Anencephalic Newborns as Organ Donors: An Assessment of "Death" and Legislative Policy

Kathleen L. Paliokas
ANENCEPHALIC NEWBORNS AS ORGAN DONORS: AN ASSESSMENT OF “DEATH” AND LEGISLATIVE POLICY

INTRODUCTION

The growing need and increasing shortage of transplant organs for infants have raised the issue of whether parents should have the right to donate organs of their anencephalic newborns before physicians declare the child legally brain dead.\(^1\) Anencephaly is a congenital defect in which development of the brain is arrested, resulting in the absence of either the cerebral hemispheres or the entire brain itself.\(^2\) From a legal standpoint, an anomaly exists in that the anencephalic newborn is not legally “brain dead” because, in most cases, the residual lower brain stem still operates and maintains the vital functions of respiration and heartbeat for hours or even days after birth.\(^3\) The maintenance of these vital functions is precarious,\(^4\) however, and, because of the absence of higher brain coordination capability, the newborn periodically “forgets” to breathe.\(^5\) These interruptions in respiration recur with increasing frequency and cause irreversible damage to organs by depriving them of blood flow and oxygen.\(^6\) By the time the anencephalic newborn is legally brain dead, the organs are no longer viable for transplantation.\(^7\)

---


4. *Id.*


6. *Id.*

7. *Id.*
In most cases, when physicians diagnose a fetus as anencephalic, the parents decide to abort the pregnancy. In some cases, however, the parents choose to have the child and volunteer the infant’s organs for transplantation to derive some good from a tragic situation. Because the use of anencephalic newborns as organ donors before they are declared brain dead is illegal in the United States, these newborns most often are allowed to die naturally, with their organs becoming nonviable for transplant purposes.

The loss of these organs has fueled a legal and ethical debate regarding the policy issues behind both determination of death and organ transplantation: Should the law declare these infants equivalent to brain dead so that their organs may be taken while the organs are still viable? Are anencephalic newborns “persons” with full rights under the law, including the right to bodily integrity and the right to die naturally? Is it unethical not to use such organs to save another life, a life that, unlike the anencephalic, has true potential? If the law declares anencephalic newborns brain dead, will this create a danger that society will slide down a slippery slope toward the utilitarian use of one human being for the benefit of another?

This Note examines the policy questions surrounding the use of anencephalic newborns as organ donors before they are declared legally brain dead. First, it defines and describes the medical condition of anencephaly. Next, it surveys the legal status of

8. Shewmon, Capron, Peacock & Schulman, The Use of Anencephalic Infants as Organ Sources, A Critique, 281 J. A.M.A. 1773, 1774 (1989) (Of the total detected anencephalic fetuses, 95% are electively aborted.); see Foreman, supra note 1, at 1.
9. E.g., Shewmon, supra note 8, at 1774; Meyer, A Choice, Not a Dilemma, NEWSDAY, Mar. 4, 1988, at 90; Dunn, supra note 1; Rovner, supra note 1, at 16.
10. Blakeslee, Law Thwarts Efforts to Donate Infant’s Organs, N.Y. Times, Sept. 9, 1986, § C, at 1, col. 1 [hereinafter Blakeslee, Law Thwarts Efforts]; see Blakeslee, Infant Transplant Program is Halted to Reassess Issues, N.Y. Times, Aug. 20, 1988, § 1, at 7, col. 1 [hereinafter Blakeslee, Infant Transplant]. In August 1988, Loma Linda University Medical Center suspended its program of placing anencephalic newborns on respirators for one week to preserve organs for transplantation. Under the program, anencephalic newborns received life support for seven days after birth. If the anencephalic newborn met brain death criteria within that time period, its organs were taken; if it did not, life support was removed and the newborn permitted to die naturally. Of eleven anencephalic newborns placed on life support, only one met brain death criteria within the one-week time period, creating fears that life support was actually strengthening brain stem function and prolonging life. Id.
anencephalic newborns by focusing on current federal and state regulations regarding the definition of death, organ transplantation, and the privacy rights of parents and children. The Note then summarizes the competing policy interests through a balancing of interests analysis, and in conclusion suggests a legislative framework that allows taking the anencephalic newborn's organs while both safeguarding against possible slippery slope consequences and maintaining the dignity of the anencephalic newborn.

**MEDICAL BACKGROUND**

The prevalence of anencephalic births has been declining steadily over the past several decades.\(^\text{12}\) A conservative estimate suggests that in the late 1980s approximately 1,125 anencephalic infants are born in the United States every year, averaging 0.3 per 1,000 births.\(^\text{13}\) Two-thirds of these anencephalic infants are still-born.\(^\text{14}\) Of the one-third born alive, studies show that only 40% will survive longer than twenty-four hours, with 35% of these surviving newborns expected to be alive on the third day and only 5% alive on the seventh day.\(^\text{15}\) These figures demonstrate that most anencephalic newborns do not survive the first twenty-four hours after birth, and of those that do, only a few survive a week’s time.\(^\text{16}\)

The devastating nature of anencephaly guarantees a low survival expectancy. Anencephaly is a congenital defect involving the central nervous system in which the brain never completely develops.\(^\text{17}\) At a minimum, the cerebral hemispheres are missing and in some cases the entire brain, including the brain stem, is absent.\(^\text{18}\)

---

13. *Id.* Other recent sources suggest that approximately 2,000-3,000 anencephalic infants are born in the United States every year, averaging one out of every 1,000 births. See, e.g., Goldsmith, *Anencephalic Organ Donor Program Suspended; Loma Linda Report Expected to Detail Findings*, 260 J.A.M.A. 1671, 1672 (1988); *Manipulating Death, supra note 1*, at 3; Capron, *Anencephalic Donors: Separate the Dead from the Dying*, HASTINGS CENTER REP., Feb. 1987, at 5.
18. *Id.*
As the above figures suggest, the medical prognosis for anencephalic newborns is certain death and the diagnosis is almost never ambiguous.\textsuperscript{19} The diagnosis is self-evident because the anencephalic newborn has no skull above the forehead, no cerebral hemispheres and no cerebral cortex; the brain, when it is present, consists of a small portion of the brain stem resting on top of the spine.\textsuperscript{20} The absence of an intact skull leaves the brain exposed to infection, thus lowering significantly the newborn’s potential for survival.\textsuperscript{21} In addition to the threat of infection, an anencephalic newborn’s length of survival depends on the strength of its brain stem’s ability to function.\textsuperscript{22}

Similar to a cable the size of the little finger, the brain stem connects the upper brain to the spinal cord and serves as a communication center for the central nervous system.\textsuperscript{23} It controls the autonomic functions of respiration and circulation.\textsuperscript{24} All anencephalic newborns begin to die as soon as they are born because the brain stem intermittently fails to support the vital functions of respiration and circulation, which in turn deprives vital organs of their oxygenated blood supply.\textsuperscript{25} These intermittent interruptions recur more and more frequently until the newborn dies.\textsuperscript{26} By the time of

\textsuperscript{19} See Arras & Shinnar, Anencephalic Newborns as Organ Donors: A Critique, 259 J. A.M.A. 2284, 2284 (1988); Foreman, supra note 1, at 1; Blakeslee, Law Thwarts Efforts, supra note 10, at 9, col. 3. But see Capron, supra note 13, at 6-7. Capron notes that although neurologists usually diagnose anencephaly accurately, cases of long survival in which an initial diagnosis of anencephaly was later discovered to be inaccurate do exist. One such misdiagnosed newborn actually had hydranencephaly and another amniotic band syndrome; both of these conditions mimic anencephaly. Id. Capron recognizes, however, that the danger of misdiagnosis itself does not pose a significant enough risk to eliminate anencephaly as a possible category on which to base a declaration of death. Id.

\textsuperscript{20} Blakeslee, Law Thwarts Efforts, supra note 10, at 9, col. 3.


\textsuperscript{22} Capron, supra note 13, at 7.


\textsuperscript{24} Id. § 2:2.

\textsuperscript{25} Blakeslee, Law Thwarts Efforts, supra note 10, at 9, col. 4.

\textsuperscript{26} Rovner, supra note 1, at 16.
death, the discontinuous blood flow has irreversibly damaged the newborn's organs, making them nonviable for transplant purposes.27

**CURRENT LEGAL STATUS OF ANENCEPHALIC NEWBORNS**

**Definition of Death**

Some state legislators have proposed defining anencephalic newborns as "dead" as a limited exception to the legal definition of brain death.28 They reason that if anencephalic newborns are so defined, no legal or ethical dilemma regarding removal of the newborns' organs exists because, theoretically, the removal would be the same as taking organs from a corpse. By extending this analogy further, they could also argue that the anencephalic newborn is nonviable like a corpse in that, in view of the certainty of death, the newborn has no potential for life. Despite the uneasiness of labeling a breathing newborn dead, one can see the evolution to this line of reasoning through the history of the definition of "death."

**Common law**

Traditionally, courts defined death as the irreversible cessation of all vital functions, specifically circulation and respiration.29 This definition became known as the heart-lung definition of death.30 Courts viewed death as an *instant* in time and, in the interest of continuity and simplicity, delineated death as the specific moment when the heart stops and respiration ends.31 In contrast to the legal perspective, the medical profession saw death as a continuing *process*, with some authorities believing that different kinds of

---

27. Id.
28. Blakeslee, *Law Thwarts Efforts*, supra note 10, at 9, col. 5; see infra notes 70-72 and accompanying text.
30. Id. The traditional legal definition of death on which courts relied until the 1960s was: "The cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc." D. MEYERS, *supra* note 23, § 3:1 (quoting *BLACK'S LAW DICTIONARY* 488 (4th ed. 1968)).
death occurred at different times.\textsuperscript{32} Medical standards for determining death varied within the different disciplines of the medical profession.\textsuperscript{33} Even had the courts acknowledged death as a process, they still would have needed to pinpoint a specific final instant for legal purposes. The heart-lung definition came under scrutiny with the advent of modern technology that altered the concept of death.\textsuperscript{34} Legal death began to take on new dimensions as a result of a clearer understanding of the process of death itself.

