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A Primer on Organ Donation

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A PRIMER ON ORGAN DONATION

LOUIS J. SIRICO, JR.¹

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I. INTRODUCTION

The number of patients waiting for organ transplants is staggering. On March 3, 2003, for example, 53,689 patients were awaiting kidney transplants, 16,916 were awaiting liver transplants, 3,830 were awaiting heart transplants, and 3,828 were awaiting lung transplants.² Still others were awaiting transplants of the pancreas, pancreatic islet cells, intestines, and dual transplants of the kidney and pancreas and the heart and lung.

Over recent years, the number of organ donors has increased only modestly, while the number of patients waiting for organ transplants has grown exponentially. For example, in 1990, approximately 20,000 patients were on the national waiting list.³ As of March 3, 2003, there were 80,517 registrations on the waiting list.⁴ However, throughout that decade, the annual number of cadaveric organ donors increased slightly; during the period of January through November 2002, these donors numbered only 6,186.⁵ (Patients can register at more than one hospital, and a donor can contribute more than one organ.) Because there were not enough donors, only 24,792 organ transplants took place, and, in 2002, 5644 people died while waiting.⁶ Yet, until medical technology develops further, organ transplantation will continue to be the only resort for many dying patients.

¹Professor of Law. Villanova University School of Law. Professor Sirico received a heart transplant in 1995.

²See United Network for Organ Sharing, *Data*, at <http://www.unos.org/data/default.asp?displayType=USData> (last visited April 27, 2004).

³See United Network for Organ Sharing, *Help Save a Life*, at <http://www.unos.org/helpSaveALife/promoteOrganDonation> (last visited April 29, 2004).

⁴See *id.*

⁵See Organ Procurement and Transplantation Network, *Data*, at <http://www.optn.org/latestData/rptData.asp> (last visited March 3, 2003).

⁶See *id.* (also reporting that another 1725 grew too sick to undergo a transplant). For an autobiographical account of one heart transplant recipient, see Louis J. Sirico, Jr., *Life and Death: Stories of a Heart Transplant Patient*, 37 REAL PROP. PROB. & TR. J. 553 (2002).

As organ donation gains increasing attention in our society, attorneys have an obligation to stay current on the issues so that they can properly advise two groups of clients: those who may need transplants and those who, if given reliable information, might consider becoming organ donors. A client in need of a transplant may wish advice about putting his or her affairs in order, and a client who retains an attorney to draft a will may be interested in learning about organ donation. Attorneys should know what a potential organ recipient should consider, how donated organs are allocated, how to become an organ donor, what myths discourage individuals from becoming organ donors, and the role attorneys can play in raising the issue of organ donation with their clients.

II. WHAT A TRANSPLANT PATIENT SHOULD KNOW

When a patient considers a transplant, he or she may be surprised to hear the physician offer this observation: "When you get a transplant, you trade one set of problems for another set of problems."

The physician's point is that a transplant does not return a patient to a time when he or she enjoyed excellent health. Certainly, receiving a transplant is a wonderful miracle, and the patient's health is usually better than it has been in a very long time. However, the patient must still deal with a host of concerns, including the threat of organ rejection, a strict regime of medication and follow-up care, the knowledge that, at some point, the transplanted organ will fail,⁷ and the consequences of living with a weakened immune system.⁸ In light of these concerns, a patient must decide whether to seek a transplant, which hospital to use, how to finance the surgery and related expenses, and how to reduce the inevitable stress and enjoy the gift of life.

For some patients, a transplant may not be the appropriate course of treatment. The patient may have reached an advanced age or may be suffering from a serious illness that has weakened the body so profoundly that a more conservative course of treatment is the better alternative. The patient may not be a good candidate if he or she has a history of alcoholism or drug addiction.⁹ In these cases, the patient may be

According to one study, the pool potential organ donors who are brain-dead is relatively stable. See Ellen Sheehy et al., *Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 667, 672 (2003). Analyzing data for the 1997-99 period, the study found that organs were not recovered from 16 percent of potential donors, because the donors were not identified or because no one requested a donation from the patient's family. When families were asked to donate, 54 percent consented to organ donation. See *id.* Similar issues arise worldwide. See Miguel A. Frutos & Manuel Alonso, *Correspondence, Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 2073 (2003) (discussing how Spain has addressed these issues, particularly by training hospital transplant coordinators in how to talk with families of patients about the opportunity to donate).

