Kidney Transplant Program

GUIDE TO UNDERSTANDING TRANSPLANT

Stanford HEALTH CARE
“The wonderful physicians and staff of the Stanford Kidney Transplant Program are always there to contact if I have a question or concern. They feel like family to me now.”

– Linda, kidney recipient
Every kidney transplant patient who comes to Stanford Health Care for care is different. But one thing all of our patients have in common is the personal—and personalized—care they receive.

We provide high-quality care, with treatment tailored to each patient’s needs. Throughout the transplant process, we provide intensive education for patients, their families and caregivers.
Located toward the back of your abdomen, kidneys play an important role in maintaining healthy body function.

Getting Evaluated for Transplant

To determine if you are a transplant candidate, the Stanford Kidney Transplant team considers two primary criteria: your overall health status and your mental wellness. It’s also essential that you have a support plan in place, because you will need a designated caregiver(s) for several weeks after transplant. You may not be eligible for transplant if you have an active infection, cancer, advanced heart or blood vessel disease, mental health issues, or morbid obesity.

THE PROCESS

Once your nephrologist refers you for an evaluation, our team will determine if a transplant is the right treatment choice for you.

As a first step, we will ask you to view our educational video to help you better understand all of the screenings, tests and the procedure involved in kidney transplant.

At your evaluation visit, you will meet individually with a transplant nephrologist, nurse coordinator, and social worker.
The Kidneys

Your kidneys filter your blood and remove waste products from your body as urine (which travels from your kidneys through your ureters to your bladder). They also regulate your body’s fluid balance, release hormones that control your blood pressure and stimulate the production of red blood cells, and break down insulin.

If your kidneys stop working, your doctor may recommend dialysis or transplant:

**DIALYSIS**

Dialysis is a procedure that removes waste products from your body that are normally eliminated by the kidneys. There are two types of dialysis: hemodialysis and peritoneal dialysis. Hemodialysis is performed multiple times a week and takes three to five hours each session, while peritoneal dialysis must be done daily. People on dialysis may experience discomfort, fatigue, and other complications of kidney failure and dialysis.

**TRANSPLANT**

A kidney transplant is a surgical procedure performed to replace the diseased kidneys with a healthy kidney from another person. Transplant may give you better quality of life and help you live longer. However, it is important for you to be aware of the risks related to surgery, transplant rejection, and possible side effects from the medications that you will need to take after transplant to prevent rejection.

Remember: dialysis and transplant are treatments for kidney failure, not cures.

This meeting will last approximately three to four hours. Blood work will be done to determine your blood type, antibody levels, and tissue type. These tests allow us to see how your immune system will likely respond to a transplant. *Please bring with you: a complete list of medications that you are taking (name, dosage, and frequency) and dates of any operations, hospitalizations or blood transfusions. You may also invite a family member or friend to join you.*

**CROSSMATCH**

If you have a living donor, as part of your screening we will conduct a crossmatch, a blood test that determines compatibility between a donor and recipient. A positive crossmatch indicates incompatibility. A negative crossmatch indicates compatibility.
The Waiting List

All accepted transplant candidates are placed on the national waiting list for deceased donor organs after the initial evaluation process has been completed. Kidneys are primarily shared within the local region from which they come, but there is also national sharing. Stanford’s local organ procurement network is Donor Network West. The United Network for Organ Sharing (UNOS) manages the national list.

Overall wait time varies based on blood type. Candidates with O or B typically have longer wait times compared to people with A or AB. Once on the waiting list, it is important that you keep your transplant coordinator updated any time there are changes in your health (blood transfusions, hospitalizations, surgeries, or diagnostic tests), insurance coverage, dialysis unit, or contact information. You will need to make sure that you do not miss any dialysis treatments, doctor visits or lab tests—and that you are ready to go at all times when you get the call to come in for your transplant.

Compliance with your current medical regimen is critical.
Types of Transplants

Your transplant team will work with you to determine which option is right for you:

**DECEASED DONOR**
Is an individual who has suffered brain or cardiac death, from whom at least one solid organ is recovered for the purpose of transplantation. The waiting time for a deceased donor kidney in the San Francisco Bay Area is five to ten years and sometimes longer, as the waiting list continues to grow every year.

