



## FROM BIRTH TO DEATH AND BENCH TO CLINIC

# THE HASTINGS CENTER BIOETHICS BRIEFING BOOK

for Journalists, Policymakers, and Campaigns

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### CHAPTER 28

## Organ Transplantation

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# organ transplantation

by Arthur Caplan

## Framing the Issue

Every day about a dozen people in the United States die waiting for organ transplants. The deaths are especially tragic since many might be prevented if more organs were available. Every day very hard choices have to be made about who will live and who will die. With close to 100,000 people on waiting lists for kidneys, hearts, livers, lungs, and intestines, the pressure to distribute scarce organs fairly and to find ways to increase their supply is enormous.

The pressure is getting worse because waiting lists are growing faster than the supply of organs. And if transplant centers were to relax their standards to include more people—such as the those who lack insurance, have severe intellectual disabilities, older persons, prisoners, illegal aliens, and foreigners who cannot get transplants in their own countries—then the lists of those waiting could easily triple or quadruple.

To close this gap, policymakers will have to consider new options for inducing people to donate organs, and organ transplant centers may have to rethink their criteria for determining who is allowed on their waiting lists and who has priority. These decisions involve many ethical and legal issues, including:

- Who on the waiting lists should get transplants first: patients in the greatest need or those most likely to benefit?
- Should certain people, like illegal aliens, foreigners, and people with a history of addiction or a criminal record, be denied a place on waiting lists?
- Should people be paid to donate their organs?
- Should federal law be changed to permit people to buy and sell organs?

## Distributing Organs: What Is Just and Fair?

Rationing is unavoidable in organ transplantation, but the system for allocating organs must be just and fair. Justice requires some rule or policy that insures that the supply of donated organs is used wisely and consistently with what donors and their families would wish, such as giving priority to saving children's lives, or to American citizens. Fairness demands that like cases be treated alike and that the allocation system be transparent, so that all who wait know why some are selected and some are not.

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## HIGHLIGHTS

- Nearly 100,000 people are on waiting lists for organ transplants in the United States, but about a dozen of them die each day because of a lack of organs.
- Rationing is unavoidable in organ transplantation, but the system for allocating organs must be just and fair.
- Value judgments and economic considerations affect who is admitted to waiting lists and who gets available organs, calling into question the justice and fairness of the allocation system.
- It is essential to increase the supply of donated organs; one option is to legalize the buying and selling of organs, but this strategy is fraught with ethical problems.
- A promising option for increasing the supply is a policy of presumed consent—unless they state otherwise, people are presumed to want to donate their organs when they die.

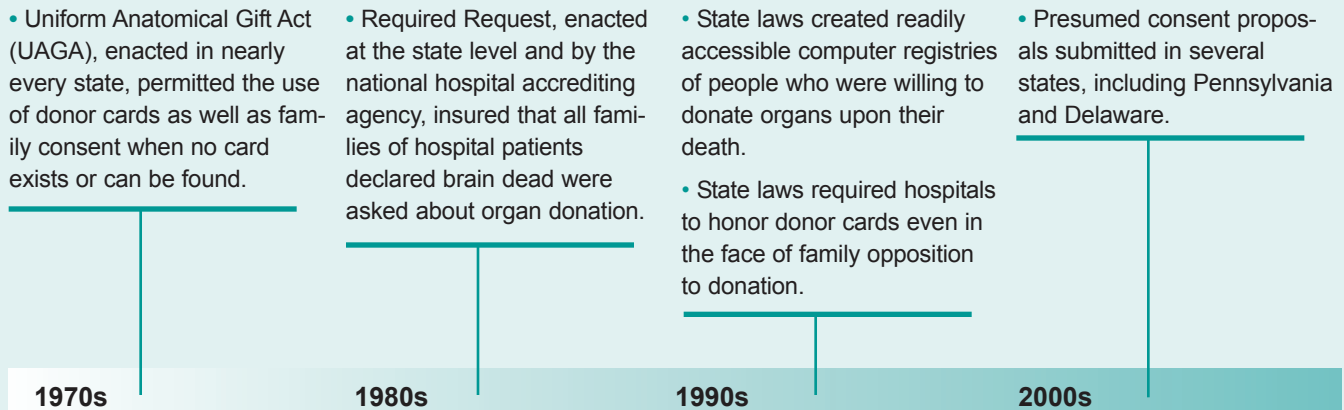
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## EFFORTS TO INCREASE ORGAN DONATION: A TIMELINE



There are valid questions about the justice and fairness of the current system. Transplant centers are the gatekeepers who decide whom they will and will not admit as transplant candidates. Their policies vary. Many nonmedical values shape their decisions, and it can be argued that some centers invoke these values in ways that are not truly just. Among these considerations:

- Many transplant centers will not accept people without insurance.
- Transplant teams rarely consider anyone over 75 years of age.
- Some centers exclude patients with moderate mental retardation, HIV, a history of addiction, or a long criminal record.
- Though American transplant centers can list foreigners, they can make up no more than 5% of any center's list. Most of non-U.S. citizens listed have substantial financial resources and pay in cash.
- Some transplant programs will admit illegal aliens, but most are children. Some transplant centers have caused controversy by refusing to retransplant illegal aliens whose initial organs, received at the same hospital during childhood, have failed.

