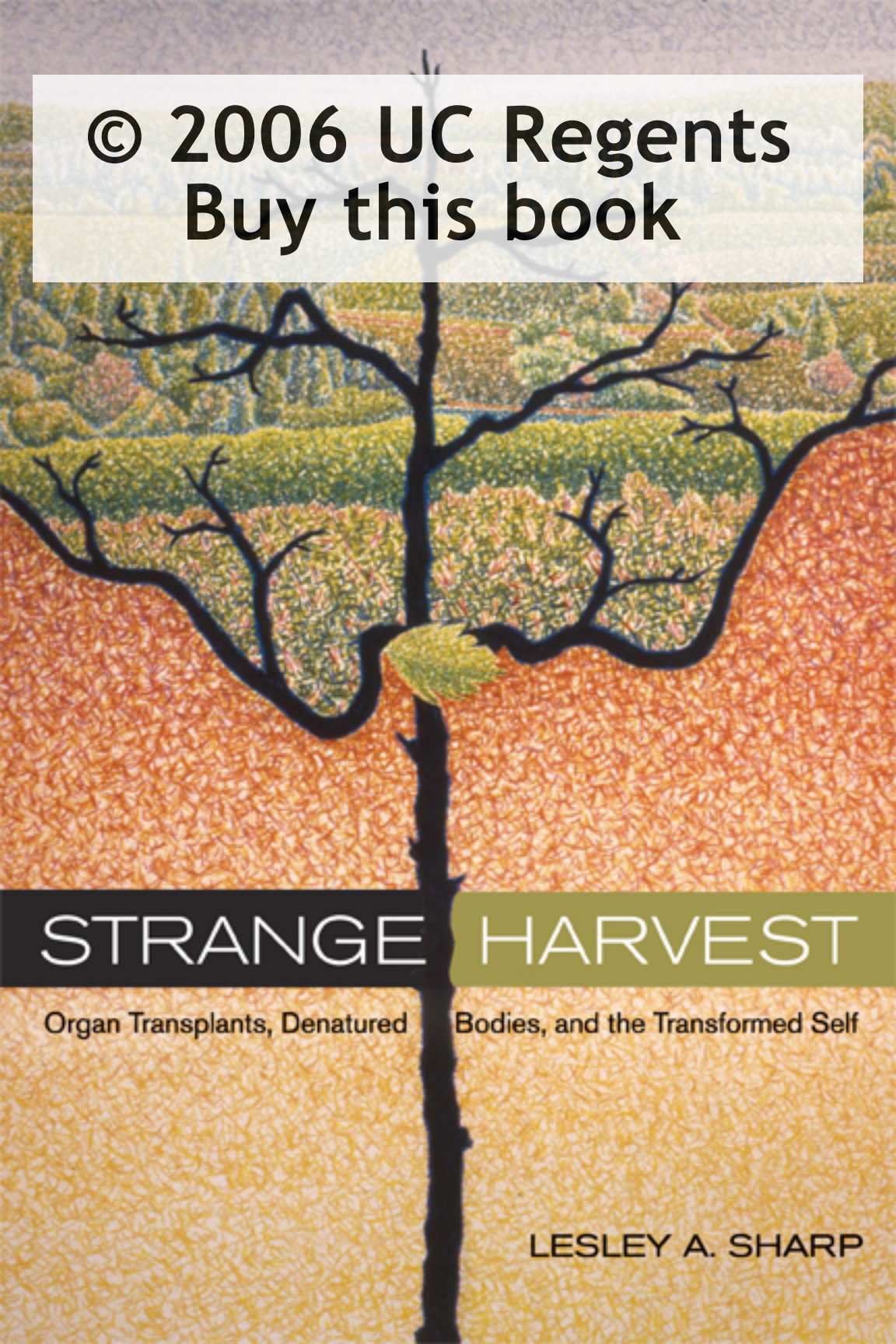


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STRANGE HARVEST

Organ Transplants, Denatured

Bodies, and the Transformed Self

LESLEY A. SHARP

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1 We Are the Dead Men

Mind over Matter

The human body is a fascinatingly peculiar thing: its size can range from under twenty inches at birth to an adult stature of more than six feet, and as it matures it masters the ability to move through the world, first by rolling over, then later, perhaps, by progressing on all fours in anticipation of a life-long bipedal stride. It can propel itself on a bicycle or in a wheelchair, or run at breakneck speed. Beneath the skin one encounters a dizzying array of systems that together enable the body to survive as well as perform astonishing tasks. As the artful renderings of anatomist Andreas Vesalius (1973) illustrate so vividly, the body's inner workings include the web of the nervous system, an interlocking musculature complex, an extensive vascular network, an elegant skeletal framework, and a sophisticated amalgamation of internal organs that can draw oxygen from the atmosphere, pump and maintain blood at a stable volume and temperature, and filter and expel inhaled, ingested, and absorbed toxins.

The brain is frequently described as the nexus of control for this body complex. This single organ drives the inner workings in exquisitely complex ways, enabling us to move, breathe, and sense the world around us. Whereas the brain, as the control center, governs bodily functions, the mind is its abstract counterpart, serving as the seat of learning, the emotional center, and the locus of the self. The mind, understood as such, enables us to create, preserve, and recall memories, and to form words into speech, manual signs, and written text; it also generates dreams. We are thus simultaneously organic creatures, cognitive beings, social persons, and private selves, categories of existence that are all inextricably linked to this mind-brain complex. The mind-brain is always at work, regardless of whether we occupy conscious or slumbering states. This sophisticated complex defines

us as alive, as functioning, and, ultimately, as human beings (Damasio 1994; 1999: 3–31, 317–55; Sacks 1973, 1985).¹

This exercise in describing ourselves in reference to the mind-brain may seem truly odd; my attempt to do so certainly strikes *me* as such. For one, it is shaped by an extreme form of biological reductionism; for another, it is an exclusively secular vision, allowing no room for musings on the soul, for instance. My intention is to underscore the ease with which we comprehend this view of our bodies. (Whether we embrace it is another matter, of course.) American culture is permeated by scientific reasoning, represented quite obviously by the pervasiveness of biomedicine as a dominant system of thought. Indeed, we frequently allow ourselves to be described in terms derived from biology, physiology, and anatomy, permitting internists, pulmonologists, cardiologists, and neurologists to probe and ponder us when all is not right with our health.

As philosopher Drew Leder reminds us, it is precisely at those moments when the body breaks down that we become painfully aware of its existence (Leder 1990; Sacks 1998), and biomedicine provides a framework for comprehending bodily disorder. At moments of sickness we typically ask, “What is wrong with me?” (cf. Zola 1978), and the answers are supplied most frequently by physicians, nurses, or other specialists who explain, “You have a lung infection,” “You’ve broken your leg in two places,” or “You’ve sustained a concussion.” Thus, within medical parlance we are frequently reduced to our functioning body parts. More important, we might accept this model of the body unquestionably and embrace such diagnoses and their associated treatments with gratitude.

Medical anthropologists have long argued that a pervasive weakness within biomedicine is the insistent separation of the body and mind in clinical discourse and treatment. Biomedicine privileges knowledge concerned with the body’s biomechanics, often to the exclusion of both the inner workings of the self, or emotions, and the individual’s place within larger social or ecological milieus. For instance, surgery occupies a more prestigious position in the biomedical hierarchy than does psychiatry, and psychosomatic disorders may quickly be dismissed as patients’ fantasies rather than being read as embodied, covert forms of protest and misery (Kleinman, Das, and Lock 1997; Sawday 1995; Schepher-Hughes 1992; A. Young 1997). Today even psychotherapy is rapidly being displaced by approaches that favor drug therapies designed to tackle problems in brain chemistry (Luhmann 2000). In contrast, within medical anthropology one encounters an established tradition of arguing for greater mind-body harmony in medicine, with propo-

nents frequently drawing on cross-cultural data to illustrate how other healing traditions reflect more holistic approaches to human suffering (Murphy 1987; Scheper-Hughes and Lock 1987).

Nevertheless, a dominant cultural logic insists on the primacy of the mind-brain as a defining principle of our humanity. We are certain, after all, that we most definitely are not chimps, or dolphins, or lizards. This sense of difference not only springs from our morphological uniqueness but is driven, too, by a widely accepted premise within American culture that our brains are radically more sophisticated than those of all other creatures in the animal kingdom. The success of anthropology as a social science is certainly driven by such principles. Our uniqueness as a species is marked by our ability to generate complex social systems, sophisticated forms of symbolic communication, and creative technological innovations that enable us to transform hostile environments into habitable ones. In addition, arguments about our special abilities are phrased in evolutionary terms, and they rest heavily on assumptions concerning the primacy of the human mind. As René Descartes so famously asserted, *cogito, ergo sum* (“I think, therefore I am”; Descartes 1999 [1637]). Within a host of other specialized fields—such as sociolinguistics, cognitive psychology, neuroscience, and artificial intelligence—it is possible to argue that the mind-brain complex defines how unique we truly are.

Against such premises, organ transfer emerges as an intriguing realm of medical practice because it insists on these forms of mind-body bracketing, yet specialists in the field still struggle to maintain a stable boundary between the two. Consider these sorts of contradictory circumstances. On the one hand, the identities of organ recipients are often reduced to their transplanted parts, so that at transplant events recipients are relegated to such categories as “the hearts,” “the lungs,” or “the kidneys.”² Organ donors, too, are rapidly reduced to the status of bodies or body parts because both procurement professionals and transplant surgeons may conceive of them primarily as repositories of reusable organs. On the other hand, cadaveric organ donation in the United States is possible because we legally sanction brain death as true death. The label of death is applied even though the artificially ventilated donor-patient remains warm to the touch, appears to breathe, and has a heart that continues to beat within its own chest. Even more bewildering is the fact that brain dead organ donors are routinely anesthetized at the onset of procurement surgery.

When we accept brain death criteria, as defined within a clinical framework, it is because we recognize that what matters is whether the mind, not the body, has ceased to function. In other words, we care greatly whether

the essence of the individual person is no longer there, and thus the body's significance in defining the self slips away. A comatose patient, while assisted by "life support," might thus be described as a broken mind-brain inhabiting a dormant body. In contrast, a brain dead individual (and, thus, an organ donor) is a mindless and dead—yet artificially maintained and thus temporarily functioning—body. The conundrum posed by brain death criteria problematizes certain assumptions about our selfhood, our humanity, and our social worth as (non)sentient human beings. It also uncovers subtle forms of medical unease over what we are certain of, versus what we can never truly know, about human death. Particularly troubling for all concerned parties are questions about the timing and detection of death, questions that quickly degenerate into existential quandaries. This is most clearly marked by the tension created between brain death and cardiac death as markers of true or absolute death. Are organ donors dead once they cease to be sentient beings, or does everyone secretly believe that true death occurs only when the body itself expires?

Such questions arise because of a flawed logic that insists on death as an either-or category of (non)existence. As we shall see, a range of involved parties understands death in more creative and flexible ways, although opinions remain muted, because to voice them publicly and openly is regarded as a dangerously transgressive act. Alternative visions defy a dominant ideological premise of organ transfer, where death occurs at a precise moment in time, coinciding with the legal declaration of the cessation of brain function at, say, Tuesday, March 9, at 5:06 P.M. If one embraces organ transfer as a social good, then one should accept, unquestionably, that brain death is a marker of true or absolute death. Nevertheless, subsequent cardiac death, or the death of the body, creeps in as contradictory evidence for nearly all concerned parties.

In response to these troublesome contradictions, Margaret Lock (2002), in her comprehensive study of brain death in North America and Japan, has described organ donors as a category of the "twice dead" (cf. Savulescu 2002; Shrader 1986). As she illustrates, this model of the double death, so to speak, is pervasive in transplant contexts: first declared brain dead, the organ donor later experiences biological death when his or her organs are removed during procurement surgery. As Lock demonstrates, historicized cross-cultural comparison proves especially helpful for underscoring that this is a Euro-American biomedical construction (or struggle). In contrast, in Japan, proponents of brain death criteria (and, thus, transplantation) have encountered especially hostile resistance from the lay public precisely because of the widespread understanding that the body houses an individual's spirit or essence,

and to remove body parts (particularly the heart) threatens a spirit by trapping it in a dangerously liminal state between life and death (Lock 1995: 7). Unlike in the United States, where key legislation supporting organ transfer spans the 1960s to the 1980s, Japan's Organ Transplantation Law took effect only in 1997. In an effort to recognize a plurality of voices, this law (inspired by the "conscience clause" of New Jersey's Declaration of Death Act) allows self-designated donors to "choose between brain death and traditional death by writing their preference on their donor cards" (Morioka 2001). In essence, Japanese citizens can designate what form of death they consider legitimate. The Japanese public nevertheless remains skeptical of brain death and critical of transplantation in general (Lock 2002), which frustrates Japanese transplant surgeons, a few of whom may have received some training in American medical or research institutions.

In contrast, within North America (and, more particularly, the United States), brain death criteria overcame legal hurdles much earlier because of a more widespread acceptance of mind-body dualism, which stresses that the self resides in the mind. As Lock and Christina Honde (1990) illustrate, the arenas that circumscribe ethical debates over medical practices expose important cross-cultural differences. Whereas in the United States ethical discussions that shape transplant policy have involved overwhelmingly those working within the clinical realm, national health decisions in Japan are regularly subjected to heated debate in the larger public sphere.

In the United States, *official* medicolegal rhetoric precludes the possibility that one can die twice. As a result, challenges are quickly silenced, a phenomenon that is especially pronounced in the realm of organ transfer. Nevertheless, anthropologists have long known that normative assumptions are regularly accompanied by unconventional thoughts and actions. Anthropologists know, too, that cross-culturally there are many ways to die. As data from a range of societies attest, death is not understood universally as the moment when a person permanently loses consciousness, or has no pulse, or when a body turns cold and gray. Instead, death encompasses a range of other possibilities far less biologically deterministic in their outlook. Separating definitions of death *per se* from what are often extraordinarily complicated ritualized forms of mourning may be difficult (Bloch and Parry 1982; Metcalf and Huntington 1991). The cross-cultural perspective reveals the limitations of the clinical assertion that the threshold between life and death is clearly marked by the measurable cessation of brain or bodily functions. Rather, anthropologically speaking, death should be viewed more broadly as a social process that allows for the possibility that a person may gradually slip away.

This is, however, a dangerous assertion within the realm of organ transfer because it ultimately destabilizes a key component of transplant ideology. In official contexts—ranging from clinical to forensic—great care is taken to identify the exact moment when death occurs. More specifically in reference to organ donors, a shift to considering death as a gradual process would inevitably generate questions about how a donor died and, potentially, who might be responsible. Such questions would expose hospital, procurement, and transplant staff to relentless lawsuits driven by accusations that these professionals orchestrate the deaths of vulnerable patients under the guise of ICU care in anticipation of the subsequent surgical removal of vital organs.

Such accusations in fact shaped the first legislative initiatives generated as protective measures in response to early instances in which transplant surgeons faced criminal charges for murdering donors for their organs (Starzl 1992: 148). I regard as absurdly simplistic the assertion that organ procurement is a medically sanctioned form of murder. As an anthropologist, I am nevertheless intrigued by the paradoxes that arise in response to this particular form of hospital death. Among the most striking developments is the manner in which transplant ideology most certainly shapes sanctioned, public sentiments and actions. Thus, I have learned to listen carefully to what people express privately as their personal perceptions, and how these may at times coincide with, and at others challenge, medicolegal rhetoric specifically about brain death. What if, instead of insisting that death can (or must) be linked to a specific, timed event, we allow it to occur incrementally, its progress marked by discrete episodes detectible sometimes by clinical tests, and at others through heartfelt sentiments of love and loss? As I will show, if we indeed pay close attention to this seepage of covert sentiments, beliefs, and turns of phrase, we discover a wondrous counterreality to the official rhetoric and public face of organ transfer in America.

