

The Little Book of Giving A.C.T.S.



About Choices in Transplantation & Sharing





About Organ and Tissue Donation

There are numerous health conditions that can lead to organ failure and require the need of a transplant. Such conditions as high blood pressure, diabetes, and kidney disease affect African Americans more than other groups. When vital organs are severely damaged as a result of disease or accidental injury, they may need to be replaced for a person to survive and return to a normal life. This book will address the common questions and concerns that you may have about organ and tissue donation.



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Why is it important for African Americans to talk about donation?

Because organ donation saves lives!

Today, in the U.S., the African American community is especially hard hit by the shortage of organs.

- African Americans comprise 13%* of the U.S. population and make up 14%* of organ donors.
- More than 35%* of the organ transplant waiting list are African American men, women and children.
- Of all the African Americans on the waiting list, 92%* are waiting for a life-saving kidney.

Because each day African Americans die waiting for an organ transplant!

- More than 117,000* people are waiting for organ transplants, and 2,200 of those are children.
- Every 10 minutes a new name is added to the national waiting list.
- 20 patients die daily awaiting a vital organ, three of which are African American.

Because education is the key to saving a life!

*Source: <http://optn.transplant.hrsa.gov>, as of 2.26.13



Common Questions?



Q. Who can become a donor?

A. Individuals of any age can indicate their desire to donate.

Q. What can be donated?

A. Organs: heart, intestines, kidneys, liver, lungs, pancreas. Tissues: eye tissues (e.g. cornea, sclera); cardiovascular tissues (e.g. heart valves, blood vessels); connective tissues (e.g. humerus, femur, rib, tendons, ligaments), peripheral blood, stem cells, whole blood; bones, and other tissues (e.g. nerve, skin).

Q. How are donated organs/tissues distributed?

A. The United Network for Organ Sharing (UNOS) matches donated organs with critically ill patients on the national waiting list by medical urgency, compatibility of blood type, body size, time on the waiting list, and geographic location.



Common Questions?



*“God blesses you everyday with life, with health, with your finances and how could you not want to bless someone else as God has blessed you?”
- Tommie, potential organ donor*

Q. Do I need medical tests to register as a donor?

A. No. *Testing is not needed before you sign a donor card or designate "organ donor" on your driver's license. At the time of donation, specific tests are conducted so that only healthy organs are actually transplanted.*

Q. Does the donor family meet the recipient?

A. No. *Most donor families are told the age, sex, occupation, and other general information about the recipient. However, if both the donor family and recipient agree, they may exchange names, correspond through a third party, and one day, even meet one another.*

Q. If I sign a donor card, will it affect the quality of medical care and treatment I receive at the hospital?

A. No. *Physicians do everything possible to save your life. Only after they determine that nothing can be done to save your life does a transplant team become involved.*



*“... they gave to anyone as he had need”
- ACTS 2:45*



*“Giving an organ does make a difference. It make a person’s life better, fuller, and richer.”
- Vidalia, kidney recipient*

Q. What if my family members oppose donation?

A. *As long as your wishes are legally documented by signing and carrying a donor card or designating yourself as an "organ donor" on your driver's license, the hospital will respect your wishes.*

Q. How much will organ donation cost my family?

A. ***Nothing!** The donor's family does not pay for the cost of donation. These costs are paid by the recipients' insurance.*

Q. Can people legally sell organs in the U.S.?

A. ***No!** In the United States there is a federal law that makes it **ILLEGAL** to sell human organs and tissues. Violators are subject to fines and imprisonment.*



Common Questions?

Q. If I have a previous medical condition, can I still donate?

A. Yes. Your medical history should not be a deciding factor in your decision to donate. Health care professionals will determine which organs are suitable for donation.

Q. How do I express my wishes to become an organ donor?

- A. 1. Indicate your intent to be a donor on your driver's license. This automatically places you on your state's donor registry.*
- 2. Carry an organ donor card.*
- 3. Discuss your decision with your family and loved ones.*

Q. Are there religious objections to organ and tissue donation?

A. The vast majority of religious groups support organ and tissue donation and transplantation as long as it does not impede the life or hasten the death of the donor. It is encouraged as a charitable act that saves and/or enhances life. If you have questions, talk them over with your pastor.



Just the Facts!

FACT: *Your life is the number one priority!*

The medical staff trying to save your life are completely separate from the transplant team. Donation takes place and transplant surgeons are called in only after all efforts to save your life have been exhausted and death is imminent or has been declared.