Value judgments may also influence the process of matching cadaver organs with patients on the waiting lists. The United Network for Organ Sharing (UNOS), a national network based in Richmond, Virginia, bears this responsibility. At present, its driving considerations are matching a donor and a recipient by blood type, tissue type, and organ size. Some weight is also given to the

urgency or need for a transplant as reflected by time on the waiting list and the person's physical condition. There has been some push in recent years to steer organs toward those who are not seriously ill so as to maximize the chances for successful transplantation. UNOS used to have to allocate organs locally, but recently it has moved to a more regional distribution, as organ preservation techniques and other aspects of organ transplantation have improved.

Debates are growing louder about the criteria that should be used to dominate UNOS's distribution process—should it be the urgency of a patient's medical need? Or should it be efficacy? In recent years, there has been a shift toward efficacy. UNOS proposed new regulations, available to the public on its Web site, in an effort to improve the fairness of the allocation process.

Furthermore, patients can increase their chances of getting a transplant by enrolling at more than one transplant center—a practice known as multiple listing. About 10% of the current waiting list consists of persons who are listed at more than one center. Critics of multiple listing say that it is unjust because it gives an advantage to people with the resources to pay for more than one evaluation and listing. Each evaluation can cost tens of thousands of dollars.

### Increasing the Supply

A number of steps have been taken over the years to try to increase the supply of organs (see box). The first attempt was from state laws permitting the use of organ donor cards or family consent

to donate a deceased relative's organs. Then, states began requiring hospitals to ask all patients' families about organ donation. Most recently, state laws required hospitals to honor a patient's donor card even when the family opposed donation.

None of these policies has significantly increased the supply of organs. Therefore, some people now argue for a shift away from a reliance on voluntary altruism in organ donation toward either a paid market or presumed consent.

## Organ Markets

Two basic strategies have been proposed to provide incentives for people to sell their organs upon their death. One strategy is simply to permit organ sale by changing the National Organ Transplant Act (NOTA), the federal law that bans organ sales. Then, individuals would be free to broker contracts with persons interested in selling at prices mutually agreed upon by both parties. Markets already exist on the Internet between potential live donors and people in need of organs, but these transactions are illegal. The other strategy is a regulated market in which the government would act as the purchaser of organs—setting a fixed price and enforcing conditions of sale. Both proposals have drawn heated ethical criticism.

One criticism is that only the poor and desperate will want to sell their body parts. If you need money, you might sell your kidney to try and feed your family or to pay back a debt. This may be a “rational” decision, but that does not make it a matter of free choice. Watching your child go hungry when you have no job and a wealthy person waves a wad of bills in your face is not exactly a scenario that inspires confidence in the fairness of a market for body parts. Talk of individual rights and autonomy is hollow if those with no options must “choose” to sell their organs to purchase life's necessities. Choice requires information, options, and some degree of freedom, as well as the ability to reason.

It is hard to imagine many people in wealthy countries eager to sell their organs upon their death. In fact, even if compensation is relatively high, few will agree to sell. That has been the experience with markets in human eggs for research purposes and with paid surrogacy in the United States—prices have escalated, but there are still relatively few sellers. Selling organs, even in a tightly regulated market, violates the ethics of medicine.

## SHOULD THE DEFINITION OF DEATH BE CHANGED?

Most donated organs now come from people declared dead on the basis of neurological criteria—the absence of brain activity. Brain death typically occurs after cardiopulmonary death, the cessation of a heartbeat and breathing. One way to expand to pool of deceased donors is to include those declared dead by cardiopulmonary criteria. This recommendation was made in 2006 by a panel of the Institute of Medicine chaired by Hastings Center Fellow James F. Childress and including Hastings Scholar Mary Ann Baily.

