

To the Workshop Participant

The Initiative on Islam and Medicine (II&M), the National Kidney Foundation Illinois and Gift of Hope, thank you for your participation in our workshops.

Our gathering seeks *to live out the Qur'anic imperatives to gain knowledge and petition God to increase us in knowledge, and to live out the Prophetic directive to seek knowledge that benefits ourselves and others*. Our aim in this project is to improve knowledge about organ donation within the Muslim community. By filling in knowledge gaps and dispelling myths, we will empower individuals to make informed decisions, ones that align with their values and ideals.

During the workshop, *you will acquire knowledge on living organ donation*. You will come to understand key ethical constructs and concepts of Islam, acquire knowledge on the biomedical and religious aspects of organ donation, and discuss these materials with community members. At the end of this workshop, you will Insha'Allah be able to navigate complex medical decisions with members of your family and community.

We thank you again for being a part of these workshops. If you have any questions or concerns, please contact name at email@gmail.com or call 555-555-5555.

Acknowledgements

This project is funded by the Health Resources and Services Administration (Grant Number R39OT31104), and represents a collaboration between the University of Chicago (primarily through its Initiative on Islam and Medicine) and the National Kidney Foundation Illinois and Gift of Hope. We thank the International Institute of Islamic Thought, the Islamic Society of North America, and the Islamic Medical Association of North America for convening educational forums that seeded this collaboration. This project's success will result from the many efforts of the community advisory board (CAB) members, mosque leaders, community volunteers, and peer educators. We are grateful for their commitment, support and perseverance.



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Organ Donation

AGENDA

8.30 – 8.45

Registration, Breakfast

8.45 – 8.55

Welcome, Survey explanation

8.55 – 9.30

Pre-Survey Assessment

9.30 – 10.10

Biomedical Aspects of Living Organ Donation

Dr. Saunders

10.10 – 10.40

Organ Transplant in the U.S.

Megan Craig

10.40 – 10.55

Coffee/Tea

10.55 – 11.50

Islamic Perspectives on Living Organ Donation

Dr. Padela

11.50 – 12.45

Facilitated Group Discussions

Peer Educators

12.45 – 13.15

Post-Survey Assessment, gift cards

13.15

Dhuhr Prayer & Lunch

ORGAN DONATION WORKSHOP SPEAKERS



Dr. Aasim I. Padela - “Islamic Perspectives on Living Organ Donation”

Dr. Padela is the director of the Initiative on Islam and Medicine, associate professor of medicine at the University of Chicago and faculty at the MacLean Center for Clinical Medical Ethics and the Divinity School. He is dually-trained in medicine and in Islam. His scholarship focuses on the intersection of community health and religion, and he has extensive experience in community-based, health education research and in conducting Islamic bioethics workshops. In his talk he will explore the different religious perspectives on living organ donation and their underlying concepts.



Dr. Milda Saunders - “Biomedical Aspects of Living Organ Donation”

Dr. Saunders is an assistant professor of medicine at the University of Chicago, and faculty at the MacLean Center for Clinical Medical Ethics. She serves as the living donor advocate physician for the University’s Transplant Center and has carried out extensive research and teaching related to organ donation and transplant ethics. Her presentation will address the medical aspects of living organ donation and she will discuss both the benefits and risks of transplantation.



Megan Craig - “Organ Transplant in the U.S.”

Megan Craig is the director of programs at the National Kidney Foundation of Illinois. She became involved with the foundation after donating a kidney in 2011, and left her former career as a journalist to run patient and professional programs for NKFI. Her talk will provide an overview of the procedural aspects of organ donation, both living and deceased, in the United States.

PROJECT PEER EDUCATORS

Moussa Abdelhak • Raed Aluofi • Mubashira Aziz • Anam El-Jabali • Mariam Eldeib • Masood Iqbal • Saleha Jabeen • Taher Kehil • Mushtaq Merchant • Afroz Rafi • Nancy Romancheck

BIOMEDICAL ASPECTS OF LIVING DONATION

Milda Saunders, MD, MPH
Living Donor Advocate Physician
MacLean Center for Clinical Medical Ethics
Assistant Professor of Medicine

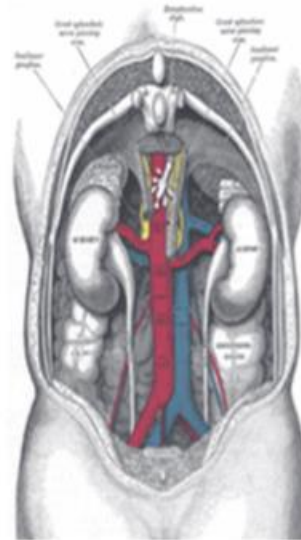
Learning Objectives

- To understand the need for living donors in the US
- To understand the benefits of living donation
- To understand the risks of living donation
- To understand the process of evaluation, selection and recovery for living donors

What do the kidneys do?

