



Your Guide to Being a Living Kidney Donor

Where Compassionate Care
Meets Innovation

Welcome

Today, there are approximately 90,000 people on the kidney transplant waiting list — and many of them wait more than five years for a kidney from a deceased donor. In some states, this wait is closer to 10 years. Sadly, many never get the call saying that an organ is available, and over 5,000 people die each year waiting for a transplant.

Living kidney donation can help change all that, providing a second chance for a healthy, longer life to someone with kidney failure (also called end-stage renal disease). The fact that you are reading this — and considering being a living kidney donor — tells us that you're an exceptional person. Donating a kidney is a selfless and generous act that will have an extraordinary impact on the life of someone who is waiting for a transplant.

Because donating a kidney also will have a significant impact on your life, the decision to become a living donor requires careful consideration. This handbook is intended to help you understand what living kidney donation involves so you can make a fully informed decision.

At UMass Memorial Medical Center's Transplant Program, we have performed more than 1400 kidney transplants, including 430 Live Donor kidney transplants, since our program began in 1986, making us one of the most experienced donor transplant teams in the Northeast. This experience translates into a track record of excellent outcomes — including a 100 percent living donor survival rate — which we trust gives you the confidence that you'll be in good hands here.

If you decide to become a living kidney donor, we would be honored to walk this journey with you. Questions? Simply call 508-334-1269 and speak to our living donor transplant coordinator. Our office hours are Monday through Friday, 8 am to 4:30 pm.

With gratitude,

The UMass Memorial Medical Center
Living Donor Kidney Transplant Program Team

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Why Be a Living Kidney Donor?

Perhaps the simplest — and most profound — reason to be a living kidney donor is that you can save the life of someone with kidney failure. An average of 12 people die each day waiting for a kidney transplant — there simply aren't enough deceased donors to meet the growing demand for kidney transplants.

This shortage of donor organs continues to be the biggest obstacle in kidney transplantation. Living kidney donation can change all that by expanding the donor pool — giving people with kidney failure a second chance at a healthy, longer life.

Living kidney donation also has many other health benefits and advantages for transplant recipients, including:

- Transplanted kidneys from living donors last significantly longer than those from deceased donors (on average, approximately 18 years for a kidney from a living donor compared to 13 years for a kidney from a deceased donor, according to the Living Kidney Donors Network).
- Recipients can be transplanted before they have to begin dialysis, which also improves their long-term outcomes.
- Living donor kidneys almost always start functioning immediately, while deceased donor kidneys are more likely to take a few days to a few weeks to start functioning.
- Recipients don't have to go on the national waiting list, which helps to shorten the waiting time for others on the list.
- The recipient has time to plan for the transplant, and avoids the unhealthy stress of waiting for a deceased donor.
- The transplant surgery can be scheduled at a convenient, mutually agreed-upon time rather than performed on an emergency basis.
- Living donor kidney transplants are the most widely studied type of living-donor procedure, with more than 50 years of follow-up information. Overall, studies show the life expectancy for those who donate a kidney is the same as for similarly matched people who do not.

Who Can Be a Living Kidney Donor?

In order to qualify as a living kidney donor at UMass Memorial Medical Center, you must:

- Be physically fit
- Be in good general health, free of diabetes, cancer, kidney disease and heart disease
- Be between the ages of 18 and 70 (donors over the age of 70 will be considered on a case-by-case basis)
- Not be pregnant, or intend to get pregnant, for at least a year after surgery

- Be a match with your recipient (more on this under Compatibility, page 3); gender and race are not factors in determining a successful match
- Have health insurance (if you don't have health insurance, we can provide guidance on how to obtain it)

Please know that not everyone who offers to be a donor meets the criteria for donation. Conditions may be discovered during the screening and evaluation process (more on what this process entails on page 9) that rule out donation.

Importantly, know that the decision to become a living donor is a voluntary one, freely given. Before donation, you should fully understand the risks, benefits, evaluation and testing, surgery, recovery and follow-up care involved in being a living donor. You may change your mind at any time during the process. Your medical information and decision will be kept confidential.

Compatibility: Am I a Match?

As a potential living kidney donor, you must first undergo a blood test to determine if your blood type is compatible with the intended recipient. If you and the recipient have compatible blood types, you'll then undergo further testing called tissue typing and crossmatching.

Tissue Typing

This involves testing the similarity of certain proteins, called antigens, found in your blood and that of a recipient. For kidney transplantation, we look at human leukocyte antigen (HLA) compatibility. The best transplant outcome happens when a recipient's HLA and the donor's HLA closely match.

Crossmatching

This blood test identifies the presence of recipient antibodies that would damage the kidney (cause rejection) from a specific donor. This test involves mixing a recipient's blood with cells from the donor. If the cells die, it indicates the presence of antibodies.

- A positive crossmatch means that the recipient has had a reaction to the donor's cells and the transplant should not occur.
- A negative crossmatch means that the recipient has not reacted to the donor's cells, and the transplant can proceed.

