



Renal ROUNDUP

For patients in the Intermountain End-Stage Renal disease Network (ESRD Network #15)

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Transplantation Supplement

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During the evaluation phase, the transplant team will be searching for evidence of:

- Bleeding disorders
- Infection
- Heart disease
- Significant lung disease (smoking)
- Malignancy (cancer)
- Gastrointestinal disease
- Substance abuse (alcohol or drugs)
- History of adherence to medical instructions
- Weight problems
- Other serious conditions that might not be improved by transplant

Getting Started? Consider a transplant!

When your kidneys fail, in order to survive you need treatment to replace the work of healthy kidneys. If you choose to receive treatment, your choices are dialysis or a kidney transplant. For many patients with chronic kidney disease, transplantation provides many advantages over dialysis.

Transplantation actually restores kidney function, whereas dialysis replaces only some functions of your kidneys. As a result, people who receive a kidney transplant may live longer and have a better quality of life than those who remain on dialysis. Transplant patients also feel better, have more energy, have fewer fluid and food restrictions, and generally have more free time than those who remain on dialysis. Another consideration is that the overall cost of a kidney transplant is significantly less than the cost of continued dialysis.

Some People Should Not Receive a Transplant

In particular, people with active malignancy (cancers) or active infections will do worse after a kidney transplant. This is because the immunosuppressive medications allow these problems to get worse, quickly. Other people may not be good candidates for a transplant because they cannot follow directions well and don't take their medicines correctly. And, there is very little data to suggest that people age 80 and older benefit from transplantation. Patients must be healthy enough to survive surgery, and have a healthy heart and lungs to be considered for transplant.

Generally Speaking, You May be a Candidate If:

**-You are on or approaching dialysis
-Your glomerular filtration rate is less than 20 ml/min**

**Requirements for transplant may vary somewhat depending on the unit you chose for transplant.*

How do you get a transplant? Talk to your doctor to see if you are a candidate!

The goal of having a transplant evaluation is to make sure that you will do better with a transplant than with dialysis, to answer your questions regarding transplantation, and to find out what needs to be done to maximize your chances of having a successful transplant. You can avoid complications post-transplant by making sure you are in good physical condition pre-transplant.

Different transplant units may have additional tests or requirements before you are placed on their waiting list.

How will I pay for a transplant?

The costs of transplantation include:

- Evaluation and testing
- Surgery and post-operative care
- Temporary housing after transplant (check with insurance to see if its covered)
- Outpatient clinic and laboratory costs
- Medications

Costs of transplant are covered by: Medicare, Medicaid, private insurances and may require out-of-pocket expenses by patients.

You **must** have a financial plan in place to be considered for transplantation. All transplant centers have financial counselors available to help you formulate this plan. Currently, Medicare covers part of the cost of anti-rejection medications, but only for the first 3 years if you qualify for Medicare only because of your kidney disease. If you qualify for Medicare based on age or disability after the first three years after transplant, then Medicare can continue to pay part of the cost of the anti-rejection

medications. Private insurance will cover these medications, but may require a co-pay. Remember, obtaining medications is your responsibility, not the health care team's.



- The point of transplantation is independence, self-management and going back to work!
- Disability is for those who are NOT ABLE to work rather than not wanting to work.
- One of the goals of transplant is to be off of dialysis and feel better, but don't assume transplantation will fix all of your problems!
- Transplantation is a great treatment modality for many, but it is not a cure for all medical problems and may in fact create a new set of challenges.
- Maintain a positive attitude, and always ask questions if you feel you haven't been given enough information to manage your care!

What is rejection?

Rejection is the body's attempt through your immune system to destroy what it perceives is a foreign tissue, in this case the new kidney. Rejection rarely causes the kidney to fail completely, but it does usually require a hospitalization. Treatment depends on biopsy results. Rejection can happen immediately or within a few days or months after transplant. It can also occur more slowly, months or years after transplant. It occurs frequently when patients do not take medications.

You don't go on the list the first day that you see the transplant team. First you need to have the transplant evaluation done. If everything turns out to be OK, the transplant team will let you know when you are on the list.

Some patients require dialysis during a rejection episode or serious illness, but its often a temporary situation.

How can you prevent rejection?

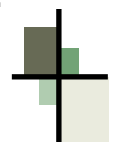
Always take your medicine on time and have lab work drawn as instructed.

What medicines will I take after I go home?

- Immunosuppressive medications will be taken everyday, for the life of the transplanted organ
- Antiviral, antifungal and antibiotic medications may be prescribed for several months after transplant to prevent urinary tract infections and pneumocystic pneumonia
- You may still require blood pressure medications. Your blood pressure may be increased due to problems with fluid retention
- Medications to protect the stomach might be

prescribed. You are more at risk for ulcers and gastric problems from the anti-rejection medications you will be taking after surgery.