The kidneys do many things that keep you healthy, including:

- make urine to remove waste from body
- help make red blood cells
- keep blood pressure at normal level
- keep your body acid in a healthy range
- regulate minerals in your blood like potassium, sodium, chloride, calcium, phosphorus; and
- control how much water is in your body



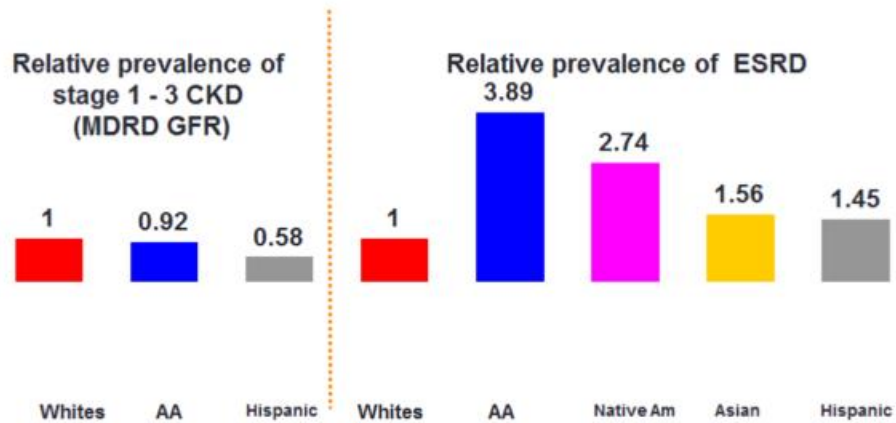
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Kidney Disease in the US

- Chronic kidney disease (CKD) is loss of kidney function that happens over months to years
 - 48 million people in US have CKD
 - Most commonly caused by diabetes or high blood pressure
- End stage renal disease (ESRD) occurs when person's kidneys stop working and they need dialysis or a kidney transplant to maintain life
 - 700,00 have treated ESRD in United States
 - Poor survival and quality of life
- Muslim Americans are at higher for kidney disease
 - Arab Americans have greater risk of high blood pressure
 - South Asian Americans have a greater risk for diabetes
 - African Americans have a greater risk for diabetes and high blood pressure

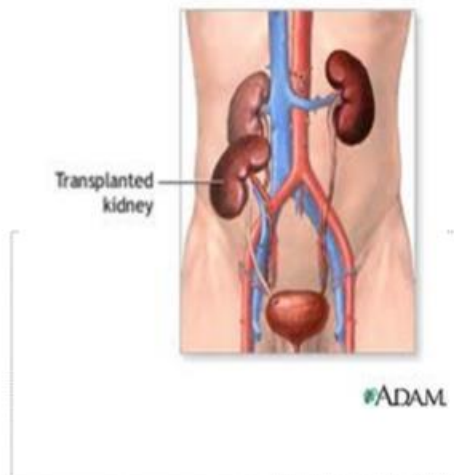
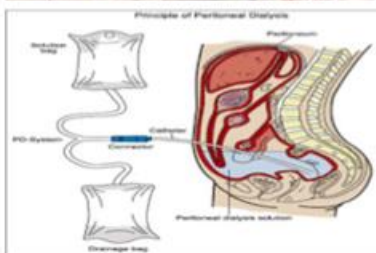
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Higher Prevalence of ESRD in Minorities



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What are the different ways to treat ESRD?



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Why Is Organ Donation Important?

- In the US, there are approximately 84,000 people waiting for a kidney transplant
- Locally, there are more than 4000 people waiting for a transplant
 - The majority of those (85%) are waiting for a kidney

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Why living donation?

- Living donor kidney transplants work better, have fewer complications and last longer than deceased donor kidney transplants (18 v 12 years)
- Reduces or eliminates time on the dialysis and waitlist
 - Over 90,000 individuals on transplant waitlist
 - Wait up to 5 years in some regions of US (Chicago 4-6 years)
- Approximately one-half (45%) of transplanted kidneys are from living donors

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Who can be a living donor?

- Living donors must be over 18 (and usually under 70)
- Must able to make an informed and voluntary decision
 - Can understand risk and benefits
 - Not receiving money or other “material consideration”
 - Not pressured to agree
- Generally must have good physical and emotional health
 - Without significant high blood pressure (controlled on 1 med) or heart disease
 - No diabetes, cancer, kidney disease, or infection
 - No current drug or alcohol abuse or uncontrolled depression, anxiety or other psych issue
 - Not obese (usually overweight is fine)

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Living Kidney Donor “Costs”

- Multiple Visits to Medical Center pre and post-donation (2 year follow-up)
- Recovery 4-12 weeks
 - 1-2 days in hospital
 - 2-4 weeks off work; up to 3 months for strenuous job or hobby
 - Missed work and family care
- Avoid pregnancy for 1 year post-donation
- Pain after surgery, usually require meds for up to a week
- Up to \$3,000 in lost wages, travel, expenses

