merely preserving lives. And, yes, we now contend with more complicated ethical issues than our forebears faced: cloning, genetic medicine, the societal and individual consequences of increased life expectancies, the impact of permitting wide latitude in individual medical choices.

But this doesn't mean that ethical decisions need be as complex as bioethicists make them, nor that modern bioethics ideology has the best answers to these emerging moral problems. In a question that evokes the case of the emperor's new clothes, Anne MacLean cogently asks, "Why should we attach more weight to the pronouncements of philosophers on moral issues than to those of other people?"97

United States Supreme Court Chief Justice Oliver Wendell Holmes infamously declared in authorizing the involuntary sterilization of Carrie Buck, age twenty-one, in Virginia.1

What had Carrie done to deserve this fate? She was born poor and powerless, the daughter of a prostitute. In 1924, at the age of seventeen, she became pregnant out of wedlock, apparently after being raped by a relative of her foster father. To cover up this heinous act, Carrie's foster family had her declared morally and mentally deficient, after which she was involuntarily institutionalized in an asylum.

Adding to Carrie's woes, in 1924 the State of Virginia enacted a law permitting "mental defectives" to be involuntarily sterilized for the betterment of society. Asylum doctors decided that Carrie was a "human defective" and therefore a good candidate for the procedure. Her mother was institutionalized, after all, and her baby, age seven months, did not look "quite normal."2 Thus, they figured, society would be best served if Carrie's genes were removed from the human race.

Carrie's guardian tried to stop the involuntary surgery in court. But the trial judge instead ordered that the sterilization proceed, relying on "experts" who testified that Carrie had unfit genes. The case
was appealed and eventually was accepted for decision by the United States Supreme Court where Chief Justice Holmes and seven of his colleagues sealed Carrie’s reproductive fate with but one lonely dissent, after which she was quickly sterilized and released.

Carrie Buck’s fate—and that of approximately sixty thousand other “defective” people involuntarily but legally sterilized in the United States between 1907 and 1965—was sealed by advocates of a pseudo-science known as eugenics. In its fundamental precepts, the manner in which it was imposed and the horrors that flowed from its acceptance, eugenics is highly relevant to an exploration of modern bioethics. First, its history shows the inhuman consequences that invariably follow when the equality of human life is disregarded in science, medicine, law, and society at large. Second, striking and disturbing parallels exist between the manner in which eugenic theories were developed and put into practice, and the way in which bioethics ideology is coming to dominate the ethics of medicine. Third, modern bioethics, like eugenics before it, creates hierarchies of human worth intended to justify medical discrimination. Now, after decades of quiescence, eugenics itself is making something of a comeback under the cover of new genetic technologies.

Eugenics originated with the English mathematician and statistician Francis Galton. A cousin of Charles Darwin, Galton believed that heredity governed “talent and character” just as it does eye color and facial features. Profoundly influenced by Darwin’s theories of natural selection and Gregor Mendel’s pioneering genetic experiments, Galton proposed, in 1865, that humans take control of their own evolution by using selective breeding techniques to improve society’s physical, mental, cultural, and social health. In 1883, Galton coined the term “eugenics” to apply to his theories, a word he derived from the Greek for “good in birth.”

Eugenics took the same path to acceptability as bioethics would nearly one hundred years later. It first became the rage in the academy and then spread rapidly in the early years of the twentieth century among the cultural elite and the intelligentsia of the United States, Canada, England, and Germany. By 1910, eugenics was one of the most frequently referenced topics in the Reader’s Guide to Periodic Literature. In its boom during the 1920s, eugenics, like bioethics today, became a serious and influential social and political movement. Courses in eugenics were taught in more than 350 American universities and colleges, leading to the widespread popular acceptance of its tenets. At one time, eugenics was endorsed in more than 90 percent of high school biology textbooks.

