

From: JD
Date: Sat, 2 Aug 2003 01:01:12 EDT
Subject: Donor Drama
To: jfreeman <at> toast <dot> net

Whoa.

I just had a new unexpected deep experience with humility.

I tell everyone to be an organ donor. I am one.

My husband received organs. Its a great idea, logically.

Everyone says to make sure you make your wishes known to your family.

Ken's been at Our Lady Of The Lake Physical Rehab hospital now for five days. I smoke so I get to visit with other smokers.

As you can imagine they are usually employees or folks with family members in the hospital. You get to know faces and medical situations long before you get to know names.

Friday I met a young girl, Lacy, who works here in MRI.

She has been diabetic for twenty years.

I told her and her fiancée about Ken's kp transplant [*Simultaneous kidney and pancreas transplant. -Ed*] and that he was diabetic for 25 years. They thought that you had to be at death's door to get a pancreas transplant.

That was true in the past and its also true that some insurance companies still consider a 'pancreas only' transplant as a way to manage diabetes an experimental treatment.

It's being done much more often now because insurance companies are discovering its cheaper to pay for a transplant than to pay for long term diabetes management and treatment for all the complications that develop from the disease. Ken and I had never heard of people getting pancreas transplants until his kidneys failed.

Lacy said she is very unhappy with her diabetes specialist and that she is having no success at regulating her sugars no matter what type of insulin therapy she tries. I told her she would probably be a very good candidate for a pancreas transplant. She's only 25 but has had to have three eyes surgeries due to diabetic retinopathy, the disease that caused Ken's blindness.

I told her I wished Ken and I had known of such treatment 10 years ago. I told her and her fiancée all about Tulane and how to get in touch with them.

I ran into her again this evening (its Tuesday). She told me that the Abdominal Transplant Center at Tulane is going to call her in five to ten days to schedule an evaluation.

Wow.

I never dreamed just a few words from me regarding our experience could potentially affect someone's life so dramatically. I know what that girl's life is like and I know what her life COULD be like.

THE OTHER SIDE

Sometime Monday evening two new girls showed up who obviously had a family member here in trouble. I chatted a little with them but found out their situation later from others who had talked with them.

Apparently their 54-year old Mom went to bed after a night of dancing and suddenly woke her husband up and said she couldn't breath. She was asthmatic and told her husband she needed a breathing treatment and to call 911 - that this was bad.

She lost consciousness before getting to the hospital in their small town. She was transferred here I think on Monday. They wanted to see if there was anything that could be done.

I started seeing these folks and their other family members Monday night and off an on all day Tuesday. I remember earlier the two girls trying to help get care and medications organized for their dad and aunt who Mom normally takes care of.

I told them I knew what a big job they had and I wished them luck.

I didn't realize at the time how serious a situation they were in.

Later I was so worried for these girls. Tuesday afternoon one of they girls told me they had lost their Mom. I heard one of them tell someone else that they found no brain activity and pronounced her at one o'clock. Now they had to start making decisions.

I told them I was so sorry.

I was thinking how close I had come to being in similar shoes a few months before. I went back to smoke two other times later in the day and in the evening and I still saw them there.

I thought to myself, *why are they still here?*

Why haven't they gone on to a funeral home?

Why are more family members showing up here at the hospital?

We sit on four wooden benches outside where we smoke that all face each other and make a cozy little box. At the beginning of my last smoke break, I was talking to Lacy and Jay (her fiancée) who were sitting on the bench to the left of me while the girls who lost their Mom were sitting on the bench directly across from Lacy on the bench to the right of me.

At the end of my smoke break is when I found out from the girls why they were still there.

During a quiet moment I asked one of the girls if they were getting everything organized. She told me they were pretty much organized now but they are donating the mom's organs.

Click.

That's why they had not left the hospital yet.

They have to wait until the doctors are finished harvesting before they can release the body back to the family to take back to their small town and prepare for a funeral.

I looked at the girl and put my hands together and told her that my husband had just received a kidney/pancreas transplant and I just kept telling her thank you.

Then I started crying and then she started crying and I went and hugged her and told her thank you again and then I hugged the other girl and told her thank you.

I'm still so moved.

These folks need to get on with funeral plans and the grief process but yet they have spent another half of a day in a place where their Mom passed away waiting for doctors to finish taking from her what she no longer needs.

THAT is bravery and I feel like a fool being around them.

I now have seen up close what a family has to go through to donate organs. I now know why they all say to make sure to let your family know your wishes about organ donation.

Its not just because they might say no if they are not sure of your wishes, its also because of what they will have to go through.

The joy will come for that family and ours someday but this is what we have to go through to get to it.

The world really is made up of circles.

Whew, I don't think I got just exactly what I'm feeling down in words here but I had to do the best I could to share.

The crying keeps coming. Sometimes its sadness and sometimes its joy at the capability for love that strangers can have for one another.

I ran into one of the girls much later in the evening and ask her if they had been told when they'd get to leave.

She said maybe around 4am.

I told her I had so much love for them and I'd be praying for them.

=====
An update on Ken, as of 05 August, 2003.

Ken was discharged from Our Lady of The Lake Rehab on July 31st, 2003.

After a check-up at the Tulane center, he and JD are back at home, working with a visiting rehab nurse, and trying to figure out what to do next.

=====
[Our Lady Of The Lake Physical Rehab hospital](#)

<http://www.ololrhc.com/cfapps/dsite/index.cfm?uid=olol&pid=2>

Our Lady of the Lake Regional Medical Center is the largest hospital in Louisiana, with 852 licensed beds. Together with its affiliated facilities, the Lake serves a 12-parish area centered in Baton Rouge and cares for more than 600,000 outpatients and inpatients each year. The hospital was established in 1923 by the Franciscan Missionaries of Our Lady, and is a member of the Franciscan Missionaries of Our Lady Health System Inc. Its main campus in Baton Rouge, La., occupies more than 100 acres with over one million square feet of building space.