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Living Kidney Donor Benefits

- The donor evaluation and surgery is paid for by the recipients insurance
- Donors can use paid medical leave (if available) or unpaid FMLA (if eligible)
- In Illinois, state employees are eligible for 30 days of paid leave for organ or bone marrow donation (5 ILCS 327 Organ Donor Leave Act)

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Donor and Recipient Matching

- First step is a blood test to determine if you are compatible or a “match” to a potential recipient
- Three tests that are done to evaluate donors: blood type, crossmatch, and HLA testing

Types of Living Kidney Donation



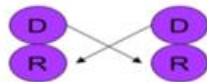
- Related (Directed)—Give to a family member
- Unrelated (Directed)—Give to a specific person usually friend or spouse
- Unrelated (Non-Directed)—Give to whoever needs it needs it (anonymous)

Types of Living Kidney Donation



Traditional Paired Exchange

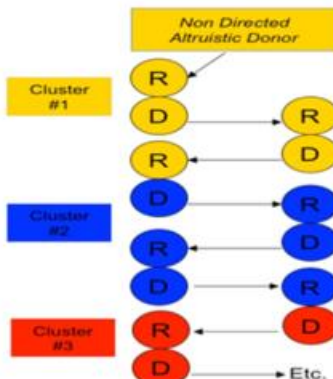
Two Pair Exchange



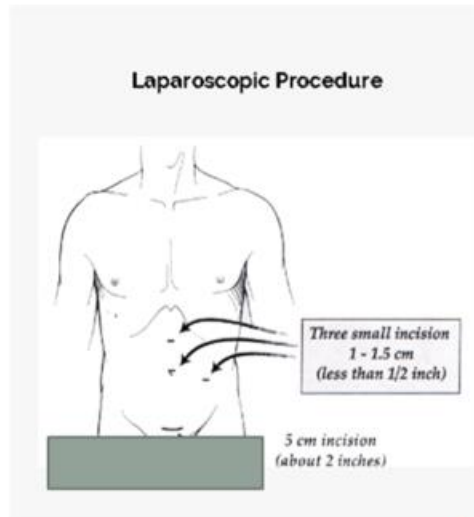
Three Pair Exchange



Chains



Laparoscopic Donor Nephrectomy



- Three small incisions and larger incision to remove the kidney
- Shorter recovery time, less post-op pain

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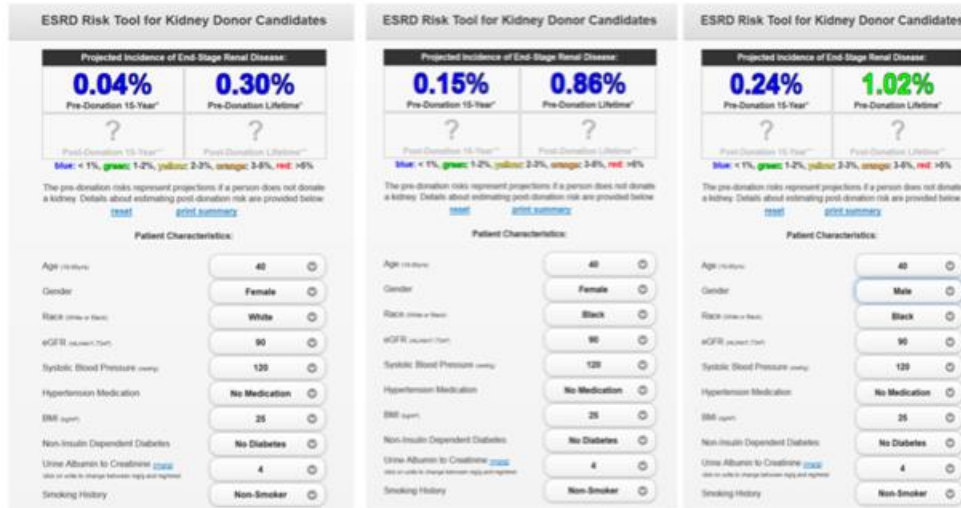
Short and Long-term outcomes

- Studies show that donation is safe in the short-term
 - Major Complications 0.2-1% (from 2/1000 to 1/100)
 - Mortality 0.03% (approx 3/10,000)
- Long term donors are at increased risk for...
 - ESRD (5-10x compared to non-donors)
 - Pre-eclampsia (2x compared to non-donors)
 - Gestational Hypertension (2x compared to non-donors)
- But overall risks long-term are still low
 - ESRD risks (0.12-0.96% over 15 years)
 - Pre-eclampsia (5.7%)
 - Gestational Hypertension (5.5%)
- If living donors develop ESRD later in life, they are given priority points on the transplant waitlist

UNOS data: <http://opn.transplant.hrsa.gov/latestData/volData.asp>
Matas, et al. AJT 2003
Johnson, EM Clinical Transplantation, 1997
Ibrahim, N. AJT 2009

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Living donation increases risk of ESRD



<http://www.transplantmodels.com/esrdrisk/>

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Myths & Misconceptions

- I'm too old or too sick to donate
- I heard that people sell organs on the black market
- My religion does not support donation
- The medical team is just looking out for the person with kidney disease
- I won't be able to go back to my regular life after donation

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How do I start the process?