⁷For survival statistics, see Organ Procurement and Transplantation Network, *Data*, at <http://www.optn.org/latestData/step2.asp> (last visited March 3, 2003).

⁸Immunosuppressive drugs are necessary to prevent rejection of the transplanted organ. For a discussion of the use and side effects of these drugs, see Michael T. Morley, *Increasing the Supply of Organs for Transplantation Through Paired Organ Exchanges*, 21 YALE L. & POL'Y REV. 221, 231-32 (2003).

⁹For a summary of indications and contraindications for cardiac transplantation, see Temple University, *Heart Failure & Transplant Program, Indications and Contraindications*

unable to show that those addictions are a part of the past and will not surface again. A successful post transplant life requires strict compliance with a regime of medications and follow-up care. If a patient is unlikely to comply, he or she is not a good candidate. For all such ineligible patients, medications and quality care may prolong life, sometimes for many years.

Any patient considering a transplant must come to grips with the reality that he or she will not live as long as a comparable healthy individual. If the patient is not a good candidate for a transplant, the patient may not survive very long with one. In addition, for such a patient, the period after the transplant may prove very difficult with constant trips to the hospital and a poor quality of life. A more conservative treatment may result in a longer, more comfortable life.

For the patient seeking a transplant, the choice of hospital is important. Perhaps the initial question for the patient to ask is how many transplants of this organ has the hospital performed? The best choice is the hospital with a medical staff that has considerable experience with the medical procedure and the care of transplant patients, both before and after the surgery. A fair number of hospitals perform only a handful of transplants of a particular organ each year. Other hospitals may have performed many transplants, but may have recently undergone a major turnover in the medical staff. Although these hospitals may be first rate and have excellent medical staffs, a patient might understandably prefer a hospital with more experience.¹⁰

According to the organization in charge of the national system for allocating organs, the patient should consider “the number of transplants the hospital has done, the survival rate at that hospital, the location of the hospital, the support systems you will have in that area (your family, friends), [and] your general feel about the hospital and its transplant team.”¹¹ Yet, a hospital with a lower survival rate may also be one that has the experience to take on risky patients that other hospitals may decline. Thus it may be more attractive than a hospital that is very conservative in admitting patients.

The prospective transplant patient should also learn about the post-transplant regime so that he or she can prepare for it. That regime includes participating in physical rehabilitation, undergoing frequent testing, at least at the beginning, making changes in diet, renewing personal relationships with family and friends, and developing a positive psychological attitude.¹² The patient may find that most of these matters require only moderate adjustments. Good insurance coverage should cover a moderate period of rehabilitation, the number of hospital visits will decrease

for *Cardiac Transplantation*, at http://www.Temple.edu/heartfailure/html/indications_html (last visited April 29, 2004).

¹⁰For data on hospitals performing the most transplants, see Organ Procurement and Transplantation Network, *Data Transplant by Donor Type, Center*, at <http://www.optn.org/rptData.asp> (last visited March 3, 2003).

¹¹See United Network for Organ Sharing, Transplant Living, *Transplant 101, Selecting a Hospital*, at <http://www.transplantliving.org/transplant101/selectingahospital.asp> (offering advice on this subject) (last visited March 3, 2003).

¹²See United Network for Organ Sharing, Transplant Living, *Transplant 101, Life After a Transplant*, at <http://www.transplantliving.org/transplant101/lifeAfterATransplant.asp> (last visited March 3, 2003).

as time goes by, and changes in diet probably will mean adhering to the standard advice about healthy eating habits.

Fitting back into the family and circle of friends may prove a greater challenge than one might expect. Immediately after a transplant, the patient will probably receive a corticosteroid, typically prednisone, in high doses, which helps prevent organ rejection. The drug frequently leads to mood swings that can puzzle and hurt loved ones who usually are the victims of the patient's bad-tempered behavior.¹³ Patients and their loved ones should have advanced notice that the early months may be a bit rocky.

