

ORGAN DONATION

Guidelines for Clients Contemplating Organ Donation

Ascertaining a client's wishes about donating his or her organs or tissues is an integral part of estate planning. This article explains the laws governing organ donation, the issues of concern to clients, and the best way to make a donation.

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The number of individuals waiting for organ transplants nationwide now totals more than 45,000.¹ During the past two decades, dramatic medical advances have transformed organ transplants from an experimental procedure to an accepted medical practice that is now routinely performed at over 250 hospitals throughout the country, and the long-term survival rates for the more common kinds of transplants are excellent. For an increasing number of patients, a transplant is frequently the only viable treatment. Unfortunately, the demand for organs far exceeds the supply, and many waiting patients will never receive a transplant. In 1992, approximately 2,600 people died while waiting for transplants.²

Estate planners have a unique opportunity: Their clients are looking to the future and are already focused on how to help others after death. This is an good time to explore the possibility of organ donation because, where organ donation is consistent with the client's wishes, the practitioner can exercise his responsibility to act in the public interest by encouraging a positive response to the great need for donors.

Practitioner's responsibilities in the estate planning process

In general, an estate planner has a responsibility to obtain complete and accurate information about the client's family, business, and financial situation; to determine the client's objectives and wishes so as to advise him about the choices available; to counsel him about the consequences, tax and otherwise, of various alternatives; and, finally, to prepare the documents needed to express and implement his goals.

Traditionally, estate planning consultations have centered on wills, inter vivos and testamentary trusts, pension planning, life insurance, and perhaps planning for children and other family members with special needs. There may also be discussion about medical insurance, long-term care insurance,³ and the client's funeral or burial wishes. An important document to be prepared is the durable power of attorney, which delegates to an attorney-in-fact the authority to manage the principal's financial affairs. This power of attorney may be effective immediately or it may be "springing," i.e., operative in the future only upon the occurrence of specified criteria, such as a declaration of incapacity by one or more physicians or other designated persons. A durable power of attorney might include, among other items, authorization to act on tax matters and qualified retirement plans, create and fund trusts, and make gifts.⁴

Unfortunately, many experienced estate advisors are sometimes reluctant to ask clients about their wishes concerning their personal care in the event of incapacitating mental or physical disability. This planning, however, is no less crucial than preparation of the client's will and power of attorney, and should encompass health care proxies and advance directives for medical care (living wills) as well as a frank discussion of the client's feelings about organ donation.

Health care proxy. A health care proxy designates an agent or surrogate who has authority to make decisions concerning medical treatment and health care when the attending physician has determined that those decisions can no longer be made by the individual. This document usually does not contain specific instructions as to decisions to be made. It is always appropriate, though, and may be necessary under state law, to communicate to the proxy—or specify in writing—if the declarant does not want to receive artificial nutrition and hydration (food and water) by nasogastric, abdominal, or other tube feeding. Most statutes allow only one agent to be named at a time, but an alternate agent should be designated in case the agent of first choice is not available or cannot act. The form of text provided by the state, if any, should generally be used so that it is easily recognizable by the medical care provider. The addresses and telephone numbers of the agent(s) appointed should also be included.

Advance directive for medical care (living will). In addition to naming a health care proxy or agent, the client should consider executing an advance directive for medical care, often referred to (inaccurately) as a "living will."⁵ In some states, this takes the form of a health care power of attorney. This document is an "instruction directive," which expresses the client's wishes as to medical treatment generally or upon becoming terminally ill with no hope of recovery or if in a comatose or persistent vegetative state or similar condition. Such wishes may include, but are not limited to, the refusal [or continuation] of life support systems like artificial respirators or ventilators that maintain continued operation of the heart and lungs after the cessation of brain function. Although many clients refuse such measures, some may specify that everything should be done to prolong life regardless of the cognitive or physiological condition.

