blood transfusion, the unit of blood will be discarded. No other patient, including your recipient, will be able to use this blood. Feel free to discuss any transfusion questions with your donor surgeon.

AFTER SURGERY

After the surgery, you will go to the recovery room, also known as Post Anesthesia Care Unit, or PACU. The anesthesia slowly wears off. You will feel tired after surgery. Nurses take your blood pressure, monitor your urine output via a catheter, provide you with pain medication and answer your questions. When you are ready, you will be transferred to the inpatient nursing floor.

The recipient will be taken from the operating room directly to the Intensive Care Unit, or ICU. Nurses will carefully monitor the recipient and the new kidney transplant. Approximately 24 hours later, the recipient will be moved to the transplant nursing floor.

The donor and the recipient will recover on the same floor, once the recipient has been transferred from the ICU.

Laparoscopic-donor nephrectomy patients usually require one to two days in the hospital. Once you are discharged home, you should be able to take care of yourself. Usually pain is well managed with oral pain medicines for one to two weeks. It is unusual to require significant pain medication after two weeks. Full healing of your incisions will probably not occur for at least four weeks and your physician will counsel you on activities that you do. You will have the opportunity to discuss things in detail with the surgeon performing the procedure, and the surgeon will answer any questions you may have prior to the procedure.

COMPLICATIONS

Complications for the donor nephrectomy include but are not limited to the following:

- Bleeding – this rarely requires a blood transfusion
- Infection that could include infection to the wound, in the abdominal cavity or in the lung, such as pneumonia
- Damage done to the donated kidney itself during the process of surgery, which might jeopardize the ability of the transplant to function. In extraordinarily rare circumstances, the kidney may be damaged so greatly that it cannot be transplanted.
- Damage to surrounding organs or blood vessels. This could include damage to the spleen, the pancreas, the intestines or colon. These injuries are rare.
- Blood clots in a person's legs, with a clot traveling to the lung, which could be potentially life threatening
- Chronic incisional pain, unusual scar tissue or development of an incisional hernia
- Abdominal problems, including obstruction of the bowels
- Many minor complications, such as an infection in an IV site, numbness in the area of an incision, or numbness or tingling in a leg or arm that is usually temporary due to positioning during surgery

Living kidney-donor surgery is estimated to have a 0.03 percent mortality (death) rate (i.e., 3 in 10,000). To put this in context, this is the approximate risk of dying in a motor vehicle accident on the streets of Metro Detroit every year or the risk of a construction worker dying on the job annually. According to the United States Census Bureau, the 2007 infant mortality rate in the U.S. is 0.64 percent (e.g., 64 in 10,000), indicating that it is about 20 times riskier to be born in the United States than to donate a kidney.

LONG-TERM COMPLICATIONS

Perhaps the most common question of a potential kidney donor is “What are the long-term consequences to my health with one kidney?”

Because living kidney donation has been practiced for more than 50 years, research has been conducted on the long-term effects of donation on the donor. In general, these studies have shown very little negative impact.

Here’s a summary of some of the research results:

- *Najarian, et al., 1992.* This study of 57 donors 20 or more years after donation measured renal function, blood pressure and proteinuria (an excess of protein in the urine) compared to their siblings. The donors showed no significant differences in health.

The study also assessed the risk of mortality from the donation process by surveying members of the American Society of Transplant Surgeons. The results yielded a mortality rate estimated to be 0.03 percent.

