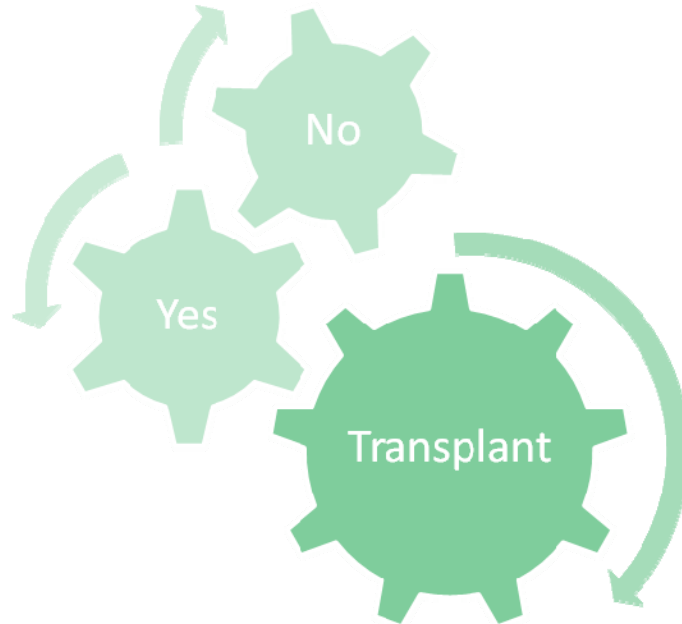


Changing Gears -

Transplantation: Is It Right for Me?



This newsletter is a resource for dialysis consumers who are thinking about transplant or for those who aren't sure if a transplant is the best option for them. Inside this newsletter are tools to help you make an informed decision whether kidney transplantation is an option for you! Inside find the following articles:

- **Frequently Asked Question and Answers About Transplantation**
- **Transplantation as an Option**
 - **Finances and Insurance**
 - **Emotional and Lifestyle Changes**
 - **Transportation and Lodging**
- **Transplant Patient talks about their Personal Experience**
- **List of Transplant Centers in Network 6 (Georgia, North Carolina and South Carolina)**



Transplantation: Frequently Asked Questions

By Lynn W. McCoy RN, CNN, Pediatric Nephrology Care Coordinator, Division of Nephrology and Hypertension, Chapel Hill, NC

Considering whether or not renal transplantation is right for you is a very personal decision that patients and their families must consider carefully. There are many members of your local healthcare team that can support you through the decision making process. Once you've decided to pursue renal transplant as a treatment for your kidney failure, your transplant team will join your local healthcare team in providing additional support specific to transplant. The following are commonly asked questions and answers you might consider as you pursue transplantation:

1. Does my insurance require a “special” referral for me to be evaluated for a kidney transplant? Some insurance DOES require your Nephrologist to obtain a referral BEFORE any appointments for evaluation are made. Check with your insurance directly or speak with someone at your employer's Human Resources office.

2. Can I choose which transplant center I go to? Yes, unless your insurance requires your transplant evaluation and surgery occur at a particular center. Again, it's important to contact your insurance company directly or speak to a representative in your HR department about the specifics of your coverage. Some insurance companies will assign you a special transplant case manager and this individual can be very helpful in addressing these and other transplant related insurance issues.

3. When will my medical records be sent to the transplant center for review and consideration for evaluation? How long before I know whether or not I can be evaluated? Your Nephrologist and dialysis staff can tell you the status of the “paperwork” that goes to the transplant center. They also have experience with the various transplant centers in your area and can give you a reasonable estimate of when you might know something. They can also provide you with a contact at the transplant center if you want to personally confirm your paperwork was received.

4. Are there educational opportunities I can access before beginning the transplant medical evaluation? Your dialysis staff, social worker and Nephrologist can help provide you with a variety of resources about transplantation. The transplant center you have been referred to also has resources such as written material, videos and or patient classes to help you through the learning process. There's lots of information to be learned, and no one expects patients to learn it all at once. If you obtain information from the internet it is wise to carefully consider the source. If in doubt, the dialysis staff, Nephrologist and transplant center can verify sources for you.



5. What is the time frame to complete the transplant evaluation for a patient with a diagnosis similar to mine? Your transplant center will be able to provide an overview of what you might expect during your evaluation, including the actual testing to be done and the implications of various results, i.e. whether additional testing required, what would exclude you as a recipient, etc.

6. When will I know my evaluation testing is complete and what the outcome is? Your transplant center will have the final word on when your evaluation is complete and whether or not you have been cleared to proceed with transplant surgery or listing for a deceased donor transplant.

7. If I have possible donors how and when can they find out if they can donate to me? The live donor evaluation process begins with identifying those individuals who are willing to consider donation. Very basic requirements include that they be in good overall health and of a compatible blood type. Your transplant center will provide potential donors with detailed information about the donor evaluation and donor surgery. A separate healthcare team will care for the potential donor throughout the process.