A MOST PECULIAR DEATH

A Brief History of Donation

Brain death is a truly peculiar category of human experience because its mere definition dictates that professional and lay parties alike must embrace medical criteria that contradict commonsense understandings of the evidence of life. Brain death was first supported by medical specialists who, by the 1960s, were increasingly confronted with the conundrum of dying patients who were nevertheless sustained artificially on respirators. Such specialists' rec-

ommendations later shaped federal policy and state-by-state legislative initiatives that render the practice of acquiring organs from patients diagnosed as “brain dead” both legally and socially acceptable. A relatively unchallenged opinion voiced within medical circles today is that brain death criteria were most certainly developed to produce a supply of transplantable organs (see, for instance, Cowan et al. 1987; Fox and Swazey 1978, 1992; Lock 2002; Starzl 1992; P. Young and Matta 2000).

The sanctioning of brain death criteria, alongside the surgical harvesting of organs, initiated a significant ideological shift in twentieth-century medicine. This shift is reflected quite clearly in the language offered by liver surgeon Thomas Starzl, who twenty years ago explained it thus in his memoir *The Puzzle People*: “With the wide acceptance of brain death in the Western world, all injured patients who come to the hospital in a helpless condition could have a fair trial at resuscitation. Then, in an orderly way, it can be determined whether these people already were dead but with functioning hearts and lungs, or if they had a chance of restoration of brain function. The quality of care and the discriminate application of such care to terribly damaged people was one of the great fringe benefits of transplantation” (1992: 148). Although Starzl’s language may strike the reader as calculating or macabre, it nevertheless exposes a seasoned surgeon’s willingness to speak frankly about the early years of transplantation. Among the most revealing developments is the manner in which ventilator use marks a clear watershed. Not only could this new technology sustain brain-damaged patients, but, when paired with cardiopulmonary resuscitation, the ventilator permitted health professionals to *revive* the dead, assess their subsequent status, and then, through an unusual form of triage, ultimately determine whether subsequent care should focus on healing or in preparation for organ procurement as yet another form of death. Although organ procurement is never described in these terms by involved professionals, such conditions have in fact become the mainstay of contemporary practices in the realm of organ transfer.

Thus, some patients might well be described as the “thrice dead” because they die, first, from a head injury, accompanied by cardiac and/or pulmonary crisis, only to be resuscitated by emergency medical technicians (EMTs) through CPR and then placed on a ventilator. These patients’ second deaths, so to speak, occur when they are pronounced brain dead while still sustained by machines. The third (and final cardiac) death, or death of the body, occurs during procurement surgery. The importance of CPR was underscored by a statement made during an interview in 2003 with Octavia Zamora, who works for an organ procurement organization based in a western state. In

Octavia's area, the speed limit had been raised from fifty-five to seventy-five miles per hour only a few years before we met; local EMTs linked subsequent drops in donation levels to the fact that victims of high-speed car accidents typically are so badly injured as to render CPR impossible. Under earlier limits of fifty-five miles per hour, there was a greater possibility of saving accident victims, who might then be declared brain dead in the ICU.

Body Trades

Much has been written on the history of transplantation in the United States, and thus I mention only the significant legislative strides that have rendered procurement a medical reality in this country.³ The advent of American transplant medicine is frequently traced to the first successful attempts at kidney transfer between identical twins in 1954. Many Americans (particularly if they are in their late forties or older) are most familiar with the highly publicized story involving South African surgeon Christiaan Barnard, who in 1967 removed a healthy heart from the body of Denise Darvall and transplanted it in Louis Washkansky, who survived for eighteen days. Within the United States, the growing desire to harvest organs from patients sustained on ventilators provided the impetus for the Harvard Ad Hoc Committee, which argued in 1968 for "irreversible coma" as a new category of death. The committee's recommendations formed the basis for the Uniform Anatomical Gift Act of 1968, which stipulated how anatomical gifts—including transplantable organs and whole bodies bound for medical research—could be offered either by oneself or one's surviving kin. As such, the act simultaneously sanctioned brain death criteria and early donor campaigns and criminalized the selling of human organs for profit.⁴

The development and marketing of the potent immunosuppressant cyclosporine by the early 1980s subsequently ensured transplant's success, enabling patients to stave off the short- and long-term effects of graft rejection.⁵ Yet, again, legislation trailed medical accomplishment. In 1982, Congress passed the Uniform Determination of Death Act, whose central purpose was to standardize the "proliferation" (CUSL 1980) of criteria found in an array of states' statutes; of particular importance was the goal to define brain death in legal terms. By 1987 this act was adopted in some form in nearly all states. The regulatory aspects of organ transfer were defined in 1984 by yet another key piece of legislation, the National Organ Transplantation Act (NOTA). Organs were to be distributed through the Organ Procurement and Transplant Network (OPTN), a contract that has been managed since 1986 by the United Network for Organ Sharing (UNOS), which is currently based in Richmond, Virginia.

Today, nearly all states—and even most major cities—can boast a transplant unit stationed within at least one of their largest hospitals. Currently, all such units are linked to a network of fifty-nine OPOs throughout the United States and Puerto Rico.⁶ These are grouped, in turn, into eleven geographic regions. UNOS, as a federally funded regulatory agency, oversees the activities of the nation's OPOs, maintaining waiting lists and establishing national guidelines designed to ensure that organs are distributed fairly throughout the country. The logistics of placement are complex; briefly, as explained by the Association of Organ Procurement Organizations (AOPO), a set of predetermined guidelines is based, for instance, on patients' levels of medical urgency, length of time on the relevant waiting list, body and/or organ size, and blood type.⁷ Organ transfer in the United States has taken on an international character, too: some patients hail from other nations; organs are at times procured from noncitizens who die in U.S. hospitals; and procured tissues and, to a lesser extent, transplantable organs may sometimes travel to other countries.

There is a national trade in transplantable human organs in the United States and, once procured, organs are most certainly transformed into precious commodities. Although buying and selling solid human organs is illegal, transplant medicine is among the most lucrative forms of medical practice within this country.⁸ The movements of transplantable organs, as precious goods, are tracked with extraordinary care. Although most organs stay within the region in which they were procured, UNOS ultimately dictates their placement. Thus, if UNOS determines that the best match for a heart procured from a midwestern region is a patient based in a Southern California hospital, the midwestern OPO cannot override this decision. Southern California, however, then assumes the debt of a heart that must later be repaid to the region of origin. OPOs, with assistance from UNOS, tally such organ exchanges and debts with great care. In short, organ transfer defines a peculiar segment of interstate trade in America.

The rhetoric of organ transfer serves to deny and even disguise the fact that transplantable organs are highly valued medical commodities. Surviving kin receive no financial recompense for the organs they "donate" as "gifts of life." Nevertheless, all parties understand on some level that organ transfer is driven in part by the desire for profit. In the words of a long-standing director of a midwestern OPO, "Health care is a business . . . let's not fool ourselves." Although they are nonprofit organizations, OPOs certainly charge for their services (at the very least this covers donor care prior to, during, and following procurement). These costs are then passed on to transplant recipients, who are also billed for their respective surgeries, as

well as for pre- and postoperative care. It is a public myth, however, that transplants are an option available only to the nation's wealthiest individuals. Few people in this country can afford to pay for a transplant out of pocket; nevertheless, with the assistance of savvy transplant social workers, patients from a wide range of backgrounds acquire support either through employer insurance plans (if not their own, then that of a parent or spouse), or by liquidating their assets, or by qualifying for disability and Medicaid coverage. The most destitute patients sometimes acquire support from private foundations or even from their own surgeons, who may dip into pools of research funds to help improve or save the lives of their most financially desperate patients.

Donor Histories

The human body is a tremendously profitable source of reusable parts. Together with the major organs (heart, liver, lungs, kidneys, pancreas, and small intestine), a range of others, categorized as tissues, include approximately fifty regularly salvaged body parts.⁹ Surviving donor kin quickly become aware of the complexity of this economy of the body, for by law they must work their way through a complicated checklist of reusable parts once they have consented to donation. The process of donation, however, is far more complicated than the mere act of completing and signing a consent form. Given that the majority of my readers will be unfamiliar with the process, I provide an overview here.

The vast majority of organ donors' deaths result from head traumas that are sudden and thus unexpected, and many are violent as well. Primary causes include motor vehicle accidents (car or motorcycle collisions, or cyclists or pedestrians being struck by moving vehicles); gunshot wounds to the head (ranging from the misuse of firearms by children to intended acts of violence between teenagers or adults); suicides (involving a handgun, hanging, or carbon monoxide poisoning from car exhaust fumes); and severe brain hemorrhages (in adults and children). Whereas in the past age limits were set on donor eligibility, today virtually anyone—ranging from newborns to octogenarians—might qualify for donor status. Nevertheless, a widespread understanding within this specialized medical community is that by far the best donors are young people because they are assumed to be healthier (that is, less disease-ridden) than older adults. At work here, too, is the understanding that the deaths of children are especially tragic, and so it is most important that some goodness emerge from the horror of their sudden loss. Fifty years ago it would have been impossible to save—or salvage—brain dead patients. Once identified as potential donors, the se-

verely brain damaged may later be disqualified for a host of reasons that can include (but are not limited to) failure to meet brain death criteria, detected infections, organ damage, or medical histories marked by certain cancers. Currently, one becomes a donor in the United States if next of kin grant consent. Even in those states where donor cards are legally defined as a form of advanced directive (a recent trend I will raise again later), procurement staff remain reluctant to take organs in direct opposition to kin. At the onset of my research, patients were automatically disqualified as donors if they were even suspected of having HIV, and later hepatitis B and C virus, infections. Advancements in immunosuppression, on the one hand, and treatments for AIDS especially, on the other, have led to a recent shift in accepting organs from such patients for transplantation in others who bear similar infections. These and other “marginal” donors now define an increasingly common source of “extended criteria” organs (Reynolds 2005) as surgeons, driven by organ scarcity anxiety, seek transplantable parts for growing numbers of patients in need. I will address the clinical and social relevance of “extended criteria” later in this chapter and again in chapter 4.

The artificial ventilator now routinely enables EMTs, as well as staff based in emergency wards and trauma centers, to administer CPR to damaged patients’ bodies, place them on artificial respiratory support, and then, through the assistance of drug therapies that control pain and blood pressure, for instance, maintain such patients in relatively stable states in ICUs. Many procedures are performed on patients already pronounced dead as a prelude to acquiring consent and procuring their organs. It is at these highly liminal moments in clinical care that procurement professionals become intimately involved with patients and their kin. Although such policies are not necessarily enforced, the majority of states in this country now mandate hospitals to alert their local OPO if they have a patient whom they believe may soon be brain dead. Some states even require hospitals to report *all* deaths to the OPO so that field staff can assess all deceased patients as potential organ and/or tissue donors. Whereas a decade or so ago many OPOs were based within hospitals that specialized in transplantation, today this is the exception rather than the norm. Typically, OPOs maintain separate offices off site, working instead with a network of hospitals that may actively assist in identifying organ donors and/or perform transplant surgeries.

Once alerted to the potential demise of a particular patient, OPO field staff enter the hospital and perform a range of tasks. Sometimes one person performs all the necessary tasks; in larger OPOs the duties may be split between two people, in part because the work at either end is exhausting, especially when a case extends over the course of several days. As one OPO

staff member explained, it can be an emotionally trying experience for the same individual to tend to the clinical needs of a depersonalized body while also trying to comfort a family in the throes of grief. Here I offer perhaps the most complex version of OPO hospital work, involving a pair of employees who work side by side, as typified by the style of a large, urban OPO whose staff I observed during the mid-1990s. Following this account, I will briefly describe other arrangements.

Knowing what to call OPO staff is itself problematic: many procurement professionals employ the title “transplant coordinator,” but this is both confusing and misleading for several reasons. First, staff who work directly with recipients in transplant units also go by this title; second, the work of OPO staff in fact focuses specifically on *procurement* (otherwise known as “retrieval” or “harvesting”) and *donation*, not on transplantation. Furthermore, OPO field duties involve both clinical and counseling roles, and so in my discussion here I use labels that reflect these responsibilities. When duties are split between two staff members, their activities typically play out as follows. The first, or what I will call the *clinical coordinator*, works directly at the bedside of a potential donor. If brain death is thought imminent, the clinical coordinator often assumes duties previously performed by hospital nursing staff, who retreat in order to care for other, more viable patients. The clinical coordinator takes regular readings of the patient’s status, and he or she may even write orders on the patient’s chart, providing directives for administering medications, especially vasopressors (or “pressors” for short) that control drops in blood pressure. Clinical coordinators generally have backgrounds in critical care nursing, so that many have worked previously in hospital ICUs. It can be difficult for lay visitors to distinguish clinical coordinators from in-house nurses because they frequently dress in hospital scrubs, wear no badge that identifies their employer, and may make little effort to clarify to family members for whom they actually work.

The clinical coordinator may be paired, in turn, with a *family counselor*, someone who arrives dressed in a suit or somewhat formal street clothes. The primary duty of family counselors is to provide emotional support to family members; typically they explain that they specialize in helping families cope with end-of-life issues. They also respond to a range of pragmatic concerns. For instance, when overtaxed nursing staff are too busy to help family members find meals or coffee, or a private room in which to talk or rest, the family counselor will respond to these needs. As with their clinically trained partners, their purpose (and employer) may be left unstated at least at the onset. Family counselors generally wear no identification badge (save that required by hospital security), allowing them the option of pass-

ing as hospital employees rather than proclaiming outright that they are from an OPO. Such practices are justified by OPO employees who stress the importance of establishing social bonds with kin before raising the topic of donation. A badge that declares that one works in organ retrieval would subvert their ability to breach the topic gradually with kin, and only once they have gained their trust as compassionate health workers. The fact that many OPOs have altered their names in recent years also facilitates this process. Whereas ten years ago most agencies bore composite names consisting of their state or region plus “OPO” (for instance, NWPO or Northwest Organ Procurement Organization), many have assumed new titles that emphasize organ donation as an act that saves lives (thus, NWPO is now LifeCenter Northwest).¹⁰ Today only a few OPOs are based within hospitals, but ten to fifteen years ago such relationships were common, only further complicating the duties of procurement work. I can only hypothesize at this point, but drawing from my data culled from fourteen OPOs of a range of sizes, it appears that employees from smaller offices are less likely to attempt to pass as hospital staff. The question of how OPO field staff should introduce themselves to the kin of prospective donors is currently a topic of heated debate. As my descriptions reveal here, procurement strategies in the United States are, oddly, both compassionate and covert.

Successful procurement rests heavily on the shoulders of family counselors. Particularly important is their skill in engendering trust among family members, for without this their attempts at procurement will fail. In those cases where family members experience callous treatment from overextended hospital staff, the OPO family counselor provides a sympathetic ear and shoulder, allowing kin to express their sadness and rage openly and free of judgment. An important strategy employed by many OPOs today is referred to as “decoupling,” where successful procurement is understood as relying on the sequential acceptance of two messages by a patient’s surviving kin (DeJong et al. 1998). The first message concerns brain death criteria, and OPOs generally rely on hospital physicians—preferably neurologists—to explain this initially to patients. OPOs thus expend much time and energy running in-house educational seminars for hospital staff on the dos and don’ts of talking about brain death with patients’ families. The OPO family counselor then follows up with another discussion or series of conversations about brain death, sometimes supported with visual aids but, more frequently, by employing vernacular language devoid of mystifying clinical jargon. As I will explain in greater detail later, metaphorical analogies abound. Only once kin begin to show signs of accepting brain death criteria (they start to talk about funeral arrangements, for instance) does the fam-

ily counselor shift to the second message: that is, the great social value of organ and tissue donation.