Types of Living Kidney Donations

There are several different types of living kidney donations:

Related

Related living donors are blood relatives of transplant candidates. They can be:

- Parents
- Siblings
- Children over the age of 18
- Aunts, uncles, cousins, half-siblings, nieces, nephews

Nonrelated

Unrelated living donors are individuals who have a relationship with but are not blood-related to a transplant candidate. They include:

- Spouses
- In-laws (related by marriage)
- Close friends
- Co-workers
- Neighbors
- Other acquaintances

Nondirected

Nondirected donors are living donors who are not related to or known by the transplant candidate. This type of donation is also referred to as an altruistic or Good Samaritan living donation.

Paired Kidney Exchange Programs

If you want to be a living kidney donor, perhaps to a spouse, relative or close friend, but you aren't a match, transplantation is still an option through kidney paired donation (KPD).

In the past, someone with kidney failure who had an incompatible donor had to wait for a deceased donor—a wait that can be lengthy. With kidney paired donation, however, kidneys can be “exchanged” between pairs, making multiple compatible living donor transplants possible.

Panel Reactive Antibody (PRA): Another Factor in Compatibility

PRA is a blood test that's routinely performed on patients who are waiting for kidney transplants. It's a way of measuring what are referred to as anti-human antibodies in the blood.

A person's PRA can be anywhere from 0 to 99 percent. This number represents the percent of the U.S. population that the anti-human antibody in someone's blood reacts with. For example, if someone has a PRA of 25 percent, it means they couldn't accept a kidney donation from 25 percent of the population.

The higher a recipient's PRA, the larger the portion of the population who are not suitable as donors — and why many transplant candidates do not match with potential donors. As a result, individuals with a high PRA usually wait much longer for a kidney transplant than patients with a low PRA.

While it's not always possible to find a compatible donor/recipient pair for everyone interested in a paired donation, enrollment in this program may increase the likelihood.

How Kidney Paired Donation Works and Who Can Participate

UMass Memorial Medical Center actively partners with two of the largest paired kidney exchange programs, the National Kidney Registry (NKR) and UNOS -KPD.

These paired exchange programs play a crucial role in facilitating transplants for patients with incompatible living donors, addressing concerns related to blood type, tissue compatibility, size, and age. Leveraging state-of-the-art technology, NKR and UNOS - KPD employ advanced algorithms to identify suitable donors from other mismatched pairs within their registries and ensure that all corresponding recipients receive transplants from compatible donors. This innovative approach allows patients to participate in multi-pair chains, enabling recipients from multiple centers to receive transplants, optimizing organ longevity, and providing a seamless experience for both the donor and recipient.

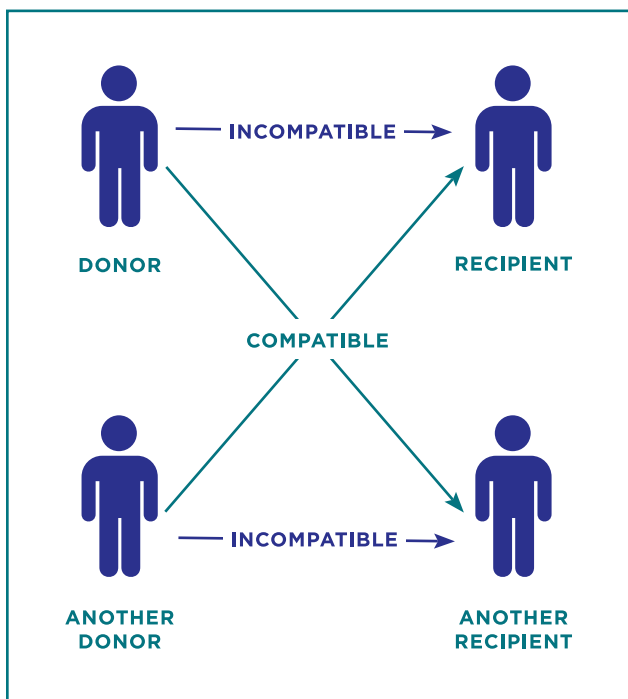


Figure 1
In this illustration, the donor in Pair A isn't compatible with the recipient in Pair A. But the donor in Pair A is compatible with the recipient in Pair B. Conversely, the donor in Pair B is compatible with the recipient in Pair A.

Questions You Should Consider as a Potential Living Kidney Donor

The decision to become a living kidney donor is a big one. It's imperative that you take the time to think through all the issues involved in donating one of your kidneys to another person. Some of the areas to explore include:

Motivation:

- Have I been totally honest with myself about why I want to donate a part of my body?
- Am I expecting anything in return for my donation (e.g., gratitude, publicity or some other kind of attention, a better relationship with the recipient)?
- Do I have other expectations about what this experience will do for me? Are they realistic?
- Am I feeling pressured by anyone to be a living donor?

Potential Pain and Discomfort After Surgery:

- Do I feel adequately prepared to deal with the pain and discomfort associated with this surgery?
- Will I be able to communicate my needs — both physical and emotional — to hospital staff and/or my family?
- Can I manage the recovery period without running into problems (e.g., boredom, anxiety, nervousness)?
- Is there anything I can do now that will improve my recovery (e.g., lose weight, stop smoking, exercise more)?