From a medical standpoint, man dies in stages.\textsuperscript{35} Death is a progression beginning with clinical death, when respiration and circulation cease.\textsuperscript{36} Following almost immediately is brain death, when brain sites successively cease to function.\textsuperscript{37} Biological or bodily death follows, when all components of the brain, including the brain stem, are dead.\textsuperscript{38} Finally, cellular death occurs when tissue dies.\textsuperscript{39} Cellular death takes place at different speeds in different organs, and the period between biological and cellular death provides the time needed for a successful transplantation.\textsuperscript{40}

During the brain death period, the brain itself dies in stages with the cerebral or higher function centers, including consciousness and intelligent thought, dying first and the lower centers, including the brain stem, which maintains respiration and circulation, dying last.\textsuperscript{41} If the higher centers are damaged, consciousness is lost permanently; heartbeat and respiration functions, however, can continue independently for a short time, or indefinitely with artificial

\textsuperscript{32} Friloux, \textit{supra} note 29, at 10-11.

\textsuperscript{33} \textit{Id.} at 11. Common medical standards used to approximate the time of death include the development and degree of the following: post mortem lividity, post mortem rigidity, loss of body heat, lysis of rigidity, clouding of the cornea and use of enzyme essay. \textit{Id.}

\textsuperscript{34} \textit{See infra} text accompanying notes 49-50.


\textsuperscript{36} \textit{Id.}

\textsuperscript{37} \textit{Id.} at 379.

\textsuperscript{38} \textit{Id.}

\textsuperscript{39} \textit{Id.}

\textsuperscript{40} \textit{Id.} Authorities have also characterized the process of dying as two phases. The first phase, known as clinical death, involves the cessation of all the body's vital functions. The second phase, or biological death, involves the loss of cellular functions. D. Meyers, \textit{supra} note 23, § 2:1.

\textsuperscript{41} Hirsh, \textit{supra} note 35, at 379.
Resuscitation can be successful, with full recovery, after clinical death and before brain death because the higher function centers have not yet been damaged. During the dying sequence, humans reach a point of irreversibility when medical technology can do nothing to restore life, and physicians ordinarily diagnose this point as death. At this point, the complete deterioration of brain tissue no longer warrants applying extraordinary measures to keep the body alive.

The consequence of the common law heart-lung definition of death was to minimize successful organ transplants because doctors feared liability if they removed organs while a patient still had the vital functions of heartbeat and respiration. If surgeons waited until heartbeat and respiration ceased, organs began to deteriorate because they could withstand only a limited time period without oxygen. The success of transplantation depended in part on the speed with which transplant surgeons removed the organs from the donor.

Modern medical technology, however, allowed physicians to artificially sustain respiration and heartbeat indefinitely, even when no possibility for restoring higher brain function or consciousness existed. Heartbeat and respiration thus could no longer serve as criteria for defining death; otherwise physicians could restore or revive "life" by artificial means. Society required a new and more modern definition of death.

42. Id. Cerebral tissue dies within four to six minutes of being deprived of oxygenated blood, while brain stem tissue can survive significantly longer. D. Meyers, supra note 23, § 2:2.
44. Id. at 379.
45. Id. at 379-80. Complete irreversible cessation of the function of brain tissue, called brain death, occurs within 10-20 minutes of deprivation of oxygen. D. Meyers, supra note 23, § 2:2.
47. Hirsh, supra note 35, at 382. Generally, brain tissue is most sensitive to an interruption of oxygenated blood flow and will suffer irreversible damage within five minutes of oxygen deprivation. The kidneys can function for up to an hour after clinical death, and the cornea and skin can survive several hours. The heart and liver can last up to 30 minutes after oxygen deprivation. D. Meyers, supra note 23, § 2:3.
49. Friloux, supra note 29, at 16.
50. Hirsh, supra note 35, at 397.
Modern view

The need for new and standard criteria for defining death grew out of modern technology and the desire to preserve viable organs for transplantation. By the late 1960s, medical tests showed that a complete absence of brain functions could provide an accurate way to establish the same physiological state of death for patients sustained on life support systems as the absence of cardiopulmonary activity in patients not on life support. The new concept called “brain death” defined death as the total and irreversible cessation of all functions of the entire brain, including the brainstem. The phasic dying process of the brain, however, required reliable and workable criteria to diagnose the total absence of brain functions. Although no clear consensus exists as to what criteria must be met, the “Harvard” criteria represent the most widely accepted diagnostic requirements to confirm brain death. These criteria require a concurrence of four conditions: “(1) unreceptivity and unresponsivity (to externally applied, intense stimuli); (2) no movement or breathing; (3) no reflexes; and (4) a flat or isoelectric electroencephalogram [EEG].” Most jurisdictions adopting brain death statutes leave promulgation of diagnostic criteria for determining brain death to the medical profession so that it may adapt the criteria to the evolution of medical knowledge and technology.

51. Id. at 381. The Ad Hoc Committee of the Harvard Medical School, appointed to reexamine the definition of death, gave two reasons for proposing a new definition of death: (1) improved means of resuscitation and support of irreversibly brain damaged individuals that allow vital functions to continue at great emotional and psychological cost, and (2) the difficulty of obtaining transplant organs under the traditional definition of death. See Annas, supra note 46, at 20.
52. Capron, supra note 13, at 6.
53. Id.
55. Id. § 4:3. Harvard’s Ad Hoc Committee on the Definition of Death issued its report containing brain death criteria requirements in August 1968. Id. § 4:4. Because of the lack of a clear medical consensus of what these diagnostic criteria should be, the existence of brain death was, and continues to be, a question of fact based on medical testimony. Id. § 4:10.
57. See D. MEYERS, supra note 23, § 4:10.
In the 1970s, most states began recognizing statutorily both the common law and brain death standards for determining death.\textsuperscript{58} This consensus demonstrated the need for uniform legislation, and the Uniform Determination of Death Act (UDDA)\textsuperscript{59} arose in 1980. The UDDA states that "[a]n 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."\textsuperscript{60} As of 1987, sixteen states legislatively adopted the statute and two states judicially adopted it,\textsuperscript{61} twenty additional states adopted substantially similar statutes, and high courts in four other states adopted a neurological definition of death.\textsuperscript{62} Most of these brain death statutes simply approve brain death as an acceptable definition of death and leave determination of brain death to medically approved diagnostic procedures.\textsuperscript{63} Under common law, a person was dead when physicians using accepted medical criteria declared him dead, and the accepted medical practice for determining death was absence of heartbeat and respiration.\textsuperscript{64} Because today brain death has become an alternative "accepted medical practice" for determining death and is one the courts have accepted, statutory authority permitting the pronouncement of death when all brain functions have totally ceased no longer exists.\textsuperscript{65} New York City

\textsuperscript{58} See Capron, supra note 13, at 6.


\textsuperscript{60} Id.

\textsuperscript{61} See Capron, supra note 13, at 6.

\textsuperscript{62} See id.

\textsuperscript{63} See D. Meyers, supra note 23, § 4:10. In re Jones (Mora), 107 Misc. 2d 290, 292, 433 N.Y.S.2d 984, 986 (1980), held that courts should limit involvement to a review of "the procedures followed and a determination that the findings are consistent with the established medical criteria . . . . So long as the profession acts within the guidelines of acceptable medical standards, it will be meeting legal requirements. No additional procedures are required, and court authorization is unnecessary."

\textsuperscript{64} Annas, supra note 46, at 20.

\textsuperscript{65} Id. at 21. Brain death criteria simply represent another medical means to ascertain death in addition to the heart-lung definition. Without respiration or circulation the brain will die. When the entire brain, including the brain stem, ceases all functions, the heart and lungs will follow. The mechanical support that can be provided for these vital functions is finite, and cardiovascular collapse will eventually occur, beginning the process of cellular death. All three systems are dependent upon each other and are necessary for survival. D. Meyers, supra note 23, § 4:4.
Health & Hospitals Corp. v. Sulsona\textsuperscript{66} reflects judicial acceptance of this point of view.

In Sulsona, the hospital sought a declaratory judgment defining the "time of death" for transplant purposes under the Uniform Anatomical Gift Act, which governs transplants but does not expressively define death.\textsuperscript{67} The court held that the Act implied a definition consistent with generally accepted medical standards that includes brain death.\textsuperscript{68} The court found that the absence of a clear definition of death had a chilling effect on transplants and that legislative adoption of the Act demonstrated the state's affirmation of its public policy of encouraging anatomical gifts.\textsuperscript{69}

Amending death statutes to define anencephalic newborns as "dead"

In May of 1986, California State Senator Milton Marks introduced a bill to amend the California brain death statute by adding the statement "an individual born with the condition of anencephaly is dead."\textsuperscript{70} The bill caused confusion and consternation among the legislators and eventually failed to meet a legislative deadline;\textsuperscript{71} no one has successfully reintroduced a similar bill to date.\textsuperscript{72} The concern centered predominantly around whether such an amendment would create a slippery slope by opening up an ever-increasing category of "dead."\textsuperscript{73}

Opponents to such an amendment claim that certainty of death based on an absence of independent heartbeat and respiration would be lost because anencephalic newborns can breathe on their own; death would become defined instead by the outlook of survival.\textsuperscript{74} Opponents argue additionally that other neurological conditions, also lethal but with longer survival periods, are concep-

\textsuperscript{66} 81 Misc. 2d 1002, 367 N.Y.S.2d 686 (1975).
\textsuperscript{67} Id. at 1003, 367 N.Y.S.2d at 687.
\textsuperscript{68} Id. at 1007, 367 N.Y.S.2d at 691.
\textsuperscript{69} Id. at 1006-07, 367 N.Y.S.2d at 690-91.
\textsuperscript{70} See Blakeslee, Law Thwarts Efforts, supra note 10, at 9, col. 4.
\textsuperscript{71} Id.
\textsuperscript{72} See Shewmon, supra note 8, at 1774. Various groups, including the California Medical Association, the California Nurses Association and the United Network for Organ Sharing, oppose the creation of special death standards for anencephalic newborns. Id.
\textsuperscript{73} Capron, supra note 13, at 8.
\textsuperscript{74} Id.
tually indistinguishable from anencephaly.\textsuperscript{75} Hydranencephalic\textsuperscript{76} and certain types of microcephalic\textsuperscript{77} conditions result in even more attractive newborn donors because these potential donors live longer, and their organs are consequently more developed.\textsuperscript{78} More importantly, opponents argue, such an amendment would create a "higher brain" standard for determining death by declaring that once the higher functions of the brain are irreversibly lost, a person is dead even if the lower functions of heartbeat and respiration still exist.\textsuperscript{79} Such a standard would mean that a patient such as Karen Ann Quinlan, who lost all higher brain functions and was irreversibly comatose, would be "dead" even though she continued breathing on her own without the aid of life support.\textsuperscript{80} For opponents to the amendment, then, the central question becomes whether society is willing to support a law that defines anencephalic newborns as "dead" for the sole purpose of retrieving vital organs, when the organ removal will in turn cause "death" as we now interpret the term.\textsuperscript{81}

Proponents of the amendment claim alternatively that anencephaly is the only exception legislatures and courts should ever make to the brain death criteria.\textsuperscript{82} They claim that if one views brain and spinal cord defects as being on a continuum of seriousness, anencephaly is unique in that it is off the end of the scale.\textsuperscript{83} The anencephalic newborn has no brain and no possibility of ever achieving higher brain functions because the infant does

\textsuperscript{75} Id. at 7.