Within one East Coast OPO in particular, I found that family counselors defined a well-developed area of in-house expertise. This OPO is based in a large and ethnically diverse city, and in the mid-1990s the director hired a team of counselors who represented an eclectic range of professions, religions, and ethnicities. This hiring practice was based on the premise that it would facilitate the rapid establishment of rapport with families whose backgrounds overlapped with those of individual counselors. Such an approach was nevertheless highly controversial within this OPO and beyond because of a dominant assumption in the realm of organ transfer that all patients or bodies are equal beneath the surgeon's knife (Sharp 2002b). Nevertheless, in this particular OPO, if it was known in advance that a potential donor was, say, Latina, the team's director would make every effort to assign a family counselor fluent in Spanish and, preferably, also of Latin American descent. Similarly, an Orthodox rabbi, who often agreed to be on call, would respond to requests to meet with Jewish families of a range of levels of observance; and an African American woman, who had worked previously as a Pentecostal minister within a storefront church, was regularly matched with inner-city African American and Caribbean families.

These elaborate pairings generally characterize only the nation's largest OPOs and were more typical in the 1990s than they are at present. Financial pressures (linked in large part to false hopes that donations would grow substantially each year) have forced some OPOs to scale back, rendering specialized hiring practices an unaffordable luxury today, except where linguistic barriers may prevent successful donation outcomes. Similarly, clinical coordinators and family counselors may have reverted to a single position in some OPOs. Smaller OPOs, such as those that serve primarily rural regions or midsize cities, have much smaller staffs (perhaps five to fifteen employees rather than fifty), their members shouldering all duties, including the clinical monitoring of a donor, talking to family members and providing emotional support, and sometimes even assisting with the actual procurement of the organs (a task performed elsewhere largely by transplant surgeons who arrive on site to retrieve organs for patients under their care).

Successful procurement also relies on support from a range of other, non-OPO employees. Family members may raise the topic of donation themselves, making the task of acquiring consent much easier. Many donor kin frequently report that a staff nurse (but rarely a physician) broached the topic of organ donation and, further, that it was this nurse's extraordinary level of emotional support that led them, in the end, to consent to donation.

Many OPOs now train ICU staff as well as other hospital employees, among whom clergy are especially important, to approach families about donation. Chaplains, after all, regularly tend to families faced with end-of-life decisions, and they define a significant target for OPO training sessions (UNOS 2000). Ruth Yoder, a chaplain based in a midwestern hospital, explained her approach as follows, one that echoed those used by local OPO staff during the early 1990s:

With families, almost universally [donors] are people who were young, vibrant and healthy—they died in a car or motorcycle accident, from a gunshot or an aneurysm in the brain. So the family has a tremendous adjustment—the person was fine only a little while ago, unlike [with] terminal[ly ill patients where families have been coping for a while with death]. . . . What I show [the family] is that their breathing is exactly the rhythm of the machine. I explain that their blood isn't cold and that there is only a little color change, but that it is the machinery that is keeping them alive. The machinery is traumatic [for kin] when family members see someone like this suddenly all hooked up to these machines. . . . I [then] ask them, "Have you ever talked to so and so about organ donation? How would they want to be remembered?" That helps a lot. . . . The initial reaction is, "He/she has suffered enough." What this means is "*I've* suffered enough." Most people are very sympathetic [to donation]. Donorship helps them make sense out of the loss. With sudden death, people do want to make sense out of it. Terminal [illness] is much harder—usually family members will say, "They have suffered enough" . . . [and that's precisely] what they mean.

Procurement is far from an easy assignment: within one East Coast OPO where I conducted research over the course of a full year, of all potential donors identified, only 18 percent in 1993 and 28.5 percent in 1994 resulted in successful procurement. The reasons the remaining cases did not succeed included the failure of patients to qualify for brain death status; the inability of OPO staff to approach kin on time; obstructionist hospital staff; and medical complications (including advanced age, history of cancer, serious heart disease, or the body "crashing," as staff so often put it, before procurement could occur). Finally, within each year more than 30 percent of kin refused consent when asked.¹¹

Procurement is emotionally trying work, exacerbated by hostility toward such work among some hospital staff, as reflected in the range of derogatory slang applied to OPO workers. Common labels include "ambulance chasers," "vultures," and the "death squad."¹² The ability of OPO staff to remain true to their course hinges on their great dedication to the human-

itarian principles that drive organ transfer. The dominant messages they convey to potential donor families include emphasizing that donation allows some good to emerge from a terrible tragedy; that loved ones, though suddenly lost, may live on in others through organ transplantation; and that multiple organ donation especially means that donors' "gifts of life" can pull a number of people back from the brink of death, allowing them to return to normal, productive lives.¹³ When I began my research on organ procurement, I was informed repeatedly that the typical burnout rate for this line of work was around eighteen months, whereas transplant coordinators who worked with patients awaiting organs often remained on the job for a decade or more (Sharp 2001). Recently, both AOPO and UNOS have begun to address the effects of what one OPO employee referred to as "sympathy burnout" among procurement field staff.

OPO staff speak specifically of the work that involves direct contact with (potential) donor families as simultaneously the most trying and rewarding of experiences. Staff put in long hours at the hospital, each assignment frequently spanning several days. Because rapport with kin is essential, OPOs are especially reluctant to switch family counselors midstream, even when they are exhausted from lack of sleep. Their primary tasks involve assisting families faced with unimagined traumas, fresh grief, and, at times, internal strife among kin on issues that may include guilt, anger at one another or even the dying patient, frustration with hospital staff, or disagreements on treatment trajectories, funeral plans, or donation. OPO work is exacerbated by the need to approach families under time-pressured circumstances—that is, a successful procurement hinges on the ability of kin to offer consent when they are still numbed by the sudden onset of grief. Donors' deaths often result from unexpected, and often heartrendingly violent, situations: a little girl has a massive aneurysm on the playground; a young boy is struck by a car on his way to school, makes his way home alone, and crawls into bed, only to fall into a coma; a sleeping teenager is shot by a friend who is playing around with his father's handgun; a fiancée has a head-on car collision and sustains a major head trauma two blocks from her lover's house; a cornered young man is shot in the head by police at the end of an hour-long car chase; a college student home for the holidays, recently rejected by a lover, shuts himself in the garage and turns on the car engine soon after his parents have left for a Christmas party; an elderly gentleman collapses in the street from a massive stroke during his lunch break and is rushed to the hospital by EMTs. These sorts of stories are all too familiar to procurement coordinators.

At times individual counselors are accepted by kin as a source of support

and guidance; at others, and especially in the case of male counselors, they might even be physically assaulted by family members who want no part of a stranger speaking to them of death. As all counselors underscore, they are often deeply moved by their encounters with donor families, whom they view as an inherently unique group of people who have made horribly difficult decisions at terrible moments in their lives. At times the catharsis of these sudden and unexpected encounters generates a level of closeness that may extend for weeks, months, or longer. All counselors who have been on the job for a few years can speak of donor kin who contact them personally when grief strikes anew. When a donation has gone well, donor kin, too, speak of compassionate counselors whom they remember with great fondness.

In part to relieve field staff of the burden, as well as to provide sustained aftercare for donor kin, by the late 1990s a number of OPOs began to hire grief counselors. Today these specialists typically direct a subsection of their OPO, offering a range of aftercare programs and more intimate forms of counseling. Prior to 1998, however, aftercare was limited to annual commemorative events, generally staged by OPOs or sometimes by regional hospitals. As Chaplain Yoder explained in 1992, at that time donor families had to fit into a particular niche by joining a six-week support group for widows and widowers, or another for parents who had lost a child. Among the most impressive shifts in OPO work is the growing understanding that donor kin, by virtue of their unusual end-of-life decisions, experience grief in specialized ways (Maloney and Wolfelt 2001). (This reality defines a key focus for the following two chapters.)

A Special Kind of Death

Sorting through the literature on brain death is a complex affair, given that the manner in which brain death has been defined or described varies, especially if traced from the 1960s through the early 2000s. Early on, for instance, brain death was regularly referred to as “irreversible coma,” as phrased by the Harvard Ad Hoc Committee (HMS and Beecher 1968). Today it is generally contrasted with, rather than equated with, coma and vegetative states, although such references linger.¹⁴ The refinement of brain death’s definition stems from more recent advances in neurology, a burgeoning specialty that now relies routinely on sophisticated forms of imaging technology to diagnose and treat brain traumas (Gean 1994). I will begin, then, with a technical description offered by Eelco Wijdicks, a neurointensivist and recognized specialist on brain death criteria. As he explains, “‘Brain death’ is the vernacular expression for irreversible loss of brain func-

tion. Brain death is declared when brainstem reflexes, motor responses, and respiratory drive are absent in a normothermic, nondrugged comatose patient with a known irreversible massive brain lesion and no contributing metabolic derangements" (2002: 1). Embedded within Wijdick's statement is the understanding that brain death is detected through the systematic application of diagnostic procedures (Wijdicks 2001). (I will return to this issue later.) Among the more confusing aspects of brain death for the clinically uninitiated is precisely how much or what part of the brain is in fact irreversibly damaged. During fifteen years of field research I have received a range of answers to the question, What is brain death? when speaking with OPO educational and clinical staff, as well as internists, transplant surgeons, and neurologists. OPO staff typically underscore what it is not: brain death is neither a coma nor a vegetative state. OPO staff are especially averse to these terms (even when either condition is described as "irreversible") because they evoke within the lay public images of injury followed by spontaneous recovery. Other interviewees (especially those who are clinically trained) sometimes describe brain death as "full" or "total" brain failure.¹⁵ Neurologists whom I interviewed in 2004 preferred to speak of brain stem failure (cf. Hill 1999; Matta 2000; P. Young and Matta 2000). As Dr. Needler, who regularly diagnoses brain death in patients, explained, "During my clinical training I learned what any physician learns—we learn about the hierarchical organization of the brain—if the brain stem has ceased to function, then the upper brain's capabilities will fail, too. This is why we speak of [the] brain stem in reference to brain death." Another neurologist, Dr. Valentine, underscored that the damage sustained from this form of head trauma is irreversible and, further, that the brain may begin to "liquefy" or "grow necrotic" even as procurement staff are in the process of assessing a donor's status. All that is left is perhaps some residual spinal activity, nothing more.

Diagnosis by a physician is a relatively straightforward procedure that requires few specialized tools, but from a lay perspective brain death is a truly confounding medical category. Oddly, too, whereas several professional organizations—such as the American Academy of Neurology and the American Academy of Pediatrics—have published diagnostic guidelines, brain death criteria have yet to be standardized either within this country or internationally (AAP 1987; Gelb and Robertson 1990; J. Lynch and Eldadah 1992; University of North Dakota 1998; Wijdicks 1995a). Within the United States specifically, mandated diagnostic criteria vary from one state to another, among OPOs, and even among hospitals located within the same city. Dr. Lazarre, a neurointensivist who described himself as one who has "diagnosed literally hundreds of brain dead patients," stressed that "brain

death is a clinical diagnosis. You don't need special tools or tests to do it. It only takes me about four minutes—it's very quick. It is not difficult for me [to recognize]—diagnosis is not [a] difficult [task]."

Regardless of protocols, in the end, the purpose of diagnostic criteria is to confirm the absence of brain activity. The systematic assessment is generally conducted by a neurologist, although any trained physician is capable of the task. (Sometimes, though rarely, a nurse may assume this duty.) In-house protocols almost always require that the assessment be administered twice and by two separate physicians, although the period of time between the two varies significantly from one institution to another. Dr. Lazarre, who proudly stated that he had "streamlined" his unit's protocol, put it thus:

DR. LAZARRE: I . . . got rid of the observation period.

L. S.: But don't two separate doctors still evaluate the patient?

DR. LAZARRE: You still need two different doctors. Some places they [conduct separate observations] six, twelve, twenty-four hours apart. I got rid of this. You don't need it. I can do the [tests] two minutes apart with two people [and that's all it takes]. If you really understand brain death—[after all] you can't become *un*-brain-dead. [He then describes the function of the hypothalamus.] You will [then] have cardiac death. We [might be able to] keep you alive for two to three days. There are those who write [about] people who can be brain dead for two to three months—but the body [falls apart eventually]. I find it hard to believe [that maintaining someone this long] is realistic or happens [very often at all].

Drawing from the literature and my field interviews, I offer the following review of brain death assessment in *adult* patients.¹⁶ First, the patients must be deeply comatose and artificially ventilated, their CAT scan and spinal fluid tests generating abnormal results. Before proceeding with diagnostic tests for brain death, the physician must also know the origin of injury, so that he or she can exclude other causes that can mimic brain death. These include hypothermia, endocrine crisis, severe acid-base abnormalities, intoxication, the presence of barbiturates and other sedatives (self- or hospital-administered), as well as neuromuscular blocking agents.

Once these are ruled out as probable causes, the physician tests systematically for brain stem activity in response to excessive noxious stimuli. The physician exerts pressure on the nail beds of the hands and feet and on the sternum (located in the upper central region of the chest). Throughout such

tests the physician watches for such reflexes as eye opening, facial grimaces, head movements, and reflex movements of the limbs. The purpose of these tests is to make certain that the patient's condition results not merely from a damaged cerebral cortex but specifically from brain stem failure. For instance, the pupils can be any shape, but they should exhibit no response to bright light. There should be no evidence of normal eye closure as the corneas are stroked, or eye movements when the head is moved briskly or when the interior of each ear is flushed with cold water. Also, brain dead patients do not gag or cough in response to a throat swab or tongue blade, or when the physician wiggles the ventilator tube within the trachea. A range of more sophisticated (and technologically mediated) diagnostics, referred to as "confirmatory tests," might then be applied. (Although required in Europe, they do not define a mandatory component of U.S. protocols.) They include cerebral angiography, electroencephalogram, transcranial doppler, and other brain imaging techniques.

In the United States the single required confirmatory technique is the apnea test, whose purpose is to document that the patient is incapable of breathing spontaneously when disconnected from the ventilator. (This ability is marked by such responses as coughing or gasping.) As recently as the mid-1990s, the apnea test was considered highly controversial within those OPOs where I conducted research. A widespread fear was that cessation of ventilation could induce cardiac arrest or other forms of trauma, circumstances that threatened the viability of organs for later transplantation (Widdicks 1995b). The apnea test has since evolved into a normative practice, in part because of a range of more recent techniques designed to prepare and stabilize the patient before and during the procedure. Common precautions include using a warming blanket to increase the core temperature of the body and administering vasopressors to counteract low blood pressure, as well as other medications to control fluid levels. Prior to the test patients are also typically oxygenated; once the patient is disconnected from the ventilator, the physician must document blood gas levels (paying particular attention to carbon dioxide [CO₂] readings) for several minutes. Depending on the hospital, the apnea test may last anywhere from three to eight minutes. As Dr. Lazarre explained, "This is the biggest stimulus to the brain [to start breathing]. You look, watching with your own eyes for no breathing movements. In the end you . . . document that there's evidence that the blood is [saturated] with CO₂ and not oxygen. . . . you draw arterial blood and then document the CO₂ [level this way]." In some instances the apnea test is repeated, although staff whom I interviewed (drawn from OPOs of a range of sizes) all reported that this was strictly optional in locations where they worked.

Today the administration of diagnostic tests defines a ritualized form of witnessing for patients' kin in some hospitals. As a neurologist, Dr. Needler prefers to have family members present when she tests for brain death because this helps her to explain more clearly what is wrong with the patient. A troublesome element here is that brain dead patients sometimes manifest what clinicians refer to as a "Lazarus sign": that is, their bodies may move as a result of residual spinal activity. Wijdicks stresses that such movements frequently occur following an apnea test, and he thus offers these cautionary words: "It should tell you that the family members should never be present during this procedure [because] it might be very difficult to discuss organ donation after this occurs" (University of North Dakota 1998). Nevertheless, some OPOs have taken the radical step of encouraging the kin of prospective donors to be present during the apnea test. Dora Tuckerman, who directs her OPO's donor family aftercare program, underscored the power of this form of clinical witnessing:

This is a very [important part of understanding] brain death because they [that is, ventilated donors] don't look dead. I ask our people [in the field] to ask if [donor kin] want to see the apnea test. They have a right to this! Otherwise, you're asking them to take on faith that this breathing thing is dead. Docs—I wish, please tell them to say *dead*. . . . I know one donor mom who was told she couldn't be there for the apnea test—she snuck in [anyway] and she was so glad she did. Then she believed [her son] was dead.