Financial Concerns:

- How will donating affect my ability to work?
- Am I financially prepared to be out of work for several weeks?
- Do I have an adequate backup plan in case I have to be out of work longer than expected?

Relationships:

- Is my family/personal/professional life relatively stable and secure?
- If not, is there anything I can do now to improve the situation?
- Do my family and/or friends support my decision to be an organ donor, or has anyone close to me shown disapproval or criticized me for wanting to be an organ donor?
- If I know my recipient, how might this donation change our relationship?

Other Issues:

- Do I fully understand the risks involved in being a living donor?
- If I decide not to go through with donation, will I feel guilty — and can I live with that?
- How will I feel if it turns out I can't be a donor?
- Am I willing to participate in a kidney paired donation if I'm not a match for the person I originally wanted to donate to?
- How does my religion view organ donation?
- How will I feel if I'm rejected during the evaluation process?
- How will I feel if my recipient has serious complications or doesn't survive the transplant?
- How will I feel if my recipient doesn't "take care of" the kidney I donate?
- Have I learned enough about the donation process to make an informed decision?

Representing Your Interests: Your Independent Living Donor Advocate

To ensure that you are fully informed about being a living kidney donor, the Centers for Medicare and Medicaid Services (CMS) and the Organ Procurement and Transplantation Network (OPTN) require that living-donor transplant centers like UMass Memorial's provide an independent living-donor advocate.

This advocate — a social worker or counselor — represents you, not the UMass Memorial Medical Center - Transplant Center. He or she is available to help you talk about your feelings and concerns, answer any questions you may have, and assist in protecting your best interests throughout the donation process.

The Organ Donation Process: What to Expect

Here is an overview of what's involved in becoming a living kidney donor:

Step 1: Screening

If you are interested in being a living kidney donor, the first step is to contact the UMass Memorial Kidney Transplant Program at 508-334-1269. Ask to speak with our living donor transplant coordinator who will conduct an initial screening that includes a 20- to 30-minute phone interview.

- You also will have to undergo a simple blood test to determine if your blood type is compatible with a recipient.
- If you and a recipient have compatible blood types, you will then undergo tissue typing and crossmatching (described under Compatibility on page 3).

We'll screen more than one donor for blood and tissue typing for a specific recipient. In certain circumstances, multiple donors may undergo a more extensive clinical evaluation, described in the next section.

Step 2: Evaluation

After blood and tissue typing and crossmatching identify you as a compatible donor, the evaluation process is divided into two phases:

Phase One:

You are scheduled for an appointment at the UMass Memorial Transplant Clinic, where you'll meet with these team members:

Donor administrative assistant who will schedule all your tests and appointments

Donor coordinator, a nurse who is knowledgeable in living donation and will be available throughout all phases of the donation process to help you and your family by providing education, coordinating tests and consults, and answering any questions you may have

Social worker, a licensed professional who will conduct a psychosocial evaluation that focuses on your readiness and suitability for being a donor.

This evaluation will cover:

- Out-of-pocket expenses
- Childcare costs
- Social, personal, housing, vocational (job), financial and environmental supports
- Coping abilities and strategies
- Understanding the risks and benefits of organ donation
- Mental health history, including substance or alcohol use or abuse and its impact on donation
- Disability benefits
- Identifying an acceptable care plan with at least one identified caretaker

Independent donor advocate, an individual who is knowledgeable about organ donation, transplantation, medical ethics and informed consent, and understands the pressures that might influence your decision to donate. The advocate is not a member of the UMass Memorial transplant team; his/her role is to represent and advise you, and protect and promote your best interests.

In addition, during phase one of the evaluation process you will undergo some initial diagnostic testing that includes:

Blood and urine tests to measure the function of your kidneys, liver and pancreas; blood clotting; blood counts for anemia and infection

Chest X-ray to evaluate the lungs, heart and chest wall

Electrocardiogram (EKG) to evaluate your heart's electrical activity and check chamber walls

Phase Two

During the second phase of the evaluation process, you will undergo more in-depth testing and screening that may include:

Stress echocardiogram - This is a basic test of heart function and an important assessment for safe anesthesia. Ultrasound images reveal any parts of your heart that may not be receiving enough blood or oxygen due to blocked arteries.

CT scan of abdomen and pelvis - This imaging test provides information about the size, blood flow and structure of your kidneys.

Nephrology consultation - A nephrologist (kidney specialist) will evaluate your medical suitability as a donor and assess any potential medical complications.

Surgical consultation - The surgeon will discuss the operation itself, the risks involved, and what to expect during your recovery period.

Psychiatric consultation - A psychiatrist may conduct a psychological evaluation to assess your understanding of the procedure, provide help with coping with the donation experience, and discuss how it may change your life. The psychiatrist will further assess if your decision to donate is voluntary and free from pressure from the intended recipient (if known to you), family members or medical personnel.

Cancer screening - Age-appropriate cancer screening is required as part of the donation evaluation. Based on your physical assessment by our clinicians and past family history advanced cancer screening may be necessary, this may include a pap smear, mammography, colonoscopy, PSA screening, and others.