**LIVING DONOR**
Is a person who donates an organ for transplantation. Living donors may be blood relatives or individuals with emotional ties to the transplant candidate. Finding a living donor match dramatically shortens your waiting time, increases long-term graft (transplant) and patient survival, and gives you the flexibility of electively scheduling your date of surgery.

**QUALITY CARE**
To see current outcomes from the Scientific Registry of Transplant Recipients Program Reports, visit the site at ustransplant.org.

**PATIENT SURVIVAL RATES**

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<th>One Year</th>
<th>Three Years</th>
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<tr>
<td>Stanford Health Care</td>
<td>96.87%</td>
<td>94.12%</td>
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<tr>
<td>National</td>
<td>97.42%</td>
<td>92.79%</td>
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**KIDNEY SURVIVAL RATES**

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<td>96.79%</td>
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<td>87.28%</td>
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Source: SRTR Program Reports-December 16, 2015
Understanding Living Donation

Kidneys from living donors are more likely to be a good match for recipients, and they also improve the chances of long-term transplant success. Potential donors undergo a complete medical and psychological evaluation to confirm they are perfectly healthy and a good match. This process takes several months. Keep in mind that while many people have a desire to become living donors, not all are suitable for donation. Current and future medical safety of living donors is our number-one concern.

**FINDING A LIVING KIDNEY DONOR**
As early as possible, we suggest you talk to your transplant team about how to identify and approach possible donors. They can help you make a plan that feels comfortable to you, follow up with potential donors who show interest, and put you in touch with donor mentors who can share their experiences.

**CONFIDENTIALITY**
Stanford respects your privacy and the privacy of your potential donor. Both you and your donor will be assigned separate doctors, transplant nurse coordinators and social workers, and your medical information will not be shared. Your donor will also be assigned an independent donor advocate.

**MEDICAL COSTS**
The medical costs of evaluation and donation are the responsibility of the recipient’s medical insurance company.

**Potential Living Donors Must Be**
- In an established relationship with the recipient: sibling, parent, child, spouse, relative, or close friend
- Competent and freely willing to donate, without coercion or financial gain
- 18 years of age or older
- A compatible match with the recipient or willing to participate in a donor exchange
- Able and willing to comply with follow-up care
- In good physical and mental health

Potential donors can begin the evaluation process by visiting the website: StanfordHealthCareLiveDonors.org or by contacting our living donor coordinator at 650.498.8382.
Knowing that my donor was evaluated with her own set of doctors and team assured me that they would not have let her go forward with donation if there was any substantial risk of future harm. This made it much easier for me to ultimately accept the wonderful gift of a kidney, and for me—life.

—Kim, kidney recipient
DESENSITIZATION
Patients are said to be sensitized when they have developed a high level of antibodies (protein substances in the blood) after receiving blood transfusion(s), previous transplant(s), or pregnancy. These antibodies can cause rejection of the transplant kidney. Stanford has an active desensitization program designed to neutralize these antibodies and allow transplantation in some cases.

ABO INCOMPATIBLE TRANSPLANTS
Ordinarily, if a person receives a kidney from a person with a different blood type, his or her immune system will recognize the organ as foreign and attack it. A process called plasmapheresis (like dialysis) is used to remove the antibodies against the different blood type. Stanford offers a protocol that allows some recipients with incompatible blood type donors to undergo this procedure so the transplant can take place.
Options for Incompatible Donors

Even though you may have a family member or friend to serve as a living donor, you still face the possibility that your donor is incompatible with you. For instance, you may have blood type A, while your donor is blood type B. Depending on your incompatibility, additional programs are available.

**PAIRED EXCHANGE**

With paired exchange, your donor exchanges his or her kidney with the living donor from another incompatible donor/recipient pair to create two compatible pairs. While it is true that your donor will not directly donate his or her kidney to you, exchanging with another incompatible pair will allow for two compatible transplants.