In contrast to the health care proxy, which is usually limited to naming a person to act for the incapacitated patient, the advance directive is specific as to the declarant's wishes and should be customized for each client. This may be a difficult matter for the practitioner to raise and discuss, but it is often even more difficult for the client to talk about with his or her family. Doing so, though, is crucial because it allows the client to focus on these issues when he or she is in good health and able to think rationally and dispassionately, and it provides guidance to the person named as proxy or agent. The client may have strong feelings about these issues, and the advisor should elicit their expression. This is especially true with respect to the subject of organ donation.

Organ donation. An integral part of personal estate planning is to ascertain the client's wishes about donating his or her organs or tissues, and if so, to what extent. As in the case of health care directives, this may be a difficult question to explore. Nevertheless, the advisor should raise this issue so that the client can consider it while competent and able to resolve it.⁶ The planner must, of course, be sensitive to any cultural, religious, and ethnic differences that might influence specific decisions by clients, as well as be aware of his or her own biases.⁷

Why is the issue of organ donation important? Most significantly, because it is the practitioner's responsibility to ascertain and implement his client's wishes. But there is also a public interest in this matter, as evidenced by the extensive waiting lists for such a large number of various human organs. Attorneys should become knowledgeable about the law and practice of organ and tissue donation, and thus increase the chances that a client's intentions will be both noticed and implemented.⁸ Estate planners are in a unique position to help solve one of the major causes of the shortage of donated organs and tissue—the failure to properly identify and refer prospective donors.

The accelerating increase in organ transplants over the last 30 years has created an escalating shortage of available human organs. As noted above, there are now more than 45,000 people registered on the national organ waiting lists of the United Network for Organ Sharing (UNOS) for

kidney, liver, pancreas, lung, intestine, heart, or multiple organ transplants. Approximately 31,700 are waiting for kidneys, 6,100 for livers, 3,500 for hearts, and the balance for other organs. ⁹ Estimates are that one-third of those on the waiting list for certain lifesaving organs (e.g., hearts) will die before an available organ is located. Although transplantation is initially expensive, it is often more cost-efficient overall than various alternatives, such as maintaining end-stage renal disease patients on continual dialysis year after year. ¹⁰

Legislation has recently been enacted (Health Insurance Portability and Accountability Act of 1996, H.R. 3103) which calls for the IRS to include organ and tissue donation information with income tax refund payments made from 2/1/97 through 6/30/97. This information will consist of a document that (1) encourages organ and tissue donation, (2) includes a detachable organ donation card, and (3) urges recipients to sign the donor card and to discuss with their families their desire to be an organ and tissue donor.

The legal framework

Uniform Anatomical Gift Act. The Uniform Anatomical Gift Act (UAGA) was first promulgated in 1968 by the National Conference of Commissioners on Uniform State Laws as a model organ donation act. ¹¹ By 1973, every state and the District of Columbia had enacted, in part or whole, some version of an anatomical gift act. ¹² UAGA provides that individuals who are of sound mind and at least 18 years old may donate all or part of their bodies at death. The donation may be for transplantation, therapy, or medical research, and may be made to a hospital, physician, or surgeon; a procurement organization; an educational institution; or even a designated individual.

If a decedent has not executed an anatomical gift form or indicated opposition to such a gift, UAGA provides that certain people may authorize a gift of all or part of the decedent's body. These persons fall within six hierarchical classes, which are, in order of priority: a spouse, adult son or daughter, parent, adult sibling, grandparent, guardian, or any other person who is authorized or under obligation to dispose of the body. Such an individual may authorize the gift, however, only if (1) no member of a prior class is available at the time of death and (2) there is no actual notice of opposition by any member of the same or a prior class.

Most states require that anatomical gifts for medical research, therapy, or transplantation be made by written document like a will, donor card, or designation on the back of a driver's license. These documents are good evidence of the donor's intent. Even though they may be validly executed, however, at death the hospital will almost always require written consent from the next of kin.