Remember every person tolerates medications differently. Side effects depend on the dose of the medications you are taking and how long you have been taking them!



Caring for your kidney includes:

- Adequate rest
- A balanced diet
- Exercise
- Sun screen (skin cancer is common after transplant so rub it on!)
- Women: annual pap/mammogram
- Men: Annual prostate test if over 40
- Colonoscopy if over 50
- Annual skin checks by a dermatologist
- Dentist appointment at least once a year
- Annual chest x-ray, renal ultrasound, bone densitometry
- Routine lab work
- If you smoke, STOP!



The new kidney goes into the pelvis, to the side of the abdomen and lower than the belly-button. The old kidneys are not removed; they stay where they are.

What else do I need to do to take care of my kidney?

You have been given a precious gift. You have an obligation to the donor to take care of the kidney they have given you in the best way that you know how.



Monitor vital signs (and glucose if you are diabetic), and urine output, and keep a record of them.

Know which medication is which, what it looks like and what it does.

Go to clinic, take all prescribed medications, and call when you're sick!

Count your pills and know when you will run out. Never run completely out! Call for refills well in advance.

Ask about your labs and keep track of them. Learn what they mean.

Recognize signs of infection, rejection, and other reasons to call the transplant center.

Contact your insurance company about the specific coverage for your kidney transplant. You may be required to use a particular transplant center, or need a referral before any appointments or evaluations are done.

How long will I need to take medications after transplant?

- **Forever**, or for the life of the transplanted organ
- **Do not ever stop a medication** without consulting with the transplant team
- **Always** tell the transplant team if you are having trouble with a medication



How will I know if I have a rejection?

Symptoms of rejection include:

- *Fever,*
- *Pain over the transplant site,*
- *Decreased urine output,*
- *Increased fluid retention i.e., swelling in the hands and feet,*
- *Rapid weight gain,*
- *Blood pressure changes*
- *Shortness of breath.*

Before you are discharged from the hospital, you will learn more about the symp-

toms to watch for.

Some patients have no physical symptoms, that's why its important to have your lab work drawn when the transplant team requests it.

Your transplant center will instruct you on how often to come to clinic.

In the beginning you'll probably need to go in to have your labs drawn 2 or 3 times a week, then gradually it will taper down to once a month for most people.

During those visits its important to let the transplant team know of any concerns. They are your advisors and will help you to learn how to take care of and manage your new kidney.

Remember planning for the cost of labs should be part of the financial plan that is worked out before your transplant. Lab work can be expensive and might not always be covered by your insurance to the extent that you think it is.

Who do I call if I get sick?

Call the transplant team for:

- Fever, chills
- Vomiting or diarrhea over 24 hrs (might not absorb medications and can dehydrate quickly)
- Decreased urine output
- Sustained rise in blood pressure greater that a week
- Persistent cough or productive cough
- New shortness of breath or decreased exercise tolerance
- New onset of pain (don't take over the counter meds without checking with the transplant team)
- Any other symptoms that affect daily functions

Go to the nearest Emergency Room if you experience chest pain, sudden rise or drop in blood pressure, severe pain or other symptoms requiring immediate attention.

Some Frequently Used Medications and Their Side Effects

Medication	Potential Side Effect
Prograf	Tremor, hair loss, neuropathy, nephrotoxicity, headache, increased blood sugar
Cyclosporine	Tremor, high BP, high blood sugar, hair growth, decreased ability to concentrate
Cellcept	GI distress, bone marrow suppression (helps to spread dose over the day), pregnancy loss and birth defects, increased risk of serious infection, increased risk of certain cancers
Rapamune	Decreased wound healing ability, swelling, GI distress
Corticosteroids	Round face, acne, decreased wound healing, bruise easily, increase appetite, swelling

Not all medications or side effects are listed here, your transplant team will teach you much more about your own medication regimen. Follow their advice and report any problems that you have! Remember to tell them about any other medications you are taking as well.

Transplant Facilities in Network #15

If you would like additional information, the Transplant Coordinator at each of these facilities can give specific details about their own kidney transplantation program. (Wyoming does not have a transplant facility.)