As would happen later with bioethics, eugenicist societies formed for the promulgation and discussion of theories, academic eugenics journals sprouted, and philanthropic foundations such as the Rockefeller and Carnegie Foundations embraced the movement, financing eugenics research and policy initiatives. Many of the notables of the time supported eugenics, including Theodore Roosevelt, Winston Churchill, George Bernard Shaw, and Margaret Sanger, leading to further expansion of the movement’s popular support.

The parallels between eugenics and contemporary bioethics are more than skin deep. Both movements reject equal human moral worth. Both are utilitarian-based, seeking to improve overall human happiness and reduce human suffering—sometimes at the expense of individual human rights. Like today’s bioethics theories, eugenics was taught in some of the world’s most prestigious universities, and most eugenics societies “were dominated by professionals such as professors, social workers, lawyers, doctors, teachers, and ministers.”

There were two general approaches to the implementation of eugenics theory. Proponents of “positive eugenics” sought to persuade young people who possessed worthy traits to marry among each other and procreate liberally toward the end of strengthening these characteristics within the human gene pool. Worried that the “proper” people were not procreating in sufficient numbers, eugenicists filled the popular culture with notions of the ideal family, urging the “belters” among the population to have many children. (Theodore Roosevelt urged members of his class to wage and win “the war of the cradle.”) There were even eugenics prizes given to large families thought to be promoting the best eugenic human traits.

Carrie's daughter died in the second grade of an intestinal ailment. Her teachers considered her very bright. During her life, Carrie married twice, sang in the church choir, and took care of elderly people. She always mourned her inability to have more children. She died in 1983.
"Negative eugenics" did not rely on persuasion. It assumed that society, guided by its precepts, had the right to prevent those with undesirable physical and moral characteristics from procreating at all. Such convictions, and the power to implement them, led to coercive and destructive medical acts and public policies that exploited and oppressed the weak and medically defenseless.

Although the movement originated in England, eugenics policies were first instituted in the United States. In 1899, the *Journal of the American Medical Association* published an article that advocated the use of the newly developed vasectomy as a "surgical treatment" to keep undesirables such as "habitual criminals, chronic inebriates, imbeciles, perverts, and paupers" from reproducing. In 1902, an Indiana physician named Dr. Harry Sharp urged passage of mandatory sterilization laws that would require all men in prisons, reformatories, and paupers' houses to be sterilized. (Before any such law was passed permitting it, he had involuntarily sterilized more than five hundred men.) Following Dr. Sharp's lead, in 1907 Indiana became the first state to pass a eugenics-based sterilization law. By 1912, eight states had sterilization laws. Eventually nearly thirty states followed suit, including Virginia, where Carrie Buck lived.

**Useless Eaters**

Eugenics helped feed—and was itself nourished by—the harsh ethos of social Darwinism, which applied Darwin's biological theories of natural selection and the struggle for survival to the human realm and relations among people and societies. "To the social Darwinists ... human society had always been a battleground for competing individuals and races in which the fittest survived and the unfit were cruelly eliminated; and, for the sake of human progress, this struggle for existence must be allowed to continue unchecked by governmental intervention or social reform." Believers in social Darwinism thus viewed the exploitation of the weak as a natural process. At the same time, social Darwinist theories worked hand in glove with eugenic notions of hierarchies of human worth to classify exploited people as inherently inferior and thus deserving of their fate. This explosive combination never quite caught fire in the United States or Canada. In Germany, however, it combusted into Nazism and the Holocaust.

In 1806, German physician Christoph Wilhelm Hufeland wrote presciently, "It is not up to [the doctor] whether ... life is happy or unhappy, worthwhile or not, and should he incorporate these perspectives into his trade ... the doctor could well become the most dangerous person in the state." Hufeland's point was that the ethics of medicine are a good indicator of the moral health of society and that when medical practice is corrupted, society is soon to follow. That certainly proved true in Germany when many German doctors came to believe that some of their patients had lives unworthy of life, an attitude that helped unleash the Holocaust.