Variability and Trust

As reflected in Dr. Lazarre's statement, brain death criteria are more streamlined in emergency rooms, ICUs, and trauma centers when their directors enthusiastically support organ donation. The presence of large transplant centers in such cities as Pittsburgh, Cleveland, San Francisco, Dallas, New York City, and Rochester, Minnesota, for instance, as well as long-standing and large-scale OPO operations, also inevitably shapes brain death protocols. Individual OPOs frequently assist smaller hospitals in forging in-house policies for brain death declaration; at the very least they initiate the declaration process by observing individual patients and assessing their medical status. Based on their readings, OPO staff may then request that proper neurological tests be performed. The varying level of engagement and willingness on the part of hospital staff to work with OPOs ultimately shapes the time lag between the two physicians' assessments, as well as the urgency with which additional confirmatory tests might be applied.

The manner in which OPO counselors approach families is driven in part

by a widespread paternalistic assumption that kin do not want, nor do they need, to know the specific details of brain failure (or, for that matter, organ procurement). Such knowledge is understood as too difficult to comprehend, too traumatic, or too cruel to describe to kin in the throes of grief. Also, too much knowledge might threaten the opportunity to acquire consent. As noted earlier, OPO coordinators generally prefer that a neurologist speak first to the family, but he or she should then withdraw so that a counselor can work directly with kin. Dr. Lazzarre, who is highly supportive of organ donation, put it thus: “[They say], ‘your job is to [try to] save the patient and diagnose brain death and ours is [to talk about] donation.’ But they have this really patronizing attitude—they’re afraid we’re going to fuck up [the process]. But it’s like the eight-hundred-pound gorilla—look, the family knows—they’re already thinking about donation—and it helps them to see some good come out of the tragedy [of the death] and so, I say, I just want to let them know that I support this, that I support organ donation.”

OPO family counselors regularly stress how important it is for them to follow the neurologist’s presentation with their own, one devoid of obscure clinical jargon. OPO counselors rely heavily on a rich array of metaphors to communicate the severity and irreversible quality of brain death to surviving kin. This range of variability in brain death protocols may account in part for the paucity of print material made available to donor kin by OPO family counselors. It may spring as well from the assumption that counselors must gauge the education level of kin on a case-by-case basis, choosing their language accordingly.¹⁷ Instead, reading materials—if they exist at all—tend to focus on two other, albeit related, themes. The first involves advice on how to cope with a sudden and inexplicable death. The second focuses on pragmatic concerns. For instance, will donation cost family members anything? Will procurement surgery disfigure the body and thus affect desired funeral arrangements? Do any religions prohibit organ donation? Even if donation is said to be anonymous, will recipients try to establish contact? Are brain death and coma the same thing?¹⁸ The answer supplied to each of these questions is a resounding no.

The Clinical Art of Procurement

While kin struggle to cope with the potential death of a loved one, the clinical coordinator evaluates the patient’s status by drawing blood, extracting lymph node samples, and monitoring life signs to determine blood and tissue type, assessing, too, the patient’s general health and thus his or her viability as an organ donor. In some regions of the United States, OPO staff may actually initiate such procedures before brain death has been declared,

and even, in some instances, before kin have arrived at the hospital. The clinical coordinator rapidly assumes responsibility for the care of an imminently brain dead patient, administering blood pressure and perhaps other medications to try to prevent the patient from “crashing” before brain death can be declared or organs procured. The clinical coordinator also orders diagnostic tests to determine the following: Does the patient test positive for various strains of hepatitis or HIV/AIDS? Does he or she have self-administered tattoos or track marks from drug use that would indicate a higher chance of exposure to such infections? How well do the vital organs appear to be functioning?

Once in communication with next of kin, the coordinator pursues other data in order to amass a more detailed health history. For instance, has the patient ever been diagnosed with or treated for cancer? If so, what kind, and how long ago? Did he or she smoke or drink heavily? What of the patient’s sexual history? Has he or she ever been incarcerated? Ten years ago these complications would have rendered most patients unsuitable as donors. In response to the growing sense of urgency over organ scarcity, however, these are now treated as *cautionary* signs by most OPOs. As a coordinator from a midwestern OPO explained in a videotaped 1998 hospital training session, exclusionary criteria had shrunk dramatically in response to the demands of transplant surgeons: “We’ve changed our criteria in the last year; [there’s] no [upper] age [limit, for example,] . . . as more and more people are added to the list and more and more people are dying every day, because of the lack of organs, the transplant surgeons are getting more and more aggressive and more and more liberal with the criteria they will accept. . . . [For us today the] only contraindication is HIV/AIDS. . . . [We] will still assess those with sepsis, [hepatitis B and C], [and] cancer . . . for instance” (University of North Dakota 1998).

Staff based in other OPOs report a similar trend in recent years. As Liza White, a clinical coordinator with eight years of experience, explained in 1994, at times she felt she had to be the guardian for potential recipients; as she put it, “some of our [region’s] surgeons are so desperate [for organs] they’ll take anything short of road kill.”¹⁹ This shift toward “more aggressive” and “liberal” criteria is a recent one. For example, in 1995 I watched an exasperated family counselor seek advice from his supervisor when he learned that a local cardiac team wanted to accept a heart even though the donor tested positive for hepatitis B. As he later explained to me, “This case is a clear rule out, but [they] still want the heart. . . . I keep telling [my boss] to tell them *no!* Otherwise it will come back to haunt you. If you say yes, it’s nothing but *greed*. This sort of thing makes [our office] look really bad.”

In the end, the supervisor's judgment call prevailed, and the patient failed to qualify as a donor. Yet nearly a decade later, placements such as these have become routine within this and other OPOs. The cautious, selective use of donors with cancer, for instance, has recently been endorsed by UNOS (Buell et al. 2003; Kauffman, McBride, and Delmonico 2000), as have those infected with HIV and strains of hepatitis, provided their organs are transferred to patients with similar infections.

In response to a question about shifting boundaries for exclusionary criteria, Dr. Salvador, a liver surgeon, offered this explanation in 2004:

With [transplant candidates whose liver failure is already attributable to] hepatitis C, we know that there is an 80 to 100 percent chance that the patient will have hepatitis C [again] within one year post transplant [and so] we ask ahead of time if [we might transplant in them a liver, say,] . . . from a donor [infected] with hepatitis C. Now, when the donor has [benign] tumors, [we might use his liver, but we have] talk[ed] to the [transplant] patient ahead of time [to acquire advanced informed consent]. We tell them that it can lower their chance of survival if they wait [for an organ] without such risks attached. [We tell them,] "You might have to wait much longer—too long—if you say no to tumors, or hepatitis C"; but if [they are] willing to take this [sort of organ,] they might get a liver sooner.

Such transplant recipients are thus faced with a lethal trade-off between severe disability or death from organ failure, and the long-term consequences of infections stemming from flesh acquired from anonymous, diseased organ donors. Acquiring informed consent from patients at the outset of joining a unit's in-house waiting list may not necessitate asking patients later if they are willing to accept a specific organ known to be infected with a particular pathogen; more often this judgment call is made by the transplant surgeon at the time of procurement or surgical implantation.²⁰ The problems associated with diseased organs only compound the already known dangers associated with long-term ingestion of potent immunosuppressants and steroids. Nevertheless, current perceptions of the ever-increasing scarcity of organs inhibit surgeons from protecting their dying patients from a range of subsequent posttransplant infections; after all, a transplanted organ bears the promise of extending the patient's life for years.

If all goes well—that is, if brain death has been declared and the donor can be maintained in a physiologically stable state, kin have consented to donation, the OPO has determined that the organs and tissues are viable for transplant, UNOS has successfully placed the organs, and surgical teams can arrive in time—the donor then proceeds to the operating room for procure-

ment surgery. AOPO provides a helpful—though somewhat sanitized—summary of what its authors term “the donation process.” I quote it at length here because this statement represents the public face of procurement as communicated to donor kin:

Once all suitable organs have been accepted by transplant programs, the surgical teams travel to the hospital to perform the organ recovery procedure. The ventilator continues to provide oxygen to the donor’s bloodstream, which in turn allows the heart to keep beating and the blood to circulate. The organ recovery surgery is performed in the same fashion as any other operation, in the operating room, under sterile conditions, using standard surgical instruments and techniques. The operation may take from one to four hours, or longer, depending on which organs are recovered for transplantation. The organs are flushed with cold preservation solution, which lower[s] their temperature and ensure[s] safe preservation until the time of transplantation. Blood samples and lymph nodes are also removed for tissue typing to ensure compatibility between the donor and the recipients. When the organs have been removed from the body, the ventilator is turned off. The surgical incisions are closed and the donor’s body is prepared for transfer to the morgue. Throughout this process, the donor’s body is treated with respect and dignity.²¹

Although this statement from AOPO is certainly informative, it fails to mention a number of procedures essential to procurement work. As one physician put it, “Surgery is messy business.” OPO staff know this all too well, and thus they filter or sanitize their descriptions of procurement surgery out of fear that too many details will undermine their ability to acquire consent for donation from kin. Some readers may be offended by some of the information that follows. I provide such details not for their shock value but to underscore the complexity of procurement work. As I will show through a careful consideration of excluded details, a key aspect of organ procurement involves the ability to depersonalize donors.

How, then, does actual procurement work differ from AOPO’s description of the “donation procedure”? First, it remains unstated who, beyond surgeons, is involved in the procurement of organs. Sometimes OPO staff bear this responsibility, especially if they work for smaller offices involved nearly exclusively in kidney and tissue procurement. Today, however, many transplant surgeons (especially when hearts, lungs, and livers are concerned) insist that they or, at the very least, another surgeon from their unit be present for and conduct the actual surgical removal of parts destined for their own patients. Thus, the timing of procurement hinges on the ability of surgical teams to coordinate their arrivals so that they can work side by side.

In addition, among the more intriguing aspects of procurement is that even though organ donors have been declared dead, they are regularly anesthetized at the onset of surgery. As several interviewees explained, this is done for two reasons: first, anesthesia relaxes the body by dampening residual spinal cord reflexes; second, it helps bolster surgical personnel psychologically in case they worry that the patient can still experience pain. Furthermore, during procurement, unlike normal surgical procedures, organs are removed, not repaired; also, because time is of the essence (and the patient is understood to be dead), the physical opening of the body and techniques for organ excision more closely approximate an autopsy or, in the acerbic words of one non-clinically trained witness, an “evisceration.”

One transplant surgeon, when asked whether procurement was in fact so different from regular surgery, responded as follows:

DR. SALVADOR: It's *totally* different. Look, the abdomen gets completely excavated. [After all,] we're not allowed to put artificial material back into the abdomen when we're done [to fill it up again and] give it shape.

L. S.: [So, then it's] no different from an autopsy?

DR. SALVADOR: Oh, no, it's *completely* different. But the patients are already deformed—many were in auto accidents and the face is damaged—they don't look like themselves at all. And the family knows that. But it is totally different. If you do [regular] surgery on a patient who is alive you try to think about how the patient will look afterwards, you try to [minimize] the scars [for instance].

As Dr. Salvador went on to explain, the incision made is much larger than in regular thoracic or abdominal surgery, designed here to expose the torso's full interior so that the surgeons can investigate the body for tumors or other abnormalities (cf. Hogle 1999, esp. chap. 9).²² Again, unlike standard surgeries, the donor's body is fully flushed of all its blood and then perfused with solutions designed to eliminate the danger of subsequent blood clotting in recipients, to stave off sepsis, and to keep the organs “alive” at the cellular level. Although a patient enters surgery on a ventilator and is administered anesthesia at the onset, once perfusion begins these earlier technological interventions are no longer necessary. Also, although not mentioned in AOPO's summary supplied earlier, among the most important surgical moments is when cross-clamping occurs—that is, when blood flow to and from the heart is clamped and stopped, at which point the ventilator is no longer of any use. In other words, it is not “when the organs have been

removed from the body" that "the ventilator is turned off," but, instead, just prior to organ excision. I have found, though, that most OPO staff are unaware of this fact unless they regularly assist in the operating room and assume technical roles during surgery.

Clearly, the surgical extraction of organs is a complex process (Gelb and Robertson 1990; Hogle 1999; Levinson and Copeland 1987), and here I focus only on those few details significant to the specific concerns that drive this chapter. Following perfusion, and while the organs are still intact, the torso's interior is covered with ice, again to preserve organ integrity. In cases involving a multiple organ donor, thoracic and abdominal surgeons may work side by side, later handing the donor's body over to the kidney team.²³ The last step involves various forms of tissue procurement, which may occur either in the operating room or later in the pathologist's lab or the morgue. The last person to leave surgery bears the responsibility of closing up the donor's torso. This might be a member of a kidney or tissue team; in other instances hospital or OPO surgical staff assume this task. The remains of the donor's body may require additional repair work in preparation for the mortician: eye caps will cover the scars of cornea removal, and dowels will be slipped in to replace the long bones of the arms and legs.

Procurement Aesthetics

Although OPO staff vehemently deny that the donor body experiences any form of mutilation, they nevertheless take precautions to shield donor kin from the details that surgeons themselves know to be true. In recent years OPOs have also begun to work closely with local funeral directors, sometimes even hiring a full-time liaison as a mortuary consultant. Field interviews with morticians in New York City, conducted by research assistant Sarah Muir in 1997, revealed that, technically speaking, the services necessary for preparing an organ or tissue donor are no different than those for an autopsy, and thus they pose no unusual aesthetic challenges. A significant concern voiced by OPO personnel is that donor families must not incur extra charges for, say, an open-casket funeral simply because the loved one was an organ donor. Furthermore, mortuary employees must refrain from offering graphic descriptions of the body's condition following procurement.

Some surgeons pride themselves on ensuring that a donor's body is handled with dignity. As Dr. Salvador explained:

I try to take into account [the donor's background]. If I know, for instance, that the donor was Catholic and female, I know the family will probably want to put a cross on her right here [tapping his own upper sternum]. [With such a donor] I try [to do a] Y[-shaped] incision

[on her upper chest instead of cutting straight up] so we can preserve the shape of the chest. This is what is referred to as “the aesthetics of the donor”—there’s a lot written on this. If this person was nice enough to donate their organs—and this family doesn’t want to see the body disfigured, don’t I owe it to them [to take such care?] But not all [surgeons] do this. . . . We [on our team, we] try to preserve the body— aesthetics [matter].

In those rare instances where members of the surgical team actually know donors or their kin, they will make heroic efforts to ensure that bodies are handled in a dignified way. One OPO staff member reported an extraordinary case involving a nurse who had assisted at countless procurement surgeries. When she suffered fatal injuries in a car accident on her way home from work late one night, her kin consented readily to donation. When it was time for her to enter the operating room, this nurse’s colleagues insisted that they alone perform the surgical procurement of her organs. Staff interviewed from two additional OPOs similarly reported that either they themselves or their colleagues assumed full responsibility for the preoperative care and oversaw the actual procurement of organs from a colleague’s child. As one interviewee explained, the task was both horrific and cathartic for all involved precisely because everyone wanted to be certain that the donor was handled lovingly and solely by those who knew either the child or the mother.

Other Ways to Die

The demand for transplantable organs has increased rapidly over the last ten years, the waiting list shifting from just under 38,000 in 1994 to more than 88,000 in mid-2005. This trend stems from a number of interrelated factors: improved surgical techniques, the burgeoning of transplantation as an attractive medical specialty, and an expansion in the number of transplant units located in cities throughout this country. In contrast, the cadaveric donor pool has only grown incrementally, from 5,099 in 1994 to 7,150 by the end of 2004.²⁴ Even if, ideally, all brain dead patients could become multiple organ donors (the full count ranging from seven to nine organs per patient, depending on how one counts), it would still be impossible to meet the nation’s ever-growing demand.²⁵ According to UNOS in 2004, “On average, 110 people are added to the nation’s waiting list each day—one every thirteen minutes,” and “on average, sixteen patients die every day while awaiting an organ” (UNOS 2004b). In response, OPOs and transplant units engage in a constant quest to identify new organ sources. These include relying on living donors for kidneys and lungs (whereby they offer one of a pair) or livers (transected livers will regenerate), domino pro-

cedures, and experimental research focusing on artificial (mechanical) organ replacement, organ cell seeding followed by tissue regeneration, and transpecies transplantation (the latter defines the focus of chapter 4).²⁶ As noted earlier, the lifting of restrictions has already expanded the donor pool. Yet another strategy involves expanding allowable causes for donors' deaths.