To prepare for the post-transplant life, the patient and the patient's family should talk with individuals who have already received transplants. Only these veterans can offer a realistic picture of what the future holds. In addition, successful transplant recipients can boost the sagging spirits of patients wondering if the transplant will be successful and if a transplant will make them invalids for life. Some hospitals sponsor support groups in which pre and post-transplant patients can share their experiences. For example, in the Philadelphia area, the support group for heart transplant patients is Second Chance.¹⁴

Patients also must plan for the expense of a transplant and a lifetime of medications and follow-up care.¹⁵ Few individuals can plan on shouldering their expenses out of their salaries and ordinary savings. Most must look to insurance and government programs like Medicare, Medicaid, TRICARE and the Veterans Administration program. Some pharmaceutical companies assist patients who are in financial need.

The patient should investigate all sources of financial aid as soon as possible. For example, the patient will want to know if an insurance policy places a cap on how much a policyholder can receive for a particular procedure or for related expenses over the course of a lifetime. The patient also will want to know if the insurer will treat the procedure as an experimental or investigative procedure that the policy does not cover. Here are some questions that a transplant patient may wish to ask the insurance company.¹⁶

- Is everything all set for my transplant? Is there anything more that I need to do?
- Do I need authorization (approval) from you before I have my transplant?
- Do I need a second opinion? If so, who will pay for it?
- Do I need to notify you when I am admitted?

¹³See PHYSICIANS' DESK REFERENCE 3064-66 56th ed. 2002 (presenting detailed information on prednisone).

¹⁴See Second Chance Heart Transplant Group, Inc., at <http://www.secondchance.mybravenet.com> (providing information on the group); see also Transplant Recipients International Organization, Inc., at <http://www.trioweb.org> (last visited April 29, 2004) (providing information on a group for transplant candidates, transplant recipients, donors, and their families).

¹⁵See United Network for Organ Sharing, Transplant Living, *Transplant 101, Financing a Transplant*, at <http://www.transplantliving.org/transplant101/financingatransplant.asp> (last visited March 3, 2003).

¹⁶See *id.*

- Am I covered for a transplant right now, or do I have to wait a certain period of time (pre-existing exclusion clause)? If yes, how long?

III. ALLOCATING DONOR ORGANS

Both the transplant patient and the potential donor may wish to know how donated organs are distributed among the many individuals needing transplants. The organization in charge of the process is the United Network for Organ Sharing (UNOS), a private nonprofit organization that receives partial funding from the federal government.¹⁷ Every health care facility dealing with transplants is a member of UNOS and supports it financially. Members of UNOS include Organ Procurement Organizations, which coordinate transplants at the regional level.¹⁸

When a patient needs an organ, UNOS places that patient on a national waiting list.¹⁹ When a donated organ becomes available, UNOS ranks patients who medically match the organ, based on such factors as age, the size of the organ, and the blood type. For organs that must be transplanted within a short time, an important criterion is the geographical distance between the organ and the patient. In almost all cases, the search for an organ begins at the local level and then extends to the regional level and beyond when necessary.

Because of the shortage of organs, perhaps the most significant criterion is the health of the recipient. If the patient urgently needs the organ to avoid dying, the patient receives top priority. Thus these patients are very frequently at the top of the waiting lists.

To gain a place on the waiting list, a patient must undergo an evaluation at a transplant hospital. The patient must meet that hospital's criteria, which are primarily based on the UNOS guidelines. The wait then begins. Depending on the specific needs of the patient and the availability of organs in the region, the wait may be lengthy. For example, today, in eastern Pennsylvania, Delaware, and southern New Jersey, hospitalized heart transplant patients are told to expect a wait of one year or longer.²⁰

There is also an underground market for kidneys from living donors. Desperate individuals can travel to other countries to receive purchased kidney, even in countries where the sale of organs is illegal, and then return to the United States for post-transplantation care. According to reports, in Manila, a female kidney carries a price tag of \$1,000, while a male kidney costs almost \$2,000. In India, the average amount that an individual can receive for a kidney is \$1,070. In urban Latin America,

¹⁷See United Network for Organ Sharing, at www.unos.org (last visited April 29, 2004).