Other tests or consultations as indicated - If any testing reveals abnormal results, additional testing may be required. For example, if we note high blood pressure during your evaluation, home blood pressure monitoring may be indicated.

The entire screening and evaluation process generally takes two weeks.

How Donors Are Selected and Notified

Once you've completed the evaluation process, the UMass Memorial Living Donor Selection Committee meets to review your suitability as a living kidney donor. The committee's decision about whether you can donate is based on:

- Your medical, surgical, psychosocial and donor advocate evaluations, together with your laboratory and diagnostic test results
- An assessment of risk based on current medical knowledge

The committee's decision is communicated to you in writing, via U.S. mail, generally within one week after your evaluation process is completed.

Just a reminder — even if you are determined to be a suitable candidate for donating a kidney, you may still change your mind and withdraw from the process. Your medical information and decision will be kept confidential. And the potential recipient will continue to receive care at UMass Memorial Medical Center.



Preparing for Surgery

Once you are cleared to be a donor, the decision about when the surgery takes place will be made jointly by the transplant team, you and the recipient. The transplant team, particularly the physicians directly involved in your recipient's care, will determine as accurately as possible the best time to perform the transplant, based on your recipient's medical condition.

Some Steps You Should Take Before Your Surgery:

Stop smoking. It is preferable that you stop smoking to be a donor, even if you're a light smoker. Smokers have an increased risk of cardiovascular (heart) and pulmonary (lung) complications with any surgery, and smoking slows healing. Your donor team can refer you to resources to help you quit.

Abstain from drinking alcohol six weeks before surgery. If you have a history of heavy alcohol use, it's very important that you tell us. Alcohol use may not preclude you from being a donor, but we do need to know. (You shouldn't return to drinking alcohol after surgery until the transplant team advises you it's safe to do so.)

Don't stop taking any prescription medications unless advised to do so by a physician. However, women who use certain hormonal birth control medications will be advised to stop taking them 30 days before surgery due to the increased risk of blood clots after surgery.

Avoid aspirin or nonsteroidal medications, such as Advil or Motrin, for seven days before surgery; these medications can affect the blood's ability to clot and put you at higher risk of bleeding.

You can eat and drink normally until noon the day before surgery. You'll have a liquid diet from noon until midnight, then nothing by mouth until your surgery.

You will need to take a laxative the day before surgery. We'll instruct you about this when you come in for your final appointment before surgery.

Blood transfusion during kidney donation surgery is uncommon, although it may be necessary. Current data at our center shows that none of our donors have needed a blood transfusion. Your donor coordinator can give you the latest information and explain the blood donation options available to you.

If you choose to donate your own blood in case there's a need for transfusion, we'll want you to donate a unit of your blood two to four weeks before surgery.

What to Bring:

Bring basic toiletries for use while you're in the hospital, as well as comfortable, loose-fitting clothes for when you're ready to go home. Because we'll already have your insurance information, there's no need to bring any documentation unless you're specifically asked. Leave jewelry and other valuables at home.

The Surgical Procedure: What It Involves

The procedure you will undergo is called nephrectomy — the surgical removal of one of your kidneys. Your kidneys are located toward the back of the abdominal cavity, just above your waist. If you put your hands on your hips, your kidneys are just about where your thumbs are. One kidney is normally located just below the liver, on the right side of your abdomen; the other is just below the spleen on the left side.

Nephrectomy Can Be Performed in One of Two Ways: Open or Laparoscopic

Although open donor nephrectomy is still practiced today (and may be necessary in some cases), the most commonly performed donor operation today is the laparoscopic donor nephrectomy. The minimally invasive laparoscopic technique doesn't require the surgeon to cut any muscle to access your kidney (which must be done with open surgery), and the hospital stay generally is shorter than with open surgery. Plus, because incisions are smaller, there's less pain and bloating after surgery.

How Laparoscopic Nephrectomy is Performed

You will be admitted to the hospital on the day of your scheduled surgery. The surgery takes place with you and your recipient in adjacent operating room suites. You'll be brought to the operating room and positioned in a flank (side) position. Once anesthesia is administered, the surgeon will make two small incisions close to your belly button, and two small incisions for the laparoscopic instruments. Your kidney is removed through the central incision near your belly button. The procedure generally lasts three to four hours. You'll be brought to the recovery room after surgery and carefully monitored. Once you wake from anesthesia, you'll be transferred to a surgical floor. You'll generally remain in the hospital for three to five days after surgery.

The Risks Involved in Surgery

As with any surgery, there are risks involved in donating a kidney. These can include infection, bleeding and blood clots. Rare complications from surgery include stroke, heart attack and death. Your donor team will discuss surgical risks with you in detail during the evaluation process. Keep in mind, however, that the vast majority of donors have no long-term complications after they donate.

What to Expect After Surgery

After surgery, you'll remain in the hospital for three to five days. During this time, your postoperative progress will be carefully monitored to ensure that your kidney function and blood pressure are where they should be.

