

COMMON

News and information

ESRD Network



Concerns

for kidney patients and their families

Opportunities in Transplant

There are many options for the treatment of End Stage Renal Disease (ESRD). These options include hemodialysis, peritoneal dialysis, and kidney transplantation. In this issue of Common Concerns we are going to focus on kidney transplantation. Specifically, we will examine the types of kidney transplants, common medications used post transplant, Medicare coverage of transplants, and we will hear from a kidney transplant recipient. Innovations in kidney transplantation have led to increased opportunities and improved quality of life for many ESRD patients. With advancements in surgical procedure and immunosuppressive drugs, patients now have many more options when it comes to kidney transplantation.

Cadaveric Donation

Historically, a cadaveric donation, a transplant kidney removed from a dead person, was the only option available to patients in need of a kidney. After a complete medical evaluation, candidates are placed on a national kidney transplant list, awaiting a kidney from a deceased person. According to the United Network for Organ Sharing (UNOS), there are currently 53,259 potential kidney recipients on the Organ Procurement and Transplantation Network (OPTN) National Patient Waiting List. The average waiting time for a kidney transplant is 3 to 5 years. Distribution of kidneys is based on a national point system that takes into account factors such as the patient's length of time on the waiting list, compatibility with the available kidney, and geographic region.

Living Donation

With current innovations in living donations, many patients in need of a kidney no longer need to wait 3 to 5 years. Now patients can look to family, friends, acquaintances, and even strangers for organ donation. Kidneys taken from relatives are less likely to be rejected by the body because of similarities in genetic make-up. If this is not an option for the patient, they may turn to friends or acquaintances for a directed donation. Yet another alternative is a non-directed donation, by which a patient receives a kidney from an unfamiliar person who is just looking to make a difference in someone's life. Some of these options are only available at certain transplant programs. Consulting with your transplant team can help you identify these programs.

Regardless of the personal relationship, there are many advantages to living donations. In such cases, healthcare professionals are well aware of the health of the donor and the kidney to be donated. Surgery can be planned ahead of time and recipients can begin their immunosuppressive drug regimen to prepare them physically prior to surgery. Generally with living donations, the transition time in which the kidneys are without blood (ischemic time) is shorter. This reduced ischemic time results in less organ deterioration and faster functioning once the organ is transplanted.

Transplantation may not be an option for all ESRD patients but if you think this form of treatment may be right for you, contact your healthcare team to discuss the possibility.

Are You a Transplant Candidate?

Although kidney transplantation is not always an option for some ESRD patients, it is an option to consider when examining your overall healthcare plan. The decision to have a transplant involves two parties: the patient and the transplant team.

As a patient you must weigh the pros and cons of all your treatment options. Your healthcare team can help provide you with the resources to do so. If you decide a transplant may be right for you, the next step is to locate a transplant facility. While all dialysis facilities must be associated with at least one transplant program, you may choose to have a transplant evaluation at any transplant program in the nation.

Although every facility differs in their selection process, there are specific criteria and tests most transplant teams take into consideration when identifying candidates. The following is a group of common risk factors and tests associated with kidney transplantation.

Risk factors that may prevent transplant eligibility:

1. Non-adherence to Treatment Prescription
2. Obesity
3. Age
4. High Blood Pressure
5. Chemical Dependency
6. Cancer
7. Infection

Tests used to detect risk factors:

1. General Health Exam
2. Dental Exam
3. Various Cancer Screenings
4. Cardiac Evaluation

Tests used to predict transplant outcomes:

1. Blood Typing
2. Tissue Typing
3. Antibody Level
4. Crossmatch

How is a Kidney Transplant Paid for?