\textsuperscript{76} Hydranencephaly is a congenital defect in which the brain develops but is destroyed by disease or infection during pregnancy. Most hydranencephalic infants die shortly after birth, but a few have survived for years. R. Weir, \textit{supra} note 2, at 41-42. Unlike anencephalic newborns, the skulls of hydranencephalic infants are intact and not subject to infection, so they tend to survive somewhat longer than anencephalic infants. Capron, \textit{supra} note 13, at 7.

\textsuperscript{77} Microcephaly covers a variety of neurological conditions including cases in which the cerebral hemispheres fail to develop. Capron, \textit{supra} note 13, at 7.

\textsuperscript{78} Id. at 7.

\textsuperscript{79} Id. at 8.


\textsuperscript{81} Capron, \textit{supra} note 13, at 8; see Hirsh, \textit{supra} note 35, at 399. Hirsh states that equating brain death with death does not necessarily mean that lack of central nervous system function is the sole criteria of death. Brain death merely recognizes that death means impossibility of continued brain function or return to consciousness. \textit{Id}.

\textsuperscript{82} See Arras & Shinnar, \textit{supra} note 19, at 2284.

\textsuperscript{83} Blakeslee, \textit{Law Thwarts Efforts}, \textit{supra} note 10, at 9, col. 5.
not possess the physical structure required to do so. In this sense the anencephalic newborn is physically unique and the limited exception to brain death cannot be broadened if anencephaly is specifically defined. In addition anencephalic newborns meet the philosophical standards underlying brain death when we define death as the irreversible cessation of all functions of the brain.  

Anencephalic newborns and irreversibly comatose patients

Black's Law Dictionary defines natural death as "a death which occurs by the unassisted operation of natural causes"; violent death, on the other hand, is "one caused or accelerated by the interference of human agency" and may be considered homicide. Under the current definition of death, removal of vital organs from anencephalic newborns or non-brain-dead patients is violent death and is illegal. Removal of life support from non-brain-dead patients is not violent death because it will not cause or accelerate the natural death process.

Brain death, in contrast to irreversible coma, is the total destruction or absence of all functions of the entire brain, including the brain stem. In irreversibly comatose patients who are not sustained by life support, some brain functioning still exists in the lower brain and maintains vital functions. Like the anencephalic newborn, recovery of consciousness by an irreversibly comatose patient is impossible, but the "body" is still alive so that neither of

---

84. Foreman, supra note 1, at 1 (emphasis added). "Any pronouncement of death is a statement of the impossibility of continued brain function, return of consciousness and interaction of the patient with his or her environment." Hirsh, supra note 35, at 399.

85. BLACK'S LAW DICTIONARY 361 (5th ed. 1979).

86. Id. The distinction lies in the difference between killing and letting die, one being an affirmative act and the other a passive act. The difference centers around causation, whether the disease or defect leads to death versus whether the act of the intervening agent leads to death. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions, ch. 2, at 63-64, 68 (1983) [hereinafter PRESIDENT'S COMMISSION].

87. See Lovato v. District Court, 198 Colo. 419, 426 n.6, 601 P.2d 1072, 1076 n.6 (1979); In re Conroy, 190 N.J. Super. 453, 464 A.2d 303 (1983). "Patients in a persistent vegetative state have relatively intact brain stem functioning (vegetative functions such as breathing) but no cerebral cortical functioning at all, such as awareness of self or others or any degree of cognition." Id. at 457 n.3, 464 A.2d at 305 n.3 (quoting Cranford, Ethical Viewpoint of a Neurologist, 45 CONN. MED. 722 (1981)).
the two patients is recognized as dead. Unlike the irreversibly comatose patient, however, the anencephalic newborn is dying because its vital functions gradually deteriorate until respiration ceases. This decline begins as soon as the infant is born and initiates a progression toward a certainty of death, which often occurs within days of birth.

**Organ Transplantation**

Under common law, the individual has no property right in his or her body nor an absolute right to dictate the use or disposition of his or her body after death. Relatives receive legal custody of the body to ensure both proper burial and peaceful repose after burial, and possess the right to sue for damages for any harm or indecency done to the body. These standards also bind relatives, who can be held liable for failure to carry out their duty to protect the body. No common law decision or precedent clearly permits an individual to donate organs for transplant purposes. The need to overcome these limitations on the use of postmortem bodies for scientific and medical purposes led to statutory enactments permitting organ donations. Before promulgation of the Uniform

---

89. *See supra* notes 12-27 and accompanying text. The brain stem has in some cases actually recovered or improved after a traumatic injury by healing itself to maintain the vital functions necessary for survival of the individual. This tendency has led to a characterization of the brain stem as a primitive "built-in survival mechanism." D. Meyers, *supra* note 23, § 4:2 (quoting Severns v. Wilmington Medical Center, 421 A.2d 1334, 1337 (Del. Super. Ct. 1980)). Medical testimony establishes that "if a patient with a brain stem injury is kept alive long enough there is generally a tendency to recover functions adequate for a vegetative existence." *Id.* In contrast, the upper brain, which regulates higher functions, is less likely to recover. *Id.* Under the Loma Linda Medical Center program of placing anencephalic newborns on respirators for one week, see *supra* note 10, one of the eleven infants lived for two months after removal from the respirator, prompting doctors to fear that use of the life support promoted survival in a vegetative state. Blakeslee, *Infant Transplant, supra* note 10, at 7, col. 2.
91. *Id.* § 17:5.
92. *Id.* § 17:7. Because of the common law proscriptions, grave robbery became the regular practice for obtaining dead bodies for use in medical research, dissection and education. Early statutes made it a felony to disinter corpses, but the courts were generally more lenient if the offender sought the body for educational rather than commercial purposes. *Id.* § 17:6.
Anatomical Gift Act of 1968, forty-four states had enacted some type of legislation providing for organ donations. The disparity among these statutes created a need for a uniform policy.

No comprehensive federal regulation of organ transplantation exists. State law still controls unless the transplant involves research or is federally funded. All fifty states and the District of Columbia have adopted the Uniform Anatomical Gift Act of 1968 (UAGA), which was designed to promote and facilitate organ donation at death. The UAGA prescribes who may make organ donations, who may receive them, and how the donation must be executed. The UAGA does not, however, define death; most states have enacted brain death statutes that define the time of death, thereby determining when transplant surgeons may remove organs without civil or criminal liability. The UAGA also exempts a transplant surgeon from liability if he acts in good faith when removing organs from a body. In addition, the UAGA requires the separation of the physician who determines death from the physician performing the transplant surgery in order to minimize any potential conflict of interest. In 1987, in an attempt to meet the demand for organs, the National Conference of Commissioners on Uniform State Laws drafted various amendments to the UAGA to

95. See D. Meyers, supra note 23, § 17:10.
96. Id.
101. UNIF. ANATOMICAL GIFT ACT OF 1968 § 7(c), 8A U.L.A. 15, 59-60 (1983). “A person who acts in good faith in accord with the terms of this Act or with the anatomical gift laws of another state . . . is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act.” Id.
102. Id. § 7(b), 8A U.L.A. at 59. “The time of death shall be determined by a physician who tend the donor at his death, or, if none, the physician who certifies the death. The physician shall not participate in the procedures for removing or transplanting a part.” Id. Some states require that two independent physicians confirm the diagnosis of death when it is based on the irreversible cessation of brain function. D. Meyers, supra note 23, § 17:11.
further simplify the donation process. Certain guidelines, however, continue to limit the donation process, including the requirement of donor consent.

Consent

Informed consent of the donor or the donor's next of kin is the most important prerequisite to organ donation. This is seldom a problem with anencephalic donors because parents usually initiate the offer to donate their child's organs in a desire to derive some "good" from a tragic situation. The consent issue becomes important, however, when the focus shifts from the presence of parental consent to protecting the rights of the newborn, whose interests may differ from those of the parents.