**CHAIN TRANSPLANTS**

Donor chains work similarly to paired kidney donations, in that they take advantage of healthy and willing—but incompatible—donors. The chain is initiated by what is called a non-directed donor. A non-directed donor is someone who offers to donate a kidney without a designated recipient, but with the explicit wish to donate to someone in need of a transplant.

**DONOR SHORTAGE**

The number of people on the kidney transplant waitlist continues to grow, with more than 100,000 Americans now awaiting a compatible donor. More than 8 percent of those on the U.S. transplant waitlist reside in the Bay Area. About 17,000 transplants are performed each year in the U.S., with approximately 10,000 deceased donor transplants and 6,000 living donor transplants occurring annually.
Surgery & Recovery

THE RECIPIENT PROCEDURE
During your transplant surgery, the donor kidney will be placed in your lower abdomen, and your native kidneys will remain undisturbed. The actual surgery takes about three hours.

After surgery, a bladder catheter will be in place for about three days. Most people recover in the hospital for four to five days, and are up and walking around on day two or day three. During this time, you and your primary caregiver will be coached on how to keep your body as healthy as possible after transplant, including taking anti-rejection medications every day.

Risks related to kidney transplant for recipients include delayed function of the donor kidney, rejection, bleeding, infection, and urine leaks.

THE LIVING DONOR PROCEDURE
During donor surgery, the surgeon will make a series of small incisions in the lower abdomen and insert a laparoscope—a tiny tube with a light and a camera—to view and access the kidney. Donor surgery takes about three hours.

Donors typically stay in the hospital for two days and return to normal activities within four to six weeks. Donors return for a follow-up appointment one week after discharge from the hospital. Additional follow-up appointments are scheduled at six months, one year, and two years after donation.

Risks related to kidney transplant for donors are similar to those involved with any major surgery, such as bleeding and infection. In the U.S., death as a consequence of donation occurs in three to four of every 10,000 donations. Being a living donor does not shorten life or lead to long-term health consequences.
The *Guide to Becoming a Living Donor* explains the donor experience in detail and is available for you to give to prospective donors.
Preventing Rejection

Your immune system works to find and neutralize foreign substances in your body like bacteria and viruses. It will think your new organ is a foreign invader and try to get rid of it.

**ORGAN REJECTION**

Rejection occurs when your body recognizes that the transplanted kidney is not the same as your own body tissues. There are two types of rejection: acute and chronic. Most acute rejections happen in the first year as the body reacts to the newly transplanted kidney. Chronic rejection happens over a longer period of time and is the primary cause of transplant organ failure over time.

In most cases, early detection and prompt treatment can reverse acute rejection. That is why it’s critical that you stay in touch with your transplant team on a regular basis and keep up with your lab tests.

Transplant Medications

**IMMUNOSUPPRESSANTS**

Anti-rejection medications, also called immuno-suppressants, are given to transplant recipients to prevent and treat rejection. Immunosuppressants “blindfold” your immune system to help keep it from attacking your new kidney. You will need to take these medications every day.

**ADHERENCE**

At every stage of your transplant, you are expected to follow your doctor’s instructions and take your medications exactly as prescribed. It is your responsibility to ask questions if you do not understand something and to be a proactive partner in your care.

If you stop taking your immunosuppressants, rejection will occur.

**SOME TYPES OF IMMUNOSUPPRESSANTS**

- Tacrolimus (Prograf®, Astagraf®, Envarsus®)
- Cyclosporine (Neoral®)
- Mycophenolate mofetil (CellCept®)
- Prednisone
- Sirolimus (Rapamune®)
- Belatacept (Nulojix®)
- Azathioprine (Imuran®)
- Basiliximab (Simulect®)
- Anti-thymocyte Globulin (Thymoglobulin®)

**POSSIBLE SIDE EFFECTS OF IMMUNOSUPPRESSANTS**

- Increased risk of infection
- Increase in blood sugar, blood pressure, and cholesterol levels
- Increased risk of developing cancer
- Nephrotoxicity (toxic to the kidneys)
- Stomach upset
- Neurological abnormalities
- Mood swings
Post-Transplant Care

After your transplant, you will need to follow up frequently at Stanford for the first four months. Then you will resume care with your primary nephrologist and complete routine lab testing on a regular basis to monitor for rejection and other potential problems. You will also continue to see us in the transplant clinic on a regular basis. Your transplant team and your nephrologist will work together closely for the life of your transplant.