Donation after circulatory determination of death (DCDD) has become more common around the world, but the practice is controversial. For one thing, it is medically more complex than donation after brain death because of the risk of organs being harmed by oxygen deprivation. In addition, there is ethical concern that DCDD will lead to substandard health care at the end of life—for example, inadequate morphine in the effort to avoid harming the organs. The Institute of Medicine report recommends ethical guidelines already used in Europe, such as preventing the organ recovery team from being the ones to decide when to discontinue cardiopulmonary resuscitation.

The core ethical norm of the medical profession is the principle, “Do no harm.” The only way that removing an organ from someone seems morally defensible is if the donor chooses to undergo the harm of surgery solely to help another, and if there is sufficient medical benefit to the recipient.

The creation of a market puts medicine in the position of removing body parts from people solely to abet those people's interest in securing compensation. A market in human organs has a model in the existing market for human eggs for assisted reproduction and research purposes, but that practice is highly controversial. Is this a role that the health professions can ethically countenance? In a market—even a regulated one—doctors and nurses still would be using their skills to help people harm themselves solely for money. The resulting distrust and loss of professional standards is too a high price to pay to gamble on the hope that a market may secure more organs for those in need.

## Presumed Consent

There is another option for increasing the organ supply that has not been tried in the United States but is practiced abroad. Spain, Italy, Austria, Belgium, and some other European countries have enacted laws that create presumed consent, or

## RESOURCES

### Web sites

- [www.organdonor.gov](http://www.organdonor.gov) – the U.S. government site on organ donation. Includes educational materials and resources, research, best practices, and legislation.
- [www.unos.org](http://www.unos.org) – the United Network for Organ Sharing. Includes data, resources, and a newsroom.

### Recent news

- Rob Stein, “Infant Transplant Procedure Ignites Debate,” *Washington Post*, August 14, 2008.
- Timothy Gower, “Fatal Flaw,” *Boston Globe*, March 9, 2008.
- Rob Stein, “In Push for Transplant Organs, Critics See Room for Abuses,” *Boston Globe*, September 16, 2007.
- Jane Brody, “For Living Donors, Many Risks to Weigh,” *New York Times*, September 4, 2007.
- Rob Stein, “States Revising Organ-Donation Law,” *Washington Post*, April 4, 2007.
- Sally Satel, “Death’s Waiting List,” *New York Times*, May 15,

2006.

### Further reading

- Robert D. Truog, “Consent for Organ Donation—Balancing Conflicting Ethical Obligations,” *New England Journal of Medicine*, March 20, 2008.
- Joyce A. Griffin, *Organ Donation*, The Hastings Center, 2007, Primer available at [www.thehastingscenter.org/uploadedFiles/Publications/organs%20primer.pdf](http://www.thehastingscenter.org/uploadedFiles/Publications/organs%20primer.pdf).
- Michael A. DeVita and Arthur L. Caplan, “Caring for Organs or for Patients? Ethical Concerns about the Uniform Anatomical Gift Act,” *Annals of Internal Medicine*, December 2007.
- Arthur L. Caplan et al., “Moving the Womb: The Ethics of Uterine Transplants,” *Hastings Center Report*, May-June 2007.
- Alberto Abadie and Sebastien Gay, “The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study,” *Journal of Health Economics*, July 2006.

what I prefer to call “default to donation.” In such a system, the presumption is that you want to be an organ donor upon your death—the default to donation. People who don’t want to be organ donors have to say so by registering this wish on a computer, carrying a card, or telling their loved ones. With default to donation, no one’s rights are taken away—voluntary altruism remains the moral foundation for making organs available, and, therefore, procuring organs is consistent with medical ethics. Based on the European experience, there is a good chance America could get a significant jump in the supply of organs by shifting to a default-to-donation policy. Donation rates in European countries with presumed consent are about 25% higher than in other European nations.

Default to donation proposals have been submitted in several states. The United Kingdom is also considering implementing presumed consent, and if it does—and if the policy is successful—that may provide more momentum for trying it in the United States. The main ethical objection to presumed consent is the perceived loss of patient autonomy—that it is wrong to take someone’s

organs without that person’s explicit consent. In addition, some people believe that presumed consent violates the 5th Amendment prohibition against taking private property without due process and compensation. Critics are also concerned about mistakes in which there is the presumption that someone consented when, in fact, either the individual had failed to indicate opposition or the record of that opposition was lost.

## On the Horizon

The need for organ transplantation may eventually be reduced by stem cell therapies. Scientists hope to repair or even replace damaged organs with new cells grown from adult or embryonic stem cells. Earlier this year, researchers at the University of Minnesota reported that they had built a beating heart in a laboratory with stem cells from neonatal and fetal rats. And British scientists are undertaking pioneering clinical trials that attempt to repair the hearts of heart attack patients by injecting them with stem cells. 🌳