Parental consent

As a general rule in cases of consent to medical treatment, in nonemergency situations parental consent is required before a minor may receive medical care. Medical treatment without such consent constitutes a battery. The rights to "custody, care and nurture of the child reside first in the parents," and are based on the constitutional protection of privacy. The United States Supreme Court commented on the role of parental consent in Bowen

104. Clapp, supra note 1, at 14; Rovner, supra note 1, at 16; see supra note 9 and accompanying text.
105. See Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941); Little v. Little, 576 S.W.2d 493, 495 (Tex. Civ. App. 1979). Some jurisdictions recognize exceptions to the requirement of obtaining parental consent prior to the treatment of minors. In some states parental consent is implied in emergency situations. In other jurisdictions, under a "mature minor" rule the court permits the minor himself to consent if, after analyzing the nature and consequences of the treatment, its anticipated benefit to the minor, and the minor's ability to comprehend fully what the treatment entails, the court finds the minor mature enough to decide. E.g., Ballard v. Anderson, 4 Cal. 3d 873, 883, 484 P.2d 1345, 1352, 95 Cal. Rptr. 1, 8 (1971). For a discussion of these two exceptions, see generally D. MEYERS, supra note 23, § 6:2.
106. Bonner, 126 F.2d at 122. But see D. MEYERS, supra note 23, § 6:2 (outlining exceptions to the general rule).
108. Id.
v. American Hospital Association\(^{109}\) saying, "In broad outline, state law vests decisional responsibility in the parents, in the first instance, subject to review in exceptional cases by the State acting as *parens patriae*."\(^{110}\) This parental prerogative is not absolute, however, and does not permit the parents to "expose . . . the child . . . to ill health or death."\(^{111}\) In such cases, the state may intervene under its *parens patriae* power to protect the interests of the infant. Courts have traditionally recognized the well-being of the child as the paramount right.\(^{112}\) Ordinarily, courts will respect the parents' right to privacy and uphold their treatment decision if it falls within the boundaries of accepted medical treatment standards.\(^{113}\) Regarding treatment decisions of severely defective newborns, the courts apply different standards and rarely overturn the decisions of parents and attending physicians.\(^{114}\) In its report, the President's Commission on Deciding to Forego Life-Sustaining Treatment concluded that parents, in consultation with their physician, are the proper decisionmakers regarding treatment of severely defective newborns, but their discretion is limited in that they cannot choose a course of nontreatment that is "clearly against the infant's best interests."\(^{115}\)

A few cases have recognized the requirement of parental consent to surgical invasion of a child for the benefit of another. In *Bonner*

\(^{109}\) 476 U.S. 610 (1986).

\(^{110}\) *Id.* at 627. The Court went on to say:

First, there is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants. Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents. Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children, but may also supervene parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.

*Id.* at n.13.


\(^{114}\) See *id.* § 14:3 (Supp. 1988).

\(^{115}\) President's Commission, *supra* note 86, at 6; *see id.* at 214-23.
v. Moran, a mother sued a physician for assault and battery when the physician performed a skin graft on her minor son, without the mother's consent, for the benefit of the minor's cousin. The court held for the mother, noting that the minor missed two months of school, suffered serious pain and possible permanent disfigurement and did not have a mature enough mind to understand the consequences of his donation. In Zaman v. Schultz, the parents sued a physician for taking considerable quantities of blood from their minor daughter, without parental consent, in order to benefit the wife of the minor's employer. Finding for the parents, the court noted, as in the case above, that the taking did not benefit the minor nor the parents. Both courts focused on informed consent and the inability of the minor to understand and make a reasoned choice. Both courts also presumed, by implication, that in these situations the parents, if given the opportunity to consent, would have acted to protect the best interests of their minor child and denied the physical invasion. Subsequent cases, however, modified this point of view by noting that in some situations the minor's best interests conflicted with the parents' interests, and parental consent alone was not sufficient to permit bodily invasions of a minor. In these cases, and most cases involving incompetents or minors, the court appointed a guardian ad litem to protect the child's or incompetent's interests from the competing interests of parents or society.

Judicial consent

In reviewing decisions regarding medical treatment of minors and incompetents, the courts have used two overlapping standards

116. 126 F.2d 121 (D.C. Cir. 1941).
117. Id. at 123.
119. Id. at 312.
120. Id. at 311; Bonner, 126 F.2d at 122.
121. See infra notes 227-36 and accompanying text.
122. See D. Meyers, supra note 23, § 15:3. The guardian's charge should be to "assure that the interests of the patient are indeed protected by a neutral and detached party wholly free of self-interest." Id. (quoting In re Eichner, 73 A.D.2d 431, 477, 426 N.Y.S.2d 517, 550 (1980), modified, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981)).
of review under the *parens patriae* power of the state.  

Under the "best interests" standard, the court first determines and then acts to protect the best interests of the patient involved.  

Under the doctrine of "substituted judgment," the court substitutes its judgment for that of the individual by first determining the individual's wants and needs and then deciding in the same manner it believes the individual would decide if he or she were capable.  

In *Strunk v. Strunk*, a case in which the donor was an incompetent ward of the state, a Kentucky court of appeals held that a chancery court has sufficient inherent power under common law to authorize the surgical invasion of the ward to benefit another. Under the *parens patriae* power, the court utilized both the substituted judgment and best interests standards of review in reaching its decision. In *Strunk*, a mother sought permission from the court to proceed with the transplantation of a kidney from her 27-year-old incompetent son to his unhealthy 28-year-old brother.  

In attempting to reach the same decision the incompetent would have made, the court substituted its judgment for that of the individual by first determining the individual's wants and needs and then deciding in the same manner it believes the individual would decide if he or she were capable.

---

123. In cases to determine whether to withdraw life support, courts have asserted the power to order the withdrawal of treatment from a patient unable to give consent under several different theories: (1) *parens patriae*; (2) inherent equity power, or the obligation to decide questions of values and rights raised by modern medical technology; (3) legislative statutes conferring authority on the judiciary to make specific decisions; (4) power to exercise and protect the constitutional right of privacy of an incompetent patient including protection from nonconsensual bodily invasions. Annotation, *Judicial Power to Order Discontinuance of Life-Sustaining Treatment*, 48 A.L.R. 4th 67, 79-81 (1986).  


"One way would be to ask, as the *Quinlan* court did, what the defective newborn would decide were he capable of doing so. We might want to ask why a defective child might want to die . . . . But this is already a false question because . . . we are in grave danger of injecting our own values onto the child who has absolutely no basis for the fears and horrors we might have for ourselves in a similar state. We project our values onto the child by this quality of life argument . . . . We are in grave danger of confusing our suffering . . . with that of the child who has never known any other existence. . . ."  


126. 445 S.W.2d 145 (Ky. 1969).  

127. Id. at 146.
have made himself, the court noted that the incompetent was greatly dependent upon his brother emotionally and psychologically and upon his brother's visits to the nursing home; that kidney transplants were highly successful and not dangerous to the donor; and that the incompetent was the only available donor within the family. In light of this overwhelming evidence, the court found the incompetent would have wanted to donate his kidney to his brother.

The court blended the two standards of review by first determining the incompetent's best interests and then presuming he would act in those interests. Because kidney transplant surgery is a major bodily invasion, the court surmised that a potential donor would not consent ordinarily unless some substantial good would result, such as saving the life of a loved one. Courts usually protect incompetents under the substituted judgment doctrine by permitting a bodily invasion and transplant to a sibling only upon a clear showing that the transplant is essential to prevent the sibling's imminent death or will result in a substantial benefit to the donor. Generally, courts have limited the use of substituted judgment to urgent medical necessities in which a high probability of success exists along with a clear duty to act, and the best interests of the donor, not the interests of others, require it.

128. Id. at 146-49.
129. Id.; see Classen, supra note 125, at 461. In a subsequent case based on Strunk, a mother sought court authorization to consent to a kidney transplant from her 14-year-old Down's Syndrome daughter to the girl's younger brother who was dying of renal disease. The court granted permission after finding psychological benefits to the girl based on her close relationship with her brother. Little v. Little, 576 S.W.2d 493, 498-99 (Tex. Civ. App. 1979). But see In re Richardson, 284 So. 2d 185, 187 (La. App. 1973), in which the court denied authorization for a kidney transplant from a 17-year-old incompetent boy to his 32-year-old sister because no evidence was shown that the woman was terminal or that the transplant was required to save her life.
130. See 445 S.W.2d 145, 149 (Ky. 1969).
132. See, e.g., In re Grady, 85 N.J. 235, 264-67, 426 A.2d 467, 482-83 (1981); see also Classen, supra note 125, at 463. A Pennsylvania court refused to force an unwilling donor to donate healthy bone marrow to his cousin who was dying of aplastic anemia. The transplant would have improved the donee's chances of survival by 40-60% and would have involved little discomfort to the donor. The court found that such an intrusion, no matter how minor, without the donor's consent would violate bodily sanctity and could not be compelled. See D. MEYERS, supra note 23, § 17:3 n.14 (citing Santa Barbara News Press, July 27, 1978, at C.14; id., Aug. 11, 1978, at A.5).
Social goals of organ donation

Since the 1950s, pure volunteerism has been the means of obtaining organs for transplant purposes.\textsuperscript{133} Shortages caused by an increasing demand for organs eventually led in the late 1960s to a campaign of encouraged volunteerism that involved massive publicity designed to promote donations.\textsuperscript{134} Volunteerism represented a praiseworthy policy choice in that it encouraged socially desirable virtues, such as altruism and benevolence, without the risk of abusing individual rights or free choice.\textsuperscript{135} Because encouraged volunteerism has failed to meet the increasing need for organs, however, some scholars have suggested a policy of presumed consent in which organs are donated automatically unless the next of kin objects or the donor is carrying a card prohibiting such a taking.\textsuperscript{136} Proponents of presumed consent argue that true informed consent is a charade because bereaved families must make a donation decision under psychologically wrenching conditions in a short period of time.\textsuperscript{137}

In the case of anencephalic donors, when the fetus is diagnosed as anencephalic, the parents choose most often to abort.\textsuperscript{138} When the parents choose to continue the pregnancy with the intention of donating the organs of the newborn, the decision is usually fully informed because the parents have had time to fully consider their decision.\textsuperscript{139} Furthermore, the advantages of aborting often significantly outweigh the advantages of continuing the pregnancy: First, the odds are high the child will be stillborn;\textsuperscript{140} and second, the physical risks to the mother are greater for a normal childbirth

\begin{itemize}
\item \textsuperscript{133} Caplan, Organ Transplants: The Costs of Success, HASTINGS CENTER REP., Dec. 1983, at 23.
\item \textsuperscript{134} Id. at 23-24.
\item \textsuperscript{135} Id. at 24.
\item \textsuperscript{136} Id. at 23.
\item \textsuperscript{137} Id. at 25-26.
\item \textsuperscript{138} Supra note 8 and accompanying text.
\item \textsuperscript{139} In 1987, Loma Linda University Medical Center received 50 requests from parents that they be permitted to donate their anencephalic child's organs. Persistent pleas led the hospital to consider the use of such donors. Blakeslee, New Attention Focused on Infant Donor Organs, N.Y. Times, Dec. 14, 1987, § A, at 18, col. 1.
\item \textsuperscript{140} See Harrison, supra note 3, at 21.
\end{itemize}
This type of fully informed volunteer organ donation thus fulfills the social policy goal of encouraging altruistic behavior and also directly benefits society by preserving the donee's life.

