Gift of Life: The Lawyer's Role in Organ and Tissue Donation

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Gift of Life: The Lawyer’s Role in Organ and Tissue Donation

By David M. English
As of December 22, 1993, there were far short of the demand, however. As of December 22, 1993, there were 33,520 individuals on the waiting list for the transplant of vital organs, including 25,065 in need of a kidney, 2,997 in need of a liver, 2,836 in need of a heart, and lesser numbers awaiting a pancreas or lung. Over 2,000 individuals on the waiting list die each year before receiving needed transplants.

The number of organ donors falls far short of the demand, however. As of December 22, 1993, there were 33,520 individuals on the waiting list for the transplant of vital organs, including 25,065 in need of a kidney, 2,997 in need of a liver, 2,836 in need of a heart, and lesser numbers awaiting a pancreas or lung. Over 2,000 individuals on the waiting list die each year before receiving needed transplants.

But the waiting list is only the tip of an iceberg. Although it is estimated that more than 60,000 individuals currently could benefit from a vital organ transplant, in 1992 there were only 7,078 donors (2,557 living and 4,521 deceased) and a total of 16,604 donated organs (kidney—10,228; liver—3,064; heart—2,172; pancreas—557; lung—535; heart/lung—48). Although statistics and estimates are not as readily available, the need for transplantable tissue far exceeds the currently available supply.

The reasons for the shortages are many, but in essence, the shortages result from the failure of many prospective donors to express their intent, the refusal of many families to consent to donation on the death of a relative, and the unwillingness or inability of many health care providers to make an effective request. The reasons for the shortages are many, but in essence, the shortages result from the failure of many prospective donors to express their intent, the refusal of many families to consent to donation on the death of a relative, and the unwillingness or inability of many health care providers to make an effective request.

ABA Initiative

At its 1992 Midyear Meeting, the ABA House of Delegates approved a resolution recommending that individual lawyers and the organized bar play an active role in efforts to relieve the current shortage of donated organs and tissue. When fully implemented, these efforts will involve not only lawyers, but also their clients, health care professionals and the general public. Sponsored by the Section of Real Property, Probate and Trust Law, the resolution is printed on p. 14.

The resolution's most ambitious goal is to make organ and tissue donation part of everyday law practice. Lawyers, as a matter of course, should raise the subject of organ and tissue donation when counselling clients on personal planning. But to educate their clients, lawyers must first educate themselves. There is a general lack of knowledge about organ and tissue donation among practicing lawyers, a deficiency that can and should be remedied. The resolution recommends that individual lawyers and the organized bar participate in efforts to inform the public. Although difficult to organize and usually lacking in immediate visible results, these efforts eventually bear fruit.

The resolution recommends the reform of state statutes—an area where the organized bar can have a major impact. The resolution recognizes that the legal community is coming to this subject relatively late in the game. A coordinated effort with health care professionals and with other groups involved in organ and tissue donation is essential.

ABA resolutions, however, are often filed away and quickly forgotten. There is a need to move forward. This article describes some of the reasons for the serious shortage of donated organs and tissue and suggests some ways for turning the resolution into action.

Educating Lawyers

Few lawyers are knowledgeable about the law and practice of organ and tissue donation. Few lawyers thus raise the subject with their clients or are adequately prepared to respond to questions. There is a need for articles and programs to educate lawyers on the legal requirements for making an effective organ and tissue donation and the methods lawyers can use to increase the chances that a client's expression of intent will be both noticed and implemented.

State law controls the requirements for making an effective organ and tissue donation. All states have enacted the Uniform Anatomical Gift Act, which was first approved in 1968 but substantially revised in 1987. The 1987 act is currently in effect in 14 states (Arkansas, California, Connecticut, Hawaii, Idaho, Minnesota, Montana, Nevada, North Dakota, Rhode Island, Utah, Vermont, Virginia and Wisconsin). The 1968 act is in effect in the remaining states and the District of Columbia. Under either act, an intention to make a gift may be indicated by signing a donor card, although states vary on whether the card also must be witnessed. Other gifting options include a donation by will (not recommended) or by a designation on a driver's license. A donor may specify particular organs and tissue and may indicate whether the donation is made for purposes of transplant, therapy, research or education.