- If a friend or family member has advanced CKD or ESRD, contact the transplant center where they are being evaluated
- If you are interested in non-directed donation, contact the National Kidney Registry
https://www.kidneyregistry.org/contact_us.php
- Find out more :
 - UNOS <https://unos.org/donation/living-donation/>
 - NKF <https://www.kidney.org/transplantation/livingdonors>

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Conclusion

- The primary goal is to prevent ESRD through healthy lifestyle, disease prevention and disease control (diabetes and hypertension)
- We can all be deceased donors and talk about our choice with family and friends
- Living donation is a wonderful thing to consider
 - Understand the risks and benefits and costs, and make the best choice for you
 - Can also help inform/support someone else

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The Organ Procurement Process

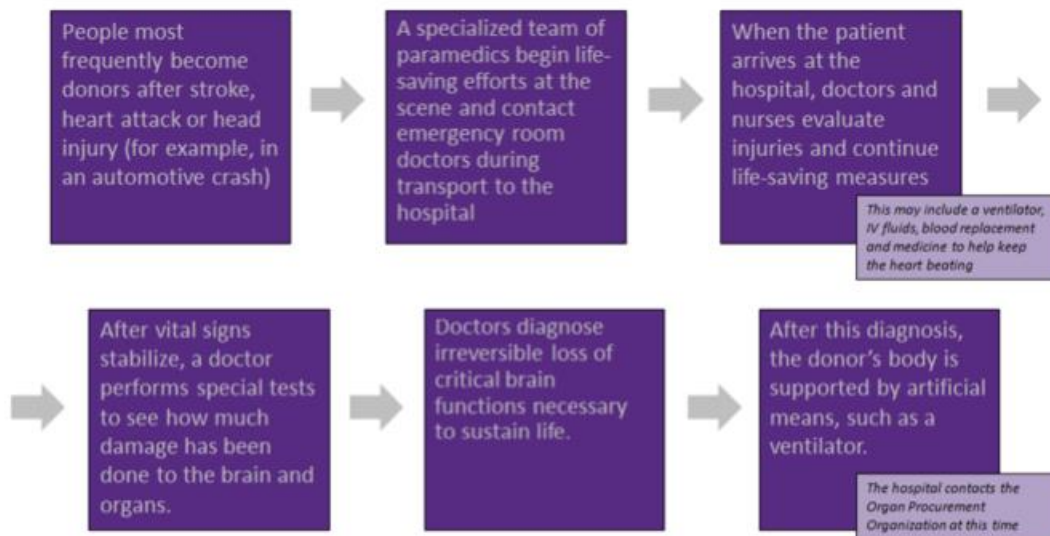


What is an Organ Procurement Organization?

- By federal law, Organ Procurement Organizations (OPOs) are the only organizations that can recover organs from deceased donors for transplantation.
- National Organ Transplant Act (1984) created national Organ Procurement and Transplantation Network (OPTN) for matching available donor organs to waiting organ recipients.
- OPTN standardized process through which organs are donated and shared across the country and created the system of federally designated OPOs.
- There currently are 58 OPOs in the United States.
- All OPOs are regulated by multiple government agencies and adhere to the highest medical and ethical standards.