If the anatomical gift is made through a will, that gift becomes effective on death, and removal of the organs does not have to wait for probate. It is *not* recommended that the donation be made by will because the medical need to act quickly (within hours of death) might be frustrated due to difficulty in locating the will. While the 1968 UAGA required that an organ donor card be signed in the presence of two witnesses, today witnesses are no longer required unless the intent is only orally expressed. The donor may amend or revoke a gift at any time by an oral or written statement. On donation, UAGA requires that the organ or tissue be taken without unnecessary mutilation and that the decedent's body be returned to the family or person who is under obligation to dispose of the body. Further, any person who acts in good faith in accordance with UAGA or any state's or nation's anatomical gift laws will not be liable for civil damages or subject to criminal prosecution for his or her act.

As a matter of common practice, even if documentation for the donation exists, physicians always seek the permission of family members. While the law of some states provides that the wishes expressed by the decedent cannot be overridden, it is customary for medical providers to abide by the wishes of the family.

Routine inquiry and required request. The 1987 UAGA added a new section entitled, "Routine Inquiry and Required Request; Search and Notification." ¹³ This section requires that a hospital ask

each patient on admission whether he or she is an organ or tissue donor. If the answer is affirmative, the hospital is to request a copy of the document of gift. If the answer is negative, the hospital, with the consent of the attending physician, must discuss with the patient the option of making or refusing to make an anatomical gift. If the patient is at or near death and there is no record that an anatomical gift has been made, the hospital is directed to consider approaching the next of kin about donation. The first two states to pass this "required request" legislation were New York and Oregon in 1985. But within seven years, 46 states and the District of Columbia had enacted some form of required request legislation.¹⁴ A federal law, The Patient Self-Determination Act, requires those hospitals and facilities that participate in Medicare and Medicaid programs to have procedures that assure patient participation in treatment decisions by advance directives and other means.¹⁵

Although these legislative measures are positive in their attempt to ascertain and document patients' wishes, in practice they have not been as successful as hoped, primarily due to the lack of enforcement by the staffs of many hospitals and other health care providers.

Determination of death. With the development of effective artificial cardiopulmonary support for severely brain-injured persons, some confusion has been created during the past several decades about how death is defined. In August 1968, the Harvard Ad Hoc Committee on Irreversible Coma published the clinical characteristics of brain death, including the neurological criteria (i.e., coma, no brain stem reflexes, 24 hours of observation, and a flat electroencephalogram (EEG)). The Committee declared that when treatment is stopped in a brain dead person, it is stopped not because therapy is futile, but because the patient is already dead.¹⁶ The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended, and in 1980 the National Conference of Commissioners on Uniform State Laws promulgated, the Uniform Determination of Death Act (UDDA), which defined death. UDDA provides that "an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."¹⁷

Thus, in accordance with this uniformly accepted definition, death is determined by the absence of all brain activity. In such cases, circulation and respiration may be maintained by artificial means in the host body only to preserve the organs so that they are viable for transplantation.

Forty-four states and the District of Columbia have enacted statutes recognizing irreversible cessation of all brain functions as an acceptable method for determining death for legal as well as medical purposes. Six states (Arizona, Massachusetts, Nebraska, New Jersey, New York, and Washington) recognize "brain death" by judicial determination rather than by statute.¹⁸ It is important to recognize that "brain dead" is the same as "dead"; the only difference is that in a "brain dead" patient, respiration and circulation can be and are being maintained only by artificial means.

National Organ Transplant Act. In 1984, Congress enacted the National Organ Transplant Act (NOTA).¹⁹ This statute established both a Task Force for Organ Procurement and Transplantation and a Division of Organ Transplantation, which is within the Department of Health and Human Services (DHHS) division of the Health Resources and Services Administration (HRSA). The Secretary of Health and Human Services is charged by statute to create a task force to study the issues, award contracts for an Organ Procurement and Transplantation Network (OPTN), and establish a Scientific Registry.