Most people believe that the medical horrors of the Holocaust bore the trademark of Adolf Hitler. In fact, the path to medical evil was laid long before Nazism was even a cloud on the German horizon. "Physicians in the pre-Nazi period began to view their skills as appropriate for killing as well as healing," the American physician and Nazi hunter Michael Franzblau says. Because of eugenic theories, social Darwinist beliefs and the deprivations caused by the war, half of Germany's mental patients were starved to death during World War I. "But that was a mere prelude," Franzblau told me. "In 1920, Binding and Hoche published their book, which really set the tone for what was to come."

The book he referred to was a tome entitled *Permission to Destroy Life Unworthy of Life* (Die Freigabe der Vernichtung lebensunwerten Lebens). Its authors were two of the most respected academics in their respective fields: Karl Binding, a nationally renowned law professor, and Alfred Hoche, a physician and noted humanitarian. *Permission to Destroy Life Unworthy of Life*, in reality two extended essays, one by each author, was a full-throated assault on the Hippocratic tradition and the sanctity/equality of human life. The authors accepted wholeheartedly the concept that some humans had greater moral worth than others. The latter were disparaged as "unworthy" of life, a category that included those with terminal illnesses, people who were mentally ill or retarded, and deformed children. Physicians ought to be allowed to kill people deemed to be life unworthy of life.
the authors argued. More than that, the authors professionalized and medicalized the entire concept, promoting the killing of those they labeled unworthy of life as “purely a healing treatment” and justifying euthanasia as a splendid way to divert money being spent on these ill and disabled people to other important societal needs.17

Binding and Hoche listed three categories of patients whom doctors should be allowed to kill ethically and legally:

1. Terminally ill or mortally wounded individuals, described by the authors as those “who have been irretrievably lost as a result of illness or injury, who fully understand their situation, possess and have somehow expressed an urgent wish for release.”18

2. “Incurable Idiots,” whose lives Binding and Hoche viewed as “pointless and valueless,” and as emotional and economic burdens on society and their families. Hoche put it this way: “I have discovered that the average yearly (per head) cost for maintaining idiots has till now been thirteen hundred marks.... If we assume an average life expectancy of fifty years for individual cases, it is easy to estimate what incredible capital is withdrawn from the nation’s wealth for food, clothing, heating—for an unproductive purpose.”19

3. The “unconscious,” who, if they were ever again roused from their comatose state, “would awaken to nameless suffering.”20

Permission to Destroy Life Unworthy of Life was thus a prescription for the medical cleansing of the weakest and most vulnerable members of Germany’s population, a prescription that would be filled with murderous precision by German doctors between 1939 and 1945.

Binding’s and Hoche’s philosophical approach was eerily similar to that espoused today by many contemporary bioethicists. It was utilitarian. It eschewed the Hippocratic tradition in favor of the “quality of life” ethic. Indeed, the Georgetown Mantra could be used to justify Binding’s and Hoche’s arguments, in that they described voluntary euthanasia as merely a matter of fulfilling the patient’s “urgent wish” (autonomy); defined killing ill and disabled people as a “healing” act (beneficence); and promoted euthanasia as necessary to fulfill other urgent societal needs that were going wanting because of the cost of caring for disabled people (distributive justice). Although few modern bioethicists agree with the manner in which Binding’s and Hoche’s proposals were ultimately implemented in Germany, and most would certainly object to the authors’ bigoted language, it is clear that the values expressed in Permission to Destroy Life Unworthy of Life fit snugly within the mainstream of the modern bioethics movement.

Permission to Destroy Life Unworthy of Life created a sensation among Germany’s intelligentsia, whose leadership—in conjunction with the growing acceptance of social Darwinism, anti-Semitism, racial hygiene, and eugenics—helped the Binding/Hoche view to be soon accepted by much of German society. For example, a 1925 poll of the parents of disabled children reported that 74 percent of them would agree to the painless killing of their own children.21 Thus, by the time the Nazis came to power in 1933, much of Germany, including its medical establishment, accepted the notion that some human beings represented “life unworthy of life.”