- *Ramcharan and Matas, 2002.* This study updates the findings from the first study above (*Najarian, et al.*), looking at health of 773 living donors 20 to 37 years after donation. Of the group, 84 had died, three of renal failure. Of the living donors, three had abnormal kidney function and two had undergone transplantation. The remaining donors had normal kidney function. The rates of proteinuria and hypertension were comparable to the general population. The study concludes that most kidney donors have normal kidney function 20 to 37 years following donation. Some donors do experience renal dysfunction or failure.
- *Undurraga, A, et al., 1998.* A study of 74 donors showed adequate renal function when compared to a control group. A trend to a slightly higher incidence of high blood pressure, proteinuria and microhematuria (excess blood in the urine) was identified.
- *Fehrman-Ekholm, I., 1997.* This Swedish study evaluated the life span of living kidney donors. Of 430 people who donated between 1964 and 1994, 41 died from 18 months to 31 years following donation. The causes of death included cardiovascular disease, cancer, injury or accidents, gastrointestinal disease, alcoholism and other diseases. None died of kidney disease. The study also showed that kidney donor survival was higher than the general population, possibly due to the careful selection of donors based on their health (i.e., donors tend to be healthier than the general population).
- *McCune, TR, et al., 2004.* This study shares the results of a program by the South-Eastern Organ Procurement Foundation tracking the experiences of living donors. Information is collected using questionnaires at the time of donation, then after three months, six months and

annually thereafter. The study reported the following findings:

- Donors relied on employer-provided paid time off (vacation and sick leave) for recuperation, but the average donor also required 12 weeks of unpaid leave before returning to work.
 - Donors had out-of-pocket expenses for transportation, lodging and childcare.
 - Anti-depressants were prescribed for about 11 percent of donors.
 - About five percent of donors were treated for hypertension.
 - Nearly 38 percent of donors reported experiencing complications from the donation, with 7.6 percent of the complications being serious enough to require hospitalization or surgery.
- *NEJM, Jan 29, 2009*. Long-term consequences of Kidney Donation. This study of 3,698 kidney donors from 1963 through 2007, at a mean of 12.2 years after donation:
 - 32.1 percent had hypertension, and 12.75 percent had albuminuria
 - prevalence of coexisting conditions was similar to that among controls from the National Health and Nutrition Examination Survey, NHANES, who were matched for age, sex, race or ethnic group, and body-mass index
 - most donors had quality-of-life scores that were better than population norms

These studies and others like them strongly suggest there are few serious long-term health consequences from donating a kidney. However, some precautions naturally are in order.

How can you protect your kidneys?

Monitoring

Your doctor should monitor your kidney function by checking your blood pressure and testing your urine and blood once a year.

- Normal blood pressure is considered to be 120/80 or lower. You have high blood pressure if it is over 140/90. People with kidney disease or one kidney should keep their blood pressure below 130/80. Controlling blood pressure is especially important because high blood pressure can damage kidneys.
- Your doctor may use a strip of special paper dipped into a little cup of your urine to test for protein. The color of the “dipstick” indicates the presence or absence of protein. A more sensitive test for proteinuria involves laboratory measurement and calculation of the protein-to-creatinine ratio. A high protein-to-creatinine ratio in urine (greater than 30 milligrams of albumin per 1 gram of creatinine) shows that kidneys are leaking protein that should be kept in the blood.
- Measuring your level of kidney function, also sometimes called GFR (short for glomerular filtration rate, which shows how efficiently your kidney is filtering your blood) requires a simple blood test for a chemical called creatinine. Serial blood tests over the years should show a stable creatinine, reflecting stable kidney function. An increase in your creatinine may reflect a decline in the ability of your kidney to adequately filter your blood and requires closer attention to determine further action. Kidney donors should have this checked every year.

Controlling blood pressure

If your blood pressure is above normal, you should work with your doctor to keep it below 130/80. Great care should be taken in selecting blood pressure medicines for people with a solitary kidney. Angiotensin-converting enzyme, or ACE, inhibitors and angiotensin receptor blockers, or ARBs, are two classes of blood pressure medicine that may provide additional protection for kidney function and reduce proteinuria. But these medicines may be harmful to someone with renal artery stenosis, or RAS, which is the narrowing of the arteries that enter the kidneys. They may also be harmful in situations that lead to dehydration. Controlling your blood pressure may require a combination of two or more medicines, plus changes in diet and activity level.