The OPTN has awarded, and renewed, a contract to UNOS, which conducts various projects to meet the federally established goals of the OPTN and the Scientific Registry. The OPTN objectives are to (1) improve the effectiveness of cadaver organ procurement and distribution, (2) increase patient access to transplantation technology, and (3) improve the system for sharing organs. OPTN is also responsible for approval of quality control and the maintenance and improvement of the professional skills of those involved in organ procurement and transplantation.

Organ Procurement Organizations. NOTA affirmed the establishment of the Organ Procurement

Organizations (OPOs) for procurement and coordination within their designated service areas and for establishing a priority list of recipients. The approximately 70 regional OPOs are at the heart of the organ donation system. These organizations, designated by the Secretary of Health and Human Services, are members of the OPTN; they coordinate the procurement and transplantation process at the local level throughout the country.

The OPO staffs are called into the hospital to organize the consent process after a physician has declared brain death and a family has decided to donate. The OPO arranges for recovery and placement of donated organs, including surgical retrieval, tissue typing, maintenance of lists of tissue characteristics of potential recipients, and transportation of the organs to transplant centers.²⁰ The OPO may also provide training for hospital personnel and designated requestors to assist in obtaining donor consent and evaluating the donor to ensure medical suitability and confirmation of brain death.

How organs are allocated. The transplant system operates by means of a nationwide network of organizations that match the organs donated to potential donees. UNOS maintains a national computer list of patients waiting for kidney, heart, heart/lung, liver, pancreas, and other organ transplants. Moreover, UNOS maintains a computer-assisted organ allocation system and an Organ Center, which allows the transplant program 24-hour-a-day access to the donor/recipient matching system. This list of potential transplant recipients, together with its information pertinent to matching them with donors, is known as the "waiting list."

UNOS requires that all cadaveric donors be matched against this waiting list. After consent is given by a donor or his family, information about the donor is entered into the UNOS computer-match program. The computer rules out potential recipients having incompatible blood types and body size. It then uses a ranking system to calculate the priority for each patient-donee remaining on the list. A list of potential recipients is printed, with patients ranked in descending point order. The priority score is determined by a number of different variables specific to the type of organ to be transplanted. For example, for kidney transplants, waiting list points are assigned according to (1) time on the waiting list, (2) age (if the recipient is under 19), (3) degree of histocompatibility with the donor, and (4) other indices of immunological compatibility.

Because time is crucial, once an organ is removed from the donor, current policy requires that the organs be offered first to local patients (i.e., within the service area of the host OPO) with highest priority. If no suitable local recipients are available, organs are then shared regionally, and finally nationally.²¹ Every attempt is made to ensure that the criteria for selection of transplant recipients is uniform and fair, and precludes any bias based on race, social class, sex, or other invidious criteria.

Voluntary nature of the donation system

The current organ donation system in America is premised on "encouraged volunteerism," which recognizes that organ donation is legally permissible where the donor or his family has freely (i.e., without coercion or undue influence) agreed to give an organ for transplantation or medical research. The extent of one's right to donate one's body or parts and organs is regulated primarily by state law. The common law right to donate human organs evolved from the common law recognition of the right of a surviving spouse or next of kin to control or determine the disposition of the cadaver of a deceased relative for burial purposes.²²

Financial considerations and restrictions. NOTA specifically prohibits buying or selling organs for valuable consideration in interstate commerce and imposes a penalty of \$50,000 or five years imprisonment, or both, for violation.²³ Similarly, UAGA, as revised in 1987, makes it a felony to "knowingly for valuable consideration purchase or sell" cadaveric organs for transplantation.²⁴ Many states also have laws prohibiting profit from the sale of human organs for transplantation.²⁵ As defined in the federal statute, the term "valuable consideration"

does not include reasonable payments associated with the removal, transportation,

implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ.²⁶

Thus, certain reasonable costs for donors are allowed. The statute does not distinguish between living and cadaver donors, and questions have been raised as to whether certain funeral related expenses (e.g., transportation of a donor's body for burial) may properly be paid or reimbursed by either the organ procurement system or voluntary organizations. Because the intent of the law was simply to prevent profiteering from body parts, many have argued that payment or reimbursement of certain costs would be legal and appropriate. These financial incentives pertain only to the procurement of organs and to the donor or his family; they have no relationship to, and would not affect, allocation of organs.

