



Organ Transplant Ethics

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Wellspring
Transplant Support Center

*...to help you understand and face all
of the challenges and opportunities of
organ donation and transplantation.*

www.wellspringtransplantsupport.com

The background of the slide is a deep blue space scene. At the top, a large, glowing planet with a bright blue and white horizon is partially visible. In the center, a smaller, similar planet is shown. The background is filled with numerous small, bright blue stars and some faint, vertical light streaks.

Some Introductions

➤ You

➤ Me

➤ Organ Transplantation

➤ Ethics

You

Case Managers/ Nurses

Social Workers



A Little About Me

- ✓ Ordained Minister, Board Certified Chaplain
- ✓ Have worked in healthcare as a hospice chaplain, a CEO of a Community Health Center, and for over 20 years went from staff, to senior staff, to department director, to VP level at the same children's hospital.
- ✓ Responsible for Child Life, Music Therapy, Pastoral Care, Social Work Services, Patient Academic Services Departments, the Ethics and Organ Donation Programs.
- ✓ Community/State Advocacy for Children
- ✓ Enjoyed many opportunities such as this – hope to have a good time!

A Little More About Me

November, 2009

An In -
Shape 195
lbs..



The two
turkeys

April 24, 2010

135 lbs. and falling



It's My Anniversary!

Three Years Ago, at Right
About this Moment, I was
given the Gift of Life.

And Just a Little More Me

August 19, 2012

Later the same day



Ethics – Some Basics

- English Positivists in Medieval Times
 - Religious Ethics
- Illuminated Times 
 - Hobbes, the Father of Modern Ethics
 - Methods: criticism and comparison
 - English and German schools of ethics (different opinions)

Ethics

- Known History begins with Ancient Greek Philosophers
 - Sophists
 - Socrates
 - Socratic schools
 - Plato
 - Aristotle
 - Epicurus
 - Stoics

Ethics – The Theories

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- English
 - Intuitionists (naturalists)
 - Utilitarians
- German
 - Kantian Ethics

Bored Yet?

When I'm bored, I
send a text to a
random number
saying "I hid the
body... now what?"

Fun and not.

07

The Relevancy of Ethics

- **Morality** - our belief about right and wrong (usually subjective and unexamined).
- **Ethics** - (a) the study of principles for choosing right action when doing right may also involve doing harm or wrong; (b) the use of ethical theory to choose the best course of action; (c) the study of what is good and bad in human character and conduct

Shifting of Perspectives

When I was a student, I studied as a student, spoke as a student, and lived with my head in the academic sand like a student.

When I became a professional. I found that books are not the tools I used (well, see AMA “In the Hand”), theories are not people and, well, stuff happens.

Continuing the Evolution

When I became a patient, and that stuff is happening to me, it's a brand new ball game.

You know those care plan meetings I used to attend where we laughed about patients and families?

That probably went on with me.

Ethics is Real Life

Do I remember all those Ethics Consults I led over the years where we made value statements and decisions *about* people that would have serious impact on lives?

Problem was, people were doing that about ME! And they got to go home. I got to wait to hear about what *they* decided for my fate.

Doing Ethics

- Ethics is something we live every minute
- It is dynamic
- It needs to be unlocked from the halls of academia so it can be informed by everyday life.
- Ethics is something we do.
- Ethics helps to define who we are as a society and as individuals.

Some Ethical Principles

➤ The Principle of **Non-Maleficence**

- First, Do No Harm
- The Sanctity of Life

➤ The Principle of **Beneficence**

- Obligation to preserve life, restore health, relieve suffering and maintain function
- To do “good”
- Nonabandonment – obligation to provide ongoing care
- Conflict of interest – must not engage in activities that are not in patients best interest

Some Ethical Principles

- The Principle of **Autonomy**
 - Right to self-determination
 - Requires decision making capacity
 - Lack should be proven not assumed
 - Competence – legal determination
 - Liberty – freedom to influence course of life/treatment

One More

- The Principle of **Social Responsibility and Justice**
 - Actions are consistent, accountable and transparent
 - not to discriminate on age, sex, religion, race, position or rank
 - Allocation of medical resources must be fair and according to need
 - Medical decisions should not make decisions regarding individuals based upon societal needs

Really, this does get more EXCITING!