A very common and important question for patients considering a transplant is, “Who pays for a kidney transplant?” This is an important issue that goes beyond just how the initial transplant surgery is covered, to how do all of the follow up medical visits and medications you are required to take get paid for? Medicare, Medical Assistance, Medicare supplements, and private insurance can all assist in the payment of a transplant and other associated costs. Each program or insurance plan may have different rules governing the coverage of a kidney transplant. Prior to receiving a transplant you should gain a full understanding of how your coverage works. The social worker affiliated with your transplant program can be a valuable resource in helping you understand your insurance and how it pays for the transplant procedure and other associated costs. Another helpful resource is the CMS Publication (#10128) Medicare Coverage of Kidney Dialysis and Transplant Services. This publication can be viewed online at www.medicare.gov or ordered by calling 1-800-MEDICARE (800-633-4227).

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WHAT YOU NEED TO KNOW ABOUT TRANSPLANT MEDICATIONS

If you have a kidney transplant, you will be required to take special medications. Specifically, there are 3 types of medication:

1. Medicine to keep your body from fighting (rejecting) your new kidney.
2. Medicine that protects you from infection.
3. Medicines to treat side effects from the anti-rejection medication.

Two important things to remember about transplant medications are:

1. You must take your medicines or you will lose the kidney transplant
2. There will be side effects from the medicine. Your physician will prescribe medications to help minimize those side effects.

As a transplant patient YOU are an important part of the transplant team! Remember:

1. Never stop taking any of your medication without calling your doctor. If you want to stop taking your medication, call your doctor first.
2. If you are having trouble paying for your medications, let your transplant team know. They may be able to assist you in finding resources to help.
3. Tell your doctor or nurse if you think you are having side effects from a medication.
4. Check with your transplant team:
 - If you miss a dose of medicine
 - If any other doctor gives you medicine
 - Before you take any over-the-counter medicine

-adapted from “Keeping Your New Kidney Healthy: Facts About Transplant Medications” American Society of Transplantation Patient Care and Education Committee

Internet Resources

www.transplantlife.com

This site sponsored by Fujisawa Healthcare, Inc. provides information for liver and kidney transplant recipients at all stages of the transplant process. Content includes success stories, medication information, transplant library, and information for ordering free education materials on-line.

www.transplantfund.org

The National Transplant Assistance Fund helps raise funds for transplant patients. This site contains information pertaining to transplant costs and expenses, fundraising ideas, and financial assistance through grants.

www.unos.org

The United Network for Organ Sharing (UNOS) administers the Organ Procurement and Transplantation

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Kidney Transplantation: The Patient Perspective

This issue of Common Concerns has focused on kidney transplantation. Although not all End Stage Renal Disease (ESRD) patients are transplant candidates, it is important that you be aware of transplant as a possible option to treat your ESRD. In the following article, Margaret “Maggie” Carey, who is a member of the Network 11 Consumer Committee talks about her experiences as a dialysis patient who subsequently received a kidney transplant.

Maggie, please give us some background about your ESRD history.

I had Polycystic Kidney Disease (PKD) and was diagnosed when I was 19 years old and pregnant. In my 30’s I began having problems with hypertension and in my 40’s I had a urinary tract infection that resulted in the removal of one of my kidneys. I was started on hemodialysis (HD), but switched to peritoneal dialysis (PD) after three months. I was on PD for about two years before receiving my cadaveric transplant about six years ago.

Why did you decide to pursue a transplant?

When I first started on dialysis I was scared and didn’t want to immediately pursue a transplant. However, as time passed I began to ask questions and do some research about kidney transplant. I began to realize that transplant might be a positive option for me and I thought that having a transplant would fit my lifestyle better than being on PD.

What do you believe was one of the more important priorities for you as a patient prior to transplant?

It was important for me to take an active role in my healthcare. I realized early that by regularly attending my clinic appointments, doing my PD exchanges, taking my medications, and asking questions of the healthcare team I was demonstrating my desire to take care of myself and to show that I would be a good transplant candidate.

Was the pre-transplant work up difficult?

No. In my case it was a matter of going through some routine medical tests, education classes, and most importantly verifying my insurance coverage. During the pre-transplant phase I realized how important it was to talk with my support system at home about what I might need from them in the event I did receive a transplant. For me, it was a full family decision and required a full family commitment.

Was waiting to receive a transplant difficult?