The Donation Process: Before an OPO is Contacted

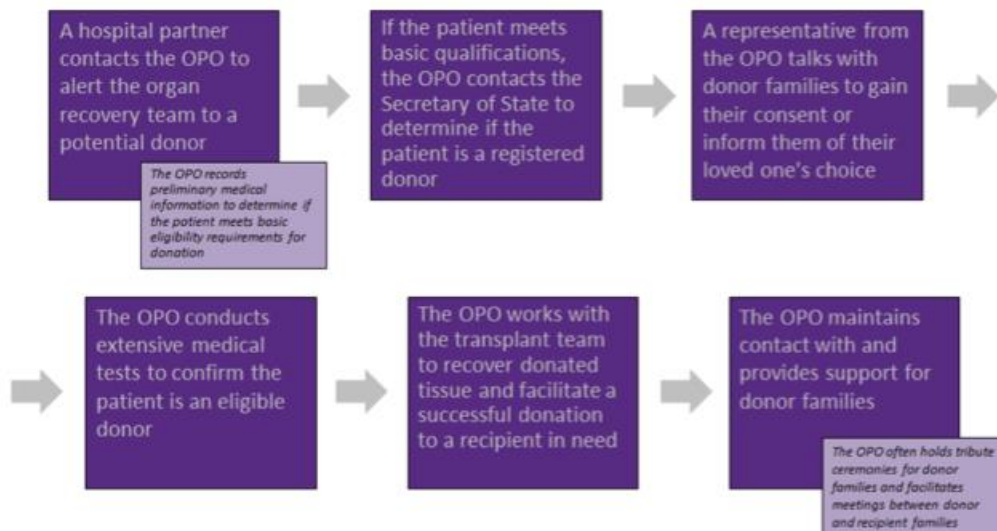


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The Donation Process: Non-Directed Deceased Donors

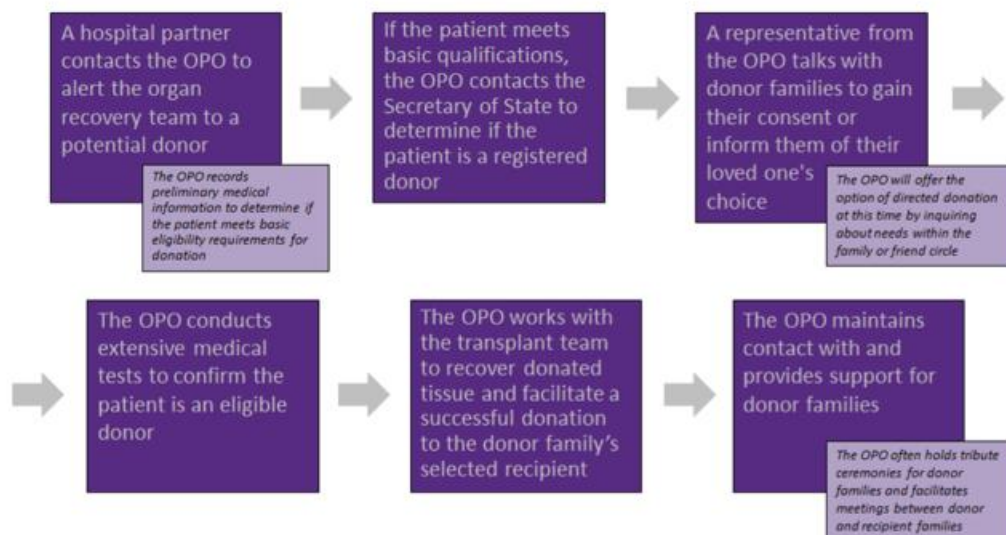


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The Donation Process: Directed Deceased Donors



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How Consent for Donation Works

Laws governing donation consent vary from state to state.

In states with laws allowing **first-person consent**, a donor's autonomous decision is final. In this case, individuals have the right to make legally binding decisions prior to their deaths, meaning permission from the donor's family or next of kin is not needed by the OPO. In this case, technically even if a family objects, the donor's decision should be honored. Most states allow first-person consent. To give consent, a person must register with his or her state organ/tissue donor registry.

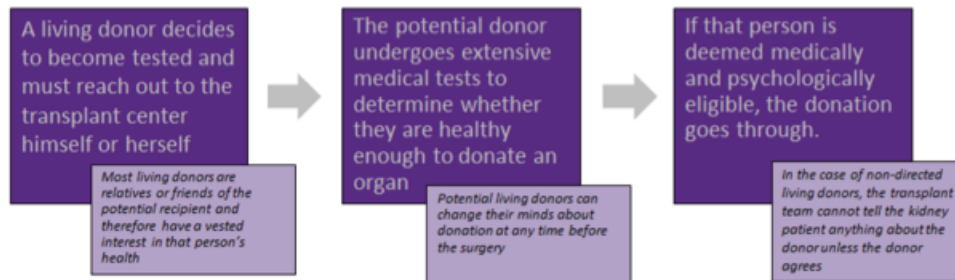
In case someone hasn't joined the first-person registry before death, family consent is still required. Family consent also always is required in the few states that don't offer first-person consent.

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The Donation Process: Living Donors

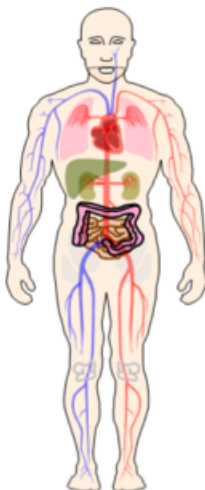


Note: The Organ Procurement Organization is not involved in living donor transplants.



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What Organs Can Be Donated?



Organ	Deceased Donor	Living Donor
Heart	Yes	No
Lungs	Yes	Yes (Partial)
Liver	Yes	Yes (Partial)
Pancreas	Yes	No
Kidneys	Yes	Yes (1 Kidney)
Intestine	Yes	No



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Vascularized Composite Allografts

A groundbreaking form of therapy known as Vascularized Composite Allografts (VCAs) returns vital function and identity to people who have suffered devastating injury or illness.