Eating sensibly

Having a single kidney does not mean that you have to follow a special diet. You simply need to make healthy choices, including fruits, vegetables, grains and low-fat dairy foods. Limit your daily salt (sodium) intake to 2,000 milligrams or less if you already have high blood pressure. Reading nutrition labels on packaged foods to learn how much sodium is in one serving and keeping a sodium diary can help. Limit alcohol and caffeine intake as well.

Avoid high-protein diets. Protein breaks down into the waste materials that the kidneys must remove, so excessive protein puts an extra burden on the kidneys. Eating moderate amounts of protein is still important for proper nutrition. A dietitian can help you find the right amount of protein in your diet.

Avoiding injury

Some doctors may advise patients with a solitary kidney to avoid contact sports such as boxing, football and hockey. One study indicated that motor vehicle collisions and bike riding accidents were more likely than sports injuries to seriously damage the kidneys. In recent years, athletes with a single working kidney have participated in sports competitions at the highest levels. Having a solitary kidney should not automatically disqualify you from sports participation. Protective gear such as padded vests worn under a uniform can make limited contact sports like basketball or soccer safe. Doctors and patients should consider the risks of any activity and decide whether the benefits outweigh those risks.

Pregnancy

Pregnancy for the most part is not a problem following donation, but a female should let the obstetrician know they have only one kidney so kidney function can be monitored.

As previously noted, some studies have shown a slightly higher risk of high blood pressure and proteinuria. These risks can be managed and monitored through regular physical exams, blood tests and urine tests.

Additional information on living with one kidney from the National Kidney and Urologic Diseases Information Clearinghouse:

Stay healthy by following normal, sound health practices and have an annual physical to monitor your health.

You should also consider your psychological health after donation. For example, some living donors report feeling depressed after donation. This feeling may be the result of fatigue following surgery, renewed demands on you by family and work while you are still recovering, or the sudden letdown following a major life event that had been

marked by lots of energy, anxiety and attention from others. A medical research study showed that nearly 11 percent of living donors were prescribed anti-depressants following donation.

Your mood can also be influenced by what happens to the recipient of your donated kidney. The recipient may reject the transplanted kidney or may die despite the transplant. It's natural to go through a grieving process in this circumstance.

A perspective on coping with the problems your recipient may endure can be found on this web site: Living Organ Donor Advocate Program – www.lodap.com

If your feelings of sadness persist, get professional help. If you donate to a spouse, family member or friend, the nature of your relationship with that person may change. You or the recipient may feel guilt, indebtedness, conflict or regret and experience manipulation and other destructive behavior. Seek professional counseling if your relationship becomes dysfunctional.

Useful web sites

www.livingdonorsonline.org

www.kidney.org

www.transplantliving.org/livingdonation

www.donatelife.net

FREQUENTLY ASKED QUESTIONS

What types of “tubes” will I have?

You will have an intravenous, or IV in your arm to keep you hydrated. This usually comes out as soon as you are drinking fluids on your own without problem.

You will have a urinary catheter in your bladder to drain your urine. This is a slender, soft, plastic tube, which is inserted during surgery. This allows the nursing staff to monitor how much urine you are making and to see if you are dehydrated. The urinary catheter stays in place for one day. Removal of the catheter is done at the bedside and takes just a few seconds.

How is my discomfort controlled?

All surgery involves some discomfort. Pain medicine (narcotics) will initially be delivered through your IV tubing. Kidney donors can switch to oral pain medicine within a day and will go home with an adequate supply.

Your doctors and nurses will be attentive to your pain control needs. The goal is to manage your pain before it is out of control. Only you can describe your pain. You need to tell the hospital staff:

- you have pain
- the kind of pain you have
- the places it hurts

Our goal is to provide the best pain relief for you. We will be using a tool called a pain scale. When your pain is controlled, you will sleep, eat, talk and move, doing your normal daily activities more comfortably. Adequate pain control is very important to allow healing, exercising and walking.

What about complications?

Kidney donors are thoroughly tested before completing the donor evaluation phase. During this time, the transplant team analyzes the test results. If there is any concern that the donor would be placed at increased risk, the planned donation is delayed or canceled.