8. If I do not have a live donor and have to be on the waiting list for a deceased donor is there anything I should know while waiting? Stay in contact with your transplant center on a regular basis. Let them know if you have any changes in your health, undergo surgeries, have a change in type of dialysis your receiving, change in insurance coverage or change in your contact information.

9. How long is the transplant evaluation good for? Does it ever expire? Evaluations or portions of it are typically good for a year to eighteen months. The evaluation will need to be updated periodically based on your current medical diagnosis and any new medical issues that may arise. When and how your evaluation will be updated may also depend on recommendations from the transplant team and your local Nephrologist.

10. Do I have to have a transplant just because that's what everyone says I should do? No, the final decision to proceed with transplant is a choice you have to make for yourself. It is a treatment just as dialysis is a treatment and has the potential for good outcomes, as experienced by many who choose transplant. There are also risks that must be considered carefully. Your Nephrologist, dialysis staff and the transplant center will support you regardless of the decision you make.

The medical evaluation and general process leading to transplant is very similar between adults and children. Developmental, cognitive, growth and nutritional considerations along with the psycho-social impact for families can be the most challenging for this patient group. Children with renal disease require active involvement across various interdisciplinary care providers.



Transplantation: A Treatment, Not A Cure

Many people think that when they get a kidney transplant they will never have to face dialysis again. Education of the patients, families, and caregivers to reassure and separate facts from myths is invaluable as a step for the consideration of transplantation. Some patients may fear the return to dialysis treatments and allow this to keep them from pursuing transplantation. Although the transplant patient always has the possibility of rejection and the return to dialysis treatments, the benefits of a transplant can outweigh the negative aspects of this reality. The transplantation process is fairly standard between transplant centers. However, there may be some differences in policies and procedures. As a patient you are encouraged to ask questions.

It is the patients' right and responsibility to ask questions. Here is a sample of important questions that you can ask your healthcare team:

- Am I medically suited for a kidney transplant?
- If I have a medical problem keeping me from transplantation, can it be corrected so I can get a transplant?
- What is the recovery time?
- What are the side effects of the medicines?
- Will any of the anti-rejection medications interfere with any medicines I am currently taking?
- Will the anti-rejection drugs be changed if one is not working?
- How often do I need to see the transplant team?
- Do I need to see a Nephrologist in addition to the transplant surgeon?
- If I live a distance from the transplant center and I have a medical problem, do I go to the closest hospital or go to the transplant center?
- What are the tests your transplant center requires and can they be done at my dialysis facility or Nephrologists' office?

For additional information regarding your insurance coverage, contact:

- The Centers for Medicare & Medicaid Services (CMS) at 1-800-Medicare (1-800-633-4227) or at www.medicare.gov
- The Southeastern Kidney Council at 1-800-524-7139
- Your insurance provider



Transplantation: A Treatment, Not A Cure (Continued)

Some other areas that need to be explored are:

- **Finances and insurance:** Most transplant centers have a Financial Coordinator to assist patients to examine insurance coverage and how it will pay for the procedure, medication, and other elements of transplantation. In some transplant centers the Financial Coordinator may also be the Social Worker. Medicare D is complex and needs to be addressed before transplantation. The transplant and dialysis facility social worker can assist in investigating how Medicare D may pay toward immunosuppressant medication. Please refer to the Centers for Medicare & Medicaid Services booklet, “**Medicare Coverage of Kidney Dialysis and Kidney Transplant Services**” for a comprehensive explanation of the Medicare process. This booklet is available at <http://www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf>.
- **Emotional and lifestyle issues:** Transplant centers have a Social Worker to help with emotional and lifestyle issues and concerns. The patient, family member or caregiver may have a work schedule, childcare, pets, or other family issues which need to be addressed before considering a transplant. Many patients do not realize that they will see a Social Worker who will assess and evaluate their needs and attempt to assist the patient to reach their needs before transplantation. Many patients have to have a psychological evaluation to ensure that they are emotionally stable.
- **Transportation and lodging issues:** The transplant center will help with applications for assistance programs or resources for transportation and lodging. The resources may not be the same for all transplant centers. The dialysis facility Social Worker can also assist with any local resources, which may be available as well as possible coordination of services.

Transplantation takes a **commitment** from the patient at the every beginning by attending pre-transplant classes. Also, after transplant, it takes a strong commitment to follow the doctor’s orders, take the necessary medication (without skipping) and letting the doctor know of any issues that may arise. Having a strong support system is very helpful. If family involvement is present, they need to be aware of the patient’s situation, needs, and responsibilities.