United Network for Organ Sharing website: www.unos.org

Arizona Transplant Centers	Phone #	Web site Address
Banner Good Samaritan Transplant Services	800-554-1923 602-251-2700	www.bannerhealth.com
Mayo Clinic Hospital-Kidney Transplant Unit	800-344-6296 480-342-1095	www.mayoclinic.org/kidney-transplant/scttreatment.html
University Medical Center/Comprehensive Transplantation Center	800-297-1250 520-694-7365	www.umcarizona.org
Phoenix Children's Hospital	602-546-0965	www.phoenixchildrens.com
Colorado Transplant Centers	Phone #	Web site Address
The Children's Hospital in Denver	800-624-6553 720-777-8463	www.thechildrenshospital.org
Porter Adventist Hospital-Transplant	888-872-8891 303-778-5797	www.porterhospital.org
Presbyterian/St. Luke's Medical Center-Transplant Center	800-758-1005 303-869-2155	www.pslmc.com
University of Colorado Hospital/ Solid Organ Transplant	720-848-2237	www.uch.edu
Nevada Transplant Centers	Phone #	Web site
University Medical Center of Southern Nevada/	702-383-2224	www.umcsn.com
New Mexico Transplant Centers	Phone #	Web site
Presbyterian Hospital/Renal Transplant Services	800-597-7217 505-841-1434	www.phs.org
The University of New Mexico Health Sciences Center/ Transplant Services	866-317-0380 505-272-3100	http://hospitals.unm.edu
Utah Transplant Centers	Phone #	Web site
University of Utah-Hospital/Transplant Center	800-824-2073 ext. 12634 801-581-6320	www.uuhsc.utah.edu
Intermountain Medical Center/Transplants Services	866-439-0480 801-507-3380	http://intermountainhealthcare.org/hospitals/imed/services/transplant/kidney/Pages/home.aspx

Many of the web-sites listed above contain inspirational stories from patients who have received transplants.

The Transplant Waiting List

After you've had your transplant evaluation, unless you have a volunteer donor, you'll be placed on the transplant waiting list. Ask your transplant center to give you more details about the waiting list; they can tell you more about the options for kidney donation that might be available to you.

Not Your Traditional Wedding Anniversary:

Husband Donates Kidney to Wife After 30 Years of Marriage



Pearls top the list as the suggested 30th wedding anniversary gift. Still, some devoted husbands may opt to purchase their bride of three decades a special spa day – or an exotic trip to sip wine by an ocean breeze.

In the case of George and Anna Riley, Bloomfield, N.M., their beverage of choice on the eve of their 30th wedding anniversary was strictly cut off at midnight. That was the “stop all food and beverage” deadline before they were both readied for major transplant surgery at Mayo Clinic in Arizona.

George's gift to Anna trumped all material things. George, on their 30th wedding anniversary, instead donated one of his kidneys to Anna, 49, who suffers from a genetic disorder that affected six other family members. It became clear early on that Anna would require a kidney from a non-blood relative, so as to not compromise the health of any remaining relatives.

More than 15 of the Riley's friends, many from their church, didn't hesitate to step forward to offer to be tested to ultimately donate the gift of life to Anna. They were prepared in particular for one young church friend to be “the” donor. So it surprised them both when George qualified to be his wife's donor, and Anna was touched that her husband of all those years would make such a generous and sincere offer.

Fast-forward to surgery day, Oct. 21, 2008, the exact day of their 30th anniversary. In pre-op, the couple's beds were wheeled together, where they held hands and blew each other kisses. Eight of their family members were allowed to come into the area to pray with them. George, 50, “usually the strong one,” according to Anna, succumbed to emotion. “I then switched our roles a bit,” admits Anna. “I had to be strong for him.”

The night before surgery, family members had thrown an anniversary party for Anna and George, even if the food had to be curtailed at midnight. The prospect of Anna having a second chance at a healthy life was all they cared about. Her condition, medullary cystic kidney disease, often leads to end stage renal disease. Anna's father, after undergoing three kidney transplants, died from the disease in 1991. But it gave Anna hope when she witnessed her younger sister, who has the same disease, go through a successful kidney transplant at Mayo Clinic.

The couple's church ties are strong, and through friends there, they were able to connect with a family close to Mayo Clinic Hospital that was willing to let them use their home during their recovery.

Anna and George credit Dr. Marek Mazur and Dr. Adyr Moss at Mayo for their combined successes in their evaluation and surgery, (“They were amazing,” Anna notes) as well as their strong faith. George was able to leave the hospital the day after surgery, and Anna, although admitting to soreness, said she felt better immediately when she awoke from the surgery.

And now, a number of months later, “We are both back at work and feel great,” confirms Anna.

Intermountain ESRD, Inc.

Network (Network #15) is a federally mandated, nonprofit Colorado corporation that contracts with the Centers for Medicare & Medicaid Services (CMS), to implement the ESRD Network program in its six-state area: Arizona, Colorado, Nevada, New Mexico, Utah, and Wyoming.

The mission of Network #15 is to facilitate the improvement of quality of care provided to ESRD patients. Network #15 is also charged with the collection and validation of information about, and treatment of persons with ESRD.

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