The relative scarcity of infant donors has further augmented a growing demand for pediatric organs resulting from new transplant techniques.142 The difficulty of diagnosing brain death in newborns and the rarity of finding infant donors who have lost brain function but retain other organs intact has led physicians to look to the possible use of anencephalic donors.143 Today, the brain death requirement effectively eliminates the availability of anencephalic organs.144 In October 1986, New Jersey Assemblyman Walter Kern, Jr., attempted to overcome the stringent demand of this requirement by proposing an amendment to the Uniform Anatomical Gift Act that would permit parents to donate the organs of their anencephalic newborn before brain death.145


142. Approximately 2,500 infants a year are born needing a transplant. Colen, supra note 1, at 12. Approximately 1,500 infants a year die without receiving a needed heart or liver transplant. Foreman, supra note 1, at 1. In early May 1987, 243 children under age 5 were awaiting organs, with 24 of the 243 under the age of 1. Up to 50% of potential donees under the age of 2 die waiting for organs. Dunn, supra note 1, at 3, col. 4.

143. Shewmon, supra note 8, at 1773. Diagnostic criteria for infant brain death has not yet been validated and is much more difficult to attain than in older patients. Id. So little is known about the nervous system of newborns less than 7 days old that no accepted brain death definition can be formulated. Blakeslee, supra note 138, § A, at 18, col. 1. A brain death definition is even harder to formulate in anencephalic newborns who lack parts of the brain necessary for diagnostic assessment. Id. Because physicians do not know for certain whether legal brain death has occurred, Loma Linda University Medical Center protocol called for removing anencephalic newborns from life support periodically to see if spontaneous breathing had ceased. Gorman, supra note 1, at 49; see Note, supra note 1, at 1545-46 (outlining the difficulties of determining brain death in young children and anencephalic infants particularly).


145. See Shewmon, supra note 8, at 1774.
Competing policy considerations

The post-mortem transplantation decision generally involves a balancing of two principles: the donor's right to bodily integrity, including ensuring his or her final wishes are followed, and the saving of another human life. In the case of anencephalic newborns, a more accurate description of the transplant decision is the weighing of the preservation of the bodily integrity of one newborn against the social value of saving another newborn's life. Implicit within this balancing test is the correlative issue of whether the legislatures or courts should permit a decedent or next of kin to withhold life from the donee. An evaluation of these competing interests will demonstrate the inherent complexity of the balancing process in anencephalic donor cases. Deciding how to implement a transplant policy that provides maximum benefits for all implicates the broader interests of economics, social policy, criminal liability and ethics.

Economic analysis

Under a strict economic analysis, the balancing factors in every transplant decision break down as follows: On one side is the cost of permitting useful transplant organs to go unused, the lost value of allowing a potential donee to die and the cost of maintaining a potential donee on lifesaving machines. On the other side is the cost of performing the transplant without consent of the donor or next of kin and the value of protecting the next of kin from mental suffering for violation of a relation's corpse. Figures suggest that

146. See Dukeminier, Supplying Organs for Transplantation, 68 Mich. L. Rev. 811, 818 (1970). The prefatory note to the Uniform Anatomical Gift Act lists the principal competing interests in transplantation cases as
(1) the wishes of the deceased during his lifetime concerning the disposition of his body; (2) the desires of the surviving spouse or next of kin; (3) the interest of the state in determining by autopsy, the cause of death in cases involving crime or violence; (4) the need of society for bodies, tissues, and organs for medical education, research, therapy and transplantation.

147. Dukeminier, supra note 146, at 818.
149. Dukeminier, supra note 146, at 821.
150. Id.
the economic cost of not taking a kidney for transplant and maintaining a potential donee on dialysis in the first year is several times that of taking the kidney without consent.\textsuperscript{151} Jury awards in wrongful death cases and wrongful autopsy cases also indicate that juries value human life much more highly than the inviolability of a corpse.\textsuperscript{152}

Anencephalic newborns are not corpses, however, but living beings under the current definition of death. The right against inviolability of the body is much stronger in such cases. The economic balancing must reflect the presence of two lives, one on each side of the scale, and this fact alters the cost/benefit analysis. In most anencephalic donor cases, both the anencephalic newborn and the potential donee have prognoses of certain death. The donation of the anencephalic organ minimizes the total economic loss inherent in two deaths by creating an opportunity to save the donee's life. Due to the permanent loss of higher functions, the anencephalic newborn offers less potential as a resource to society than the donee whose potential for life becomes significantly increased by receipt of the transplant organ. The costs to be balanced rest ultimately on a weighing of the value of allowing a potential donee to die against the mental or ethical cost to society of "taking" a life with less potential.

\textit{Social policy}

The general social policy that saving or preserving life should be given highest priority does not necessarily apply in all cases.\textsuperscript{153} In some situations society approves the sacrifice of human life for specific social purposes, such as in times of war\textsuperscript{154} or when allocating scarce resources.\textsuperscript{155} The metaphor of triage helps clarify the competing principles of social utility—the greatest good for the greatest number—and equality—regarding each life as equal—inherent in these situations.\textsuperscript{156}

\textsuperscript{151} Id. at 823.
\textsuperscript{152} See id.
\textsuperscript{153} Id. at 820.
\textsuperscript{154} Id.
\textsuperscript{156} See id.
Triage grew out of battlefield medicine and is "the practice of sorting patients according to the urgency of their needs under emergency conditions in which such needs are likely to be urgent and medical resources scarce."157 This system focuses primarily on medical needs and medical salvageability and prioritizes patients to receive scarce resources according to need.158 In certain situations, however, social utility factors enter and override medical priority, as in times of war when the priority sometimes is not to assist the more seriously injured first, but to get those less injured back to the front quickly where they can aid the common good.159 Differing moral values underlie these two types of utility: Medical utility recognizes the equal value of life without regard to rank or position in the community, while social utility recognizes the differing value of each individual to the community.160 In the case of the neonatal intensive care unit, commentators who emphasize the social utility factors in a triage situation have stated that "[(b)ecause it is impossible to treat all infants in need, preference should be given those with the greatest hope of surviving with maximal function.]"161 Other commentators criticize this emphasis because it requires both an assessment of the patient's social worth and presents an amorphous definition of "maximal function."162 They point out that the common good, which is the focus of social utility, includes principles and values that are as important as other social goals. For instance, the common good may value equality of life more than the interest of promoting the highest quality of life.163

This conflict between medical and social utility exists within the anencephalic donor issue as well. The transplant situation is an emergency situation because the needed organ is a scarce resource and the donee will die shortly if he or she does not receive it. With

157. Id. at 548.
158. Id. at 551. In the most formal triage settings, patients are also sorted by set categories. Id.
159. Id. at 551-52.
160. Id. at 552-53.
161. Id. at 555 (quoting Jonsen & Garland, A Moral Policy for Life/Death Decisions in the Intensive Care Nursery, in ETHICS OF NEWBORN INTENSIVE CARE 142 (A. Jonsen & M. Garland eds. 1976)).
162. Id. at 556.
163. Id.
anencephalic newborns the question is whether to hasten the death of one life in order to preserve another life. Taking organs from anencephalic newborns before death would be sacrificing a person with no probability of survival for a person with a higher certainty of survival and one of higher maximal function. Under a strict medical utility perspective, the anencephalic life could not be taken because each life is of equal value regardless of social worth. Factoring in social utility criteria, however, requires looking at what action will benefit the largest number.\textsuperscript{164} Saving the donee's life places him or her back into the community where he or she serves as a resource for the common good. Because the anencephalic newborn will die no matter what action is taken, utilizing his or her situation to benefit society as a whole makes social sense.

The question comes down ultimately to a determination of the common good. On one hand is the value embodied in the preservation of the donee’s life at a level of functioning that enables him or her to contribute actively to the community. On the other hand is the value, moral and psychological, of maintaining the dignity and equality of the anencephalic newborn’s life regardless of his or her social worth. Appeals to social utility generally have a heavy presumption against them and ordinarily are justified only in certain situations.\textsuperscript{166} In transplant cases, however, the courts have recognized a need to compromise between medical and social utility principles. Society has placed a high value on scarce organs and has attempted to encourage donations because it recognizes the social utility of saved lives.\textsuperscript{166} In living donor transplant cases, the courts protect the value of equal regard for each life by requiring that a living donor receive a benefit from bodily invasions.\textsuperscript{167} In some cases, this benefit may even take the form of the donor’s spiritual gain from the heroic act of sacrificing one part of the body in order to benefit the mental health of the whole.\textsuperscript{168} Parents of

\textsuperscript{164} See id. at 551-52.

\textsuperscript{165} Id. at 553.

\textsuperscript{166} See Dukeminier, supra note 146, at 818.

\textsuperscript{167} See supra notes 116-19, 131 and accompanying text.

\textsuperscript{168} Dukeminier, supra note 146, at 855 n.172. Often the donor benefits from being permitted to help others, especially when the donee is a close family member. In fact, studies have shown that “donors feel happier and better about themselves in the first year after
anencephalic newborns often seek this type of spiritual gain when
they choose to donate the organs of their infant.169

In the case of anencephalic donors, social policy must balance
these competing principles. Societal consensus must determine
which course of action, preserving the life of the anencephalic new-
born or saving the life of the donee, has a higher value to the com-
mon good. A carefully structured anencephalic donation policy can
mediate between these competing principles and achieve an out-
come that takes into account social priorities in emergency situa-
tions while preserving the dignity of the anencephalic newborn.