Organ Transplantation

A Little History

- 1954 living relating kidney transplant(Dr. Joseph Murray and Dr. David Hume Boston)
- 1962 cadaveric kidney transplant by (Dr. Joseph Murray and Dr. David Hume Boston)
- 1963 lung transplant (Dr. James Hardy Mississippi)
- 1967 liver transplant(Dr. Thomas Starzl Colorado) and heart transplant(Dr. Christiaan Barnard South Africa)
- 1981 heart/lung transplant(Dr. Norman Shumway California)
- 1983 FDA approves cyclosporin

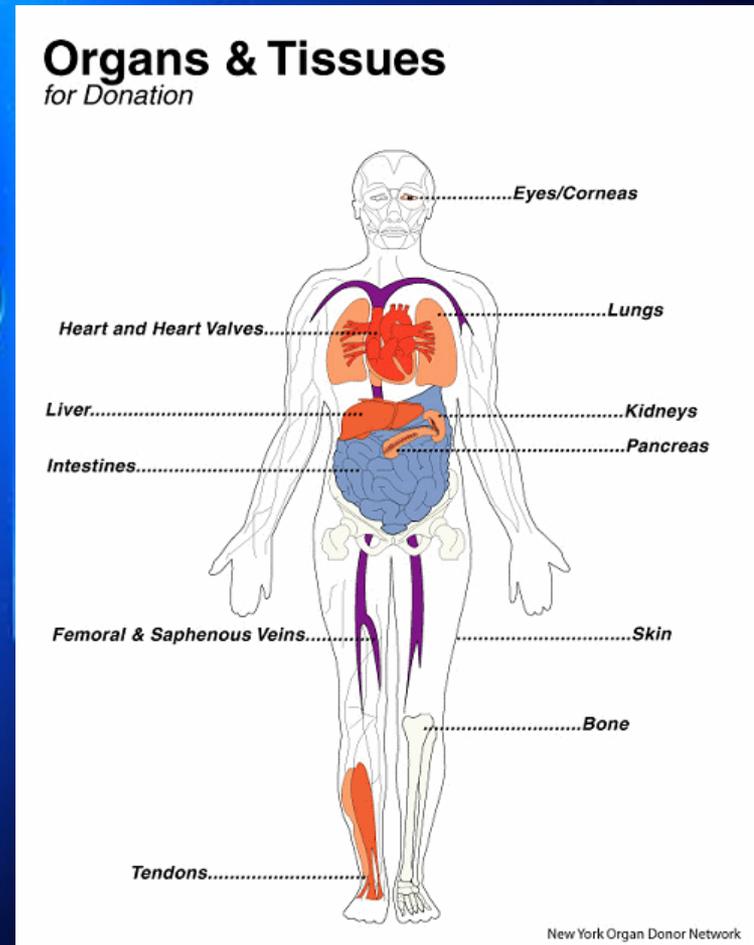
Organ Transplantation

A Little Data

- ❑ As of April 19th, 2013 there were **117,963** candidates for transplant on the waiting list.
- ❑ As of April 19th, 2013 there had been **1,150** organ donors year to date.
- ❑ Over **100 MILLION** Americans are currently registered as organ donors.
- ❑ As of April 19th, 2013 **580** have died year to date living on the waiting list.

WHAT ORGANS AND TISSUE WE CAN DONATE

- One person can help 50 people
- There is no age limit
- All major faith groups/religions endorse
- Traditional funerals can still be had
- Communication the key