One of the most significant shifts to occur in recent years involves procuring organs from patients who die not from brain death but instead from medically assisted forms of cardiac arrest. As noted briefly in the introduction, such donors are variously referred to as "non-heartbeating cadavers" or "non-heartbeating donors" (NHBDs), or the process itself as "donation after cardiac death" (DCD) or following "asystolic" death (UNOS 2004a; DuBois 1999; Fung 2000; Institute of Medicine 1997; Mandell et al. 2004). These are patients who never qualify for brain dead status. Instead, clinical staff have determined these individuals will suffer cardiac arrest, at which time they will not be resuscitated. When under such circumstances kin grant consent to organ donation, they and OPO staff inevitably become involved in a death watch of sorts. Cardiac arrest may occur spontaneously or when a patient is removed from the ventilator, in either the ICU or the operating room. When the heart stops beating, all pause briefly so that kin may have a final moment with the patient; then the patient (now donor) is rushed off to surgery, or else kin are ushered out of the operating room so that procurement work can begin (Greenberg 2003; Roach 2003: 167–95). Just as brain death protocols vary among hospitals, so, too, do those for NHBD or DCD. For example, the amount of time (or what is generally referred to as "the count") allotted between cardiac arrest and the surgical opening of the donor may range from as little as three minutes in state-of-the-art transplant centers to eight minutes in smaller and more cautious hospitals.

Such circumstances require an advanced directive from the patient (as stated in a living will, for instance) or from close kin who agree to a "do not resuscitate" order in anticipation of cardiac arrest. The actual procedures involved are, at the very least, murky. In some quarters they represent a blatant defiance of the credo that medicine must do no harm (Agich 1999; Fox 1993; Lynn 1993; Veatch 1997). Prior to surgery (and, thus, cardiac death), such patients have already endured a range of invasive procedures designed specifically to assess their viability as donors and even prepare them for organ procurement. As one OPO staff member explained, such procedures can be hard on field staff, for whom the excision of lymph nodes from the groin area for medical testing is especially troubling precisely because the often comatose patient is still alive and thus can conceivably experience pain. Such

patients are regularly administered medications to control their blood pressure. In addition, as one perfusionist attested, some teams who work in “high crime areas”—where patients are likely to be people of color and poor—may even initiate organ preservation techniques before family consent has been obtained. Critics underscore that such procedures defy rules of informed consent, favoring procurement needs over very basic forms of patient care and perhaps even endangering the patient’s life. Renée Fox, a sociologist who has conducted research in the realm of organ transfer since its onset in the 1950s, has gone so far as to describe the DCD protocol as “an ignoble form of cannibalism” (1993: 231). As she explained during a PBS Online Forum:

This [protocol] consists of a set of procedures for obtaining organs from patients on life support who have suffered a brain injury and lack a neck pulse, with presumably no chance for recovery, but who are not brain-dead. This protocol entails administering high doses or [*sic*] two drugs to the patient-donor—the anticoagulant heparin and the antihypertensive phentolamine mesylate (Regitine)—in order to prevent blood clotting and widen blood vessels so that the organs procured will be optimally viable for transplant. I am not a physician, but as I understand it, these medications provide no benefit or comfort to the patient who is the prospective donor, and there is the possibility that they may mask the continuing activity of the patient’s neck pulse. In the case of Regitine, there is the danger that through its secondary effects, it may induce or hasten the patient’s death. (Fox, DeVita, and Ritchie 1998)²⁷

Transplant surgeon Dr. Salvador expressed his reluctance in obtaining organs from such patients:

DR. SALVADOR: I have a really hard time with this. . . . Actually there is a reason why [there is the category] of the non-heartbeating [donor], how it came about. Initially this was [tried] in Spain. They actually have an organized system for this kind of donation. [In Spain] it’s for people who have an acute heart disorder—they suffer heart failure in the street and then they bring them to the OR. The Spanish system . . . [is] a very well organized system. The other system [like what happens here in the United States is very different]: [here] you have a family who wants to donate but only if it’s cardiac arrest. This part gets more tricky. Here they bring the patient to the OR and they stop all support—the vent[ilator] and hemodynamic [support] and then, hmm [pause] . . .

L. S.: You sit and wait?

DR. SALVADOR: Right. And when the heart stops you harvest the organs. . . . In this case you can't harvest the heart, I think. I don't like [to harvest organs from these] patients, but others [here on my team] don't mind.

As liver surgeon Thomas Starzl wrote, "Acceptance of brain death in 1968 was a boon to transplantation" (Starzl 1992: 150); so too, he could later argue for DCD, for by 2003 some OPOs had embraced this protocol with gusto. Whereas in the 1990s the testing of such protocols in Pittsburgh and Cleveland was hotly contested in the transplant literature (Agich 1999; DeVita 1993; Lynn 1993; Weisbard 1993), today DCD is experiencing rapid routinization.²⁸ By 2003, DCD had become a standardized procedure within five of the eight OPOs where I conducted on-site interviews. As an employee in one of the nation's smaller OPOs explained, for three years running her staff had obtained organs from only three DCD donors per year, but by 2003 the number had increased to thirty.

The use of DCDs or NHBDs is hardly new. As Starzl's memoir (1992: chap. 14) reveals, cardiac death was the precursor to organ procurement in the early days of experimental transplant surgery in this country. The practice dropped out of fashion as CPR techniques became standardized, alongside advanced knowledge on how to medicate patients in such a way that they could be sustained on ventilators even when brain dead. The significance of the DCD *revival*, then, is that it marks a breakdown in contemporary ethical codes of medical behavior. The desperate search for new sources of transplantable organs has thus *reintroduced* procedures that now threaten the humanity of dying patients, adding to their discomfort and suffering and even, potentially, accelerating their deaths.

Donation Denial

Such are the circumstances of successful procurement. Those kin who refuse to consent to donation are inevitably viewed as uninformed, superstitious, or overly conservative in their religious views, woefully uneducated, or confused by the belief that only cardiac death is a legitimate marker of a patient's final demise. As a result, public outreach programs—in the form of public service announcements, health fairs, and talks staged in schools, hospitals, businesses, and places of worship—are viewed by OPO personnel as powerful panaceas to any form of lay resistance to organ donation.

A tension that has long characterized OPO work is that staff view non-

consenting kin as obstructionist, and they regularly vent their anger and frustration over failed procurement attempts during in-house staff meetings (Sharp 2001). Unfortunately, the world of organ procurement is, in some regions of the United States, fiercely competitive. For instance, some OPO directors may go so far as to attempt to impose monthly quotas on their field staff. In reality, of course, it is impossible to predict the number of gunshot head wounds, auto accidents, strokes, or suicides that will occur in any given month in an OPO's catchment area. As a result, a field team may sense that it remains inescapably in debt, so to speak, to UNOS, to whom their administration submits annual predictions that then determine their funding level for the year.

Institutionalized anxiety over organ scarcity has led some OPOs to push for national policies that approximate "presumed consent," an approach that has proved highly successful in several European countries (BBC 1999). Under presumed consent, patients who die while hospitalized are assumed to approve of organ donation unless they have officially registered their opposition with a state agency. By 2003–4, a number of OPOs had successfully lobbied within their states for new legislation that has since transformed a signed donor card on a driver's license from being mere evidence of a potential donor's desire into a mandated advanced directive (like a living will). Previously, the decision to donate lay with surviving kin to determine; under new legislation, OPO staff can conceivably override the protests of kin and procure organs without their consent. Sabrina Bowers, a staff member from an OPO based in a western state, described this new policy as "'feel good legislation' [because] no one ever votes against this sort of thing." As she explained, it would be unlawful if her staff did not act on this "directive" as designated by the patient. When framed by this new legislation, even supportive hospital personnel become new sources of frustration for such OPO reformers. As Sabrina elaborated, a doctor who counsels a family that the decision to donate is "an option" is in fact acting in direct opposition to the new law.²⁹

Rather than viewing those who say no to donation as uninformed or obstructionist, I offer an alternative reading. Although such acts certainly defy the ideological premises of organ transfer, they may also be interpreted as highly creative—albeit subversive—understandings of death as a complex biosocial process. As described in the following section, even kin who understand brain death criteria and who have consented to donation may still voice the opinion in private that the donor's death occurred during procurement surgery. Even more surprisingly, an array of involved and well-informed professionals embrace this sentiment, too.

RECONSTRUCTING DONOR HISTORIES

Seeing and Believing: Professionalized Strategies for Depersonalizing Donors

The merging of legal criteria with transplant ideology has indeed transformed brain death into a clinical reality, such that the public face of organ donation proclaims it unequivocally as a great social good. Nevertheless, the daily practices of organ transfer uncover a more complex set of relationships and meanings. All involved parties openly acknowledge one thing: whereas brain death is a legitimate or “real” form of death, brain dead donors still appear, feel, and may even behave as if they are alive. As a result, brain death criteria evoke the disturbing sense that seeing is *not* believing: these criteria demand that clinical knowledge override what our senses tell us. Brain dead patients seem to breathe, but cannot think; we can touch and hold their warm hands, but they do not respond; and they may move, but only as a result of residual spinal cord reflexes and not because they sense that we are there beside them.

This strange, liminal nature of the brain dead patient was expressed succinctly by Dora Tuckerman, an OPO grief counselor. Dora raised the issue spontaneously during an interview, asking me, “Have you ever been there?” to which I gave a puzzled look. She clarified: “Have you ever . . . [seen an organ donor]?” I gave her a brief overview of an experience I had had while observing two of her colleagues in the field. She then said, “I have—once. [The donor] was on the vent[ilator] for ten days. [The sister] had been there for many, many days [and she was exhausted]. We had a problem getting him declared—[although] she believed he was dead. Then she called me up [and said,] ‘I don’t want him to be alone—can you go?’ I’d never gone [before], and when I saw—you know, they don’t look any different from someone who’s sleeping.”

As Dora’s response indicates, understanding brain death as true death is in many ways an intellectual exercise, one dictated by the premises of transplant ideology. It can nevertheless be extraordinarily difficult for the observer to conceive of such patients simultaneously as mere bodies and thus as *completely* dead. Among the most shattering experiences is witnessing reflex movements from residual spinal activity. During one case where I was an observer in 1995, an ICU nurse attempted to flee the room after a designated donor appeared to shrug in response to a question she had posed about his status. The OPO clinical coordinator coaxed her into staying and then calmed her down (and me as well) by explaining that this was merely a “Lazarus response” caused by a still active spinal cord. Both mortuary lit-

erature and fiction are rife with dramatic accounts of corpses that appear to respond to external stimuli (Proulx 1993; Roach 2003: 98–103; see also Hogle 1999: 65; Wetzel et al. 1985).³⁰ In the words of Dr. Valentine, a neurologist, however, this is no different from “the chicken that runs around the barnyard after its head has been cut off.”

Nevertheless, even highly experienced clinicians can be unnerved by movement in brain dead patients. The surgeon Dr. Salvador reported that such responses led him to delay procurement surgery in at least one instance. As he explained, “I had [a] pediatric—a baby [who] moved on the [operating] table. [The baby] had complex spinal movements. I [called] for a reevaluation [of brain death] and [we] waited five more hours for the reevaluation [before proceeding with] the harvesting.” The fact that guidelines for pediatric donors are far more conservative than for adults accounts in part for the extra caution taken by a range of involved professionals. These guidelines stem from the knowledge that infants and children recuperate differently than adults in response to severe brain trauma (Ashwal 2001; Gean 1994; Otte et al. 1989; Sarti 1999). Health professionals regularly make unusually heroic attempts to save children’s lives. As OPO staff member Sabrina Bowers explained, in her city’s local trauma center, brain death assessments for adults occur six hours apart, but “we wait twelve hours for children because we want to be very careful with them.” Field supervisors in some OPOs thus concur with Wijdicks (University of North Dakota 1998), advising their staff to keep kin away from the donor as much as possible to minimize the risk of their exposure to spontaneous movements from the dead.

The process of depersonalization is standard to medical care in this country, in which the most dramatic levels of professional detachment frequently arise in (especially non-hospice) contexts where clinicians must care for the dying (Nuland 1993; Rothman 1991). In hospital settings, brain dead patients clearly define a highly troublesome category, for they are viewed simultaneously as patients, as unconscious (albeit terribly damaged) human beings, and as still-warm dead bodies that move. On a very basic level, the semantics of organ transfer alone quickly set up layer upon layer of medical double binds for the researcher. Simply knowing, for one, how to refer to this liminal category of nonperson may be difficult. Such labels as “cadaver,” “corpse,” and “neomort” deeply offend surviving kin, who always refer to their loved ones by name. In contrast, procurement staff walk a tightrope between respecting the emotional fragility of kin and remaining true to the ideological premises that drive their work. Acceptance of brain death criteria requires at the very least a great leap of faith, given that see-

ing is not believing. Even more subtle shifts in faith are at work, too, rendered visible when transplant ideology clashes with private musings over the mystery of death. As we shall see, such shifts are reflected in professional behaviors and turns of phrase. At such moments as these, death emerges as a remarkably complex biosocial process.

Metaphors of Death

Within ICU settings family coordinators rely heavily on metaphorical thinking as a tool for talking with kin about death. Such an approach enables them to skirt the more technical aspects (and details) of the clinical management of brain dead patients. Dora Tuckerman, for instance, offered this example: “One of the . . . coordinators [here likes to say,] ‘It’s like you have a complex form of farm machinery and the driver falls off.’ That’s what the brain is,” a description that is used widely by others within the same OPO. On two other occasions research participants from separate OPOs described brain death as “a house where there’s nobody home.” More basic explanations involve defining brain death in reference to what it is not: the patient is “not like someone who is asleep—they will never wake up,” or through technical analogies, likening a hemorrhaging brain to a leaky hose or a broken and irreparable container.

Clinicians, too, may revert to metaphorical thinking. Among the more elaborate and poetic descriptions was the following, provided by the neurologist Dr. Lazarre:

L. S.: Are you concerned with the mind or the brain when you talk about brain death?

DR. LAZARRE: The brain. I’m like a plumber . . . I think about both. [But] with brain death you lost your mind a long time ago. [Look, you can] think [about this as being] just like a fully decorated house. Consciousness is [a world of] color in the [fully decorated] house. [In a] vegetative state you just have the scaffolding up. There’s still some residual structure of a brain [there]. [But] with brain death [pause] everything is reduced to dust.

Metaphors similarly abound in the visual imagery used to illustrate informational pamphlets, among which the most prominent involves vegetation, or what I have referred to elsewhere as the “greening” of the donor body (Sharp 2001), a topic I will discuss in greater detail in the final section of this chapter. A pamphlet circulated nationally in the mid-1990s, one intended for use by hospital chaplains, bore an image of three aspen trees clustered before an open field void of other life-forms, with stately mountains

in the distance. Imagery such as this now defines a widespread, powerful genre of representation that ultimately clouds or denies the clinical reality of hospital death and organ procurement; the stand of aspens, for instance, evokes instead a sense of serenity. Also notable are attempts to grapple with death ultimately as an unknowable category. How might we describe a rose's perfume to someone who has always lacked the sense of smell? Similarly, can the clinically trained describe a necrotic brain to a family member with no understanding of neurology? The power of the metaphor lies simultaneously in its ability to obscure the dark realm of brain failure while also rendering the intangible somehow knowable. While the family counselor walks a fine line between comforting kin and nudging them toward consent, such metaphors also inevitably facilitate a smoother transition toward the depersonalization of the patient, who may then be thought of with greater ease as occupying the newly established status of organ donor. This process is especially evident in the work conducted by OPO clinical coordinators, who oversee the actual medical care of donors.