Criminal liability

A transplant surgeon may be liable for aggravated assault or
homicide should he or she take an organ from an anencephalic
newborn who has not been declared legally dead.170 Criminal homic-
die refers to the unlawful killing of another human being and is
usually classified as either murder or manslaughter.171 Murder re-
quires malice aforethought172 or deliberate intent to take a life,
whereas the lesser charge of manslaughter does not require deliber-
ation or premeditation.173 Malice exists when the actor intends to
take the life of anyone, including but not limited to the actual vic-
tim.174 A jury can thus convict a transplant surgeon of homicide
even though he or she does not harbor an evil motive toward the
specific donor.175 Nor will a humanitarian or well-intentioned mo-
tive, such as to relieve pain and suffering, absolve an actor from
liability if his or her intent was to end the patient’s life.176 Even if

<sup>169</sup> See supra note 9 and accompanying text.
<sup>170</sup> See Hirsch, supra note 35, at 395.
<sup>171</sup> W. Lafave & A. Scott, Criminal Law § 7.1 (2d ed. 1986).
<sup>172</sup> Id. The common law definition of murder is the “unlawful killing of another ‘living
human being’ with ‘malice aforethought.’” Id.
<sup>173</sup> Id. § 7.9.
<sup>174</sup> D. Meyers, supra note 23, § 7:5.
<sup>175</sup> Id. § 7:6.
<sup>176</sup> Id. The Appellate Division of the New York Supreme Court stated this principle:
“The actor’s motive, no matter how kindly, is legally irrelevant, and this remains true not-
withstanding the fact that the consent of the deceased had been obtained, or that the actor
firmly believed his conduct to be morally justified.” In re Eichner, 73 A.D.2d 431, 450, 426
the victim was near death and the actor merely accelerated its onset, he or she still would be liable.\textsuperscript{177} Consent of the victim cannot serve as a defense, excuse or provocation, nor will it change the characterization of the crime to a lesser degree of homicide.\textsuperscript{178} Under criminal law, one cannot consent to one's own death nor, in some cases, to the infliction of serious bodily injury upon oneself.\textsuperscript{179} Under current law, then, parents of anencephalic newborns cannot consent to the death of their child by the removal of organs for donative purposes. A transplant surgeon likewise cannot claim parental consent nor humanitarian motives as a defense to killing a human being. The transplant surgeon can take organs from an anencephalic donor legally, however, if a statute permits the taking.\textsuperscript{180} Justifiable homicide is defined as "[a]n act which the law positively . . . permits [an actor] to perform."\textsuperscript{181} A legislative enactment exempting transplant surgeons and parents from criminal sanctions in anencephalic donor cases would authorize an act that current law forbids.

When a transplant surgeon takes an organ from a living donor and faces aggravated assault or homicide charges, he or she may claim the common law defense of justification.\textsuperscript{182} The Model Penal Code states that an action is justifiable when "the harm or evil sought to be avoided by such conduct [the donee's death in this case] is greater than that sought to be prevented by the law defin-

\begin{flushright}
\textsuperscript{177} D. MEYERS, supra note 23, § 7:8.
\textsuperscript{178} Id. § 7:9.
\textsuperscript{179} Dukeminier, supra note 146, at 852.
\textsuperscript{180} See id. at 854-55.
\textsuperscript{181} BLACK'S LAW DICTIONARY 778 (5th ed. 1979).
\textsuperscript{182} Dukeminier, supra note 146, at 855. Black's Law Dictionary defines justification as "maintaining or showing a sufficient reason in court why the defendant did what he is called upon to answer, particularly . . . as a defense to criminal charges of assault or homicide . . . ." BLACK'S LAW DICTIONARY 778 (5th ed. 1979).
\end{flushright}
ing the offense charged [the taking of the anencephalic life].”

The judge or jury balances the evils and, in view of the alternatives available, decides whether the plight of the organ recipient in transplant cases outweighs the risk of the donor's death or impairment. In the case of anencephalic donors, a transplant surgeon could argue that the transplant results in a greater overall quantum of good because it saves another life and the parents receive a mental health benefit by sacrificing their anencephalic newborn to aid another. This argument, however, lacks the certainty of lawful excuse that is present with statutory permission to conduct the transplant.

**Ethical principles**

The categorical divisions among philosophers who write about normative ethics parallel the split in the moral perspectives regarding the anencephalic donor issue. The rule-oriented ethicist has pre-set rules that define how members of society ought to behave to preserve society, and he or she looks to these rules to decide specific cases. The consequentialist ethicist, on the other hand, looks at a situation to determine its consequences, whether benefits will result and if so, to whom. Consequentialists are subdivided further. Utilitarians take an empiricist perspective and believe the right action is the one that will provide the greatest good for the greatest number. Situationist ethicists look at individual situations and attempt to work out consequences that are in the best interests of a particular patient.

The Hippocratic rules that underlie the medical profession are “(1) to save or preserve life at all costs, (2) to relieve suffering, and (3) to do no harm to the patient.” With today's technology, the rule of saving life at all costs often conflicts with the other two

---

184. Dukeminier, supra note 146, at 855.
185. Towers, Ethical and Legal Responsibilities of the Physician Toward the Dying Newborn, in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients 228, 232 (1982).
186. Id.
187. Id.
188. Id. at 232-33.
189. Id. at 233.
rules; for example, successful resuscitation of a patient may actually prolong pain and suffering and cause harm to the patient. 190 Before blindly applying a rule, physicians should consider other factors, including potential consequences to, and the best interests of, the patient involved. Regarding application of the rule "to save or preserve life at all costs" in anencephalic donor cases, the question becomes whether the physician should save the life of the donee or preserve the life of the anencephalic newborn. If the physician takes the anencephalic organ, he or she harms the donor. If the physician does not take the organ, he or she, in effect, harms the donee. Some philosophers see no moral difference between the act of letting someone die, which is intentional and deliberate if the actor is in a position to save the life, and the act of killing. 191 Moral responsibility attaches to the act of doing nothing in the same way it attaches to the act of doing something. 192 In the case of anencephalic donors, if the two newborn lives are of equal intrinsic value, the act of killing the anencephalic newborn or of letting the donee newborn die has the same consequence, a lost life, in either case. The utilitarian would favor the transplant because instead of two certain deaths, it provides one certain death and one probable life, a greater quantum of overall good. 193 In contrast, the situationist would focus on the best interests of the anencephalic newborn and the immediate family in deciding on a course of action. 194

Under the general ethical principle of preservation of life, a person should not endanger his or her own life unless he or she acts for the love of another, or the danger results indirectly from his or her own actions. 195 The law parallels this principle by not creating a duty to aid another if such actions would place oneself in dan-

190. Id.  
192. Id.  
193. See Towers, supra note 185, at 232. But see J. Rawls, A THEORY OF JUSTICE 3-4 (1971) ("Each person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override. For this reason justice denies that the loss of freedom for some is made right by a greater good shared by others.").  
194. See Towers, supra note 185, at 232-33.  
195. Dukeminier, supra note 146, at 857.
Society condones an exception to this principle, however, when one acts in self-sacrifice solely from the desire to help others and not for financial gain. Under this principle, parents of an anencephalic newborn are giving up the limited life of their infant in an act of self-sacrifice when they donate the newborn's organs. The motive is purely charitable; the parents receive no gain other than the psychological benefit of acting to aid another. In such cases, society also benefits indirectly from the altruistic acts of its members.

**Privacy Rights**

Every person in the United States is entitled to the protections guaranteed by the United States Constitution including the right of privacy. This right of privacy includes a parental right of discretion in raising their children and the right to exercise their child's privacy rights. A presumption that the parents will act in their child's best interests underlies the exercise of these rights. In the case of anencephalic donors, however, parent and child privacy rights come into conflict.

**Personhood**

The Supreme Court has interpreted the United States Constitution to require live birth as the accepted criterion for recognition as a "person." An anencephalic newborn lacks the physical capa-

---

197. Dukeminier, supra note 146, at 858.
199. See Griswold v. Connecticut, 381 U.S. 479 (1965) (stating that the right of privacy is a peripheral right emanating from the penumbras of several fundamental constitutional guarantees).
200. See supra notes 107-11 and accompanying text.
201. Roe v. Wade, 410 U.S. 113, 158 (1973). In Roe the Court stated: The Constitution does not define "person" in so many words. [The Court then listed each provision in which the word appears.] But in nearly all these instances, the use of the word is such that it has application only postnatally. None indicates, with any assurance, that it has any possible pre-natal application. All this, together with our observation . . . that throughout the major portion of the 19th century prevailing legal abortion practices were far freer
bility of ever achieving higher brain activity, including consciousness and intelligent thought, which many consider the essence of being human. This situation is clearly different from an irreversibly comatose patient who once had higher brain functions but has now lost them, or from the severely retarded or demented individual who still retains some level of consciousness and awareness. If legislatures or courts define anencephalic newborns as "nonpersons" with no legal protection under the fourteenth amendment, surgeons could remove the newborns’ organs for transplant purposes without criminal liability. The problem with this approach, however, is the lack of consensus regarding what constitutes personhood or being human. The law has drawn an arbitrary line on the continuum of human development at the moment of birth to distinguish between abortion and infanticide and has granted the

than they are today, persuades us that the word "person," as used in the Fourteenth Amendment, does not include the unborn.

Id. at 157-58.

202. Harrison, supra note 3, at 21; see Raphael, Handicapped Infants: Medical Ethics and the Law, 14 J. MED. ETHICS, 8, 8 (1988); cf. Note, Brain Birth: A Proposal for Defining When a Fetus is Entitled to Human Life Status, 59 S. CAL. L. REV. 1061, 1069 (1986) (proposing that a fetus should acquire personhood and legal protection at the point when neocortical brain activity begins because intellectual functioning is a uniquely human characteristic). Some scholars suggest criteria for personhood that would exclude anencephalic newborns. See Fletcher, Four Indicators of Humanhood—The Inquiry Matters, HASTINGS CENTER REP., Dec. 1974, at 5-6. Fletcher's four criteria for "personhood" include neocortical function, self consciousness, relational ability, and happiness. He argues that neocortical function is the key to humanness and is necessary for the presence of the other listed traits. Id. According to Fletcher, without neocortical functioning a person is nonexistent. Id. at 6.