You will have some pain after surgery from the incisions, gas and bloating. This will diminish in the days following surgery and can be controlled with pain medication. You'll have one or two intravenous lines during and after the surgery so we can give you fluids to keep you hydrated and administer medications (one of these lines may be used to deliver your pain medication after the surgery).

You'll also have a catheter (drainage tube) in your bladder so we can monitor how your remaining kidney is functioning during and after the surgery. This means that you won't need to get up to go to the bathroom immediately after surgery. The catheter and intravenous lines are usually removed within two to three days after surgery.

As soon as your bowel starts moving after surgery, you'll be able to begin eating and drinking again. If you can keep down sips of water, you can progress to clear fluids, and then to a regular diet within the next two days. You'll be out of bed and walking independently before you're discharged from the hospital.

Some Other Facts to Keep in Mind:

- You'll be given prescriptions for pain medication and stool softeners when you're discharged, but these are only for the immediate postoperative period (generally one to two weeks); you shouldn't need medications after that.
- You should be able to return to your regular activities and exercise within two to three months after surgery.
- There are no dietary restrictions following donation — but we do encourage you to eat a healthy, well-balanced diet.
- While excessive alcohol use is always dangerous, you can consume alcohol in moderation post-donation; your transplant team will let you know when it's safe to drink.
- Female donors should wait one year after donation to become pregnant; the body requires time to recover from surgery and adjust to living with one kidney before pregnancy.
- Kidney donors may engage in sexual activity as soon as they feel well enough to do so after donation.
- We advise you not to drive for at least two to three weeks after surgery. You must be physically and mentally strong with normal reflexes, and not have any abdominal pain or discomfort before you decide to drive. Nor should you be taking any medication that can affect your mental alertness, such as pain medications containing narcotics (e.g. Vicodin, Percocet or Tylenol with codeine), which can affect your mental alertness.
- As for travel, we recommend that you not plan any vacations or trips outside the United States for at least four weeks, preferably eight to 12 weeks, after your surgery.

While you'll continue to receive regular medical care from your primary care provider after your donation, the UMass Memorial Medical Center transplant team will follow you for a minimum of two years after your donation to monitor your postoperative physical condition, and provide ongoing education and support. And we're always just a phone call away if you have any questions.

Financial Considerations in Kidney Donation

It's only natural to be concerned about the costs involved with being a living organ donor. Here are some important things to know:

Insurance Coverage

Most medical costs associated with living organ donation are covered by the recipient's health insurance. The government requires all certified transplant centers — like UMass Memorial's — to charge the recipient's insurance an acquisition fee. This fee covers the medical costs related to what's referred to as the "donor protocol," which includes your medical evaluation, transplant procedure and postoperative care.

Anything that falls outside this protocol, however, is not covered by the recipient's insurance. These costs could include annual physicals, travel, lodging, lost wages and other nonmedical expenses. Plus, any health issues found during your evaluation that aren't related to the donation will need to be covered by your own personal health insurance. That's why our transplant team asks for your health insurance information before your evaluation.

Any future health problems relating to your donation may not be covered by the recipient's insurance, and life-long medical follow-up becomes your financial responsibility.

Time Off From Work

Before your donation, it's important to tell your employer about your upcoming surgery, and what this means for your ability to work. It's recommended that you speak to your company's human resources department about disability insurance coverage, medical leave and possible paid time off. If your job provides disability insurance coverage, you will most likely be entitled to disability pay for being a living donor. But check with your employer. When it's time for you to return to work, be sure to tell your employer about any restrictions or short-term special needs you may have.

National Donor Assistance Fund

The National Living Donor Assistance Center is a federally funded program to assist agreeable, eligible donors with the reimbursement of travel and subsistence expenses toward living organ donation. This program isn't intended to promote or encourage donation. Funds are not provided as a gift or reward for being a donor.

For more information, visit www.livingdonorassistance.org.

Recent Changes to the Family Medical Leave Act

On August 28, 2018, the U.S. Department of Labor issued an opinion letter on living organ donation that protects the job security of living donors who are covered under the Family and Medical Leave Act. This important clarification ensures that eligible employees who seek to use time off to donate an organ to help save another life are entitled to unpaid, job-protected leave.

National Organ Transplant Act

To address the nation's critical organ donation shortage and improve the organ matching and placement process, the U.S. Congress passed the National Organ Transplant Act (NOTA; P.L. 98-507) in 1984. The act established the Organ Procurement and Transplantation Network to maintain a national registry for organ matching. The act also called for the network to be operated by a private, nonprofit organization under federal contract and made the buying and selling of human organs illegal.

Tax Law

Effective January 1, 2012, the Commonwealth of Massachusetts has a law in place relating to the expenses involved in organ donation. It allows for donors who are full-time Massachusetts residents to claim a state tax deduction for the following expenses incurred and related to organ donation:

- Travel expenses
- Lodging expenses
- Lost wages, not to exceed \$10,000

This law applies to all or parts of human bone marrow, liver, pancreas, kidney, intestine or lung donations. For more information, please visit the Commonwealth of Massachusetts website at <http://www.mass.gov/dor/individuals/filing-and-payment-information/guide-to-personal-income-tax/deductions/medical-relateddeductions.html#Human>.