FACT: *Organs are matched by factors, including blood and tissue typing, which can vary by race.*

FACT: *The computerized system does not select recipients based on wealth or fame. When you are on the transplant waiting list, what really counts is the severity of your illness, time spent waiting blood type, and geographic location. Factors such as race, gender, income or celebrity status are not considered when determining who receives an organ once you are on the waiting list.*



Just the Facts!

FACT: Bone marrow donors do not feel pain when the marrow is removed because anesthesia is used. Soreness and/or stiffness may be felt for a week or so post-donation.

FACT: People of all ages and medical histories may be donors. Physical condition, not age, is important. Ultimately your medical condition at the time of death will determine what can be donated.

FACT: Donation does not change the appearance of the body and does not interfere with having a funeral, including open casket services.



*“I was able to have an open casket funeral even though I donated my son’s organs. It did not interfere with the body. Organ donation is just a wonderful thing.”
~ Doris, organ donor mother*



Types of Donors

There are two common types of organ and tissue donors:

1. **Living Donor**: A family member, friend, or unknown donor who gives a kidney, part of a liver, lung, pancreas, bone marrow, or blood to another person.



“You have to get to a point when you begin to operate outside of that space of fear and that’s what organ donorship does, it is a way of affecting life, impacting life and saving peoples lives.”
- Audria, living donor daughter

2. **Deceased donor**: A person who has been declared “brain dead” and whose family has offered one or more organs or tissues to be used for transplantation.



“My son was giving, very caring, and always had a smile on his face. We decided we wanted to do organ donation. His spirit lives on in other children.”
- Tara, organ donor mother



The Donation Process

(Deceased Donation)

Giving the gift of life through donation requires a great deal of teamwork between physicians, nurses, hospital staff, the Organ Procurement Organization (OPO) staff and transplant teams. To help better understand the steps to successful organ donation, we have divided the process into four major steps:

Step 1: Identification and Referral

Identification: Hospital staff identifies a potential donor.

Referral: The OPO is contacted to evaluate the potential organ donor and determine the medical suitability of each organ.

Diagnosis: After evaluation and testing by a physician unrelated to the transplant process, the diagnosis of brain death is determined and shared with the family.



*“We wanted to make something positive about this situation and give life to others through this tragedy. . . It really still feels good.”
- Judy, organ donor wife*

Step 2: Consent

First Person Consent: In the U.S., all 50 States honor first person consent law. This means that your driver's license and/or donor card act as a binding legal document indicating your decision to be an organ/tissue donor.



“Stretch out your hand to heal and perform miraculous signs and wonders through the name of your holy servant Jesus.” - Acts 4:30

Step 3: Evaluation and Maintenance

Support: To maintain the flow of oxygen to all potential donated organs, the deceased donor must be placed on a ventilator along with other support systems.

Recipient Identification: The process of organ placement begins immediately following consent for organ donation. Donor information such as blood type, body size and geographic location are entered into the United Network of Organ Sharing (UNOS) database identifying potential recipients who best match the available organs.

Step 4: Organ Recovery

Recovery: The recovery of the organ is performed by a surgical team in the operating room. Tissues are generally recovered within 24 hours, following organ donation.

What Organ Can be Donated?

Deceased Donation

Heart

Liver

Lungs

Kidney

Pancreas

Intestines

Living Donation

Segment of the liver

Lobe of a lung

Kidney

Portion of the pancreas

Portion of the intestine



The Transplant Process

While not a cure, organ transplantation is a therapy that could save or enhance a person's life after disease or accidental situations have caused end-organ failure.

The transplant process has multiple phases:

Phase 1: Evaluation and Referral

Evaluation: The transplant team's evaluation includes a medical, psychiatric, psychosocial and financial assessment.

Insurance Coverage: Insurance benefit plans can vary. Private insurance may or may not pay the total cost of a transplant. Medicare pays for most kidney transplants and sometimes covers the cost of heart and liver transplants. State Medicaid programs may also cover the transplant as well.

For those patients in need of financial assistance, the transplant program social worker or financial coordinator can assist the patient and his or her family with resource information.

Referral: Once the evaluation is complete and the patient is determined to be a transplant candidate, the transplant staff will place the patient's name and medical information into the national transplant waiting list database. At the time of the evaluation and again at listing, the patient is told about living donation as an option.

Phase 2: Waiting

Each transplant candidate is unique. Depending on how sick the candidate is and the availability of a suitable organ, he/she may wait a few days or several years for an organ transplant.