¹⁸See United Network for Organ Sharing, *Who We Are, Membership*, at <http://www.unos.org/whoWeAre/membership.asp> (last visited April 29, 2004).

¹⁹For a detailed description of the organ donation process from both the medical and regulatory viewpoints, see Morley, *supra* note 8, at 225-38.

²⁰For information on waiting times for types of organs in various regions of the country, see Organ Procurement and Transportation Network, *Data*, at <http://www.optn/latestData/rptData.asp> (last visited March 3, 2003).

the price of a kidney can exceed \$10,000.²¹ According to one report, a number of Israelis have illegally purchased kidneys in the United States for \$200,000.²²

For the recipient, the risk of purchasing a kidney may be high. According to a recent study of British recipients of kidneys from India—sometimes called “transplant tourists”—such transplants may result in a one in three chance of dying and a 50% chance of a failed graft.²³ However, a less systematic study found good success rates among Israelis and Palestinians who illegally purchased kidneys in a number of other countries.²⁴

For the seller of a kidney, the benefits are not always abundant. A recent study surveyed 305 sellers of kidneys in India where such sales have been illegal since 1994.²⁵ As one might expect, most of the sellers lived below the poverty line. Most reported that since the organ sale, annual family income had declined as had the individual's health. Survey participants were asked what advice they would give to someone like them who was considering selling a kidney. Of those responding, 79% would not recommend making the sale. The authors of the study concluded, “Although patients with kidney failure deserve access to optimal treatment, such treatment should not be based on the exploitation of poor people.”²⁶

On the subject of moving to a market economy in which donors could openly sell organs, a group of prominent physicians has recently considered the proposal and rejected it:

In the final analysis, we believe that a market system of organ donation fosters class distinctions (and exploitation), infringes on the inalienable values of life and liberty, and is therefore ethically unacceptable. In contrast, nonmonetary recognition of donation appeals to our notions of equity and, most important, does not subvert the altruistic social good that must be preserved in a revised system of organ donation. We urge Congress to retain the prohibition established by the National Organ Transplant Act, against payment for organs in the United States.²⁷

Instead, they recommend incentives that would encourage individuals to donate organs. These incentives include donor medals of honor, reimbursement for the

²¹See Francis L. Delmonico et al., *Ethical Incentives—Not Payment—for Organ Donation*, 346 NEW ENG. J. MED. 2002, 2004 (2002).

²²See Michael M. Friedlaender, *Viewpoint, The Right to Sell or Buy a Kidney: Are We Failing Our Patients?*, 359 THE LANCET 971 (2002). According to the same sources, young Iraqi men sell their kidneys for about \$500.

²³See N.G. Inston & A.R. Ready, *Correspondence, The Right to Buy or Sell a Kidney*, 359 THE LANCET 948, 948-49 (2002).

²⁴See Friedlaender, *supra* note 22.

²⁵See Madhav Goyal et al., *Economic and Health Consequences of Selling a Kidney in India*, 288 JAMA 1589 (2002).

²⁶See *id.* at 1592.

²⁷Delmonico, *supra* note 21, at 2004-05. See also 42 U.S.C. 274e(a) (1994) (forbidding the sale of organs in interstate commerce).

funeral expenses for a deceased donor,²⁸ and organ exchanges that permit a donor who wishes to give a kidney to a recipient who is incompatible to donate to a compatible recipient and, in exchange, gain priority status for the donor's intended recipient in the allocating of cadaveric organs. They also recommend giving paid medical leaves to organ donors, awarding the highest priority on the waiting list to previous kidney donors who now need kidneys because of medical problems associated with the donation, and providing life and disability insurance to donors whose health suffers as a result of the donation. Although there is considerable academic discussion about legalizing the sale of organs,²⁹ these authors represent the view of mainstream medicine.³⁰

IV. BECOMING AN ORGAN DONOR

In recent years, efforts to encourage individuals to donate organs have increased dramatically. Sports and entertainment celebrities regularly appear in print and electronic appeals. In addition, organ transplants are becoming a regular staple of television dramas. However donations still come nowhere near meeting the needs of dying patients.