Some have advocated an experimental change in the law to permit an exemption for a limited onetime death benefit payment for donation (with a maximum such as \$1,000).²⁷ It is asserted that such payment or other nominal reimbursement to the donor's family would act as a reasonable incentive to families and thereby increase the number of organs donated, expand the organ donor pool, and save many more lives. The various persons involved in the transplantation process (recovery and transplant surgeons and their teams, hospital staff, and transplant coordinators) are compensated, and the public cannot be expected to tolerate payment to everyone except organ donors.²⁸

A new Pennsylvania law establishes an "Organ Donation Awareness Trust Fund."²⁹ This statute provides for voluntary contributions of any amount to the fund by means of taxpayers' state income tax returns or in response to public appeal, and for voluntary contributions of \$1 via driver's licenses or identification cards. After payment of expenses, 10% of the fund may be spent by the State Department of Health to pay service providers for reasonable hospital and other medical expenses, funeral expenses, and incidental expenses incurred (up to a maximum of \$3,000) by a donor or his family in making an organ donation. The balance of the fund may be expended for grants to certified OPOs and to provide public information and education about organ donation awareness.

In 1991–1992, the National Kidney Foundation convened a National Consensus Conference, through regional public forums, to survey public opinion. A number of respondents expressed strong support for financial incentives—especially reimbursement of expenses upon the death of the donor, such as limited payment (e.g., \$2,000) of funeral costs. Among the forms of nonfinancial compensation evaluated, the most favored was to be designated a preferred recipient in the event of future need.³⁰

Other financial incentives that have been proposed from time to time include income tax incentives, estate tax deductions, reduction of the donor's hospital bill, a discount on insurance premiums for donors promising donations on death, a contribution to the charity of the donor's choice, preferential access to an organ or tissue bank, and credits for college tuition or vocational training expenses. Some have gone even further and advocated a totally open free market for cadaver organs.³¹ Others have proposed a combination altruistic/commercial organ system that would supplement the existing organ donation system by adding a commercial market component.³²

Presumed consent. An alternative to the current voluntary system, under which it is presumed that a person does *not* wish to donate human body parts, would be a "presumed consent" system, under which the presumption is that the decedent *does* want to donate. Physicians would take needed organs and tissues unless the individual carried a card prohibiting donation or his relatives could rebut a presumption of consent. Presumed consent systems are now in effect, to varying degrees, in 16 countries.³³

A noted ethicist has argued that because the circumstances under which families of a recently, and often suddenly and unexpectedly, deceased person must be approached are psychologically wrenching, it is doubtful that there can be rational deliberation or a truly informed consent or protection of the donor's personal autonomy. Rather, hospitals should be required to use all suitable cadaver organs for

donation unless (1) an individual has placed his or her name on a central computer registry, indicating objection to transplantation, (2) an individual carries a card stating that he or she does not want to be a donor, or (3) family members have objected to donation. Such a policy would improve the system for organ procurement, assure autonomy and free choice, and equitably allocate the burden of decision with respect to cadaver donation.³⁴