Surgical complications in kidney donors are rare, but can include infection, bleeding, pneumonia, blood clots and damage to nearby organs. The risk of death with this type of surgery is very rare, but nonetheless has happened. The surgeon will discuss the above risks and others with you in detail. You should feel free to ask any questions regarding risks at any time.

When can I go home?

You will usually go home between the first and second day after surgery, depending on many factors. A patient needs to be walking, drinking fluids and have good pain control prior to discharge. The surgical team and nursing staff will discuss discharge planning with you and make specific recommendations regarding activity, diet, etc.

The surgeon will usually see you for a follow-up visit within four weeks of discharge. You can always call your surgeon at any time with questions.

Additional visits to see your surgeon will be arranged based on individual needs. We highly recommend an annual check-up with your family physician (primary-care physician) for a blood pressure check, blood test for creatinine (kidney function) and a urinalysis. It is a requirement for transplant.

Transplant Centers are required to contact you and obtain follow up health information on each living donor at six months, one-year, and two-years post donation. If you choose to donate, you are committing to maintain this follow-up and assist in providing the information.

How long will my recovery take?

Every donor is unique and therefore each donor's time frame varies. Many donors find that regaining their previous energy level takes four to six weeks. Others find the time frame to be shorter or longer. You can certainly start walking and increasing your activity as soon as you feel able. Each day, plan on doing just a little bit more but always within reason.

You can help your recovery by keeping an active and healthy lifestyle before surgery. After surgery, you will be taking care of yourself. Dedicate yourself to gently increasing your daily activities. Walking is a wonderful way to do this.

When can I drive?

You can typically start driving two to three weeks after surgery. If you are still on narcotics, or your ability to make quick movements while driving is still limited, returning to driving may be longer. Please check with your surgeon for permission to drive. Remember to always wear your seat belt, starting with your ride home after discharge.

When can I go back to work?

Kidney donors generally return to work in two to four weeks. Your own return to work is determined by the nature of your work and activity levels among other things. Some patients consider returning to work for half days for the first week.

If you have a job that requires heavy lifting, the surgeon may ask you not to return to work for up to six weeks to allow adequate time for the incision to heal and strengthen.

Time off work is not reimbursable by the recipient's insurance.

What guidelines should I follow after surgery?

- Drink extra fluids, including water, for several weeks.
- Eat a healthy diet.
- Avoid driving for two to three weeks, and while you are taking pain medicines.
- Avoid lifting items heavier than 10 pounds. You may do light housework or similar activities.
- Avoid vigorous activity until cleared by your surgeon.
- Gradually increase activity and exercise as tolerated. Walking is a great form of exercise.
- You may resume sexual relations in two to four weeks as you feel ready.

What will my life be like with a single kidney?

Your life span, physical activity and current lifestyle should not be affected by being a kidney donor. Donors are able to resume all pre-surgical activities and lead very healthy and productive lives.

Transplant physicians have studied donors for more than 30 years and have seen no increased incidence of high-blood pressure, diabetes, kidney or other diseases over the rates in the general population. We have seen no change in life expectancy. You do not need to be on a special diet or routinely take special medications. The remaining kidney actually grows approximately 30 to 50 percent larger and works harder than before. After one to two years, it will do approximately the work of one and one-half kidneys.

Post-donation kidney function and how chronic kidney disease (CKD) and end-stage renal disease (ESRD) might potentially impact the donor in the future to include:

- On average, donors will have a 25 to 35 percent permanent loss of kidney function at donation.
- Baseline risk of ESRD does not exceed that of members of the general population with the same demographic profile.

- Donor risks must be interpreted in light of the known epidemiology of both CKD and ESRD. When CKD or ESRD occur, CKD generally develops in mid-life (40 to 50 years old) and ESRD generally develops after age 60. The medical evaluation of a young potential donor cannot predict lifetime risk of CKD or ESRD.
- Donors may be at a higher risk of CKD if they sustain damage to the remaining kidney. The development of CKD and subsequent progression to ESRD may be more rapid with only one kidney.
- Dialysis is required when reaching ESRD.
- Current practice is to prioritize prior living kidney donors who become kidney transplant candidates.