203. Harrison, supra note 3, at 22.

[O]ne might argue that the possession of or capacity to exercise rights is dependent on the capacity to experience the consequences of exercising the rights in question. In other words, the capacity to take an interest in something might be crucial to being able to have a right regarding that thing. Since the comatose person cannot know life at all, especially a comatose infant who has never known it, he cannot properly be said to have an interest or a right in this regard at all. As such, no moral wrong is done in not saving his life. On this view, the possession of rights exists along a spectrum; while the comatose person may experience pain or even hunger, and may have rights based on such capacities, he may not have other capacities necessary to having other rights.

abnormal newborn more protection than the abnormal fetus.\textsuperscript{204} Defining anencephalic newborns as "nonpersons" requires certain safeguards including absolute accuracy of diagnosis and prognosis.\textsuperscript{205} The absence of the brain or cerebral hemispheres, however, is always an unambiguous diagnosis.\textsuperscript{206} The strongest policy arguments against this definition are that it demeans the product of human conception and creates a danger of extending the classification of nonperson to other less severely handicapped newborns.\textsuperscript{207}

A better method of dealing with the legal status of anencephalic newborns may be to create a new definition, with the same legal implications as brain death, called "brain absent."\textsuperscript{208} Such a category treats the anencephalic newborn as a person who, because of a physical deficiency, is the equivalent of "brain dead."\textsuperscript{209} Legislatures and courts can narrowly define this category to limit it to anencephalic newborns without risk of it expanding to include those with less severe handicaps.\textsuperscript{210} Because this category treats the anencephalic newborn as a person and a full member of the moral community deserving of respect, transplant surgeons may take the infant's organs only if the taking is done without the infant suffering and without violating the infant's right to die naturally by prolonging life unnecessarily.\textsuperscript{211} Under this definition the anencephalic newborn cannot be maintained artificially solely to recover organs or to serve as a means to benefit another because this would violate the moral law that persons possess an intrinsic worth that society cannot reduce to an instrumental value to others.\textsuperscript{212}

\textsuperscript{204} Raphael, supra note 202, at 8; see supra note 201 and accompanying text. Under well-accepted medical practice, physicians may abort an anencephalic fetus right up until the moment of birth. See Harrison, supra note 3, at 22; Rovner, supra note 1, at 16.
\textsuperscript{205} Capron, supra note 13, at 9.
\textsuperscript{206} See Dunn, supra note 1, at 3, col. 4; supra notes 19-20 and accompanying text.
\textsuperscript{207} Harrison, supra note 3, at 22; see supra notes 73-80 and infra notes 254-61, and accompanying text.
\textsuperscript{208} See Arras & Shinnar, supra note 19, at 2284; Harrison, supra note 3, at 21.
\textsuperscript{209} See Harrison, supra note 3, at 21.
\textsuperscript{210} Id. at 21.
\textsuperscript{211} See Arras & Shinnar, supra note 19, at 2284.
\textsuperscript{212} See id.
Rights conflict

One can define rights as the claims an individual can make against the collectivity.213 In the case of anencephalic newborns, the privacy rights of the parent and the child are in conflict. Only the parent may exercise the child's privacy rights;214 however, in exercising the child's privacy right, including the right to control the child's body, the parents' choice to donate an anencephalic newborn's organs is at odds with the child's natural right to life and treatment.215 The danger inherent in such a choice is that the parents will decide in their own self interest and not the child's.216 Another danger is that focusing solely on the beneficial consequences of taking the anencephalic child's organs will blur respect for the individual rights of the child;217 such an emphasis tends to subvert the constitutional mandate of equal protection of the laws by creating social worth criteria for ending a life.218 Conservatives claim that the principal criterion implicated in treatment decisions is the child's right to life.219 If the state enters the decision process to protect the rights of the child, it interferes with the privacy rights of the parents in both raising their children and in exercising their child's privacy rights and with the public policy presumption that parents will act in the best interests of their child.220

214. See supra notes 107-115 and accompanying text.
215. See Schneider, supra note 213, at 166-73.
218. See Schneider, supra note 213, at 170-71; cf. Robertson, Discretionary Non-Treatment of Defective Newborns, in GENETICS AND THE LAW 451, 458 (1975) (“Caring for defective newborns ... reinforces societal commitment to values of life, equality, and the non-allocation of rights by meritocratic or other discriminatory principles and thus produces respect for the life and moral equality of all persons.”).
219. Schneider, supra note 213, at 166.
220. See Parham v. J.R., 442 U.S. 584, 602 (1979), which states that

[the law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.

See supra note 110 and accompanying text.
In *In re Guardianship of Barry*, the Florida Court of Appeals held that the parents could validly assert the privacy interest of their 10-month-old terminally ill infant. The court exercised substituted judgment "guided primarily" by the judgment of the parents who were responsible for their child's well-being. Because financial constraints did not motivate the parents' decision, competent medical evidence supported their decision and their consent was fully informed, the court found that the state's interest in prolonging the life of the infant did not override the infant's best interests, which required removal of the infant's life support. The court based its decision on the fact that the infant's condition was irreversible, with no reasonable medical probability of gaining a cognitive state. The court also declined to require judicial review in every case concerning withdrawal of life support from a non-brain-dead infant, asserting that the decision traditionally belonged with the infant's parents and their advisors.

In contrast, in *In re Grady*, a case in which parents sought authorization to have their Down's Syndrome daughter sterilized, the New Jersey Supreme Court held that "[i]t must be the court's judgment, and not just the parents' good faith decision, that substitutes for the incompetent's consent." The court retained the
power to make a final determination of a medical treatment decision, stating that the parens patriae power allowed the state to intervene to protect those who could not protect themselves. Recognizing the difficulties of determining the best interests of an incompetent patient, the court stated: "We do not pretend that the choice of her parents, her guardian ad litem or a court is her own choice. But it is a genuine choice nevertheless—one designed to further the same interests she might pursue had she the ability to decide herself." A number of courts are deferring to the family as the proper institution to assess the patient's best interests because no acceptable objective criteria exist to determine a patient's best interests. While acknowledging that the weight of authority was against it, the court in Grady claimed inherent power to intervene to protect the important constitutional privacy right of the incompetent.

In a California case that followed the reasoning of Barry, In re Phillip B., the court held that the right of privacy protects pa-
rental autonomy, and the state must overcome a serious burden of justification before it can abridge the parental autonomy presumption. The court noted, however, that parental rights are not absolute, that the state may interfere to protect the infant's well-being, and that "[o]ne of the most basic values protected by the state is the sanctity of human life." The court also stated: "Of course, the underlying consideration [in ordering medical treatment of a minor] is the child's welfare and whether his best interests will be served by the medical treatment." Through this qualification of the parental autonomy presumption, the court acknowledged implicitly the possibility of an inherent tension between the privacy right of parental discretion and the best interests of the child. In cases regarding medical treatment of incompetents, Phillip B. thus takes a middle position between the poles of Barry, which emphasized the importance of parental privacy and discretion, and Grady, which emphasized the role of the courts in preserving the incompetents' right of privacy.

In an expansive interpretation of the right of privacy in In re Quinlan, the New Jersey Supreme Court held that the right of privacy includes a patient's decision to decline treatment even if this will lead to death. In certain circumstances, the court found a personal right to control one's own body may override the state's general interest in preserving life. In Quinlan, the court also noted that the focal point of the decision was the patient's poor prognosis and the lack of a reasonable probability of return to a cognitive life. Later, in In re Conroy, the same court qualified this right of self-determination, however, saying it may yield in some cases to a countervailing societal interest in preserving the person's life.

234. Id. at 801-02, 156 Cal. Rptr. at 51; see supra note 110 and accompanying text.
235. Id. at 801, 156 Cal. Rptr. at 51 (citing U.S. Const. amend. XIV, § 1).
236. Id. at 802, 156 Cal. Rptr. at 51.
238. Id. at 39-40, 355 A.2d at 663.
239. Id. at 40-41, 355 A.2d at 664.
240. Id. at 54, 355 A.2d at 671.
242. Id. at 348, 486 A.2d at 1223.
The courts thus are not in agreement in determining the balance between parental autonomy and the state power to protect incompetents. Most courts draw some line beyond which parental discretion may not reach, but often decline to intervene unless the state interest is compelling. In reviewing or determining treatment decisions of infants, courts have considered the following factors: the infant's right to live or die, the parents' competing privacy interests, the state's interest in upholding the value of life, the quality of life of the newborn should it survive, and the risks of treatment to the infant in light of the prognosis.

Unlike other handicapped infant situations, in anencephalic donor cases the balancing of competing rights and interests does not require consideration of the potential quality of life of the infant, nor the projected financial costs of care on the parents, nor the long term emotional and psychological burden on family life. The anencephalic newborn has no potential for meaningful life and a very short life span. These facts significantly alter the

243. The court in Quinlan attempted to protect incompetents from the conflicting interests of parents and the state by requiring approval of Hospital Ethics Committees for decisions to withdraw treatment. This requirement recognized implicitly the impermissibility of one family and their physician making such important decisions alone. P. Riga, supra note 125, at 156-57. Riga suggests that the promulgation of authoritative and specific criteria to describe defective characteristics when treatment may be withheld would "'lessen the risks of delegating treatment [decisions] to parents, physicians or committees'" and "'would represent a collective social judgment, rather than idiosyncratic choices of parents and committees, as to when social costs outweigh individual benefits.'" Id. at 162, 166 (quoting Robertson, Involuntary Euthanasia of Defective Newborns: A Legal Analysis, 27 STAN. L. REV. 213, 266 (1975)).


245. See In re Guardianship of Infant Doe, No. 1-782A157 (Ind. Cir. Ct., Apr. 14, 1982). In this case, parents chose to withhold treatment, including food and corrective surgery, from their Down's Syndrome child. The lower court held that the value of parental autonomy outweighed the infant's right to life when such right to life could not guarantee even a minimally adequate quality of life. The Indiana Supreme Court upheld the lower court's decision. Indiana seals documents of sensitive cases and therefore no public records of this case are available. Burger, supra note 231, at 290 & n.75.

246. Costs of caring for a defective child can be staggering. In a 1976 case, six months of treatment for a premature baby cost $104,403.20. Note, supra note 216, at 228 n.27 (citing Stinson & Stinson, On the Death of a Baby, 7 J. MED. ETHICS 5, 10 (1981)).

247. "[A defective child's] presence may adversely affect the stability of the parents' marriage and the emotional well-being of siblings." Id. at 228.

248. See supra notes 12-27, 83 and accompanying text.
policy approach used to determine a standard of evaluation. Physicians generally agree that they should not take extraordinary measures to preserve the life of an anencephalic newborn.249 Because of the certainty of death in a short period of time, the balancing factors favor allowing the anencephalic newborn to die. The state’s interest in upholding the value of life, however, mitigates against the affirmative act of taking organs, which harms the anencephalic newborn by hastening death. Yet, the state may also protect the countervailing value of preserving the donee’s life.