Other Forms of Semantic Policing

In their professional efforts to dehumanize the brain dead, procurement specialists must be masters of technological euphemisms. For instance, in any other context a ventilator is typically referred to as "life support," yet this phrase is never used in procurement circles. Holly Franz and her colleagues emphasize the importance of employing what Ruth Richardson (1996) refers to as "semantic massage" when OPO staff address the kin of potential donors:

Choose words carefully when talking with the family about the patient's condition. After brain death is declared, the healthcare team must declare with certainty that the patient is dead. It must be stated explicitly that brain death is not coma, that the patient will not recover, and that [although] the heart is still beating and the body is warm—the person is dead. This information must be stated simply, without obscure medical terms, acronyms, or other jargon that serve to confuse most families. The care given to the brain-dead patient should never be referred to as "life support." Better terms are "artificial" or "mechanical support." (Franz et al. 1997: 19; italics in original)

As Jacquelyn Slomka (1995) has argued, the phrase "life support" can prove detrimental to humane end-of-life care. As she explains, nurturing is pivotal to much of the work performed by health professionals, especially nurses. Among the most difficult aspects surrounding the termination of care involves hydration "therapy," which is administered through "feed-

ing” tubes. When labeled and imagined as such, nurses may find it truly difficult to cease administering such basic forms of care to patients who lie at the brink of death. As a result, their patients may suffer more because they are not allowed to die. In response, Slomka (not unlike Franz et al.) advocates the development of more neutral terminology that shies away from references to care, therapy, and life-sustaining treatments.

OPOs are well aware of these dilemmas. Field staff are instructed to take an active part in dehumanizing brain dead individuals in a manner that goes beyond mere shifts in labeling of patients. Again, I quote from Franz et al., who offer guidance on proper decorum when in the presence of hospitalized organ donors. Shifts in language and behavior are intended to assist kin, hospital staff, and OPO workers in shaping their perceptions of donors: “*Avoid talking to the patient once brain death has been declared. It is common for nurses and other staff to talk to patients who are unresponsive, which may continue even after brain death has been declared. Members of the healthcare team may need to remind one another to be more conscious of this habit so that their message to the family about the patient’s death is not undermined*” (Franz et al. 1997: 20; italics in the original).

As such instructions reveal, the ideology of organ transfer insists that ventilated brain-dead patients are already dead, and the policing of semantics and associated behaviors is critical to successful OPO outcomes. A final form of dehumanization is evident in the style of clinical care administered to prospective donors. Because the greatest urgency rests with the ability of OPO staff to preserve the integrity of transplantable organs, they must focus their efforts on protecting organ viability by stabilizing the physiological status of bodies maintained on artificial support systems. In Linda Hogle’s words, this “cyborgic technology” reassigns a patient to the liminal status of “living cadaver” (1995b: 204, 206–7; see also Lock 2002, 2003). It is for such reasons that hospital nursing staff readily shift their attention to other patients whom they feel they can still heal. From their perspective, it is truly odd that such intensive care is applied to patients who have been pronounced dead. Among the more troubling aspects of brain death is that it clouds widely accepted views on how we do—or should—die, a fact that is clearly borne out by a case I witnessed in which a patient literally died twice.

The Patient Who Couldn’t Die

Mr. Faustman was a forty-nine-year-old Euro-American man who collapsed midday on the sidewalk as a result of a massive stroke, and after a passerby called 911, he was taken by ambulance to a nearby hospital. For the first twenty hours of his hospitalization he remained alone because it took some

time to identify and track down his kin. Relying on information found in his wallet, police eventually paid a visit to his apartment, where he lived alone. With the landlord's assistance, the police acquired the names of two adult daughters, both of whom flew in immediately to be at their father's bedside. Within a few hours of their arrival, Willie Otis, the OPO family counselor, sat down with the two sisters and explained, "Your father has had a massive bleed to the head—the hospital has done everything it can to try and save him, but there's just not anything else we can do." Willie added that Mr. Faustman was about to be declared brain dead because "much of the brain has been destroyed." The consent process was rocky: although one daughter readily gave consent, the other was highly suspicious of Willie and began to scream, "You're not going to take his organs!" Willie then asked the nurses to find a room where they could talk privately; in the end, the daughter granted consent as a means to support her sister. Soon afterward their mother (who was in the midst of divorce proceedings with Mr. Faustman) arrived from another distant city. She, too, gave her consent, as did a third daughter who was unable to be there.

Procurement is too complex an affair to proceed smoothly on a regular basis with no glitches, and this case was no exception. A few hours later a doctor from the unit approached Willie and said, "Boy, they've had a bad day, haven't they? It doesn't get much worse than this. I really feel sorry for them. A fuck of a bad day." Willie then turned to me and said, "There's always another story." Within Mr. Faustman's apartment the two daughters had found evidence that their father was gay, something their mother already knew. As Willie explained to me, "Look, this is [Metropolis]—if he's gay, the lover will show up." Indeed, within a few hours of the wife's arrival, this is precisely what happened. At this point Willie confided to the attending physician, "I don't want this gay information broadcasted." He and his supervisor back at the home office decided together to withhold information from UNOS on Mr. Faustman's sexual history until serology tests came back for HIV and various strains of hepatitis. According to Willie's partner, the clinical coordinator Kathy Green, Mr. Faustman did in fact test negative for HIV but positive for hepatitis B. Although by evening the daughters and their mother had already retreated to a local hotel to await word that the procurement surgery was over, and various local transplant teams stood poised and ready to come and begin harvesting his organs, in the end Mr. Faustman was deemed too high-risk a case to qualify as an organ donor. As a result, he never entered surgery.

Early the next morning Gabriel Evers, another clinical coordinator, arrived to relieve Willie and Kathy, both of whom had been at work in the

hospital for the last two days. Gabriel's primary assignment was to assist hospital staff in disconnecting Mr. Faustman from the ventilator. As Gabriel later explained, however:

It became a feud [over] who wanted to do what . . . and then [the hospital staff] got really confused about pulling the plug. One of the doctors said we should just keep him on oxygen but [that will keep the] heart going! This doc [then] wanted to declare the death upon *disconnecting him*. He wanted to *throw out the death certificate* [declaring brain death] *and do it again!* I said, *You can't do that! HE'S DEAD!* So I had to tell him what to do. I said, Get the family in here to say their good-byes and then get them out of here and disconnect him. . . . Most hospitals won't just take someone off the life support. But you know, a patient like this can go for six weeks just on the respirator—because as long as the heart is still getting oxygen, it can keep on beating. The heart can keep going—they can potentially die six weeks later. . . . [Eventually] they took him off the respirator—they stopped giving him oxygen. By then, I'd left—my work was over. . . . In the end, they did [reissue the death certificate].

I was curious to see how Mr. Faustman's demise was officially reported by his family, and so I searched the local paper that week for his obituary. As I recorded in my field notes, Mr. Faustman was found on the street and hospitalized on May 20, and he was declared brain dead on the evening of May 21. His obituary, however, recorded that he had died "suddenly on May 23," this date coinciding with the time he was disconnected from "life support" by the hospital physician. In the end, Mr. Faustman indeed died twice.

Personhood and the Brain Death Conundrum

The case of Mr. Faustman reconfirms arguments put forth by Margaret Lock (2002) that organ donors are a category of the twice dead. I would like to expand this argument by exploring how this specific account uncovers the manner in which shifting or competing explanatory frameworks are also at work. We might consider Mr. Faustman's case, for instance, as offering unquestionable evidence of severe cognitive disjunction. Even more compelling is how transplant ideology so readily confounds the ability to view death as an intricate social process. In contrast, Mr. Faustman's case insists on such an alternative reading.

Medicolegal guidelines dictate that death is something we can map out, track, and declare; in turn, the act of declaring death is time-bound, and thus death inevitably must occur only at a very particular, recordable moment. End-of-life hospital work and procurement activities both rely heavily on

this model: in caring for organ donors, specialists in each domain must embrace brain death as absolute death. Pat Fisher, who works for an East Coast OPO, expressed this idea in blunt terms: "The donor is dead—not sort of dead, not kind of dead, but dead. D-E-A-D dead. This kind of hedging is destructive to donor families . . . and the work we do in my office." During such horribly mixed-up moments as Mr. Faustman's demise, death nevertheless emerges as both a social process and a social drama. Mr. Faustman's death, after all, involved a host of end-of-life events marked by a full range of physiological breakdowns. First, when found, he was unconscious and alone. Once he was hospitalized, staff were able to stabilize him, although he never revived as a cognitive being. As his brain deteriorated, his body nevertheless continued to function, albeit through the assistance of mechanized support. Following the removal of the ventilator, his heart quickly failed, and he turned cold and gray. Throughout this process professionals and surviving kin withdrew their support at various moments, depending on which stages they considered to be the most significant markers of his death. Nurses were among the first to withdraw, clearing the way for OPO staff; Mr. Faustman's kin retreated to a hotel only once they believed he was bound for surgery; an attending physician, however, still viewed Mr. Faustman as a living patient when he failed to qualify as a donor. OPO staff left the hospital only when procurement became impossible, although they regarded Mr. Faustman as dead much earlier than all other participants.

Significantly, parties involved in or who witness donor management do not necessarily embrace brain death as evidence of true death even if they are supportive of organ donation. Research conducted by Franz et al. (1997) vividly illustrates this. Drawing on result from a survey involving 172 families from three OPOs, where respondents consisted of 102 kin who had consented to donation and another 62 who had not, these authors found that a significant proportion on both sides had not fully understood brain death criteria (cf. Siminoff et al. 2001 for a similar discussion). A full 20 percent believed that brain dead individuals could recover; 28 percent equated brain death with coma; and 12 percent assumed the heart had already ceased to function. An additional 6 to 9 percent answered "I don't know" to each of these questions. Statements generated from interviews offered evidence for why this was so. For example, when asked whether brain death is the same as a coma, a forty-seven-year-old man, whose wife had been a donor, responded as follows: "They are dead. Well, they're not dead. . . . It depends on how you look at this." A thirty-two-year-old wife who denied consent explained: "I think a little of both. . . . My emotions are telling me that [his brain is dead], but the rest of him is still alive until I do what I have to do."

Finally, a donor's thirty-year-old daughter put it as follows: "She was breathing. Her heart was going. . . . They're telling you that she's dead, but she's still there" (Franz et al. 1997: 17–18).

My own interviews with donor kin generated similar responses. As one father explained of his teenage daughter, "As far as I'm concerned, she died on the operating table." In response to these sorts of answers, though, Franz et al. reach this limited conclusion: "The difficulty many laypeople have in understanding the concept of brain death cannot be underestimated [*sic*]" (1997: 17). The policing of language and gesture, as outlined earlier, defines the main component of the solutions Franz et al. offer in response. In doing so, however, these authors overlook the possibility that kin regularly consent to donation although they may not accept brain death criteria as evidence of true or absolute death. An important question that must be answered is, What leads some to consent to organ donation even when this is so?

One possibility is that OPO counselors are especially persuasive or even coercive at moments when kin are already destabilized by the shock of a sudden death. Those working for the nation's largest OPOs do in fact speak regularly of developing ever more "aggressive" tactics for acquiring consent. Yet my data support an alternative and more subtle reading. For one, I assert that those who say no to donation will probably always do so, regardless of the educational messages they receive, or the "aggressive" tactics they might endure. Nevertheless, a widespread belief among OPO staff is that most kin say no specifically because they are unaware of the official stance of their respective religious faiths. For this reason much effort has focused on culling succinct (and, thus, superficial) statements from clerics of all stripes to illustrate that there is a near-universal acceptance of organ donation (for example, see DCIDS 2004). The nonreligious in turn may be labeled as "superstitious" or "uneducated." My own data reveal, however, that informants' visceral reactions to what happens to the body at the time of death play a large role in determining consent outcomes, whether or not they are religious. Those who say no to donation understand death as a time of suffering, and this is a process that persists when the brain has failed, as the body itself breaks down and, even, at times, after the body has turned cold and gray. For such reasons these kin feel strongly that the patient—or body—must remain undisturbed and intact if death is to be peaceful. Certain faiths and cultures may even view discussions of death, or of the dead themselves, as threatening to this process.³¹ As such, the activities of OPO staff emerge as dangerous work because of the volatile emotional responses they evoke in kin who hold different beliefs about the *process* of death.

On the other hand, kin who consent to donation are frequently capable of embracing competing models of death simultaneously (although they generally refrain from voicing contradictory beliefs within earshot of OPO staff). Two models are particularly relevant here. The first relies on clinical definitions of death, whereas the second focuses on more intimate understandings of the selfhood of the beloved. Kin consent to donation when they understand that the social being they know and love is irretrievably lost to them. Their desire to perform a great act of kindness by helping strangers in need bolsters their commitment. Nevertheless, many kin regularly accept as well that the inner self, soul, or spirit finally dies (or departs) only once the body itself fails entirely. In cases of brain death, this occurs during procurement surgery; for DCD, it coincides with the cessation of the heart-beat. Such understandings are key to organ transfer's success, although ironically they run contrary to organ transfer's ideological assumptions about death.

Donor kin are not alone in embracing a model of the multiple death, or, when understood in its more sophisticated form, of death as an intricate social process mediated only in part by medicolegal interventions (and definitions). Procurement professionals may express similar ideas: at times this is reflected in the rhetoric of persuasion, at others, such beliefs are voiced explicitly during private interviews. For instance, among the most effective messages offered by OPO counselors is that donors can live on in others, granting new or "second" lives to transplant recipients who, in turn, frequently describe their own surgeries as cathartic "rebirths." These same professionals also privately acknowledge the tenuous quality of brain death. During staff meetings at one OPO, employees regularly distinguished brain death from cardiac death by describing individual donors as moving from the state of being "kind of" or "sort of" dead in the ICU to being "dead dead" following procurement surgery (Sharp 2001; cf. Hogle 1995a). Such donors are, in Lock's words, "good-as-dead" (Lock 2003; cf. Greenberg 2003; Siminoff 2004).

Hospital-based physicians, too, readily speak of the dissonance that prevails between official rhetoric and private beliefs (Youngner et al. 1989; Youngner, Arnold, and DeVita 1999). For example, I had the following exchange with Dr. Lazarre:

- L. S.: When you talk about brain death, are you thinking about a brain dead patient or a brain that's dead? Also, is it possible to say that someone can die twice—first brain death and then cardiac death?

DR. LAZARRE: Sure—I can keep the rest of your body alive. The rest of your body is alive artificially. Does this mean you die twice? The way you should die [is that] dead is dead. Brain death should mean that you're dead. But in [this state within the United States]—it's very conservative [politically here]. . . . You're only dead by brain death if you want to be. Only if your family doesn't accept it for religious [definitions of] death.

Another neurologist put it thus:

DR. NEEDLER: It [brain death] is synonymous with death, which we're taught to say [to families] in the ICU [but] I'm not really convinced of that [although it's no way to live]. . . . [To me] the person is irrevocably gone—we don't even expect them to do even what a baby can do. I try to convey to the family that I'm not horrified by this—I wish to see them grow, but they're not going to grow.

In these senses, then, the biological breakdown of the brain and body undermines the social functioning of the person valued for his or her sentient qualities. These and related sentiments are not unusual: Lock herself reports that “among the thirty-two intensivists (specialists who work in ICUs) whom I interviewed between 1995 and 1997, not one believes that brain death signals the end of biological life,” although they embrace the understanding that the brain is irreversibly damaged and that this will eventually lead to “complete biological death” (Lock 2003: 171–72). An internist whom I interviewed, and who works closely with transplant recipients, offered yet another point of view. Rather than describing organ donors as dying twice, she stressed that “we need to view death as a process that we undergo gradually over time.” When taken together, these views offered by donor kin, OPO staff, and physicians provide a more gradual and thus subtle model of donor death, albeit one that runs contrary to the official rhetoric of organ transfer. When death is framed exclusively as a biological process, typically the brain dead donor moves from head trauma, to mechanical ventilation, to brain death declaration, to anesthetized surgery, to the physiological death of the body during procurement, culminating much later in final decomposition at the cellular level. Such is the specifically medicolegal trajectory of brain death.