And the List Continues



➤ Bone Marrow

➤ Cord Blood

➤ Placenta

➤ And the Easiest of All: Blood

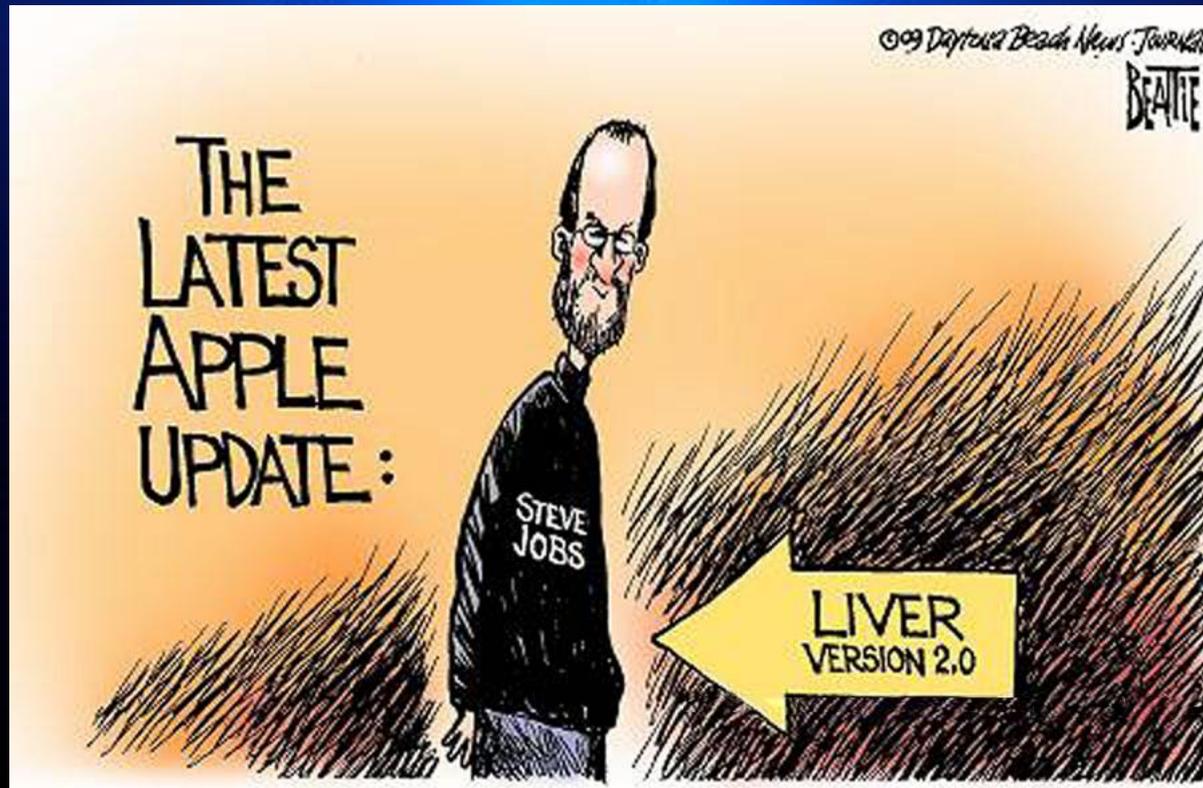
Who Decides?

- Organ allocation in the US is governed by federal law and regulation under the **US DHHS**
OPOs have exclusive, defined service areas
Central to these requirements is the stipulation that that allocation be based on *medical criteria*, as opposed to social criteria (social worth or wealth).

Equitable Organ Allocation

- Maximize the number of organs available for transplantation
- Maximize patient and organ survival, including maximizing the number of life-years gained
- Minimize the number of deaths while waiting for a transplant
- Minimize disparities in the opportunity to receive a transplant among similarly situated transplant candidates

Does This Work?



Some Wonder

UNet

- A secure internet-based transplant information database
 - Created by UNOS for organ transplant centers and OPOs
- Register patients for transplants, match donated organs to transplant patients, and manage the critical data of all patients
- Computer network is accessible 24/7.

Type of Donors

➤ Deceased

- These are donors who have been declared **brain-dead** and have indicated that they wish to donate their organs
 - organs are kept viable (alive) by ventilators or other mechanical mechanisms