Each year roughly 6,500 organs come from living donors.³¹ However, almost all these donations are limited to kidneys because a human being's second kidney is not essential to one's well being. By contrast, the recently deceased are the source of hearts, lungs, livers, and intestines.³²

Because death must precede an overwhelming number of transplants, a donor must make known his or her desire to donate while still alive. To be sure, close relatives of the deceased may choose to make the donation. However, unless the deceased has made his or her wishes known, the relatives, facing a tragic loss, may hesitate to authorize a donation. Moreover, many hospitals will not accept a donation unless the donor's family consents, even when the donor has clearly expressed his or

²⁸See, e.g., 20 Pa. Cons. Stat. § 8622(b)(1) (Supp. 2003).

²⁹See, e.g., David Kaserman, *Markets for Organs: Myths and Misconceptions*, 18 J. CONTEMP. HEALTH L. & POL'Y 567 (2002); Julia D. Mahoney, *The Market for Human Tissue*, 86 VA. L. REV. 163 (2000); Shelby E. Robinson, Comment, *Organs for Sale? An Analysis of Proposed Systems for Compensating Organ Providers*, 70 U. COLO. L. REV. 1019, 1035-50 (1999) (these three articles providing analyses of market systems for allocating organs).

³⁰See American Medical Association, AMA Policy Finder, *Policy H-140.897: Cadaveric Organ Donation: Encouraging the Study of Motivation* (encouraging pilot studies to investigate the effectiveness of financial incentives, but stating that "payment for an organ from a living donor should not be part of any study" and that "financial incentives should apply to cadaveric donation only, and must not lead to the purchase of donated organs.") at http://www.ama-assn.org/apps/pf_online/pf_online?f_n=resultLink&doc=policyfiles/HOD/H-1 (last visited April 29, 2004).

³¹See Organ Procurement and Transplantation Network, *Data*, at <http://www.optn.org/latestData/rptData.asp> (last visited March 3, 2003) (providing this statistic).

³²Living individuals can donate segments of livers, lobes of lungs (which do not regenerate), and portions of the pancreas (which do not regenerate, but usually do not reduce function appreciably). See Organ Procurement and Transplantation Network, *Donation & Transplantation, About Donation, Living Donors*, at <http://www.optn.org/about/donation/livingDonation.asp> (last visited March 3, 2003) (providing this information).

her intent to donate.³³ Thus it is critical that potential donors make a commitment to donate and communicate this decision to their loved ones.

Although potential donors can communicate their wish to donate with only a verbal statement, a more reliable method is for the individuals to put their wishes in writing.³⁴ Typically, the donor can proceed in three ways. First, in some hospitals, patients seeking admission are given the option of signing documents stating their wishes to be organ donors. Second, in many states, when drivers receive or renew their licenses, they have the opportunity to have "organ donor" printed on the license. Third, potential donors may also sign organ donor cards and carry them in their wallets. These cards are distributed by the national, regional, and local components of the organ donor network.

V. DISPELLING MYTHS ABOUT ORGAN DONATION

Many people have heard the story of the man on a trip who goes to a bar and wakes up in a bathtub filled with ice water. The man sees a note by the telephone advising him not to move and to call the police. The police know exactly what to do because they have encountered this situation before. The man was drugged and his kidneys were removed to be sold in the underground organ market. Of course, the story is a myth.³⁵

Urban myths like this one do not encourage people to have faith in the organ donation program. Lawyers ought to have sufficient knowledge to enable them to respond to clients who have heard similar stories. Here are four myths about organ donations and some corrective information.³⁶

Myth: If I agree to become a donor and then have a serious accident or become extremely ill, my doctor might be so anxious to harvest my organs that he or she will not make the best effort to save my life.

Reality: Your treating physician is not involved in the transplant surgery. Very often, the transplant takes place in a different hospital. Thus, your doctor has no incentive to sacrifice you for a transplant.

Myth: I am too old. My organs are too ancient to help anyone.

Reality: You may be surprised at the upper age limit for donors. For example, kidney donors may be in their 60s, and heart donors may be in their 50s. The age limit seems to keep rising.

³³Organ Procurement and Transplantation Network, *About Donation, The Critical Shortage*, at <http://www.optn.org/about/donation/criticalShortage.asp> (last visited March 3, 2003) (providing this information).