The Emotional Side of Things: What to Expect

It's extremely common for living kidney donors to feel a range of emotions leading up to and after surgery.

You may feel anxious or scared prior to surgery, or have doubts about your ability to go through with it. You might feel guilty or depressed if your recipient doesn't do well after surgery. You may feel angry or frustrated if you don't bounce back as quickly as you thought you would after surgery. These are all absolutely normal emotional responses and, importantly, you don't have to deal with them alone.

The UMass Memorial Medical Center living kidney donor transplant team is here for you every step of the way. You'll be encouraged to discuss your fears and concerns during the evaluation process, and our team is always just a phone call away at any point pre- and post-donation. Plus, we offer access to an array of resources to help you deal with the emotional side of things after surgery.

Support Services for Living Donors

The UMass Memorial Medical Center Transplant Education Support Group — Open to donors and recipients, this support group meets on a monthly basis. A different topic is presented each month.

For information, call 508-334-1269.

Peer-to-peer support — Your transplant team can put you in touch with others who have gone through the donor process, so you can ask questions and learn firsthand from someone who's walked in your shoes.

National Kidney Registry — This organization aims to facilitate live donor kidney transplants within or between multiple transplant centers, and is committed to making kidney donation easier, safer, and more convenient for living donors. Their website offers details on numerous benefits available to kidney donors including the Donor Shield and Voucher programs. www.kidneyregistry.org

Living Donors Online — Through this online message board, living organ donors can interact with others who have donated an organ or are considering donation. Postings offer encouragement and support for those who are going through the donation process. This online community also includes an education section, links to relevant websites, updates on media reports about organ donation and living organ donor buddies. www.livingdonorsonline.org

United Network for Organ Sharing — UNOS collects and manages data about every transplant in the U.S., develops organ transplantation policy, and provides education and support to the living organ donor. Visit www.transplantliving.org/livingdonation.

National Kidney Foundation — This is the major volunteer health organization dedicated to preventing kidney disease, improving the health and well-being of individuals and families affected by kidney disease, and increasing the availability of all organs for transplantation. Its website includes a section dedicated to living kidney donors. Visit www.kidney.org.

Your Rights as a Living Kidney Donor

Our team respects your rights as a patient and recognizes your uniquely individual health care needs as a living kidney donor. We want to partner with you in making decisions about your evaluation and care during the organ donation process. It's our responsibility to:

- Provide you with respectful and considerate care
- Ensure that you are fully informed about your evaluation and the entire donation process — preoperative, inpatient hospital care, and post-donation care and treatment
- Maintain your privacy and confidentiality

If You Change Your Mind About Being an Organ Donor

We want to remind you that organ donation is completely voluntary. You can change your mind about organ donation at any time in the donation process and withdraw as a donor. Your medical information and decision will be kept confidential. And the potential recipient will continue to receive care at UMass Memorial Medical Center.

If You Have Concerns or Complaints

Beyond the Patient Bill of Rights (see following page) you have the right to voice your concerns or complaints regarding the quality of care or services you receive at UMass Memorial Medical Center. Voicing such concerns will in no way compromise your access to care or treatment. If you have a concern or feel your rights have not been respected as a living kidney donor, contact:

Department of Patient Care Services

UMass Memorial Medical Center

55 Lake Avenue North
Worcester, MA 01655
508-856-3701

The Office of Quality Monitoring

The Joint Commission

One Renaissance Boulevard
Oakbrook Terrace, IL 60181
800-994-6610
complaint@jointcommission.org

UNOS Patient Services

888-894-6361

FAQS: Frequently Asked Questions About Living Kidney Donation

Here are some frequently asked questions that we didn't cover elsewhere in this handbook — or that bear repeating:

Can I live normally with one kidney?

Yes. For the donor, there is little risk in living with one kidney because the remaining kidney compensates to do the work of both kidneys.

Will donating a kidney prevent me from having children?

No. Kidney donation will not prevent a woman from becoming pregnant, or a man from fathering a child.

When can I start taking my birth control pills again?

Women taking the pill or other form of hormonal birth control must stop 30 days before organ donation due to the risk of blood clots after surgery. We advise you to wait at least one month but recommend restarting three months after surgery.

Will I have to be on bed rest following surgery?

No. In fact, you'll be out of bed and walking independently before you're discharged from the hospital.

Will I have to give up sports or exercise, or otherwise experience a significant limitation in my activities?

No. You should be able to return to your regular activities and exercise in two to three months following surgery. Because we carefully screen donors, this means that only people who are in very good health are selected; they recover well and their risks of future complications are extremely low.

How soon after surgery can I start exercising?

Actually, you'll start exercising as soon as you wake up from anesthesia. You'll be coached to take deep breaths to make sure you're getting air deep into your lungs, which helps prevent pneumonia. You'll also begin to exercise the muscles of your legs by flexing and relaxing. You'll be helped out of bed the day after surgery and begin walking in the hospital; walking helps prevent complications such as blood clots, pneumonia and muscle wasting. You're encouraged to continue a program of daily walking when you go home. Note that you shouldn't lift anything over 10 pounds for six weeks after surgery in order to prevent a hernia.