“No one claimed private ownership of any possessions, but everything they owned was held in common.” - Acts 4:32

Phase 3: The Transplant

Donor matching: When a donor organ matches a candidate on the wait list, the transplant surgeon and local physician talk to make sure the patient is in good health to receive the transplant. If so, the organ is accepted and the patient is called to the hospital.

Recovery:

After the transplant procedure, depending on the type of transplant, the patient will stay in the hospital between a few days and a couple weeks.

Phase 4: Follow-up

Therapy:

Patients must take anti-rejection drugs everyday. This therapy begins immediately prior to transplant and continues for the rest of their lives to prevent the body from rejecting or destroying the new organ. Annual cost of these drugs range from \$15-20,000.

Additional care: Follow-up visits with the transplant are program required. During the first month the patient must have blood work done and be seen by the transplant team 2-3 times/week. Eventually return visits and lab testing will decrease to 1/month, then once a quarter, once every six months and finally, once a year.



Living Donation

Becoming a living donor is a voluntary decision that involves careful consideration. It is important to educate yourself about the donation process.

Making the Decision

While many people are willing, not everyone can be a living donor. Potential donors must be: (1) over the age of 18 (2) willing to donate, (3) physically fit, (4) in good general health; and (5) free from high blood pressure, diabetes, cancer, kidney disease and heart disease.

Testing

The potential living donor must undergo a blood test to determine if blood type is a match to the recipient. If blood type is compatible, the next steps are a medical history review and a complete physical examination.

Living Donation Costs

All medical expenses associated with living donation are covered by the recipient's insurance. Any costs incurred by a living donor outside of the evaluation and transplantation procedure (i.e. travel, lodging, lost wages) are not covered by insurance.



There's a lot of ways that we can help and its not going to impact anybody, in a negative way, in terms of your health.

-Betty, daughter is a kidney recipient



Religious Beliefs



The death of a loved one often raises spiritual and religious issues. When faced with the decision of organ and tissue donation, a person's religious position on the subject becomes very important. As the decision is being made, the question may arise, "What does my religious tradition believe about organ and tissue donation?" Here are a few perspectives on religious beliefs from several Christian based religions:



"This is our Christian responsibility, and so the task that lies ahead is how do we go about erasing the fear? From a spiritual perspective, it is done from love."

~ Reverend Harris T. Travis



*“It is more blessed to give than to receive.”
-Acts 20:35*



*“Sometimes when we talk about needs, we can help persons even when we’re gone by just fulfilling some of the needs, with things we cannot use anymore.”
-Reverend Claude Ray James*

African Methodist Episcopal

Organ and tissue donation is viewed as an act of neighborly love and charity by this denomination. They encourage all members to support donation as a way of helping others.

Baptist

The Southern Baptist Convention adopted a resolution in 1988 encouraging physicians to request organ donation in appropriate circumstances and to “encourage voluntarism regarding organ donations in the spirit of stewardship, compassion for the needs of others and alleviating suffering.”

Catholic

Catholics view organ donation as an act of charity and love. Transplants are morally and ethically acceptable to the Vatican.





Episcopal

The Episcopal Church passed a resolution in 1982 that recognizes the life-giving benefits of organ, blood, and tissue donation. All Christians are encouraged to become donors "as part of their ministry to others in the name of Christ, who gave his life that we may have life in its fullness."

Presbyterian

Presbyterians encourage and support donation. They respect a person's right to make decisions regarding his or her own body.

United Methodist

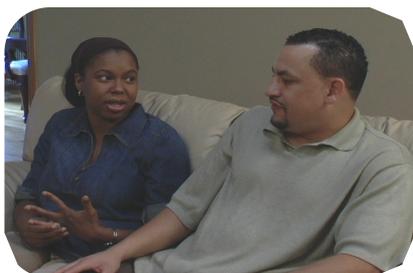
"The United Methodist Church recognizes the life-giving benefits of organ and tissue donation, and thereby encourages all Christians to become organ and tissue donors by signing and carrying cards, attesting to their commitment of those in need, as a part of their ministry to others in the name of Christ, who gave his life that we might have life in its fullness".

"I know I don't need my earthly body after I die, so if I know that I could give someone a better quality of life and longer life, I would want to do that."



Family Conversations

For many families organ and tissue donation can be a sensitive topic, but it is something that every family needs to discuss.



*"We talk about life and the great afterlife but we don't talk about dealing with the death part of it. We don't really have those conversations."
- Smith family*

"I was shocked that my mother was an organ donor. I didn't know that. Then I found out that my nephew is and he is much younger than me and I didn't know that either."

Many families don't want to talk about organ and tissue donation, because it often makes us think about death and the loss of a loved one, but lets think about life.