A Patient's View: A New Kidney, A New Life

By Dixie Moncus, Kidney Transplant Recipient, Olin, NC

Have you had or are you waiting for a kidney transplant? If so, then I know how you feel. My name is Dixie Moncus and I have waited for and received three kidney transplants since 1998. **I love to share my story with other End Stage Renal Disease (ESRD) patients and their families because I truly believe that knowledge, education, and support are the key to a positive outlook and then a positive result in a good and healthy lifestyle.**

I would like to share a little bit about me, my history with ESRD and the way that transplantation has changed my life for the better. My kidney problems all result from when I was a young child. As an infant I began to get tonsillitis on a very regular basis. Every time that I would be diagnosed with it, I would be treated and sent back home. Sounds okay-right? Wrong! Unfortunately at the time, medical technology had not realized yet the magnitude of strep on kidney function. I struggled, of course along with my parents, battling these constant infections until the age of four when they were finally removed. By this time, it was too late. Too much infection and too many antibiotics had taken their toll on my body. At the age of 12, I decided like many girls, that I would try out for the cheerleading squad at school. I made the team and then the required physical led my parents and me to hear that my blood pressure was way too high for someone of my size, age and history. Something was wrong! I was sent to a pediatric specialist who then sent me to the hospital and performed kidney scans and further tests to determine that I indeed had significant kidney issues that would need to be carefully monitored. I did pretty well for the next several years; some medications, some diet changes, and constant blood pressure checks kept me doing okay. It wasn't until I became pregnant and had my two children that my problems really began. My kids were just too much of a strain on my blood pressure and therefore also on my kidneys. My Nephrologist would continue to watch me for the next 5 years until finally he called me at work one day and said, "Dixie, it's time. We are going to have to start dialyzing you now." This took place on a Friday afternoon and on Monday morning I was in the hospital having a perm-cath put in to use immediately for dialysis and a Tenckhoff catheter to use later for peritoneal dialysis. Talk about a lot to take in for me and my family in a weekend! I did fine on peritoneal for the next two years. I then received my first call that someone had donated their kidneys and I was hopefully going to receive one of them. I fortunately did because of the good match and it did great for 3 years until I ended up having to go on



hemodialysis for about 9 months. Then my second call came and off to the hospital we go for what we hoped again would be a good match. I again was blessed to hear that someone and their family had graciously donated their kidney. The match was good and the kidney was a huge help, but it never “woke up” completely after surgery and so it was able to perform the job of producing the urine but not of clearing the blood to the point that my body needed it to. It still however kept me off of dialysis for the next 16 months until my Nephrologist again decided that it was time to go back to peritoneal dialysis in order to get me “cleaned out” better. I did peritoneal and some hemodialysis for the next few months until call number 3! The kidney that I now have, I am so very grateful for at the age of 37, is functioning extremely well. I also am sure to take extremely good care of it. It has now been 2 years ago as of January 21, 2009 since my transplant. It has given me such a wonderful new life just as my other transplants did during their time. I am lucky to say that three loving families, a team of amazing doctors, hospitals, and medications have given me a chance to enjoy getting up everyday. I get to watch my kids grow up, go to work teaching computers to our elementary kids, and not have to worry daily about whether I am healthy. I know I am healthy, I know I am doing great, and I know that life is good and meaningful.

No matter how long it takes, whatever kind of road that you have to travel to get there, do it! Do it and be patient and grateful for the chance. As ESRD patients, we are both blessed and burdened. We have been diagnosed with a disease that is severe, is life-threatening, and hard to deal with at times; but we have also been blessed. There are so many other illnesses and diseases that patients are diagnosed with everyday that there are not other options for them. We have the opportunity to dialyze and receive a healthy transplanted kidney full of life and health, and new beginnings. Appreciate that opportunity and realize that somebody else also wanted you to be here when they offered you a part of them. **Whether your transplant came from a living-related, living non-related, or cadaver donor; it was given to you with love. I am very loved.**

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Transplant Centers **Georgia**

- Egleston Children's Transplant (LifeLink of Georgia)
800-605-6175 or 404-785-1405
- Emory University Transplant (LifeLink of Georgia)
877-509-9877 or 404-727-0717
- Medical College of GA Transplant (LifeLink of Georgia)
706-721-2874
- Piedmont Hospital Transplant (LifeLink of Georgia)
888-605-5888 or 404-605-4600

North Carolina

- Carolinas Medical Transplant (LifeShare of the Carolinas)
800-562-5752 or 704-355-6649
- Duke University Transplant (Carolina Donor Services)
919-684-5859
- Pitt County Memorial Hospital Transplant (Carolina Donor Services)
252-744-2620
- UNC Hospital Transplant (Carolina Donor Services)
888-263-5293 or 919-966-9950
- Wake Forest University Baptist Medical Center Transplant (Carolina Donor Services)
336-716-4541

South Carolina

- Medical University of SC Transplant (LifePoint)
800-277-8687 or 843-876-1580

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