As a donor, will I have to take medications for the rest of my life?

No. You'll be given prescriptions for pain medication and stool softeners when you're discharged from the hospital, but you'll likely only need to take them for a week or two. After that, you don't have to take any medication related to your organ donation.

Will I need a nurse to take care of me when I come home from the hospital?

While you're likely to be tired and weak when you first come home, you shouldn't need professional nursing care. You will need a friend or family member to do food shopping, prepare some meals, and help you if you need it for the first week or two.

How long will I be out of work after organ donation surgery?

Everyone recovers differently, with varying degrees of fatigue and pain. You should allow yourself a minimum of four to six weeks for recovery, but you may need as long as eight to 12 weeks. If possible, we recommend that you be able to take eight weeks, should you need it.

Will I need to come back to UMass Memorial Medical Center for checkups?

Yes. Organ donation is a major surgical procedure, and you'll need to be closely monitored to make sure your recovery is progressing as it should. Generally, you'll need a follow-up visit a week after you're discharged from the hospital, and another checkup four to six weeks postoperatively. It's also important that you schedule an appointment with your primary care provider soon after discharge, and maintain a schedule of annual checkups with him or her for the rest of your life.

What if I have questions that aren't answered in this handbook?

Simply contact the UMass Memorial Living Transplant Program at 508-334-1269. We're here to make sure that all your questions are answered so that you feel fully informed and confident that you're making the right decision.

Why Choose the UMass Memorial Live Donor Kidney Transplantation Program?

Selecting a transplant center where you will donate a part of your body to help someone with kidney failure is a major decision. We appreciate your consideration of our program, and would be honored to help you make this life-changing contribution to someone whose kidneys are failing.

When Considering a Transplant Center, It's Important to:

- Learn about the number and type of transplants the center performs each year
- Ask about the center's organ donor and recipient survival rates
- See how the center compares to others by reviewing statistics in the database maintained by the Scientific Registry of Transplant Recipients

To help you evaluate our program, we've enclosed a sheet that gives you an overview of our kidney donation volume, patient and graft survival, and living donor survival.

Ready to Take the Next Step to Be a Living Kidney Donor?

Simply call 508-334-1269 and ask to speak to our living donor transplant coordinator. Our office hours are Monday through Friday, 8 am to 4:30 pm.



Patient Bill of Rights

As part of UMass Memorial Medical Center, the transplant program fully supports the Patient Bill of Rights, which states that every patient has the right:

To freedom of selection of a physician except for emergency medical treatment, provided that the physician is able to accommodate the patient

To receive, upon request, an itemized bill reflecting charges from the physician and/ or the facility including laboratory charges, pharmaceutical charges, and thirdparty credits and charges

To obtain, upon request, the name and specialty of the physician or others responsible for your care or coordination of care

To confidentiality of all records and communication as provided by law

To have all reasonable requests responded to promptly and adequately within the capabilities of this facility

Upon request, to obtain an explanation as to the relationship, if any, of UMass Memorial to any other health care facility or educational institution as it relates to your care or treatment

Upon request, to receive any information which this facility has available relative to financial assistance and free care as well as any rules that apply to your conduct as a patient at UMass Memorial

Upon request, to inspect your medical records and receive a copy for a fee determined by the current rate of copying expenses

To refuse to be examined, observed or treated by students or any other staff member without jeopardizing access to psychiatric, psychological, or other medical care and attention

To refuse to serve as a research subject and to refuse any care or examination when the primary purpose is educational or informational rather than therapeutic

To privacy during medical treatment or care within the capacity of UMass Memorial

To lifesaving treatment in an emergency without discrimination because of source of payment or delay due to discussions of source of payment

To informed consent to the extent provided by law, including the right to accept or refuse medical treatment, including foregoing or withdrawing life-sustaining treatment or withholding resuscitative services

To appropriate assessment and management of pain

To be free from seclusion, physical restraints and medications that are used as restraints when they are not medically necessary

To have a family member or other representative and your own physician notified of your admission to the hospital

To formulate advance directives and revise those directives at any time; in Massachusetts, the tool for implementing your advance directives is a health care proxy

To receive care in a safe setting free from all forms of abuse or harassment

To interpreter services upon request

To be informed about the outcomes of care and treatment that was provided, including unanticipated outcomes

To receive information about your responsibilities while receiving care, treatment and services

Non-discrimination Notice

UMass Memorial Medical Center complies with applicable Federal and State civil rights laws and does not discriminate on the basis of race, color, national origin, citizenship, alienage, religion, creed, sex, sexual orientation, gender identity, age, or disability. Further, UMass Memorial Medical Center does not exclude people or treat them differently because of race, color, national origin, citizenship, alienage, religion, creed, sex, sexual orientation, gender identity, age, or disability.

UMass Memorial Medical Center provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, and other formats)

UMass Memorial Medical Center also provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact Interpreter Services, 774-441-6793 (TTY 711).