We ask you to be prudent in your activities, however. We do not recommend high-risk activities such as bungee jumping or kickboxing. Different people respond differently to donation. Most people feel good about donating their kidney. However, you could feel depressed or angered after kidney donation. Organ donation may uncover unexpected family dynamics. If this occurs, it is important to seek professional help to understand these feelings.

Do I have to see a doctor after kidney donation?

Yes. You will see the surgeon within four weeks after you are discharged. It is important to have your blood pressure, urinalysis and kidney function blood tests (serum creatinine, and urine protein) checked at six months and every year following donation. Transplant Centers are required to contact you and obtain health and social information on each living donor at six months, one year and two years post donation. If you choose to donate, you are committing to this required follow-up coordinated by the transplant program where you have the living donor surgery. After which, we strongly recommend annual follow-up and routine care with your family doctor.

If any infectious disease or malignancy pertinent to acute recipient care is discovered during the potential donor's first two years of post-operative follow-up care these findings:

- will be disclosed to the donor
- may need to be reported to local, state or federal public health authorities
- will be disclosed to their recipient's transplant center
- will be reported through the OPTN Improving Patient Safety Portal

What is my financial obligation as a donor?

Most people who have kidney disease are eligible to receive benefits from the federal Medicare program. These benefits always extend to the potential donors, which mean that the donor evaluation, hospitalization and surgery are completely reimbursed by the recipient's insurance.

Even when a non-Medicare patient has a private insurance carrier that provides benefits to help in the cost of the donor work-up and surgery, the federal Medicare program will cover certain services rendered to the donor. It is wise for the recipient to know the details regarding his or her insurance coverage. A contact person at the insurance company should be able to tell you whether kidney transplant and kidney donation are covered under the recipient's particular contract. It is a possibility that future health problems related to the donation may not be covered by your insurance. Your ability to obtain, maintain or afford health, disability or life insurance may be affected. You should check with your current insurance regarding health benefits, short and long-term disability and life insurance to help clarify these issues. Donation may have a negative impact on the ability of the donor to obtain future employment. Additionally, the medical evaluation of the potential donor may discover problems that prevent him or her from donating and require life-long follow-up at the donor's expense. Whatever the recipient's insurance is, you,

the donor are not expected to pay expenses directly related to the donation of a kidney. Personal expenses of travel, housing, child-care costs, telephone and television while in the hospital and lost wages related to donation are not covered. However, resources might be available to defray some donation related costs.

If you inadvertently receive a bill for a test directly related to your kidney donor evaluation, we apologize. Please immediately forward the bill to the transplant financial coordinator.

If you have questions or concerns regarding finances during this time, please contact our transplant financial coordinator.

Can I continue with plans to have children after I am a kidney donor?

Yes. Medical evidence has found no increased risk to you or your baby to proceed with and carry a pregnancy if you have donated a kidney. For general recovery reasons, you should plan on waiting a few months after kidney donation to become pregnant. Please make sure your OB/GYN knows that you were a kidney donor.

What if I change my mind about being a kidney donor?

Some people have no problem making a decision to be a donor. Other people find the decision much more difficult and spend a great deal of time soul searching, talking to other donors and getting information from the Internet. They may need to ask lots of questions and take time to think things over. Agreeing to be a kidney donor is a very personal decision. The only "right" decision is the one that's right for you.

You can change your mind at any time about being a kidney donor. Talk to your transplant nurse coordinator, independent donor advocate or transplant social worker about your concerns or decision. All information will be confidential.

Feel free to ask questions

We hope this booklet has helped answer your questions about kidney donation. Throughout this process, please feel free to ask questions to clear up any information that you do not understand.

All information that takes place between you and a member of the transplant team will be strictly confidential.

The transplant team will support your decision, no matter what it is.