³⁴For a form for making advance directives, see, e.g., 20 Pa. Consol. Stat. 5404 (Supp. 2002).

³⁵See Urban Legends Reference Page, *You've Got to Be Kidneying*, at www.snopes.com/horror/robbery/kidney.htm (accessed Oct 18, 2002).

³⁶See United Network for Organ Sharing, *Newsroom, Media Information, Myths*, at <http://www.unos.org/news/myths.asp> (last visited April 29, 2004) (providing the basis for much of the discussion in the text).

Myth: If I donate an organ, the surgeons will mutilate my body.

Reality: The surgeons remove the organs in a professional manner. An open casket funeral is still possible.

Myth: Why put my loved ones through this difficult ordeal in order to prolong someone's life for a few months?

Reality: Transplants usually succeed. After one year, recipients of cadaveric kidneys have a survival rate of 95 percent.³⁷ After five years, the rate is over 81 percent.³⁸ Almost 70 percent of heart transplant patients are alive after five years.³⁹ As these statistics demonstrate, donating an organ is not an empty gesture, but a gift of life.

VI. THE ATTORNEY'S ROLE

When a patient is seriously ill or near death, he or she may have difficulty thinking clearly about whether to sign an organ donation directive. If a patient has just died, the family may be too emotionally distraught to think clearly. Family members may not know the wishes of the deceased or may disagree among themselves over what the deceased would have wanted. In this case, a hospital may choose not to accept an organ in order to avoid a difficult controversy that might cast an ugly shadow on the donation program.

In contrast to these end-of-life scenarios, the attorney has the opportunity to raise this sensitive issue as part of a discussion on estate planning. At this point, the attorney is speaking with a client who is sufficiently composed and able to make a thoughtful decision. Although the attorney would not think of pressuring the client into making a commitment of his or her organs, the attorney can provide information by explaining the need for organs and addressing the concerns that typically arise.

Rules of professional ethics support the attorney in raising the issue. The American Bar Association Model Rules of Professional Conduct, Rule 2.1 states: "In rendering advice, a lawyer may refer not only to law but to other considerations such as moral, economic, social and political factors, that may be relevant to the client's situation."⁴⁰ The American Bar Association Model Code of Professional Responsibility, Ethical Consideration 7-8 states in part: "A lawyer should exert his best efforts to insure that decisions of his client are made only after the client has been informed of relevant considerations. . . . Advice of a lawyer to his client need not be confined to purely legal considerations."⁴¹

³⁷Scientific Registry of Transplant Statistics, *Transplant Statistics, Annual Report, Data by Organ, Table 6.7*, at http://ustransplant.org/annual_reports/ar02/ar01_main_organ.html (last visited March 3, 2003) (providing this information).

³⁸*See id.*

³⁹*See id.* at Table 11.7.

⁴⁰ABA (1983).

⁴¹ABA (1980). Admittedly, these provisions seem designed for governing communications with a client in a litigation context. However, the underlying principle would seem to extend to nonlitigation settings as well.

Including in the will a desire to donate organs is an inadequate way for the client to make a commitment. Because organs must be harvested immediately upon death, medical personnel cannot wait until someone reads the will. Although a statement in the will that the testator wishes to donate does help to clarify the donor's intent, the need for quick action requires the donor to carry an organ donor card or have "organ donor" stamped on his or her drivers license. In addition, the attorney should encourage the organ donor to inform family members of his or her wishes.

VII. CONCLUSION

An organ transplant can permanently change a patient's perspective on life. These changes may include "shifts in values, beliefs and priorities for life, changes in what is considered important versus unimportant, greater emphasis on the present, decreased preoccupation with the distant future, increased interest in family, friends, one's place in society, greater transpersonal awareness, increased appreciation of life, decreased procrastination, [and] increased awareness of interpersonal relations."⁴² If the recipient experiences such transforming changes, the organ donor and the donor's family should also benefit from such a profound encounter with death and life.

⁴²John Craven & Susan Farrow, *Surviving Transplantation*, 167 (Univ. of Toronto Press 1993). See also Louis J. Sirico, Jr., *supra* note 6, at 573-75 (reaffirming these conclusions).