Mandated choice. An alternate method of obtaining consent is mandated choice. Under this approach, all competent adults would be required to decide, and prospectively record, whether they wished to become organ donors on their death. Their preferences regarding donation would be recorded on their driver's license renewals or income tax forms or in connection with performing some other task required by the state. Because individuals would have to contemplate their own deaths and the disposition of their bodies, it is argued that this policy would preserve and enhance individual autonomy. The donor's decision, which could not be revoked subsequently by the family, would allow the individual to assert control for himself and ensure that his wishes were honored. Such a system would also reduce the stress placed on families of dead or dying patients by the current system.³⁵

Comprehensive legislation, the Cadaveric Organ Donor Act (CODA), has been proposed to create a national organ donor registry. If enacted, this statute would establish a single national uniform database to record the donative intent of all U.S. citizens and residents—whether as donors, restricted donors, or non-donors.³⁶ This system would be in accord with a recent Gallup poll which showed that an overwhelming 82% of respondents believed it was more appropriate for an individual to make this decision himself rather than leave it to family members.³⁷

Public attitudes. A recent survey by the Gallup Organization on the public's attitudes toward organ donation and transplantation³⁸ revealed that nearly nine out of ten Americans (87%) support the general concept of organ donation. This support correlates positively with higher levels of education. More than two-thirds (69%) reported they are "very likely" or "somewhat likely" to donate their own organs after death. Virtually all respondents agreed that organ donation allows something positive to come from a person's death.

The Gallup survey confirmed a phenomenon of which many estate planners are aware; i.e., that more than one-third of those replying admit to some level of discomfort with thoughts of their own death. But the percentage of those who were uncomfortable thinking about their own death decreased from 47% in the age 18–24 range to 31% in the group aged 55 and older. While the majority of Americans believe that their families support the idea of organ donation, many did not know the views of their relatives on the issue. Barely half of those who said they wanted to become organ donors (52%) had told their family of their wish, although the majority expressed willingness to have that conversation with family members. The fact that family permission is routinely required for organs to be donated further emphasizes the importance of the estate planner's raising these issues and encouraging open family discussion whenever possible.

Issues of concern to clients

The efforts to save life. The practitioner should emphasize that if the client decides to become an organ and tissue donor at death, every effort will be made to save his or her life in case of accident or illness. Donation is considered only after all possible life-saving efforts are exhausted. Practitioners should outline to clients the established medical guidelines that determine brain death and how the determination of brain death is made based on strict medical and legal standards, as described above. Clients should be reassured that death will be declared only after all brain activity has ceased, and only when the circulatory and respiratory systems cannot function without the assistance of artificial means of support. Estate planners should further point out that the physician who certifies a patient's death cannot be involved with organ donation or transplantation.

Religious views. Organ and tissue donation is considered a "gift of life" to others and is supported and endorsed by all major religions. These include Protestantism, Roman Catholicism, Unitarianism,

*Can I choose
what is donated
open case?*

Judaism, Hinduism, Islam, and Buddhism. Of course, if there is any question, the client should be encouraged to consult his or her religious advisor.

Disfigurement of the body and burial arrangements. There is no disfigurement of the body when organs are removed for transplantation. The removal is carried out as a regular surgical procedure and an open casket funeral is possible, if desired.

The removal of organs and tissues will not delay or interfere with customary funeral or burial arrangements. Throughout the transplantation process, the donor's body is treated with utmost respect and dignity.

Costs. There is no cost to the donor's family or estate. Once consent is given for donation, all costs associated with organ and tissue recovery are assumed by the OPO. Funeral and burial expenses, however, remain the responsibility of the family. There is no payment for organ donation.

Change of mind. If the client changes his mind, he should simply tear up the organ donor card or directive and inform his family. If the back of the driver's license has been signed, the donor card portion can be marked out. If registered, the donor should tell the registry to remove his name from its membership.

Organs and tissues that can be donated. The donation can be inclusive (i.e., for all needed organs and tissues), or it may be limited. One person's gift can benefit one, several, or many individuals. The organs needed most are kidneys, hearts, livers, lungs, and pancreases. Tissue donations include eyes, skin, heart valves, bone, and bone marrow. One may also donate the entire body for anatomical study. Besides cadaver donation, in certain circumstances a kidney or bone marrow may be received from a "living related" donor—typically a close family member.