Types of Donors

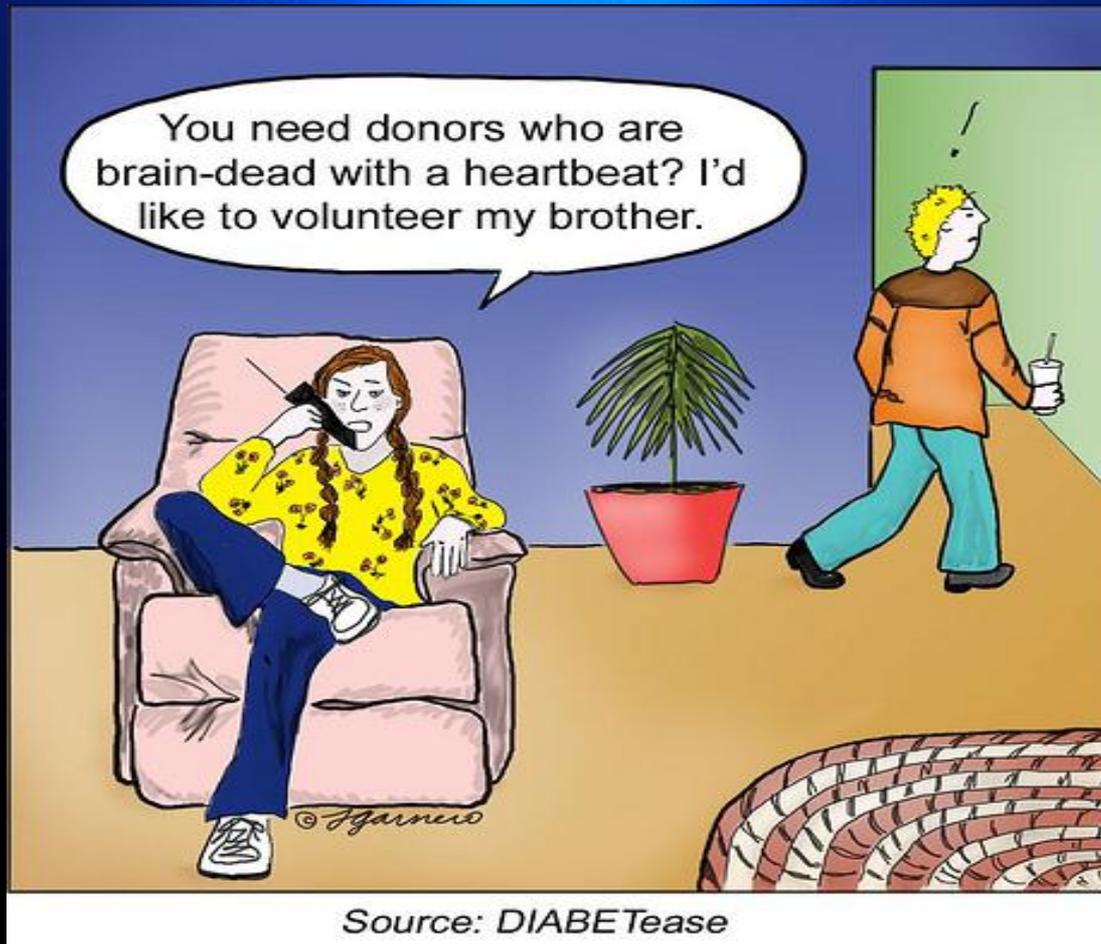
➤ Living Donor

- donates an organ or part of an organ in which the remaining organ can regenerate or take on the workload of the rest of the organ
- e.g. primarily single kidney donation, partial donation of liver, and, of course, blood!

Types of Donors

- Donation after Cardiac Death
 - Organ donation can occur after cardiac death.
 - Patient Is **not** declared brain dead, but is declared prior to organ/tissue procurement
 - The patient has a non-recoverable illness or injury and has suffered neurological devastation.
 - Family / Patient is considering withdrawing treatment

The Process of Donation



The Process of Donation

- Where the process of organ donation **should** begin is before the subject ever becomes more than something we really don't want to think about.
 - *Education and Awareness should begin early*
 - *Communication is key*
 - *No one wants to die – but no one can make decisions for themselves after they do.*

The Principle of Autonomy and Informed Consent

- The First Step in the Donation Process: Informed Consent
 - Just because your driver's license states you are an organ donor, that doesn't mean that you will be one.
 - If you become eligible to be considered as an organ donor, you are, by definition, unable to express your wishes.
 - And the decision to proceed goes to...your family.

The Principle of Autonomy and Informed Consent

- Most of these decisions have to be made at a less than optimal time.
 - A family is losing someone they love.
 - I often have told families that if there is ever a time to be selfish, this is it.
 - BUT, if you step out of that for a moment, do you know your loved one's thoughts about organ donation?
 - If not, license or not, if they are not comfortable, there will be no donation.

The Principle of Autonomy and Informed Consent

- Should something be done? The number of donors does not come close to meeting the need.
- Currently, donation is just that – a freely given gift by an individual that is not coerced, but is given out of a sense of *altruism*.
- But the concept of true altruism cannot be legislated – or can it?

The Principle of Autonomy and Informed Consent

- Required Request – 1984 Patient Self-Determination Act
- Mandatory Registration
 - You would be required through some government function to say yes or no to donation – legally binding
- Presumed Consent
 - It is presumed that unless you have declared in writing to the contrary, that you will be a donor.