VCAs involve the transplantation of multiple structures that may include skin, bone, muscles, blood vessels, nerves and connective tissue – for example, face transplants, hand transplants or uterine transplants.

VCA requires a specific authorization, separate from a standard donor registration. Authorization for VCA is never assumed as part of a registration to be an organ, eye and tissue donor. VCA authorization must be specifically stated by an individual on his/her donor registration or by the legal next-of-kin if authorizing the donation at the time of death.



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How Organs Are Matched

UNOS (United Network for Organ Sharing) is the keeper of the national list of people waiting for organs. UNOS matches donated organs with transplant candidates in ways that save as many lives as possible and provide transplant recipients with the best possible chance of long-term survival.

The matching criteria developed by the transplant community, is programmed into UNOS' computer matching system. Only medical and logistical factors are used in organ matching. **Personal or social characteristics such as celebrity status, income or insurance coverage play no role in transplant priority.**



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The Waiting List

114,322*

people need a lifesaving organ transplant (total waiting list candidates) in the US.



14,543*

donors have allowed for

30,415*

transplants in the United States this year

20

people die every day waiting for an organ in the United States

*Based on OPTN data as of December 6, 2018

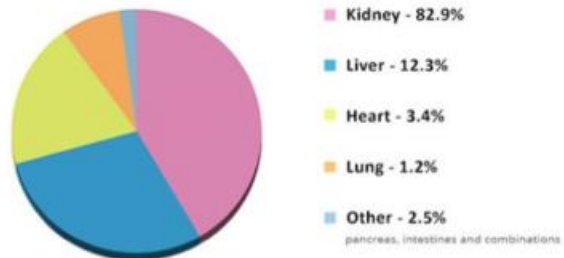


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What Organs are needed the most?

Kidneys are the most needed of all organs. Out of all Americans currently on the waiting list for a lifesaving organ transplant, more than 100,000 need a kidney, but only 17,000 people receive one each year. Every day 12 people die waiting for a kidney.

Organs People Are Waiting For (7/2017)



Total is more than 100% due to patients included in multiple categories.

African Americans and Hispanic Americans make up the majority of people waiting for a kidney, due to chronic illness like Diabetes and High Blood Pressure.



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Who receives an organ?

Potential recipients determined by:

Blood Type:	Must be compatible
Size:	Height, weight compatible
Geography:	Time between recovery & transplant
Urgency:	Heart, liver, lung candidates
Time Waiting:	Kidney candidates



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Common Myths and Misconceptions

Myth	Fact
If they see I'm registered to be a donor, the hospital staff won't try to save my life.	The only priority of the hospital staff is to save your life. Donation is impossible until all lifesaving methods have failed.
My family won't be able to have an open-casket funeral if I'm a donor because my body will be harmed and disfigured.	Through the entire donation process, the body is treated with care, respect and dignity. An open casket funeral is possible for organ, eye and tissue donors.
My family will have to pay for the donation.	There is no cost to donors or their families for organ or tissue donation. Costs are assumed by the recipient or the recipient's health insurance.
If I'm in a coma, they could take my organs.	Comas and brain death are not the same. People can recover from comas, but not from brain death. Brain death is required before donation can be considered.
Somebody could sell my organs on the Black Market.	Federal law prohibits buying and selling organs in the U.S. Violators are punished with prison sentences and fines.



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ISLAMIC PERSPECTIVES ON LIVING ORGAN DONATION

AASIM I. PADELA, MD MSC



LEARNING OBJECTIVES

OBJECTIVE 1:

To understand relevant legal and theological concepts relating to living organ donation

OBJECTIVE 2:

To be aware of the different Islamic rulings on living organ donation

OBJECTIVE 3:

To be able to navigate the reasons in favor and against living organ donation from an Islamic perspective

SUHAILA NEEDS A KIDNEY

Suhaila:

- 37 year old female
- Married with 3 children
- Diabetes type 1
- Kidney Failure

Suhaila's doctor informs her she needs a kidney transplant



Sharif:

- 30 year old male
- Married with 1 child
- No medical history

Sharif is Suhaila's only sibling:

Can he donate his kidney?