A substantial majority of individuals who sign a donor card or make the appropriate indication on their driver's licenses will not become actual donors. There are numerous reasons for this fall-off, but the most significant is donor suitability. About 2.2 million Americans die each year, but only a tiny fraction of these people are suitable candidates for organ donation. Estimates vary, but the most frequently quoted numbers range from 10,000 to 27,000 eligible persons. Inhibiting factors include advanced age, the necessity that the donor's death occur in a hospital and, most importantly, the cause of death. Most eligible organ donors die from severe head trauma or other accident, causes of death that are least likely to damage the relevant organs.
anyone can donate corneas, and donations of skin may be made by individuals well into their seventies. Less restrictive eligibility guidelines also apply to donations of bone.

Another reason for the fall-off is health care providers' practice of requiring the family's consent before implementing a donation. Consent is necessary in the absence of a document of donation, but the presence of a donor card will make no difference. Health care providers still require the family's concurrence. Usually family consent is demanded even when the family cannot be located. Even though the 1968 anatomical gift act implicitly and the 1987 act explicitly provide that a document of donation is binding, the practice of requiring family consent persists.

Signing a donor card is only a first step. The prospective donor also must discuss the decision with his or her family to increase the chances that he or she will become an actual donor. A 1993 Gallup poll reveals that 93% of Americans are very or somewhat likely to consent to a donation on behalf of a relative if the relative has requested it, but only 47% would consent when the relative's wishes are unknown. Moreover, the mere signing of a donor card or designation on a driver's license is unlikely to make the family aware of the prospective donor's intent. An estimated 3% of donor cards will come to light when a prospective donor dies.

Educating the Public

The shortage of donated organs and tissue cannot be attributed to lack of public awareness. The 1993 Gallup poll found that 85% of Americans approve of organ donations for transplant, and 69% say they are very likely or somewhat likely to donate their own organs. But there is a gap between the American public's interest in making a donation and the willingness to follow through. Only 28% of those polled had signed a donor card or made a designation on their driver's licenses, and more than half of all families refuse consent following the death of a prospective donor.

Many misconceptions about organ and tissue donation are a major reason for the failure of individuals and families to follow through with donations. Reluctant donors fear that:

- the physician will begin the donation procedure while the donor is still alive or will hasten the donor's death to obtain needed organs;
- organ or tissue donation will result in the disfigurement of the donor's body;
- the donor's family or estate will have to pay for the procedure;
- donation may violate the tenets of the donor's religion; and
- donation will delay the donor's funeral arrangements.

The most powerful of these fears, the first, appears to result from a misunderstanding of the standards for determining death. The misunderstanding arises because medical science cannot yet transplant organs from an individual whose heart has stopped. Organ donors therefore are individuals who have been declared brain dead but for whom artificial supports continue to be maintained. This necessity to maintain oxygenation and circulation leads to the fear that a person might be declared dead while appearing, at least to a layperson, to be alive. This misunderstanding is less of a concern for tissue donation because tissue can be retrieved after respiration and circulation cease.

Sales professionals know that to make a sale one must overcome the customer's objections. But for lawyers there is a different motivator: the obligation to provide clients with complete and accurate information. Although not all clients or their families will be interested in making donations, lawyers owe a duty to those who might be so inclined to make certain they are fully informed.

The subject of organ and tissue donation should become part of the fabric of everyday law practice. Whenever it is relevant to a client's situation, the lawyer should raise the subject. Certainly the subject should become part of the estate planning conference. Estate planning today covers much more than the traditional will and trust. It also includes planning for the end of life, of which organ and tissue donation very much form a part.

Several national organizations—The Living Bank, the United Network for Organ Sharing (UNOS), and the American Red Cross—offer excellent literature on organ and tissue donation that concisely explains the need for donations and the procedures, as well as addressing many of the misconceptions. By maintaining a supply of these pamphlets, a lawyer can provide clients with the necessary information while reserving his or her time for what lawyers do best: answering questions and counseling clients on their objectives.