If you believe that UMass Memorial Medical Center has failed to provide these services or discriminated in another way on the basis of race, color, national origin, citizenship, alienage, religion, creed, sex, sexual orientation, gender identity, age, or disability, you can file a grievance with:

Office of Patient Advocacy

55 Lake Avenue North

Worcester, Massachusetts 01605

Phone: 774-442-3701 (TTY-711), Fax: 774-441-7766,

PatientCareServices@umassmemorial.org

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance a patient advocate representative is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services

200 Independence Avenue, SW

Room 509F, HHH Building

Washington, DC 20201

Phone: 800-368-1019 or 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

Language Assistance Services

If you speak a language other than English, language assistance services are available at no cost to you.
Call 774-441-6793 (TTY: 711)

Español (Spanish)- ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 774-441-6793 (TTY: 711).

Português (Portuguese): ATENÇÃO: se você fala português, tem à sua disposição serviços linguísticos gratuitos. Ligue para 774-441-6793 (TTY: 711).

Tiếng Việt (Vietnamese); CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 774-441-6793 (TTY: 711).

العربية (Arabic): ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 774-441-6793 (رقم هاتف الصم والبكم: 711).

Shqip (Albanian); KUJDES: Nëse flitni shqip, për ju ka në dispozicion shërbime të asistencës gjuhësore, pa pagesë. Telefononi në 774-441-6793 (TTY: 711).

नेपाली (Nepali); ध्यान दिनुहोस्: तपाईंले नेपाली बोल्नुहुन्छ भने तपाईंको निम्ति भाषा सहायता सेवाहरू नि:शुल्क रूपमा उपलब्ध छ। फोन गर्नुहोस् 774-441-6793 (टिडिवाइ: 711)।

繁體中文 (Chinese); 注意：如果您使用繁體中文，您可以免費獲得語言協助服務。請致電 774-441-6793 (TTY: 711)。

Русский (Russian); ВНИМАНИЕ: Если вы говорите на русском языке, вы можете воспользоваться бесплатными услугами перевода. Звоните 774-441-6793 (телетайп: 711).

Kreyòl Ayisyen (French Creole); ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 774-441-6793 (TTY: 711).

ខ្មែរ (Cambodian); ប្រយ័ត្ន៖ បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតល្អូល គឺអាចមានសំរាប់បំរើអ្នក។ ចូរ ទូរស័ព្ទ 774-441-6793 (TTY: 711)។

한국어 (Korean); 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 774-441-6793 (TTY: 711)번으로 전화해 주십시오.

Français (French); ATTENTION : si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 774-441-6793 (Télétype : 711).

Italiano (Italian); ATTENZIONE: Se parlate italiano, potete usufruire di servizi di assistenza linguistica totalmente gratuiti. Chiamate il numero 774-441-6793 (TTY: 711).

λληνικά (Greek); ΠΡΟΣΟΧΗ: Αν μιλάτε ελληνικά, στη διάθεσή σας βρίσκονται υπηρεσίες γλωσσικής υποστήριξης, οι οποίες παρέχονται δωρεάν. Καλέστε στον αριθμό 774-441-6793 (TTY: 711).

Polski (Polish); UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 774-441-6793 (TTY: 711).

हिंदी (Hindi); ध्यान दें: अगर आप हिंदी बोलते हैं, तो आपके लिए भाषा सहायता सेवाएँ मुफ्त में उपलब्ध हैं। 774-441-6793 (TTY: 711) पर कॉल करें।

ગુજરાતી (Gujarati); સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 774-441-6793 (TTY: 711).

Division of Solid Organ Transplantation

UMass Memorial Medical Center - University Campus
55 Lake Avenue North, Worcester MA, 01655



A cutting-edge teaching hospital with over 700 beds and 7,000 caregivers, UMass Memorial Medical Center is dedicated to ensuring the health and well-being of our communities across Central Massachusetts. With our academic partner, UMass Chan Medical School, we are the source of academic and clinical excellence in primary and specialty care, community service, teaching and research. We are relentless in our pursuit of knowledge and applying innovation and compassion to the care of adults and children, at the bedside, in the emergency department or operating room, in the clinic or community, or even at home.

Visit www.ummhealth.org/medical-center.

General information: 508-334-1000



UMass Memorial Health is the largest not-for-profit health care system in Central Massachusetts with more than 15,500 employees and 2,100 physicians, many of whom are members of UMass Memorial Medical Group and Harrington Physician Services. We are the clinical partner of UMass Chan Medical School. Our comprehensive system includes UMass Memorial Medical Center, UMass Memorial Health – Harrington, UMass Memorial Health – HealthAlliance-Clinton Hospital, UMass Memorial Health – Marlborough Hospital, and UMass Memorial Health – Community Healthlink. Together, we impact every aspect of life in the region by making health and wellness services available to everyone, at the bedside, in the clinic or community, or even at home, advocating for social equality and providing economic stability and opportunity. There are many ways to heal. We pursue them all. Relentlessly.

Visit www.ummhealth.org.

To find a physician in your community,
call 855-UMASS-MD (855-862-7763).