Your living donor advocate will also be available to discuss any further questions or concerns you may have. Please keep in mind that this booklet is for information only. Your individual treatment and experience may vary.

Closing thoughts

The decision to donate a kidney and the act of doing so is an important and personal process. Giving of oneself in this way is a gift to a family member or friend and to the community in which we live. It is of immeasurable value. We feel privileged to be involved in this work. We will always strive to make this a positive and successful experience for you and your recipient.

Thank you for your interest in kidney donation at Beaumont Hospital.

DEFINITIONS OF TERMS

Acute rejection

Acute rejection can happen at any time after a kidney transplant. During an acute rejection episode, the serum (blood) creatinine rises. This can usually be treated by taking a higher dose or a different type of immunosuppressive medicine until the creatinine returns to a baseline.

Antibody

Product of the immune system that helps the body fight infections and foreign substances.

Antigen

The “marker” that stimulates the body to produce antibodies.

Anti-rejection medicine

These drugs are taken by the recipient every day through the life of the transplanted kidney. They are also known as immunosuppressive medicine. They help prevent the immune system from rejecting the new kidney.

Autologous blood

Your own blood donated for yourself before surgery.

Bladder

The part of the urinary tract that receives urine from the kidneys and stores it until you urinate.

Blood typing

A blood test that indicates blood group. You can be type O, A, B or AB. The recipient’s blood type needs to be compatible with the donor’s blood type to receive the kidney transplant.

BUN

Blood urea nitrogen, or BUN, a waste product from the kidney. Your BUN value is an indication of waste products being created by the body.

Chronic kidney disease (CKD)

Occurs when the overall function of the kidneys declines to less than 10 percent of normal. When this happens, treatment such as dialysis or a transplant is needed to replace lost kidney function and support life.

Chronic rejection

Chronic rejection is a process that may happen after a kidney transplant. It can develop over months or even years. During this process, the creatinine slowly rises. There is no known treatment for chronic rejection.

Chronic renal (kidney) failure

Permanent damage to both kidneys that cannot be reversed; it is treated by dialysis or a kidney transplant.

Creatinine

A product of muscle metabolism. Creatinine level serves as a very good indicator of kidney function.

Crossmatching

A test to find out if the blood of the kidney donor and the person receiving the kidney are compatible (see also blood typing).

Deceased donor

An individual whose tissues or organs are donated after his or her death, sometimes called a "cadaveric donor." Such donations come from two sources: patients who have suffered brain death and patients whose hearts have irreversibly stopped beating. The latter group is referred to as "donation cardiac death" (DCD) or as "nonheartbeating" donors.

Dialysis

A process that cleans and balances the chemicals in the blood when a person's kidneys have failed. Dialysis may refer to hemodialysis or peritoneal dialysis.

Diastolic

The bottom blood pressure number. It shows the force of the heart muscle at rest. Diastolic is when the heart expands and fills with blood.

Donor nephrectomy

Removal of a kidney for donation from a living person.

End-stage renal (kidney) disease

Condition in which the kidneys no longer function and dialysis or a transplant is needed to replace lost kidney function and support life.

Glucose

A type of sugar found in the blood.

Hypertension

Another word for high blood pressure.

Immunosuppressive medicines

Medications taken by the recipient every day the transplanted kidney is functioning. They help prevent the recipient's immune system from fighting against and rejecting the new kidney. Also known as anti-rejection medicine.

Intravenous, or IV

A small catheter placed into a vein; refers to the fluids and medicines that are injected into a vein through a needle or catheter.

Kidneys

Two bean-shaped organs located beside the spine, just above the waist. They remove waste and balance fluids in the body by producing urine.

Living non-related kidney

Sometimes called "emotionally related kidney." Includes kidneys donated from someone who is living, but not blood related, such as the spouse, or an emotionally close friend.

Living-related kidney

Donated by a blood relative such as a mother, father, sister, brother, son, daughter, cousin, aunt or uncle.

Nephrectomy

Surgically removing one or both kidneys.

Nephron

A section of the kidney made up of millions of tiny blood filtering tubes.