Reforming the Law

Various federal and state laws regulate organ and tissue donation. The National Organ Transplant Act of 1984 created a system of organ procurement organizations (OPOs). The Omnibus Budget Reconciliation Act of 1986 requires that all Medicare- and Medicaid-certified hospitals establish written protocols to assure that families of potential donors will be made aware of the option to donate, and that the applicable OPO will be notified of potential donors. No federal law, however, directly encourages the signing of an organ donation document.

State law on the subject can only be described as a morass. Although all states have enacted the 1986 or 1987 version of the Uniform Anatomical Gift Act, there are many significant variations on such matters as the obligations of emergency personnel and whether and under what...
circumstances families must be approached with requests for donations.

Organ and tissue procurement is a national system and there is a need for uniformity. For that reason, the ABA resolution affirms that all states should proceed to enact the 1987 revision of the Uniform Anatomical Gift Act, an act that specifically addresses some of the reasons for the chronic shortage of available organs and tissue. The 1987 act clarifies that a family cannot veto a previous expression of gift. More importantly, it anticipated the 1990 federal Patient Self-Determination Act by requiring that all hospitals inquire whether each adult patient is an organ donor, request a copy of the document of donation and place the document of donation in the patient’s medical record. Finally, the 1987 requires emergency medical personnel and hospitals to search for documentation of donations by patients who die or are near death.

The Need for a Coordinated Effort

Organ and tissue donation and transplantation involve many organizations and groups of professionals. Physicians, nurses, donor and recipient coordinators and other health care professionals are involved in the removal and transplantation process. The procedures are carried out in hospitals, but hospitals also play an active role in identifying donors. Each of the 50 or so OPOs is responsible for coordination within the designated service areas and for establishing a priority list of recipients. UNOS, a non-profit corporation in Richmond, Virginia, maintains the recipient computer network and sets overall policy under the direction of the Department of Health and Human Services. Groups such as The Living Bank and the American Red Cross supply donor cards and educational materials. The American Red Cross also is quite active in tissue donation.

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American Bar Association
Section of Real Property, Probate and Trust Law
Report to the House of Delegates

RECOMMENDATION

RESOLVED THAT the American Bar Association supports efforts to educate the public about the critical need for organ and tissue donations, and supports efforts to inform the legal community and clients of the opportunities to make these donations.

BE IT FURTHER RESOLVED THAT the American Bar Association urges all lawyers to raise with their clients, when appropriate, the topic of organ and tissue donations and to provide donation forms to those clients who indicate an interest in making a donation.

BE IT FURTHER RESOLVED THAT the American Bar Association urges the legal community to coordinate its efforts with respect to organ and tissue donations with the efforts of the medical community, including doctors, nurses, paramedics, hospitals, organ and tissue registries (in particular, The Living Bank, the only national multi-organ and tissue donor registry), and others involved in organ and tissue transplantation.

BE IT FURTHER RESOLVED THAT the American Bar Association supports efforts to bring uniformity, comity, and universality to the law and practice of organ and/or tissue donation and encourages all states to enact the 1987 version of the Uniform Anatomical Gift Act.

Individual lawyers and the organized bar must coordinate their efforts with these groups. Assistance should be sought, for example, when organizing local organ and tissue donor campaigns, in developing materials for distribution to clients and in the preparation of materials for training lawyers.

Individual lawyers and the organized bar also must lend their assistance to the solution of another major cause of donated organ and tissue shortages: the failure to properly identify and refer prospective donors. Among the problems are:

- an unwillingness by many hospitals to encourage the identification and referral of potential donors;
- a lack of knowledge of the criteria for determining death or inability or failure to make the proper assessments;
- confusion or absence of proper protocol for referral of prospective donors to the OPOs;
- failure of some health care professionals to handle requests for family consent properly; and
- the failure of some health care professionals to even approach families with requests for consent.

Conclusion

The shortage of donated organs and tissue is a problem that can be solved. The problem will not disappear by the efforts of lawyers alone. A coordinated effort is essential. But by becoming participants in the process, lawyers can at least lend a hand while they serve clients and perform an important and much needed public service.

David M. English is a law professor at the University of South Dakota in Vermillion, South Dakota.