How About Incentivizing?

- We can sell our blood, why not get paid for donating bone marrow?
- Or, with living donation, how about a price tag put on a kidney, or a portion of a liver or lung?
- Or, if a family is put in the position of “donating” how about we pay funeral expenses or just give them a cash payment in “honor” of their loved one?

Altruism v. Utilitarianism; Is an organ or tissue a gift or a commodity?



And On The Recipient Side

- Hearing the words “your only hope is an organ transplant.”
- Then, when you find your head and tongue, you ask “so what do we need to do”?
- You hear: “First, we have to see if you are eligible.”

What is Eligible? Haven't We Earned It?



The COMMITTEE – The Home of Beneficence

- The Patient
 - Current Health Status
 - Current Psychological Status
 - Support System
 - Medical History
 - Potential Barriers to Success
 - Age
 - Potential to Benefit vs. the Risk
 - Financing

The Committee – The Front Line Against Non-Maleficence

- Would the transplant process actually benefit the patient?
- Is the patient capable of optimizing her/his opportunity?
- Will the community at large benefit from the patient getting this opportunity?
- Are we doing the right thing – for the patient, for the donor, for the community?

The COMMITTEE

- Lot's To Think About
- Lot's of Information to Sort Out
- Responsible for the allocation of very scarce resources.
- I've served, and even chaired, those committees – it's not an easy job.
- But the harder job is given to the patient and family who await the literal decision for their life...or death.

You Think of All the What Ifs

What if my insurance won't cover everything?



Your insurance only covered the removal of the damaged organ...you'll have to put the transplant in yourself!

What if I don't Pass the Socially Deserving Test



What if?

**The Dr. Said this was the Biggest
Operation that Can Be Done**



There Are So Few Organs



The Ethics of Hope

Andy's Story

- 58 Y.O. With End stage Cirrhosis
- Primary Physician Made Hospice Referral
- Liver Transplant Physician Wanted to Keep in on Waiting List
- Andy Wanted Both
- He Couldn't Have Both

Who Determines When Hope Dies?

A human being can live for
40 days without water
8 minutes without air
But not even 1 second
without hope....