If we in turn trace the demise of the social person and the self, death emerges as a different sort of *social* process. We can depart from this world in various ways, depending on individual readings of what defines the key aspects of our selves. At times such readings are linked to biological

processes, such as aging. As Dr. Needler said of vegetative and brain dead patients, “They’re like a baby again. There’s some humanity [there] but [there’s] not really a developed mind.” An even more stringent approach is reflected in the opinions of OPO staff, who understand that the self dissipates with coma and is irrevocably extinguished when the brain fails. As a result, such donors should no longer be treated as if they are full-fledged human beings, as evident in the range of semantic policing described earlier in this chapter.

Some kin, however, understand the social process of death in ways that ultimately defy a clinical model of death. A brain dead state (not unlike coma) renders it impossible for kin to detect traces of the person locked within. Kin nevertheless continue to respond to a brain dead person with the understanding that he or she might somehow still be there in small part. They willingly caress and speak to such patients up until the moment they are taken to surgery. The ability of kin to maintain a sense of connection is facilitated by the fact that brain dead patients do not appear dead. Thus, the unresponsive donor retains some essence of a unique life. Donor kin frequently understand the donor’s private self (or, for some, the soul) as departing only during or by the end of procurement surgery—that is, only once the body has become an empty shell.

At work here is a subtle distinction between the *social person* as cognizant (and communicative) human being and the far more *private, hidden self*. With brain death, I argue, kin are far more likely to accept that the social person is no longer there (and, thus, has died) because evidence of the behaviors and responses they associate with social behavior is gone. Put another way, the social person dies as the brain fails, and it is for this reason that kin ultimately consent to donation. As for the unique, private self, kin frequently feel that this lives on in the body and persists until the donor is ultimately and truly a cadaver. Sadly, the official ideology of organ transfer denies the legitimacy of these sentiments and associated subtle distinctions. In the realm of organ procurement there is no room for such existential possibilities.

With these sentiments in mind, I argue for a radical shift in frames of reference so that we might recognize the wider range in which death is culturally constructed. Unfortunately, when involved parties question the reductionistic quality of ideological premises driving organ transfer, they are quickly silenced because they are perceived of as challenging the legitimacy of brain death criteria. For instance, procurement professionals view questioning within their own ranks as a sign of weak faith or work-related fatigue. Similarly, when donor kin state that a loved one died during procure-

ment surgery and not in the ICU, OPO staff insist that kin have misunderstood the definition of brain death (or may assume that they themselves failed in their mission to communicate what this term means). But what if we read such statements as evidence of an acceptance of the inevitability of death, albeit under circumstances radically different from those promoted in the messages delivered by OPO counselors? I regularly encounter donor kin who embrace organ donation as among the most important decisions they have ever made in their lives, yet these same people may still question or challenge the assertion that brain death is true death or, even more important to them, that it is a natural way to die. When the father of a teenage donor states, “She died on the operating table,” he does not mean that OPO staff orchestrated her death but, rather, that the essence of his daughter departed when her organs were procured and her body ultimately failed.

Anesthetizing the Dead

One of the most peculiar aspects of procurement involves the manner in which organ donors are surgically managed. As noted, although organ donors already have been declared brain dead, they are nevertheless anesthetized at least during the first portion of procurement surgery (Gelb and Robertson 1990; Levinson and Copeland 1987). This practice is rarely discussed, and it is not even necessarily understood by closely involved parties. When I posed questions about why dead patients need to be anesthetized, I was informed by three OPO staff members, two neurologists, and two internists (both of whom work closely with prospective transplant recipients) that I must be misinformed. The subsequent musings of one neurologist exemplified the responses I received from two other physicians. As Dr. Valentine responded, “I suppose it might be used in order to suppress residual spinal activity?” Dr. Lazarre put it thus: “You need to ask an anesthesiologist that one. As far as I know they don’t need anesthesia. The only reasons might be that the spinal cord may still be perfused and alive, and capable of triggering vasomotor reflexes (i.e., unstable blood pressure) in response to painful stimuli such as cracking the chest open or cutting the abdomen open.”

Procurement surgery is indeed complex and can generate a host of complications that require immediate response from the anesthesiologist (Gelb and Robertson 1990: esp. 809–11; Levinson and Copeland 1987). Dr. Salvador, who regularly retrieves organs from donors, offered this explanation:

The [donor] patient is brain dead, [and] you have an anesthesiologist, but it’s not really for anesthesia. They are there to oxygenate the patients [and] monitor the hemodynamic [status—that is, blood pressure;

for this] they may administer pressors—you see, the longer you are brain dead . . . the greater the requirement is for pressor support [in anticipation of drops in blood pressure]. [Anesthesiologists] also give drugs to paralyze the patient to relax the abdomen more for us [to make our work easier]. . . . But [once] the blood has been removed [by the perfusionist] the anesthesiologist is no longer necessary.

Yet another transplant surgeon, Dr. Paluchi, explained the need for anesthesia as follows in a note: “The donor is brain dead, i.e., dead, so that anesthesia per se is not needed. We do need to give muscle relaxation [*sic*] as there are spinal reflexes which lead to stomach muscle contractions while operating. Anesthesia is also needed to[o] or at a least a nurse, so that the blood pressure can be regulated and drugs [such as] insulin can be given.” Clearly, then, anesthesia plays a pragmatic role here, serving to relax the body so that the donor will not move and potentially jeopardize the delicate work of removing still vital organs.

There is, however, another purpose at work. As Adrian Gelb and Kerri Robertson write, neuromuscular reflexes “may range from muscle twitching to complex movements of the limbs and trunk. For the unsuspecting in the operating room, this can be most disconcerting and staff may require frequent reassurance that the donor is indeed dead” (1990: 809). The neurologist Dr. Needler similarly underscored this fact:

L. S.: I understand that brain dead donors are anesthetized—

DR. NEEDLER: Yeah, I know: Why, if they’re dead?

L. S.: Exactly.

DR. NEEDLER: They are dead. My understanding is that the anesthesia [is used] to relieve the people who work in organ procurement. . . . Although I think it’s very rare, [I think they’re thinking,] “What if they’ve been given the wrong information that the person is brain dead but [they’re actually in another state]?” This would be horrible—they would feel they were assisting in an evil cause. It is a way to avoid [participating] in the evil cause [of being responsible for harming someone]. If they know they are anesthetized [then they know] the patient didn’t experience [any pain].

L. S.: This may sound naive, but if someone is brain dead from brain stem failure, could they still experience pain?

DR. NEEDLER: [No.] Pain is a cortical phenomenon. [She offers a detailed description of cases where patients

have experienced extreme upper brain trauma but show no responses to intractable pain.] If the brain stem isn't functioning you can't have upper brain function.

Linda Hogle, who has conducted field research on this subject in both the United States and Germany, confirms that anesthesia does, in fact, help quell anxieties among surgical staff. As she explains, although donor bodies may be handled as passive objects (laid out, for instance, on a gurney or operating table, with both the body and the face covered with a surgical drape), they nevertheless exert a "type of agency" because "the body responds" to a range of stimuli during surgery. In addition to the need to monitor hemodynamic systems, "more disconcerting are reactions not considered to be characteristics of dead bodies. Spinal reflexes may cause the body to move, as if the body is reacting to the incisions. Blood pressure and respiratory changes have been reported at the moment of incision and during the procedure. Neither reaction is supposed to happen in 'dead' bodies, even brain-dead ones, and neither the chemical agents nor the physical actions being carried out explain such reactions in the reported cases" (Hogle 1999: 164-65, citing Emmrich 1994; Wetzel et al. 1985).

Hogle's interviews with operating room staff in Germany uncovered specific concerns over the limited application of anesthetics:

Since no deep-pain control is used, individuals who are unsure or unconvinced about the implications of brain death are concerned that the person may be able to sense pain even if he is incapable of expressing it. Therefore, he may be dying an agonizing death, according to detractors. Neurologists insist that pain response is no longer possible in brain death. Not using additional anesthesia is another way of cognitively placing the body closer to the state of being an organic mass as opposed to a patient in an indeterminate state of animation . . . both opinions about pain response are theoretical because they are impossible to test.

As Hogle concludes, both the body and the surgical staff "flinch" in response to this paired "invasion of bodily boundaries" and the "invasion of the boundary between life and death" (1999: 165).

In recent years, these sorts of concerns have driven heated debates among anesthetists (anesthesiologists) based specifically in the United Kingdom. The related literature proves especially helpful, given that the authors are the very specialists who are most intimately involved in the minute-to-minute surgical management of organ donors. Key questions focus on

whether brain dead and/or DCD donors require anesthesia; whether necessary procedures should even be referred to as anesthesia; and whether either brain dead or DCD donors are in fact fully dead. As David Hill, an anesthetist, asserts, "The greatest misconception is that the donor will be dead in any ordinary sense of the word. Most people equate death with what [another author] calls 'asystolic' donation, not the warm, pink, pulsating, breathing (albeit by machine), reactive state that we call brainstem death. It may come as a considerable shock to know that the donor will always need to be paralyzed for the surgery, and may or may not have anaesthesia" (Hill 1999, citing Pallis and Harley 1996: 46). Hill's statement is rooted in the assumption that organ donors are best imagined as liminally dead patients rather than as full-fledged cadavers.

The quandaries associated with this position are addressed in detail by P. J. Young and B. F. Matta, both of whom specialize in neurosurgical critical care. Specifically, they question the recommendations appearing in a 1999 pamphlet on organ donor procurement surgery, as published by the Intensive Society of the United Kingdom. More specifically, they object to the general statement that "brainstem dead patients do not require analgesia or sedation." Echoing earlier arguments by clinicians I interviewed, they assert that anesthesia quells the doubts of surgical staff, and rightly so, given the lack of confirmatory tests to show without a doubt that the donor experiences no pain. They also insist that death is best viewed not as a discrete event but as a process:

Firstly, under few circumstances do we allow operative surgery with muscle relaxation and without analgesia or anaesthesia, leading to a psychological compulsion to provide anaesthesia. Second, the hypertension and tachycardia that accompanies the donation operation can be distressing for operating theatre personnel to witness and for this reason alone one should always administer anaesthesia or agents to control these reflexes. [A shift in blood pressure] . . . could be considered to represent an organism in distress and probably occurs at a spinal level, although we are unaware of EEG studies during organ collection to confirm this. Third, death is not an event but a process and our limited understanding of the process should demand caution before assuming that anaesthesia is not required. (P. Young and Matta 2000: 105)

J. Wace and M. Kai offer a more contentious response, identifying in particular the "transplant lobby" as undermining necessary anesthesia requirements for donors. Further, they challenge the assertion that DCD and

brain dead donors are truly dead. Speaking of events that transpired at a conference of Medical Royal Colleges, Wace and Kai express the following concerns:

This conference was intended to facilitate beating heart organ donation but only concluded that the state of brain stem death was a state of unsurvivable coma and, quite rightly, stopped short of equating it to death itself.

Many anaesthetists clearly have been very uneasy about the transplant lobby's rather rash assumption that organ donors do not require anaesthesia. Many anaesthetists do administer an anaesthetic to these patients, with good reason, as set out [by Young and Matta]. The problem the transplant lobby have with giving donors an anaesthetic is the perceived additional difficulty in telling the donor's relatives that the donor is not dead but in an unsurvivable coma.

It is time all anaesthetists realised that to not administer an anaesthetic to a donor (who is not by any definition dead) is to commit an act of possibly barbarous dishonesty. Whatever the effect on donor numbers, one cannot condone such action. (2000: 590)

In this sense, then, organ donors exist in an unusual state of nonbeing, but not full death. B. Poulton and M. Garfield, however, react "with dismay" to these assertions. They argue instead that in administering anesthesia one ultimately grants consciousness (or life) to a patient who should already be treated as dead. Unlike the other authors cited here, then, Poulton and Garfield refute the necessity of anesthetizing donors. Key to their argument (or what Wace and Kai equate with the "transplant lobby") is the assertion that, even if we view death as a process, the practice of anesthetizing donors undermines messages communicated to surviving kin:

Appropriate concentrations of volatile anesthetics could only *produce* unconsciousness if the individual was conscious to begin with. . . . Consciousness in the absence of brainstem reflexes is a theoretical possibility, but if this was known to be the case in a particular individual, we believe that few of us would be comfortable in informing relatives that their loved one had "died." Death is clearly a process but many would argue that the persistence of consciousness, more than the function of any organ system, defines human life. Death may well be inevitable for individuals meeting the brainstem criteria, but to render a conscious mind unconscious for the purpose of organ harvest could well be considered as an act of euthanasia. (Poulton and Garfield 2000: 695; italics in the original; see also Turner 2000)

As these heated debates make clear, regardless of the stance asserted by organ transfer ideology, the uncertainty of death still haunts some neu-

rointensivists and anesthesiologists who, in the United Kingdom at least, willingly voice their concerns. The positions asserted by these clinical specialists are fed at times by what they witness during surgery; at others, they more closely approximate the position of procurement professionals, whose work must insist that a being for whom there is no hope of revived consciousness is already fully dead.

Clearly, the inability to grasp fully the minute details of the process of death underlies this troublesome debate. The lack of universal criteria, paired with diagnostic limitations, proves particularly irksome. As Matta explains, "Defining a moment at which death occurs within the dying process is necessary but arbitrary, and differs across societies. A brain might be defined as dead in the United Kingdom, yet the same brain would not be dead in Europe and vice-versa. . . . While there is no evidence to suggest consciousness persists in these patients (with obvious reasons), the absence of a direct measurement of this makes it only a belief that has not, and perhaps cannot be, confirmed" (2000: 695–96). In the face of uncertainty, those medical specialists most intimately involved in managing the ultimate demise of organ donors frequently insist that these patients be handled as if they were still alive. Critics, though, view such approaches as unethical because they are tantamount to acknowledging that surgical teams practice euthanasia. At the heart of this conundrum is the fact that one can never be certain if organ donors retain the ability to sense the world around them.

Just as surgeons themselves should care, in Dr. Salvador's words, about the "aesthetics" of the donor body, the art of anesthesia is likewise guided by aesthetic principles in response to a troubling set of existential quandaries.³² Given that the majority of American OPO field staff never enter the operating theater, they can embrace with greater ease the understanding that brain death is an absolute state of nonexistence. As such, they accept the premise that an organ donor can experience no further trauma during surgery. Those who have more intimate experience with the actual "procurement," "retrieval," or "harvesting" of organs, however, come face-to-face with the open-ended and unknowable qualities of donors' deaths. This then leads them to ponder the likelihood of physical pain as well as the point at which one can sense the ultimate demise of the patient. The actions of those specifically in charge of the surgical management of organ procurement are driven in part by a "what if" approach, such that they administer anesthesia as a means to stave off persistent doubts while also preserving the dignity of patients whose bodies house parts coveted by transplant surgeons.

BODY ECONOMIES

If I wind up brain-dead with usable parts, someone's going to use them, squeamishness be damned.

M. ROACH, *Stiff* (2003: 291–92)

As reflected in the previous discussion, the ideological premises of organ transfer overshadow a host of contradictions, particularly about how we must perceive of, talk about, and manage patients who are sustained artificially in half-dead states. Responses expose the fact that potential donors (and donor bodies) are valued in radically different ways by assorted parties. OPO staff, for instance, insist that the technology of ICU patient care creates the illusion that brain dead donors are still alive. Yet donor kin who grant consent may silently question this assertion, sensing instead that a damaged brain may rob the beloved of their humanity but not necessarily their essence or life force. All participants nevertheless agree that organ transfer is of great social worth because it grants life to others who are at the brink of death. Through the act of consent, goodness can spring from horrific tragedy and grief. As we shall see, however, such principles define only a fraction of the value assigned to organ donors and their transplantable parts.