*"I think once you take the death out of it, it's more comfortable and appealing because you're not taking a life . . . I can give part of my liver to someone and still be living and that's great. . . but they never show you that."
- Graham family*



*“I have no silver or gold
but what I have I give you in the name
of Jesus Christ.” - Acts 3:6*

It's not always a discussion about “do I want to be a donor when I am no longer on this earth, but what if I needed an organ?” What if your mother needed a kidney? Would you want someone to make a donation? When it hits home or once it gets close to you that's when you really start thinking about it.



*“I didn't have any idea how
they felt and they didn't have
too much of an idea how I felt.”
- Simmons family*

Making the decision to become a donor doesn't have to be a painful one. Having discussions with your family helps you to express your concerns, ask questions, and understand how each other feels.

*“We need to discuss these things before you get
critically sick so when the decision needs to be
made you will have a directive in place.”*



“There was no poverty among them, because people who owned land or houses sold them and brought the money to the apostles to give to others in need.”

- Acts 4:34-35

The 5 Keys to Living Healthy



Be more physically active. Walking 30 minutes a day 5 times per week can greatly improve your health.



The food choices that we make today can affect us for many years to come. Eat healthy and aim for a healthy weight by choosing foods that are lower in fats, calories, and salt.



Cut back on alcoholic beverages. Drinking too much alcohol increases the risk of liver damage, heart-related problems, and some forms of cancer. More than 2 drinks per day can also raise blood pressure.



Stop smoking and reduce second hand smoke. There's no one way to stop smoking that works for all so talk with your doctor and check for programs in your community to help you quit.



Visit your physician regularly to check your blood pressure, cholesterol and blood sugar levels.



Next Steps! How to become a Donor?



*“Organ donation is a positive, powerful way to contribute to our community. Talk over your fears with your pastor, discuss your views with your family.”
Judy, organ donor wife*

Indicate your intent on your driver's license

Find out from your local department of motor vehicles how you can indicate on your license that you want to be a donor.

Sign a donor card

Sign the card included in this booklet, and carry it in your wallet. Have two people witness your signature, preferably family members.

Tell your family

Tell your family members that you have decided to become an organ and tissue donor so they will understand your wishes and support them.



Important Dates

January

National Volunteer Blood Donor Month

February 14th

National Donor Day

April

National Organ and Tissue Donation/Donate Life Month

June/July

U.S. Transplant Games: The U.S. Transplant Games is a 4-day athletic competition that occurs every 2 years among organ transplant recipients. Competition in the U.S. Transplant Games is open to anyone who has received a life-saving solid organ transplant.

July

World Transplant Games: The World Transplant Games is a 9-day sporting event held every 2 years among recipients of life-saving organs. The purpose of the World Transplant Games is to promote the importance of organ donation and the success of transplantation through the demonstration of athletic excellence in the area of sport and competition.

August 1st

National Minority Donor Awareness Day

November

National Marrow Awareness Month

National Donor Sabbath: A weekend devoted to encouraging faith communities to spread the word about the importance of organ and tissue donation.

National Give Thanks, Give Life Day (Thanksgiving Day)



Additional Resources

African American Community Health Advisory Committee

www.aachac.org

American Society of Multicultural Health and Transplant Professionals

www.asmhtp.org

Coalition on Donation

www.donatelife.net

Department of Health & Human Services Health Resources and Services Administration, Division of Transplantation

www.organdonor.gov

Department of Health & Human Services, Office of Minority Health

www.omhrc.gov

Gift of Hope Organ and Tissue Donor Network

www.giftofhope.org

National Institutes of Health, Health Information

www.health.nih.gov

LifeLink Foundation

www.lifelinkfound.org

National Minority Organ Tissue Transplant Education Program

www.nationalmottep.org

National Institutes of Health, National Institute of Diabetes and Digestive Kidney Diseases

www.niddk.nih.gov

The Organ Procurement & Transplantation Network

www.optn.org

United Network for Organ Sharing: Organ Donation & Transplantation

www.unos.org



Be an Organ & Tissue Donor!

**A Single Donor can help save
and enhance the lives of more
than 50 people!**

**Organ Donation is an act of
charity, compassion
and neighborly love.**

**Organ and Tissue Donors leave
a miraculous legacy.**



Now the whole group of those who believed were of one heart and soul, and no one claimed private ownership of any possessions, but everything they owned was held in common.

-Acts 4:32.



*Giving A.C.T.S.
“About Choices in Transplantation
&
Sharing”*



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of the National Institutes of Health



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