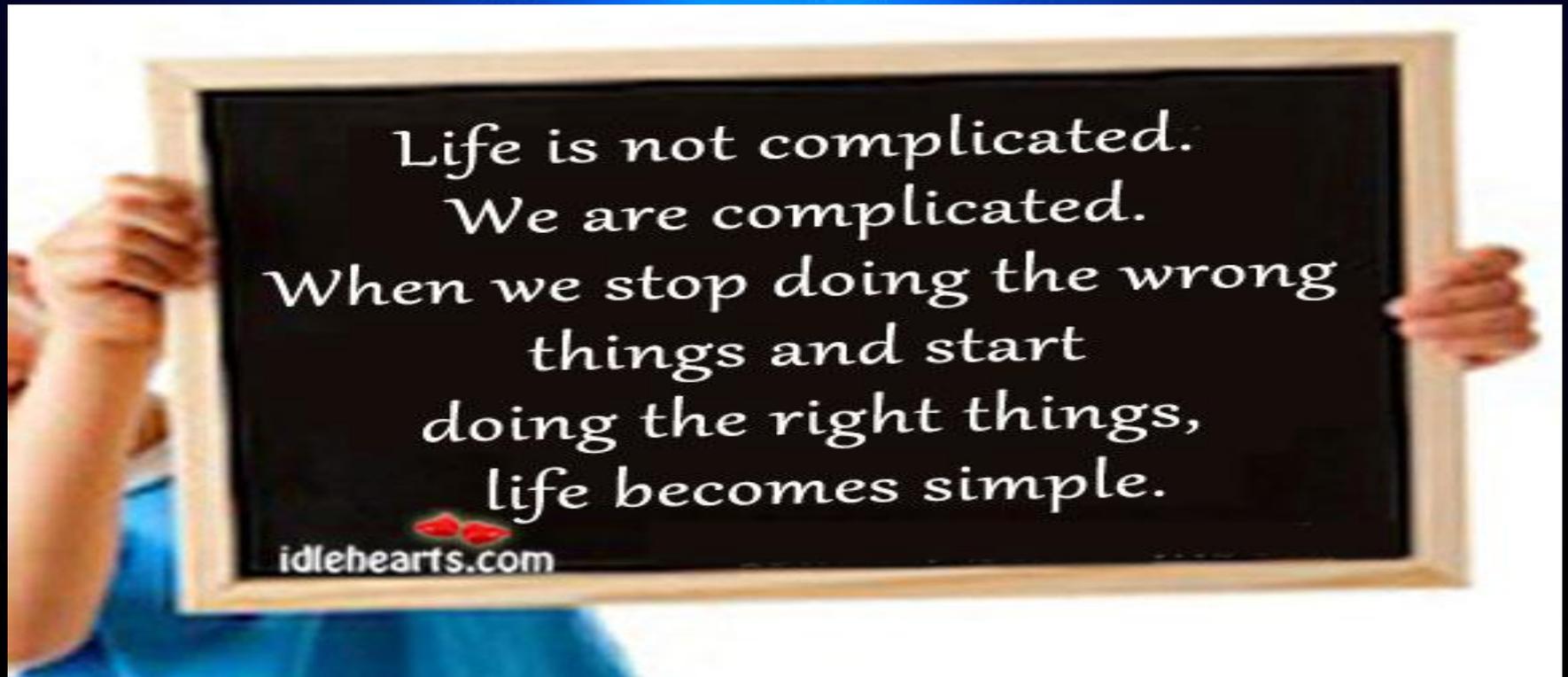
Case Study

- The patient is a two year old who has survived three cardiac surgeries and multiple interventions.
- She is currently in foster care, her mom has a personal history with drug abuse and a sketchy compliance history with the child's care.
- The patient will certainly die without the a heart transplant.

Case Study

- Transportation could be a problem.
- Finances are a problem.
- Safe living situation is a challenge.
- The mom, as reported by the state, has taken some steps to get her life together.
- A grandmother has come into the picture to help.
- Do we list this patient?

Sum It Up



Easy for them to say!!

Some Thoughts

- Organ Donation/Transplantation & Autonomy
 - Who decides who is going to be a donor?
 - Who decides who is going to be a recipient (or not)
 - How much should lifestyle, impact on society, and individualism be considered?
 - Should \$\$\$ always have to be involved?

More Thoughts

- Organ Donation/Transplantation and Beneficence
 - Should living donors be paid?
 - Should deceased donor families be compensated?
 - Are we obligated to preserve life, restore health, relieve suffering and maintain function in every case?
 - Nonabandonment – obligation to provide ongoing care
 - What about changes in finances, jobs, insurance
 - Conflict of interest – must not engage in activities that are not in patients best interest

More Thoughts

- Organ Donation/Transplantation and Non-Maleficence
 - First, Do No Harm
 - Is taking a healthy organ from a living donor doing harm?
 - Is coercing a family into organ donation doing emotional harm
 - The Sanctity of Life
 - Sometimes the equation of death = life is hard to understand.

More Thoughts

- Organ Donation/Transplantation and Social Responsibility and Justice
 - Presumed Consent? 
 - Should condemned prisoners be obligated to be donors.
 - Should any kind of prisoner be obligated to be donors.
 - Is the current allocation system just?

One More

- Organ Donation/Transplantation and the Ethics of Hope
 - Should organ transplantation even be brought up before a potential recipient has been evaluated to be listed?
 - With DCD deaths, what happens if the heart does not stop beating within the allotted time frame? Do we re-intubate, resuscitate?
 - Who's to say there is no hope?

Resources

- A Case Management Journey Through Liver Transplantation

By Mary Beth Newman, MSN, RN-BC, A-CCC, CMAC, CCP, MEP, CCM, and Cristina Walter, MSN, RN-BC, CCM, CCP

– http://www.dorlandhealth.com/social_work/clinical/A-Case-Management-Journey-Through-Liver-Transplantation_806.html

Resources

- **The Courage to Fail: A Social View of Organ Transplants and Dialysis (Google eBook)**
- **Psychological aspects of organ donation: A critical review and synthesis of individual and next-of-kin donation decisions. Radecki, Carmen M.; Jaccard, James Health Psychology, Vol 16(2), Mar 1997, 183-195**

Resources

- <http://organdonor.gov/materialsresources/>
- Financial Matters: 
<http://www.transplantliving.org/before-the-transplant/financing-a-transplant/directory/>
- www.wellspringtransplantsupport.com



DONATE



LIFE

®