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AGENDA

PART 1: Introduction to relevant legal and theological concepts

- Human dignity (*ḥurma* and *karāma*)
- Dire necessity (*ḍarūra*)
- Public interest (*maṣlaḥa*)

PART 2: Introduction to *fatawa* on living organ donation and their conditions for permissibility

- Fatwa 1: Late grand mufti of Pakistan, Muhammad Shafi'i (1966)
- Fatwa 2: Islamic Fiqh Academy of India (1989)
- Fatwa 3: Islamic Fiqh Assembly Muslim World League (1985)
- Fatwa 4: Fatwa Council of North America (2018)
- Fatwa 5: Ayatullah Nuri Hamedani

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PART I: RULINGS ON ORGAN DONATION

Three broad positions¹:

- ◆ Organ donation is impermissible, because it violates human dignity (*ḥurma* and *karāma*)
- ◆ Organ donation is impermissible in principle, but is conditionally permitted on the basis of dire necessity (*ḍarūra*)
- ◆ Organ donation is permissible with several stipulations, because it serves general public interest (*maṣlaḥa*)

PART I: **Rulings** – Human Dignity – Dire Necessity – Public Interest || PART II: Fatawa – Conditions

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HUMAN DIGNITY

■ There are two theological constructs that together form an Islamic conceptual analogue to human dignity³:

1. Sanctity of the human body: *karāma*
2. Inviolability of the human body: *ḥurma*

PART I: **Rulings** – **Human Dignity** – Dire Necessity – Public Interest || PART II: Fatawa – Conditions

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HUMAN DIGNITY

1. Sanctity (*karāmah*)

- Arabic root: honor
- Special status of human kind above all of God's creation
- Shared in equal measure by every individual
- Positive rights

"We have honoured (karamna) the sons of Adam.. And conferred on them special favours, above a great part of our creation" - [17:70]

PART I: Rulings – **Human Dignity** – Dire Necessity – Public Interest || PART II: Fatawa – Conditions

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HUMAN DIGNITY

2. Inviolability (*ḥurmah*)⁴

- Arabic root: sacredness, prohibition
- Human body is considered sacred (both deceased and alive)
- Negative rights

How can the integrity of the human body be violated?

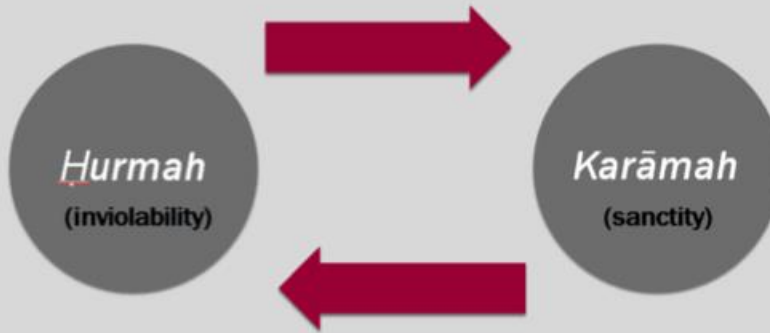
- i. Through violation of the body's intactness (e.g. mutilation)
- ii. Through violation of the body's functionality (e.g. suicide and harmful interference with bodily functions)
- iii. By the objectification of the body (by using body parts for unnatural purposes or commodifying them)

PART I: Rulings – **Human Dignity** – Dire Necessity – Public Interest || PART II: Fatawa – Conditions

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HUMAN DIGNITY

Violating bodily integrity compromises human sanctity



Preserving sanctity entails the preservation of bodily integrity

PART I: Rulings – **Human Dignity** – Dire Necessity – Public Interest || PART II: Fatawa – Conditions

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How might human dignity
(*karāma* and *ḥurmah*)
relate to living organ donation?



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DIRE NECESSITY

Dire Necessity (*al-ḍarūra*)⁵

- Arabic root: harm and injury
- Legal maxim: “Circumstances of necessity make the unlawful lawful” (*al-ḍarūrāt tubīḥu al-maḥẓurāt*)
- When can a normative prohibition be overturned?
 - If X then Y; but X is “fuzzy”
 - Life threat, risk for loss of limb or disability, no alternative available
 - Some jurists accept less substantial injuries

→ Varied application

PART I: Rulings – Human Dignity – **Dire Necessity** – Public Interest | | PART II: Fatawa – Conditions

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How might dire necessity relate
to living organ donation?

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PUBLIC INTEREST

Public interest, common good (*maṣlaḥa*)

- Arabic root: benefit, interest, good
- All aspects of Islamic law are in accordance with the realisation of benefit and the preservation of human interests
- Classification of *maṣlaḥa*⁶:
 1. *Al-Mu'tabarah*: public interests explicitly mentioned by the Qur'an and Sunnah
 2. *Al-Mursalah*: human interests not found in scripture, product of juridical reasoning
 3. *Mulghāh*: interests that have been rejected, or run counter to scripture

PART I: Rulings – Human Dignity – Dire Necessity – **Public Interest** | | PART II: Fatawa – Conditions

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PART I: Rulings – Human Dignity – Dire Necessity – **Public Interest** | | PART II: Fatawa – Conditions

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PART II: ISSUING FATAWA

Introduction to *fatawa* on living organ donation and their conditions for permissibility

- Fatwa 1: Late grand mufti of Pakistan, Muhammad Shafi'i (1966)
- Fatwa 2: Islamic Fiqh Academy of India (1989)
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PART I: Rulings – Human Dignity – Dire Necessity – Public Interest || PART II: **Fatawa** – Conditions

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FATWA 1: LATE GRAND MUFTI OF PAKISTAN

“If the same treatment is given to man that his skin, hair and organs are subjected to cutting and clipping for the use of other person(s) this will be against human sanctity and honour and the divine intentions of his creations. That is why (the) use of human organs through their trade and clipping and cutting etc. has been declared as severe crime and totally forbidden.