[Abdominal Transplant Center at Tulane](#)

<http://www.tulanetransplant.com/>

The Tulane Center for Abdominal Transplant specializes in the treatment of all diseases involving the liver, pancreas, and kidneys; not just transplants. Our approach is individualized to ensure that each patient receives the best, most cutting-edge care tailored to their specific needs.

[Donate Life](#)

<http://www.kidney.org/general/dlmonth/index.cfm>

If you can't get it done today, it can wait until tomorrow. But for 80,000 Americans on the national waiting list for life-saving organ transplants, tomorrow may never come. According to the National Kidney Foundation, only one out of three on the waiting list will ever receive a transplant due to the critical shortage of organ donors in the U.S.

In fact, seventeen people die each day while waiting.

"One donor can save or improve up to 50 lives," says Brian J.G. Pereira, MD, president of the National Kidney Foundation. "At a time when a new name is added to the transplant waiting list every 13 minutes, we urge all Americans to think about organ donation – the gift of life. Donors also need to discuss this decision with their families, since family consent is required, in most states, at the time of donation."

[The National Kidney Foundation](#) is committed to the goal of increasing the availability of all organs for transplantation. For more information on organ donation or for a free donor card, call (800) 622-9010.

http://www.kidney.org/general/dlmonth/facts_glance.cfm

Kidney / Pancreas transplant:

<http://www.kidneytransplant.org/kidney-pancreastransplant>

Some clinical studies have shown that diabetic patients undergoing kidney transplantation alone have a lower graft survival when compared with diabetic patients undergoing kidney and pancreas transplant procedures together. It is customary in most centers to transplant both kidney and pancreas together from the same donor. Monitoring is then done for the rejection episodes of both organs via the kidney graft. Most patients enjoying a normal life away from dialysis and threat of hypoglycemic or hyperglycemic episodes.

The operative procedure takes approximately five to seven hours for both organs together, and most patients are hospitalized for two to three weeks. [*when there are no complications...--Ed.*] Pancreas-only transplantation is also considered in very selected cases where renal failure is not present but diabetes management is difficult, or where the patient is under threat of other severe complications, such as blindness. Selectivity is based on a graft survival rate of at least 15 to 20 percent below that of kidney/pancreas, though recent advances in this field have led to improved outcomes with pancreas-only transplants.

RESOURCES :

Some of the information was designed for the elderly, but all forms can and should be examined by everyone. You need to investigate what needs to be done to make your wishes known *and accepted* by your family, your state, and your medical providers.

While many states make it easy to sign an organ donor agreement on the back of a drivers license, most donor organizations recommend additional documentation that clearly states your intentions.

These were collected and published by the American Bar Association.

Caring Conversations Workbook, published by the Midwest Bioethics Center, 1021-1025 Jefferson Street, Kansas City, MO 64105-1329 (Tel. 816-221-1100). This is both a workbook and advance directive. It can be downloaded for free from their web site:

<http://www.midbio.org>

A comprehensive do-it-yourself workbook on planning for end-of-life care.

Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, by Robert Pearlman, *et al.* and the Veterans Administration Medical Center, Seattle, WA. A comprehensive do-it-yourself workbook on planning for end-of-life care. Order through the National Technical Information Service web site:

<http://www.ntis.gov>

Five Wishes Advance Directive. Published by Aging with Dignity. This nationally used and very popular advance directive focuses on ways of talking about health care wishes and needs. Can be purchased and downloaded from their web site:

<http://www.agingwithdignity.org>

Also available by mail order from P.O. Box 11180, Tallahassee, FL 32302-3180.

What To Do After Signing Your Health Care Advance Directive

Advance planning for health care is always a work in progress.

That's because circumstances change, and lives change. One's values and priorities even change.

As a sage remarked, *"The world looks different when you're horizontal rather than vertical."*

FIVE TIMES TO RE-EXAMINE YOUR DIRECTIVES.

1. Before each annual physical exam.
2. At the start of each decade of your life.
3. After any major life change – such as a birth in the family, marriage, divorce, re-marriage, and especially after the death of a loved one.
4. After any major medical change – such as being diagnosed with a serious disease or terminal illness. Or if such conditions worsen.
5. After losing your ability to live independently.

IF YOUR WISHES CHANGE...

Make a new advance directive if your old one no longer reflects your wishes.

Ask about the proper way to cancel or amend your existing directive in your state.

If you change your advance directive, it is important to notify everyone who has copies of your old medical directive forms.

WHAT TO DO WITH YOUR ADVANCE DIRECTIVE

1. Keep the original copy of your health care advance directive and these work sheets or other notes some place they can be easily found.
2. Give your chosen proxy a copy of the directive plus any worksheets or notes. Make sure your proxy knows where to find the original.
3. Give your doctor a copy of your directive. Make certain it is put in your medical record. Make sure your doctor will support your wishes. If your doctor has objections, you need to work them out or find another doctor.
4. Carry an advance directive wallet card with you.
5. If entering a hospital or nursing home, take a copy of your directive with you and ask that it be placed in your medical record.
6. Some organizations offer to register advance directives electronically and enable health care institutions to access them electronically. Some churches and synagogues keep advance directive on file for members. You may wish to consider such a service.

[American Bar Association,
Commission on Legal Problems of the Elderly](http://www.abanet.org/aging/)
<http://www.abanet.org/aging/>
Washington, DC