FOLLOWING A HEALTHY LIFESTYLE

Before transplant - Staying mentally and physically active will help prepare you for the transplant transition. Don’t put your life on hold; continue doing the things you enjoy while waiting for your transplant. Keep learning, spend time with friends and family, exercise and eat right, and be sure to keep in contact with your transplant team.

After transplant - Receiving a kidney transplant is a precious gift. Help protect your new kidney by taking your medications every day, eating a well-balanced diet, managing your stress, and keeping yourself physically active. Talk to your transplant team about creating a wellness plan that is right for you.

PREGNANCY AFTER TRANSPLANT

Women should avoid pregnancy for at least one year after receiving a transplant. Talk to your transplant team if you are considering pregnancy in the future. Your anti-rejection medication regimen may need to be adjusted.

There is limited information on male transplant recipients who become fathers, but it appears that the frequency of birth defects in children of transplant fathers is no different than it is in the general population.
After my transplant, with the new energy that I had, I think I became even more physically active than I had been prior in my life. Soon after that transplant, I became involved in participating in the World Transplant Games....It really indicated to me the value of physical activity.” — Randall, kidney recipient and avid cyclist
Preparing Financially

INSURANCE COVERAGE
Make sure that you understand what benefits your health insurance covers, including your required co-payment amounts, any “caps,” and total out-of-pocket deductibles for the year. You should also find out which pharmacies carry transplant medications in your community, and if mail-order pharmacies are covered under your plan.

If you pursue living donation, your insurance should cover your donor’s transplant-related medical expenses, including evaluation, surgery, and follow-up care. Check with your insurance provider to find out if there are any coverage limitations.

Transplant financial coordinators at Stanford are available to assist you before and after your transplant. They can assist in providing coverage options, resolving billing issues, and following up for authorizations and/or denials. Regardless of your insurance coverage, be sure to inquire about patient-assistance programs; they may be able to help you cover some of your costs.

MEDICARE
If you are covered by Medicare, keep in mind that coverage ends at 36 months after transplantation if your eligibility was based on End-Stage Renal Disease (ESRD). If you are on Medicare due to another disability, it will provide coverage for the duration of the disability. If you are over age 65, coverage is indefinite.

ASSOCIATED COSTS
Out-of-pocket costs for an organ transplant can add up. In addition to medication co-payments and insurance coverage gaps, you should also plan for additional expenses. For example, you will want to consider transportation costs like gas and parking, housing for the first one to three months if you do not live in the area, time off from work and child care, as well as food expenses for your caregiver and/or your family.

TAKING THE NEXT STEP
As you explore kidney transplant as a treatment option, please remember these three key things:

1. Have a caregiver who will be with you, especially during the first few weeks.
2. Stay motivated and committed to following your transplant team’s instructions.
3. Secure health insurance to cover your transplant and follow-up care.

If you would like to speak with a transplant recipient or living donor mentor, please let us know. We can also put you in touch with support groups in your area. For questions about the Kidney Transplant Program, please call us at 650.725.9891.
Resources

STANFORD KIDNEY TRANSPLANT PROGRAM
stanfordhealthcare.org/kidneytxprogram

STANFORD HEALTH LIBRARY
Free and open to the public
stanfordhealthcare.org/healthlibrary

UNITED NETWORK FOR ORGAN SHARING (UNOS)
unos.org

DONOR NETWORK WEST
donornetworkwest.org

NATIONAL KIDNEY FOUNDATION (NKF)
kidney.org

SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS (SRTR)
srtr.org

This information is not intended to replace the medical advice of your doctor or healthcare provider. Please consult your healthcare provider for advice about a specific medical condition.
For questions about the Kidney Transplant Program, call us at
650.725.9891

For Interpreter Services, call
650.723.6940

For more information, visit
stanfordhealthcare.org/kidneytxprogram