Rejection

The process by which the body responds to a “foreign object,” such as a new kidney. Rejection can be acute or chronic (see definitions: acute rejection and chronic rejection).

Renal

Having to do with the kidneys or referring to them.

Systolic

The top blood pressure number. It measures the force of the heart muscle as blood is pumped out of the heart chambers (contractions).

Tissue typing

A blood test that evaluates if there is a tissue match between organ donor and recipient antigens, it is done before a transplant (also see cross matching and blood typing).

Transplant

Transferring organs or tissues from a donor to a recipient.

Ureters

The tube that carries urine from each kidney to the bladder.

Urethra

The tube from the bladder that allows urine to flow out of the body.

Urinary tract

The system made up of the kidneys, ureters, bladder and urethra. It produces, moves, stores and eliminates urine.

Transplant administrative staff

Alan J. Koffron, M.D.

Director, Multi Organ Transplantation

Dilip Samarapungavan, M.D.

Medical Director, Multi Organ Transplantation

Becky Harris-Burns, R.N., B.S.N., C.C.T.C., M.B.A.

Director, Multi Organ Transplantation

Transplant nephrologists

Dilip Samarapungavan, M.D.

Ravi Parasuraman, M.D.

Vijay Mudunuri, M.D.

Transplant surgeons

Alan J. Koffron, M.D.

Steven Cohn, M.D.

Vandad Raofi, M.D.

NOTES AND QUESTIONS

Living kidney donor initial consent for evaluation

Our transplant center believes this booklet, "Your Kidney Donation Decision: What You Need to Know," has important written information to assist your decision making and to learn about the kidney donation process in addition to short and long-term considerations. Please also note that it is a federal crime for any person to knowingly acquire, obtain or otherwise transfer any human organ for valuable consideration (i.e., anything of value such as cash, property, vacations). Your signature below confirms that you have received and read the donor education booklet along with the materials listed below, and have had the opportunity to have all your questions or concerns answered regarding being a potential kidney donor candidate. Our center will keep this form on file in your medical record.

Materials:

- Your Kidney Donation Decision: What you need to Know
- "Long Term Complications, Risks and Outcomes after Kidney Donation"
- "Consensus Statement on the Live Organ Donor"
- Pamphlet "You May Need a Blood Transfusion" Some things to know
- Pamphlet "Your Surgical Experience"
- Pamphlet "Managing Your Pain"
- "Advantages of Living Donor Kidney Transplants/Did You Know?"
- Long Term Recommendations for Kidney Donors
- Pamphlet "UNOS Facts and Figures"
- Pamphlet "OPTN Kidney Paired Donation Pilot Program"
- CT Angiogram Scan
- Low Cost Free Clinics
- Beaumont Kidney Transplant Program Evening Seminar listings

- Latimes.com - "Researchers confirm safety of kidney donations"
- US News HEALTH Best Hospitals in Michigan
- SRTR Data comparing Beaumont Transplant Center to the Nation
- Other: _____

I consent to proceeding with testing as a potential kidney donor free from inducement and coercion. I have received and read the booklet "Your Kidney Donation Decision: What You Need to Know" along with the materials listed above, and have had the opportunity to have my questions and concerns answered regarding being a potential kidney donor candidate.

Additionally, in the event that I go through kidney donation surgery, I commit to follow-up at the transplant clinic at six months, one year and two years post operatively so that my kidney function can be checked to monitor my wellbeing and to allow the transplant center to conform to UNOS reporting regulations (alternate arrangements may be made for patients with special circumstances, i.e. out-of-town donors, to fulfill this requirement closer to home).

I have been informed that I may decline to donate at any time. I understand that I can speak with the appropriate members of my team at any time during my evaluation, should I have further questions.

Signature of donor candidate

Printed name of donor candidate

Date received

Signature of transplant center staff member providing booklet

3601 West 13 Mile Road
Royal Oak, Michigan 48073-6769
248-898-5000
TDD: 248-898-1986

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