There is no maximum age for organ and tissue donation, and everyone can be considered a potential organ donor, regardless of age or medical history. Donations are sometimes taken from persons over age 70. Many factors are taken into consideration, and each donation is a medical decision unique to the circumstances and conditions.

How to make a donation. The two most important actions a practitioner can take are, first, to advise and encourage the client to discuss the issue of organ and tissue donation with his or her family and, second, to document the client's wishes. If the client does, or does not, want donation, or wants limited donation of only certain body parts, that should be documented. The best way to accomplish this is by (1) having the client sign an organ donor card, (2) including the instruction in the advance directive for medical care, or (3) executing a simple document, such as that shown in Exhibit 1 on this page. Registration or filing of such a document is by no means required or necessary, although the client's desires may best be served by providing a copy of the donor card or advance directive to his family and physician.

Exhibit 1. Organ Donor Declarations

This is to inform you that I want to be an organ and tissue donor if the occasion ever arises. Please see that my wishes carried out by informing the attending medical personnel that I am a donor. My desires are indicated below:

In the hopes that I may help others, I hereby make this gift for the purpose of transplant, medical study, or education, to take effect upon my death.

I give:

/ / Any needed organs/tissues

/ / Only the following organs/tissues

Specify the organ(s)/tissue(s)

Limitations or special wishes, if any

This is a legal document under the Uniform Anatomical Gift Act or similar laws, signed by the donor and the following two witnesses in the presence of each other.

Donor's signature

Donor's date of birth

City and state

Witness

Witness

Next of kin

Telephone

The issue of registration is being explored, and there are several voluntary registries already in existence. It is anticipated that extensive registration may be accomplished through the various state Departments of Motor Vehicles. The organ donor card (or directive) is a legal document recognized in all states, and should be valid if the client moves. The client's wishes regarding organ donation should *not* be included in the will, as the time elapsing from the moment of death until the will is located may cause the donation to be too late to be effective.

The role of the client's family. The significance of the client's discussion with his family, as well as with the estate planner, cannot be overemphasized. Although the documentation described above is important, in most cases the next of kin, in the order of priority outlined earlier, are requested to consent to donation. Some states have statutes which provide that the client's wishes, if expressed by an organ donor card or driver's license designation, cannot be overridden. In practicality, though, enforcing the donor's wishes may become secondary to the physicians' need to deal with the decedent's survivors. The medical team, in its effort to respect the feelings of those who are grieving, often follows whatever course of action the next of kin authorize. This procedure may also provide reassurance of avoidance of liability claims. Studies are being conducted to determine the most appropriate and effective means of approaching families for obtaining consent to donation.³⁹

The emotional impact of organ donation on decedents and survivors has been, and likely will continue to be, one of not only personal fulfillment, but also final fulfillment. Most families feel positive about the donor's decision, saying that the pain for them is lessened and that there is comfort in knowing that this gift gives life and hope to others.⁴⁰ Professional observers report that donation serves as a means of consolation for many families and helps in the grieving process.⁴¹

In 1992, the American Bar Association's House of Delegates adopted a resolution supporting efforts to educate the public about the critical need for organ and tissue donation. It urged the legal community to coordinate within itself as well as with the medical community, including doctors, nurses, paramedics, hospitals, organ and tissue registries, and others committed to organ and tissue transplantation.⁴² Although there is great need, a 1990 study of hospital medical records indicated that despite legal and policy initiatives, only 33% of medically suitable potential donors actually became donors; the results in 1993 were similar. The reasons include failure to identify patients as potential donors, failure to ask the family to donate, and the family's refusal to consent. More public recognition and debate of the issue would certainly improve this situation.⁴³

Conclusion

The ever-expanding role of the estate planner should include discussion and documentation of the client's wishes concerning all aspects of personal health care planning, including health care proxies, advance directives for medical care, and organ donation. Because of the sensitive nature of these issues, considering them may be difficult. The estate planner, however, may be better suited than anyone else to raise them.