Body Counts

As my earlier discussions make clear, brain dead patients experience a transformation in value, shifting in status from that of human being to a repository of harvestable organs. Organs, too, are similarly transformed. Once removed from the original bodies that housed them, organs shift to being prized commodities (Sharp 2000b) that must be handled with great care. Because it is illegal to buy and sell organs in the United States, their worth is clouded by the language of an unusual gift economy. Donated organs have long been described as “gifts of life,” for which donor kin receive no monetary compensation, nor even reciprocal favors from OPOs, transplant teams, or organ recipients (or their insurance companies). Within the framework of the gift economy, donor kin also assume an elevated social status: alongside organ donors, they are frequently described, for example, as transplant’s “unsung heroes” and “stars.” Regardless of the fact that transplant medicine is unquestionably among the most lucrative of medical professions, the rhetoric of organ transfer glosses over this reality. As James Frick, a perfusionist and surgical technician who advocates compensation, asserted during an informal discussion, “Look, we’re *all* sustained by this industry—whether through surgery or even through [your] research—let’s stop kidding ourselves, we *all* profit from it, [so] shouldn’t donor families get something, too?” Donor

kin are nevertheless expected to give willingly and selflessly to anonymous strangers. As critics assert, paying donor kin for their acts of kindness would debase the Samaritan act so intrinsic to organ donation, defile the sanctity of donors' deaths, and potentially drive the economically disenfranchised to place dying kin (or themselves) at risk when lured by promises of economic gain.

The medical worth of the donor body itself is reflected in a numerical language employed by a range of staff from assorted professional organizations. For instance, those who work for OPOs regularly speak of the "seven-organ donor" or even "nine-organ donor" as the quintessential success case. Currently the body's value is similarly quantified by UNOS and other organizations. A popular statement is that one body may generate fifty or more reusable parts, a figure that has climbed steadily over the last few decades as clinical medicine finds ever-expanding ways to reuse the human body (Fehar, Naddaff, and Tazi 1989; Flye 1995; Hogshire 1992; Kimbrell 1993; Machado 1998; Murray 1987). Monthly and annual tallies are also maintained by UNOS and individual OPOs as a means to track how many organs are procured and transplanted. Individual transplant units maintain their own body counts: at public forums and conferences, surgeons and their staff will inevitably cite the number of surgeries they have performed within a week, month, or year. Finally, even organ recipients are subjected to quantification, falling into a given unit's numbered hierarchy of transplants. For example, they regularly identify themselves as "the third lung" or "heart number twenty-five" from their respective hospitals. Lower numbers accrue greater value: in one hospital I watched staff over the course of four years repeatedly go to extraordinary lengths to extend the life of a recipient who held the esteemed status of "heart number one," a patient who, in turn, always signs his name on personal notes and greeting cards followed by "#1." It is worth noting, too, that an unwavering agenda within all involved organizations is the constant drive to increase their numbers of acquired organs.

Scarcity, Recycling, and Renewal

Scarcity breeds anxiety, which in the realm of organ transfer is reflected in a language that contrasts successful organ reclamation with the tragedies of lost opportunities. Evelyn Brown, a nurse whom I met in the Midwest and who was married to a lung recipient, put it thus as long ago as 1992: "I don't know too much about it, but I know there is a shortage of organs. I hadn't really thought much about it before all of this, but now it seems to me it's a shame to waste all of those organs when there are people who need them." Evelyn's words reflect an ongoing concern that OPOs consistently fail to capture all the nation's eligible donors. Beneath this sentiment is the

understanding that once patients shed their personhood and revert to donor status, redefining them as vessels harboring reusable parts is intrinsically unproblematic and a natural aspect of this process.

Public outreach programs today are driven by a heightened sense of scarcity anxiety, where promotional slogans are designed to encourage people to offer their bodies willingly to meet transplant's needs. As noted in the introduction to this book, a range of genres abounds in these messages; among the most popular is a "greening" of the donor body, a strategy that draws heavily on nature imagery (Sharp 2001). Promotional campaigns, T-shirts, campaign buttons, posters, and bumper stickers all bear messages underscoring that organ transfer is a regenerative process, as one might encounter in nature. Associated imagery assumes several forms.

One dominant approach draws directly on references to recycling. Just as the ecology movement perceives bottles, cans, and plastic containers as renewable resources, within the realm of organ transfer, human body parts can be reused to replenish dying patients. Two of the most established slogans are "Recycle Yourself" (often displayed against a triangular recycling emblem) and the complementary celestial version, "Don't Take Your Organs to Heaven—Heaven Knows We Need Them Here."³³ Yet another approach transforms the donor body into an astonishing array of greenery. As noted earlier, an artist's rendering of an isolated stand of aspen trees graced the cover of one organization's pamphlet on brain death. In a range of other contexts, images designed to underscore the social worth of organ donation are similarly devoid of people, illustrated instead with pictures of trees, leaves, or flowers. Some images go so far as to offer visual puns. Consider, for instance, a change of address card issued by UNOS that featured the image of a repotted, flowering plant to illustrate the message, "We've Been Transplanted" (figure 1). Grafted tree branches and leaves appear on transplant and donation-related literature, too, offering an only slightly veiled reference to the surgical "grafting" of organs to recipients' bodies. In still other contexts, the shapes of various flora may appear reminiscent of particular organs. As I detail elsewhere, strange-shaped clouds can resemble livers and pancreases, or leaves may be clustered in such a way as to form a heart or to suggest a pair of lungs or kidneys (see Sharp 2001, figures 1–4).

The butterfly, too, has recently achieved iconic status. This image was first adopted by the National Donor Family Council, a grassroots organization that lobbies for the needs of donor families. For several years a pink butterfly has served as its logo, gracing its letterhead, newsletter, and other print materials. NDFC members also regularly sport butterfly pins at organ transfer events. The image of the butterfly is now popular among OPOs across



Figure 1. Moving announcement issued by the United Network for Organ Sharing in December 2002. Design by Kevin Smolen. Image used by permission of UNOS.

the nation as a symbol of the spirit of organ donors, of hope, or of the ever-repetitive circle of life and thus, again, renewal. As I will detail in the next chapter, even UNOS has adopted this symbol: in a newly established memorial on its corporate grounds, one may now stroll past a butterfly garden.

Through this ecology of the body, plant and other associated imagery draws on established traditions that recognize nature's regenerative properties (Bloch and Parry 1982). Such imagery, then, bolsters a public image of organ transfer as a life-giving force. The frequent playfulness of associated slogans and images underscores the great social worth of organ donation while successfully obscuring references to a darker reality: that is, that organ transfer relies heavily on the inevitability of tragic deaths. The power of recycling imagery lies in its ability to focus our attention on the idea that death can beget life as part of a larger circular process of natural regeneration.

The Politics of Waste and Social Redemption

Of concern, though, too, are anxieties over wastefulness. Whereas a body placed in a grave could conceivably replenish the soil, in the realm of organ transfer such an action is understood as a terrible waste of precious goods that could serve a far better purpose by rejuvenating the bodies of sickly human beings. The failure of some kin, then, to grant consent is frequently

interpreted by OPO staff, surgeons, and involved lay parties as yet another example of wasteful consumerism in a throwaway society. Furthermore, whereas organ donors assume an elevated social position, procurement professionals may quickly relegate failed cases to the status of medical waste or refuse. Among the most virulent language employed by OPO staff is that reserved for those bodies that in the end are unable to generate transplantable parts.

This method of devaluing a failed donor is exemplified by the language employed by the clinical coordinator Gabriel Evers when he described in retrospect the case of Mr. Faustman. As noted earlier, Gabriel was called in to relieve two exhausted coworkers; contact transplant units and tell them that there were in fact no organs available from this disqualified donor; and assist ICU staff in removing Mr. Faustman from the ventilator over the objections of an attending physician. A day later, when I asked him how it all ended, Gabriel offered this assessment:

It got ruled out fifteen minutes before packing the donor to go to the OR. [But] this donor was crappy from the get-go. The [medical and social] history said so! [He had a] history of hypertension . . . [and] the kidneys were shitty! And then there was the boyfriend who didn't even know he'd collapsed on the street. . . . [Later I was the one who had] to call [the kidney surgeon], and he starts yelling at me over the phone, saying, "What the hell are you giving me these shitty kidneys for?" . . . The donor was garbage from the get-go!

As Gabriel's words illustrate, the politics of social redemption define an ever-shifting ground in the realm of organ transfer. In this account, Mr. Faustman moved from being a potential source of valuable organs to little more than medical refuse. His kidneys were "shitty," and his body (and its associated history) "crappy" and "garbage from the get-go." As such language makes clear, in the end the blame or fault rests with the donor himself as his parts in essence move from "treasure" to "trash."³⁴ Such views have their counterparts among donor kin.

Organ donation, when it succeeds, grants surviving kin the hope that they may assist others in need. As a result, some kin opt for donation even when they know that a member of their own community will object. Donor kin often recount stories of neighbors, coworkers, and distant kin who express astonishment or disgust when they learn of the decision to donate organs, especially when the donor was a child. Some of the more strident criticisms they endure focus on their willingness to have the body cut open so its parts can be removed. Instances in which kin decide in favor of donation over widespread cultural objects become cherished stories among OPO workers. For

example, Octavia Zamora, an OPO worker from the Southwest, recounted during an interview in 2003 the story of one of the few Native American donors her organization could claim in more than ten years of personal experience. In this case, the mother explained her decision to offer her son's organs as an extension of giving as practiced within her own culture, even though it defied established mortuary customs. In other instances, when kin are angered by a death, they may decide to donate because they perceive this act as redeeming the donor socially or spiritually. (Such decisions thus emerge as potentially punitive, too.) This is precisely what happened in one case I tracked in 1995. The donor, who was a teenager and a member of a notorious street gang, was shot in the head by a rival. As his mother explained to an OPO family counselor, "My son did nothing to help anybody when he was alive, but I'm going to make damn sure he does something now that he's dead!" To allow such a son to slip through the cracks would in essence only reconfirm that his life had been a wasted one.

Alternative Strategies for Recovering the Dead

As the language of needless waste underscores, the ever-growing shortage of transplantable human organs emerges as a terrible—though not inevitable—national tragedy. Yet another strategy used by UNOS and the nations' OPOs to alert the public to transplant's needs is the practice of supplying regular body counts of patients who have died while awaiting transplants. As indicated in the introduction, no publication on organ transfer is complete unless it supplies such figures. This approach serves as a powerful reminder that, as human bodies go to waste, others suffer or, worse yet, also waste away and die. For this reason, according to transplant ideology, the nation's lay public should willingly and without hesitation offer themselves in death to others so desperately in need.

In response to the chronic shortage in body parts, alternative solutions are gaining support, a trend that has become especially pronounced since 2000. Proposals now under serious consideration range from altering current donor protocols to instituting legislative reforms; each, too, has its own base of constituents. Those who work in clinical settings are more likely to advocate the need to streamline even further the criteria for the determination of death (Agich 1999; DuBois 1999; Fung 2000; Greenberg 2003; Lock 2003). To paraphrase a suggestion offered during an interview with neurologist Dr. Needler, for example, why not expand the donor pool to include vegetative and comatose patients? Given that the brain injuries sustained by such patients can compromise their chances at full recovery, perhaps we should seek permission from kin to remove them, too, from ventilators so

that we might make use of their vital organs. In turn, many others—frequently from outside OPOs—enthusiastically support proposals that OPOs be permitted to offer donor families a range of financial incentives as rewards or as compensation for consenting to donation (AMA 2003; Arnold et al. 2002; Bailey 1990; Blumstein 1993; Goldberg 2003). Many OPO staff, in turn, advocate that the United States should follow the lead of European nations and institute presumed consent laws so that all dead patients could potentially be relegated to donor status automatically and without the consent of kin (AMA 1994; C. Cohen 1992; Michelsen 1991). New advanced directive laws, as outlined previously, in fact offer a version of this very strategy. All advocates assume that public outreach and education programs have failed to convince enough people to designate their willingness to be organ donors, and thus more aggressive strategies are in order.

These proposals define three key trajectories: widen the definition of death, entice donor families with financial rewards, or override the rights of next of kin to make end-of-life decisions and instead coerce donation out of the nation's general population. In my interviews I have found that the strongest proponents of such proposals have great difficulty imagining the slippery slope of these tactics. Yet one need only turn to several decades of writing in bioethics or the long-term fascination with organ banks in science fiction to realize the inherent dangers of such proposals.³⁵ The more pronounced criticisms identify the dangers of preying on the poor and socially disenfranchised whose kin might find financial compensation too enticing to resist; the gradual instatement of euthanasia as a means to acquire organs from a widening pool of patients who are not yet dead; the deliberate withdrawal of medical care from sickly patients who are considered of far greater value when dead; the need to rank dying patients in terms of their social worth, such that those who are less valued are allowed to die so that their parts can sustain others of greater value; and the erosion of medical professions more generally, as doctors, nurses, and others become specialists in orchestrating death rather than saving lives. When framed by the ideological premise that organs are growing increasingly scarce, current anxieties over this national tragedy sadly overshadow an already shaky ethical code that guides organ retrieval.

CONCLUSION

Within this chapter I have sought to provide a comprehensive portrait of the intricacies of organ procurement, as well as its associated ideological

dilemmas. I realize that some portions of this chapter may have alarmed certain readers, leading them to question the legitimacy of organ transfer. Do procurement specialists and transplant surgeons ultimately orchestrate patients' deaths? Does corporate greed drive the desire for transplantable human organs? Do the clinical practices of organ transfer offer evidence of widespread medical failure? I am quick to answer that such reactions are far too simplistic (not to mention evidence of knee-jerk paranoia). Instead, it is the highly unusual circumstances of organ transfer that ultimately enable this discussion to occur at all. The value of these unsettling questions lies, then, in their ability to expose the peculiar and contradictory array of practices shaping transplant medicine in America.

I argue that the assertion that brain death is "true death" is a consequence of embracing organ transfer as an act of great social worth. After all, if the purpose of organ transfer is to save lives, it makes little sense for physicians to orchestrate the deaths of donors merely to acquire organs for other patients. Nevertheless, we would do well to acknowledge publicly that brain dead organ donors experience (or, perhaps better put, undergo) death in stages, the process itself carefully mitigated by conflicting cultural and medical understandings of what it means to die. As the person fades away, the body follows soon after.

Organ donation hinges on the sort of logic outlined in this chapter: its medicolegal success and social acceptance ultimately insist that we be reduced to our mind-brains. Or, put another way, organ harvesting is driven by the assertion that when the mind-brain no longer functions, we cease to be ourselves, to be full-fledged human beings and, thus, truly alive. Furthermore, the harvesting of transplantable organs and the legitimacy of cadaveric organ donation rest on a pairing of lay trust with medical knowledge of brain death as a knowable category, as an absolute and unquestionable state of nonexistence, as something easily detectable in medical and social terms. This chapter has sought to explore the pitfalls of brain death criteria when viewed through medical, emotional, and social lenses. As such, it indicates a need to move beyond the assertion that the brain dead are merely living cadavers or neomorts.

When kin decide to give to others in need, they do so because they understand the social worth assigned to the donor body. Unquestionably, the "gifts of life" reaped from a donor save a wide assortment of dying patients and may radically improve the quality of life of many others. A kidney transplant removes a middle-aged mother from dialysis, skin grafts facilitate the healing of a firefighter who was badly burned on the job, a replaced patella allows a karate instructor to walk—and work—again, and a new heart al-

lows an infant to leave the ICU and go home to her parents. As such idealized scenarios assert, donation allows great good to arise from terrible, unimagined tragedies, so that donor kin may at least cling to this small comfort for the remainder of their own lives. As described in detail in the following chapter, “gifts of life” enable donors to live on in the bodies of others. As such, organ transfer offers truly unique ways to experience life and death in America.