The balancing process comes down ultimately to a rights conflict between the anencephalic newborn’s rights to bodily integrity and to die naturally against the donee’s right to life. The anencephalic newborn’s parents embody this rights conflict in that, while theoretically exercising the privacy right of their infant, they also exercise the right to life of the donee by choosing to donate their newborn’s organs.

**Balancing of Interests**

The issues involved in transplanting organs from anencephalic newborns are best approached from a balancing of interests perspective to determine if the end of saving the donee’s life justifies the means of taking the anencephalic’s life. Proponents of permitting anencephalic newborns to serve as organ donors argue from a utilitarian point of view that not to use viable organs when they can serve the ultimate good of saving human life is unethical. They focus on the beneficial consequences to the donee and view the issue as a simple choice between either prolonging the donee’s life or

249. See Note, supra note 216, at 251. In 1982, Surgeon General C. Everett Koop stated: [M]edicine may never have all the solutions to all the problems that occur at birth. I personally foresee no medical solution to ... an anencephalic child ... . In these cases the prognosis is an early and merciful death by natural causes. There are no so-called “heroic measures” possible and intervention would merely prolong the patient’s process of dying ... . For such infants, neither medicine nor law can be of any help.

Id. at 251 n.195 (quoting Handicapped Infants: Oversight Hearing on the Treatment of Handicapped Infants Born with Other Defects Before the Subcomm. on Select Education of the House Comm. on Education and Labor, 97th Cong., 1st Sess. 5 (1982) (statement of Dr. C. Everett Koop, U.S. Surgeon General, Dept. of Health and Human Services)); see Raphael, supra note 202, at 8 (stating that very few people, even Roman Catholics, would advocate that doctors take special measures to preserve the lives of anencephalic newborns).
permitting the certainty of his or her death. They argue that due to the anencephalic newborn’s lack of a brain and potential for higher functions, and because of the certainty of diagnosis, the brain death definition of death should not apply. The brain death standard of complete cessation of brain activity, including the brain stem, was designed to protect comatose patients who possess a remote chance of recovering their higher functions. Proponents of anencephalic donations argue that the voluntary nature of the parents’ donation, the psychological benefits parents receive by lessening their tragedy, and the benefits to society in the form of altruistic behavior and preserved resources justify such donations. Proponents also note that the present policy prohibiting donation of organs of anencephalic newborns until they are brain dead is incompatible with the medical practice of aborting anencephalic fetuses right up until the moment of birth. The law has drawn an arbitrary line at live birth whereupon the anencephalic newborn suddenly gains new rights.

Opponents to permitting anencephalic newborns to serve as donors argue that using value of life considerations, which refer to the worth or social utility of one person’s life to others, such as financial and emotional burdens on families or resources saved, will lead to a dangerous slippery slope. They support the sanctity of life principle that is based on a belief in the intrinsic worth and equal value of every life and parallels the legal concept of

250. Arras & Shinnar, supra note 19, at 2285.
251. In a letter to the editor one parent of an anencephalic newborn would have liked to have had the choice to donate her infant’s organs.
   In the utter depths of our despair we would have had at least the comfort that our daughter’s death was not meaningless if the result had been life for other babies . . . . If there is any “moral dilemma” its resolution should lie with those who must also bear the grief, not for “society” in general. Meyer, supra note 9, at 90.
252. See supra note 204 and accompanying text.
253. Id.
255. Comment, supra note 254, at 1337 n.61.
   Nor can the suffering of others, no matter how tragic or personal, be considered more weighty than the life of the unconscious, terminally ill patient or
They say that respect for the inherent dignity and inviolability of a person is a moral good that outweighs the evil of another's death due to natural causes. Opponents argue that any other approach does not focus on the best interests of the anencephalic newborn and could become a justification for taking organs from comatose, mentally deficient or other handicapped individuals who become a burden to society. In relative value of life judgments, parents and society often receive the benefits of the decision instead of the patient. To maintain the intrinsic worth of each individual, opponents argue, physicians should base treatment decisions on a balancing of the burdens of treatment against the possible benefits solely from the patient's perspective. Balancing from the patient's perspective ensures that the patient receives the benefit of the donation and prevents those making the decision from acting in their own self-interest.

Opponents argue also that by taking organs from a non-brain-dead infant, society is saying, in effect, that the donee's life has more value than the infant's life being taken. Although the donee arguably has more potential for a longer life and a higher "quality of life," to accept this as a justification for taking a life, they claim, defective newborn. The long and short of the matter is, quite simply, that if one individual must sacrifice his life for the benefit of others—no matter how noble the motive—however useful for the benefit of others, then we have acknowledged the principle . . . [that] rational utility can justify practically any outcome.


Ideals that support our sense of exalted human worth can have practical limitations. For instance, statisticians . . . constantly weigh the costs of saving individual lives against various societal benefits. We have a variety of ends other than the mere biological existence of all individuals . . . . High value of individual life is vital—but when high-tech medicine sustains merely vegetative human life, the doctrine of infinite worth has surpassed its limits . . . . Sentient, not comatose, human life is an end in itself.

Id.

256. See supra note 201 and accompanying text.
257. Shewmon, supra note 8, at 1779. But see Letter to the Editor, Anencephalic Infant Dilemma, L.A. Times, Dec. 21, 1987, at 6, col. 4 ("There is nothing dignified or humane about denying a transplant opportunity to an organ recipient.").
258. Steinfels, supra note 16.
259. See supra text accompanying notes 166-69, 197-98, 216.
260. See Comment, supra note 254, at 1348-49.
sets a dangerous precedent for the rights of all incapacitated or comatose patients. Such a precedent creates a new brain death standard in which loss of higher functions or consciousness becomes the equivalent of death, with presence of independent heartbeat and respiration no longer indicative of "life." Any error or uncertainty in diagnosis thus closes the door on such individuals.261 Opponents claim that placing the medical profession in a position of active killing versus passive withdrawal of treatment is contrary to the Hippocratic oath not to harm and will threaten the integrity of the profession and its role as "healer."262 Current policy protects the profession by keeping the issues of death and dying separate from the issue of transplantation and by requiring that physicians firmly establish death before even raising the transplantation issue.

**LEGISLATIVE PROPOSAL263**

Any proposal that permits the taking of anencephalic newborn organs prior to brain death must address the concerns outlined above. Current death statutes are inadequate. The best means to achieve this is first to create statutorily a category for anencephaly outside the ordinary continuum or stages of death. Brain death is an arbitrary line the law draws along the process of death to define legal death. Because the anencephalic newborn has no brain and lacks potential capacity for higher functions, its situation is unique and can be defined very narrowly as equivalent to brain dead. This "brain absent" category264 is the only means to avoid the slippery slope outlined above.265

Second, in order for this categorical exception to succeed, a legislative proposal must ensure the absolute certainty of diagnosis by requiring at least two concurring physicians' opinions. Ordinarily, the diagnosis is unambiguous and the few cases of misdiagnosis are not significant enough to thwart uses of the exception.

---

262. See Hirsh, supra note 35, at 394-96.
263. This proposal is loosely structured on the procedures for treatment termination decisions outlined in In re Welfare of Colyer, 99 Wash. 2d 114, 660 P.2d 738 (1983).
264. See supra notes 208-212 and accompanying text.
265. See supra notes 73-80, 254-61 and accompanying text.
A third essential requirement is that parental consent be fully informed and purely voluntary, with no evidence of self-interest or coercion. A panel of legal and health professionals can ensure this by reviewing the circumstances of the case prior to the birth of the infant. In order to recognize and respect parental autonomy, including the power to exercise the child's privacy rights, this panel should give considerable deference to the parents' and physicians' mutual decision. Such a review panel must concur in the decision after examining the diagnostic process and interviewing the parents. Should disagreement exist among the panel members or among family members, they should have recourse to court application for judicial review.\(^6\)

Fourth, to maintain the integrity of the transplant process we must ensure no conflict of interest exists in the physicians involved; the physician performing the transplant surgery must be one other than the physician determining the time of death, which the Uniform Anatomical Gift Act of 1968 currently requires for all transplants,\(^7\) and one other than the physician diagnosing the anencephaly in the first place. Finally, the process must retain, to the greatest extent possible, the dignity of the anencephalic newborn by minimizing suffering and avoiding extraordinary medical intervention that would be withheld ordinarily, such as the attempted resuscitation of stillborn infants.\(^8\) Parents should make the transplant decision before birth if possible or soon thereafter so that life support, which only serves to prolong dying, can be minimized.

A legislative framework enabling parents of anencephalic newborns to donate their infant's organs before legal brain death is possible. Safeguards built into the proposal limit the scope of application and prevent any slippery slope dangers. In summary, such a proposal must:

1) create a "brain absent" category specifically limited to anencephaly that declares such infants equivalent to brain dead;

---

266. See Note, Birth Defective Infants: A Standard for Nontreatment Decisions, 30 Stan. L. Rev. 599, 629-32 (1978) (suggesting that judicial review of parental decisions to withhold treatment be limited to considerations of infeasibility of treatment and integrity of the decisionmaking process).


2) demand accuracy of diagnosis by requiring confirmation by two physicians;
3) require a fully informed and voluntary choice by the donor parents;
4) require a review of the diagnosis and parental decision by a panel of health and legal professionals;
5) provide opportunity for court intervention should disagreements exist among panel or family members;
6) limit potential conflicts of interest by requiring the diagnostic physicians be separate from the transplant surgeons;
7) require a donation decision be made and approved prior to birth if possible;
8) preserve the dignity of the donor newborn by minimizing extraordinary medical intervention that prolongs the dying process.

CONCLUSION

This legislative proposal cannot alter the ultimate fact that the anencephalic newborn's death will be hastened for utilitarian purposes. A donation process can be structured, however, in a humane and strictly controlled way that minimizes slippery slope possibilities and maintains respect for the dignity of the anencephalic newborn. Clearly articulated policy goals and compassionate attitudes by those implementing and participating in the process ultimately define the character of such donations and can make such transplants viable alternatives.

Kathleen L. Paliokas