Transplantation is one of the most remarkable success stories in the history of medicine. Transplants of organs and tissues, such as kidneys, livers, hearts, pancreases, lungs, bone, skin, veins, eyes, and corneas, are now a widely accepted part of medical treatment. But the need is critical. In the interest of saving the lives of others and helping the client to evaluate and express his or her wishes in this emotionally sensitive area, the estate planner has a clear obligation to address organ and tissue donation.

For further information on organ donation, contact UNOS (telephone: (804) 330-8567, or fax: (804) 330-8596), your local OPO, or your local affiliate of the National Kidney Foundation. All these organizations have informational pamphlets also suitable for distribution to clients.

1

12 UNOS (United Network for Organ Sharing) Update 26 (Apr 1996).

2

"The UNOS Statement of Principles and Objectives of Equitable Organ Allocation," 10 UNOS Update 25 (Aug 1994).

3

Barreira, "Long-Term Care Insurance—A Necessary Option to Consider," 7 NAELA (National Academy of Elder Law Attorneys) News (July 1995).

4

See, e.g., Van Dolson and Whitaker, "Gifts by Agents Under Durable Powers of Attorney," 9 Prob. & Prop. 32 (Sept/Oct 1995).

5

Deciding to Forego Life-Sustaining Treatment, President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, pp. 136-7 (Mar 1993).

6

Collett, "Counseling the Terminally Ill Client," 8 NAELA Quarterly 16 (Winter 1995).

7

Richards, "Ethical, Spiritual and Cross Cultural Implications: Some Considerations for Elder Law Attorneys," 8 NAELA Quarterly 4 (Fall 1995).

8

English, "Gift of Life: The Lawyer's Role in Organ and Tissue Donation," 8 Prob. & Prop. 10 (Mar/Apr 1994).

9

UNOS Update, Note 1 *supra* .

10

UNOS Statement, *supra* note 2, at 28.

11

UAGA of 1968, 8A U.L.A. 63 (superseded by UAGA of 1987).

12

Cate, "Human Organ Transplantation: The Role of Law," 20 J. Corporation L. 71, n. 24 (Fall 1994).

13

UAGA section 5, 8A U.L.A. at 47.

14

Cate, *supra* Note 12, at 73, n. 48.

15

OBRA '90, P.L. No. 101-508, sections 4206, 2751.

16

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newsroom fact sheets



Organ Transplantation and Donation Facts at a Glance

- People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what organs and tissue can be donated.
- On average, 110 people are added to the nation's organ transplant waiting list each day--one every 13 minutes.
- Organs and tissues that can be donated include: heart, kidneys, lungs, pancreas, liver, intestines, corneas, skin, tendons, bone, and heart valves.
- On average, 70 people receive transplants every day from either a living or deceased donor.
- There is no national registry of organ donors. Even if you have indicated your wishes on your drivers' license or a donor card, be sure you have told your family as they will be consulted before donation can take place.
- More than 87,000 people are on the nation's organ transplant waiting list. Almost 700 of them are 5 years old or younger.
- All major religions approve of organ and tissue donation and consider donation the greatest gift.
- On average, 18 patients die every day while awaiting an organ, simply because the organ they needed did not become available in time.
- An open-casket funeral is possible for organ and tissue donors.

Related Internet Sites

Coalition on Donation

www.donatelife.net

National Marrow Donor Program

www.marrow.org

American Red Cross (blood and tissue donation)

www.redcross.org

The Organ Procurement and Transplantation Network

Operated by UNOS under contract with HRSA.

www.optn.org

U.S. Department of Health and Human Services Web site for Organ Donation

www.organdonor.gov