(...) In this matter it (Islam) has not permitted the use of these organs even with the consent and permission of a person”⁷

PART I: Rulings – Human Dignity – Dire Necessity – Public Interest || PART II: **Fatawa** – Conditions

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FATWA 2: ISLAMIC FIQH ACADEMY OF INDIA

“If a healthy person, in the light of the opinion of medical experts, is sure that he/she can live with one kidney only, it will be **valid** for him/her to donate one kidney to an ailing relative, if it be necessary to save his life while no alternative is available, but without charging any price.”⁸

PART I: Rulings – Human Dignity – Dire Necessity – Public Interest || PART II: **Fatawa** – Conditions

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FATWA 3: ISLAMIC FIQH ASSEMBLY MUSLIM WORLD LEAGUE (1985)

Taking organs from a living body and transplanting them in the body of another human being, who depends on this for his survival or to revive one of the functions of an essential organ, is a **permissible action**, which does not negate human dignity, in terms of the donor; in as much as the benefit of this action is enormous.

In fact, it is the best of all assistance to the recipient, and this is a legitimate and praiseworthy deed, as long as the following **conditions are met (...)**⁹

PART I: Rulings – Human Dignity – Dire Necessity – Public Interest || PART II: **Fatawa** – Conditions

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FATWA 4: FIQH COUNCIL OF NORTH AMERICA

“The Fiqh Council agrees with many individual scholars and national and international fatwa councils in considering organ donation and transplantation to be Islamically permissible in principle. All fatwas that have allowed transplantation have allowed donation as well. Done with a good intention, organ donation may be regarded as a rewarded act of charity.”

“However, similar to the general themes within these other fatwas, the Fiqh Council makes its general allowance subject to the following conditions:..”(see handout)

PART I: Rulings – Human Dignity – Dire Necessity – Public Interest || PART II: **Fatawa** – Conditions

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FATWA 5: AYATULLAH NURI-HAMEDANI (SHIA)

“If the life of a Muslim depends on the transplantation of an organ from a deceased Muslim, and a non-Muslim replacement does not exist, then the severance and transplantation of the organ is permissible, and per caution the blood money (diyah) should be paid so that it may be spent on the deceased; but selling is not permissible. But before death, there does not seem to be a prima facie reason for not permitting sales, unless the danger of death or unbearable side effects exists – in which case it is not permissible”²

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GENERAL CONDITIONS FOR THE PERMISSIBILITY OF ORGAN DONATION¹

- The reason for donation of an organ is that another individual (or group of individuals) have a dire need for such an organ
- The decision to donate is freely taken by the living donor, who is legally qualified to donate
- Donating ovaries and testicles is prohibited (Sunni view)
- Donating a vital organ (e.g. heart) is prohibited

ḍarūra

Moral accountability for one's actions (*taklīf*)
Informed consent and freedom of choice

Protection of lineage (*ḥifz an-nasl*)

Prohibition of suicide

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GENERAL CONDITIONS FOR THE PERMISSIBILITY OF ORGAN DONATION¹

- Organ removal and transplantation should take place with great care to make the smallest incisions and least amount of procedures performed
- Living donation should not endanger the donor's life and any harms should be minimized
- Monetary and non-monetary compensation for organ donation is prohibited (Sunni view)

ḥurma; violation of intactness
prohibition of mutilation

ḥurma; violation of functionality

ḥurma; objectification

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TERMINOLOGY: LIVING AND DECEASED

- Differentiation between living and deceased donation is challenged by different understandings of **brain death** (death determined by neurological criteria)
- Brain death remains contested among Islamic jurists:¹⁰
 - Legal death (equal to death determined by cardiorespiratory criteria)
 - Dying state
- What are the implications?
 - Are brain death donations considered living or deceased within an Islamic framework?
 - How do the aforementioned conditions apply to brain death donors?

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Q&A



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LIVING ORGAN DONATION BALANCE SHEET

The decisional balance sheet is used to explore all pros and cons of living organ donation during the peer-led group discussions.

Short-Term Outcomes	
Pros	Cons
Donor	Donor
Recipient	Recipient
Religious	Religious

Long-Term Outcomes	
Pros	Cons
Donor	Donor
Recipient	Recipient
Religious	Religious