

WHILE YOU ARE WAITING

SPRING 2007; EDITION 2



Greetings and Happy Spring from the Transplant Office at the University of Wisconsin Hospital! We hope this finds each of you doing well. Our newsletter is published bi annually and is our way of saying 'hi' to all of our patients eagerly waiting for a kidney transplant. We hope that the information enclosed will enlighten you and help you cope with the stress that may be associated with waiting for your gift of life.

DID YOU KNOW?

- ❖ Keeping your weight in a reasonable range will decrease complications following transplant? Target your Body Mass Index (BMI) below 35 (at least!). Our physicians are continually monitoring this value and it may become LOWER in the future as more research is done on obesity and transplantation. Ask your physician to calculate your BMI or you can go to cdc.gov to calculate it yourself!
- ❖ When the Transplant Coordinator is notified that a kidney is available for you, we will have approximately ONE hour to find you? Make sure our office always has your current contact information.
- ❖ The UW Transplant Program is embarking on a new era in transplantation. On 8-17-06, the first live donor kidney transplant was performed with a blood type incompatible donor. It was, and continues to be, a huge success! If you have had an interested donor disqualified in the past, due to incompatible blood type, and you are interested in pursuing this option, please call your coordinator to further discuss.
- ❖ If you needed a stress test as part of your workup for listing, please call your coordinator to see if you need to repeat this test if you have not done so in over a year. Depending on your clinical situation, you MAY need to have this done annually and your pre-transplant coordinator can guide you.
- ❖ Annual medical updates are necessary to keep you current on our waiting list. Men over 40 years old should have annual PSA blood tests. Women over 40 years old need annual mammograms. Patients over 50 years old need a colonoscopy; so if you just turned 50, and you are on the waiting list without a CURRENT colonoscopy, please call your coordinator to discuss. **All patients** need annual physical reports faxed to our office. Lastly, all females, adolescent and older, need an annual pap smear.
- ❖ The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.

PLEASE REMEMBER....

- ❖ ...to check with your dialysis unit or physician's office to be sure the monthly blood sample is being drawn for our Transplant Center
- ❖to update your transplant coordinator with ANY changes in your address and/or phone numbers. We need to be able to reach you any time of the day or night.
- ❖to update our financial coordinator if you have had ANY changes in your insurance coverage.
- ❖ ... to call your transplant coordinator with changes in your health or if you are hospitalized.
- ❖ ...to have any medical information, such as tests, discharge summaries from hospitalizations, etc... faxed to your transplant coordinator
- ❖ ...to NEVER assume that your medical records are sent to the Transplant Coordinator when requested. ALWAYS make a follow up phone call to your transplant coordinator to assure records are transferred.
- ❖ ...if you receive a blood transfusion to be sure it is leukopoor (or filtered) blood to avoid developing antibodies.
- ❖ ...to notify your transplant coordinator if you have received a blood transfusion.
- ❖ ...if you have arranged a charter flight to bring you to our transplant center, please have all of that information handy for use 24 hours a day/7 days a week.



BE PREPARED FOR YOUR PHONE CALL FOR TRANSPLANT!

- ❖ What to remember to pack
 - ❖ Driving Directions
 - ❖ Loose fitting clothes (ie. Elastic waist pants/shorts, t-shirts)
 - ❖ Non-skid slippers or shoes with closed toes
 - ❖ Your **complete** medication list and pill bottles
 - ❖ Dialysis supplies to get through 24 hours if on Peritoneal Dialysis
 - ❖ Personal Toiletries
 - ❖ Your insurance cards
 - ❖ Phone card and/or cell phone
 - ❖ List of your physicians/health care providers/pharmacy and their phone numbers/addresses
- ❖ Keep your pager/cell phone on and charged at all times
- ❖ Keep in mind that at the time of discharge, depending on your insurance, you may need to pay for a one month supply of medication. Be prepared for this potential expense and think ahead about how you will pay for it.
- ❖ If you live a distance from our Transplant Center, have a plan in place for transportation that will be available to you at any time of the day or night.

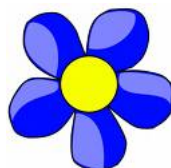
A NOTE FROM OUR SOCIAL WORKERS:

The Challenge is Living Your Life While Waiting for the Call

After you get on a transplant waiting list and before you get "the call" to come in for surgery, there's a bizarre limbo land of waiting. The transplant waiting list may run opposite to all the ways you've taken control of your illness and adapted to having it.

What DOES work if you begin to feel helpless? Here is a list of 12 ways you CAN take control while you are waiting for transplant. Remember, preparing for transplant is a marathon process rather than a sprint, so you decide over time which of these sounds useful or do-able. Sustaining the motivation for transplant over time takes creativity and commitment.

1. Stay in contact with us and make sure we can reach you.
2. Plan the details of what happens when you get the call.
3. Continue to do things you enjoy, and that make you YOU, apart from kidney disease. Making time for activities, friends, and joy helps manage stress, lower anxiety, and provides healthy distraction. Don't put your life on hold for transplant.
4. Learn your medications and work out a system to keep track of them.
5. Follow the current treatment recommendations by your healthcare team, and ask if you have questions about their advice.
6. Learn your insurance benefits—and we mean the details: caps, meds coverage, etc.
7. Have a plan for the cat/ baby/ grandma.
8. Make plans for your time away from work, what paperwork will need to be completed, and how you'll cope without that wage.
9. On the other hand, if you're disabled now, find out if you are likely to remain disabled after transplant. Take time to think about your own return-to-work goals, and to check out available re-training/ schooling.
10. Connect with folks who have had transplant: in person, or on-line.
11. Ask your doctor about exercise.
12. Watch out for symptoms of depression, stress, or addiction—and get treatment if these are problems for you.



IMPORTANT PHONE NUMBERS TO KEEP HANDY

(CUT HERE)

UNIVERSITY OF WISCONSIN HOSPITAL TRANSPLANT DEPARTMENT

MY COORDINATOR'S NAME _____

MY COORDINATOR'S PHONE NUMBER (608) _____

GENERAL TRANSPLANT OFFICE PHONE NUMBER 608-263-1384

TRANSPLANT OFFICE FAX NUMBER 608-262-5624

FINANCIAL COUNSELOR/INSURANCE QUESTIONS 608-263-1503

(CUT HERE)