I was very fortunate that my wait was very short. However, during that waiting period I tried to live my life fully each day and pay close attention to my healthcare needs at the time. I was still a PD patient and that required my full attention. I was also in regular contact with the transplant team keeping them updated on my physical health and overall well being.

Tell us about the day you received your kidney.

I received about 12 hours notice that a kidney was available. I immediately checked into the hospital and received some final tests and clearance to go ahead with the transplant. The surgeon explained to me all the risks associated with transplant and surgery. I went into receive the transplant about 7:30 am and I was back in my room by 11:00 a.m. My transplant went well and my recovery was routine with the normal pain associated with a surgery. What surprised me most was the incredible amount of energy that I had right from the start. I had not realized how tired I was used to feeling. It was a very exciting and challenging day all at the same time.

What has life been like post transplant?

It has been good. However, just like when I was on PD I have to pay very close attention to my health and I have to be especially vigilant with my medica-

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tions and clinic appointments.

What would you like to tell other patients who are thinking about pursuing a transplant?

I know that not every ESRD patient is a transplant candidate, but if it interests you it is important to talk with your MD about transplant as a possible treatment option. It is also critical that as a patient you educate yourself about what it means to get a transplant and what all is involved. It is important to keep in mind that once you receive a transplant your work as a patient isn't over. I have had to be very aware of my medications, my health in general, and to follow up with my MD's and transplant team. I also am aware that the chance exists that my transplant can fail, but I have learned to live each day and appreciate what I have. If you decide to pursue a transplant, remember that it is a treatment option and not necessarily a cure for your kidney disease. But if you do decide to pursue transplant, I believe that keeping a positive attitude through the whole experience will greatly benefit you in the long run.

Network (OPTN).

Search this site for more information on organ matching and sharing, transplantation data, and the national waiting list.

www.tppp.net

The Transplant Patient Partnering Program, sponsored by Roche, uses the expertise of transplant doctors and coordinators along with the insight of patients to provide a realistic understanding of the transplant experience. Search this site for downloadable resources for patients and family members.

www.ustransplant.org

The site of the Scientific Registry of Transplant Recipients provides a variety of statistical information including transplant center-specific reports.

www.lifeoptions.com

Life Options is supported by Amgen Renal Services and administered by the Medical Education Institute, Inc. Visit Kidney School, and interactive, web-based learning program to learn about treatment options and for tips on how you can live life to the fullest.

ARE YOU A DIALYSIS OR TRANSPLANT PATIENT WHO LIVES IN WISCONSIN OR SOUTH DAKOTA?

If you answered, "yes" to this question, you should consider serving on the Renal Network 11 Consumer Committee. The Consumer Committee is made up of 13 ESRD consumers from the states of Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin. The members of this committee help to support Network 11 in its mission to assess and improve the quality of care provided to individuals with End Stage Renal Disease (ESRD). Specifically the Consumer Committee works to assist in the development of educational materials, such as this issue of *Common Concerns*, to educate ESRD patients. If you would like more details about serving on this important committee, please call Mark Meier at 1-800-973-3773.

National Kidney Foundation Calendar of Events

The **NKF of Michigan** will be hosting a series of R.I.S.E. programs to be held February 19, 21, 26, and 28 in Detroit. This program gives ESRD and transplant consumers the opportunity to look at employment, volunteering, or continuing education as a means of enhancing their quality of life. For more information, contact the Michigan NKF at **800-482-1455**.

The **NKF of Minnesota** will hold the annual “Gift of Life Celebration” in Bloomington, MN on March 27, 2003. The Kidney Walk is scheduled for spring of 2003. For more information contact the Minnesota NKF at **952-544-7300**.

The **NKF of South Dakota** will be sponsoring KEEP events for pre-ESRD screening in January and February. Join in the festivities and help raise money for the NKF by attending the Mardi gras fundraiser on February 1, 2003. The annual Kidney Walk will take place on March 8, 2003. For more information on any of these events, call the South Dakota NKF at **605-338-0518**.

Contact the **NKF of Wisconsin** at **800-543-6393** for a listing of upcoming events.