The new Nazi rulers of Germany immediately sought to act against these “useless eaters.” In 1933, the German government sought to legalize voluntary euthanasia. (A front-page New York Times article described the proposal sympathetically as making it possible for physicians to end the tortures of incurable patients.) Protective guidelines were to be included in the law, many of which were remarkably similar to those espoused by euthanasia advocates today, including that voluntary requests be “expressly and earnestly” made, and if a decision was made by relatives for incompetent patients, that the motive for killing (ironically) “not contravene morals.”22

These proposals were eventually withdrawn because of vehement opposition from German churches. However, mandatory sterilization laws were officially enacted within six months of Hitler’s becoming chancellor of Germany. Based on eugenic theories, special “Hereditary Health Courts” were established to judge the “hereditarily sick.” Among those targeted were the mentally retarded, the mentally ill, epileptics, alcoholics, and people with “grave body malformations.” At the law’s inception, it was estimated that more than 400,000 people would be sterilized from the hospitals and mental institutions alone.
Sterilization was actually imposed on up to 350,000 disabled and other “undesirable” people between 1933 and 1945.23

Throughout the 1930s, the idea of actually killing useless eaters gained increasing popularity, and not by accident. The Nazi government molded German public opinion. Popular entertainment became an especially effective tool in this unremitting propaganda campaign, particularly motion pictures, an industry that Joseph Goebbels effectively controlled.

The wildly popular movie *I Accuse* (*Ich klage an*), one of the most notable of these propaganda films, has a particularly eerie resonance in today’s medical climate. The primary plot concerns a woman pianist who grows progressively disabled due to multiple sclerosis. Unable to play her beloved music, deeply worried about becoming a burden to her physician husband, she begs for euthanasia.

As the wife and husband struggle with her MS, a subplot develops around a university professor who lectures students on how only the “fit” survive in nature. He illustrates his teaching with graphic documentary scenes of asylums from Nazi film archives, which depict disabled patients as grotesque and inhuman. It is in this context that the parents of a disabled infant beg the doctor to kill their child as an act of mercy.

Finally they have their way. The baby is killed off camera, an act depicted as difficult but eugenically correct for the overall health of the Volk. The ailing wife then commits suicide with her husband’s help, a scene played, to the sound of a mournful piano, for all the pathos it is worth. The husband is arrested, and the movie ends with his impassioned accusation to the judges about the inhumanity of laws preventing euthanasia:

No! Now, I accuse! I accuse the law which hinders doctors and judges in their task of helping people. I confess ... I have delivered my wife from her sufferings, following her wishes. My life and the lives of all people who will suffer the same fate as my wife, depends on your verdict. Now, pass your verdict.24

It is not hard to imagine these same words appearing in the transcript of one of the trials of Jack Kevorkian, many of whose victims, in fact, were nonterminally ill women disabled by multiple sclerosis. Moreover, the word “deliverance” is the favorite euphemism used by the pro-euthanasia/suicide Hemlock Society to describe assisted suicide. And that isn’t all. The moral values, philosophy, and even the words expressed in *I Accuse* are alive, well, and in practice in the United States, Canada, and much of the West, more than sixty years after its release.

With the German population progressively prepared for the killing of “useless eaters,” one task remained before implementation could commence: the medical profession had to reject the Hippocratic requirement that a physician’s loyalty is to each and every individual patient. “Between 1933 and 1945, German physicians did not take the Hippocratic Oath,” Dr. Franzblau told me. “Instead, they took an oath to the health of the state, known as the Gesundheit. Thus, doctors had a dual loyalty, to their patients yes, but their first loyalty was to Germany.”25

German doctors, to recall Dr. Hufeland’s warning, were now among society’s most dangerous members. Many physicians accepted wholeheartedly the eugenics-based theories, reinforced by Nazi racial ideology, that some humans—disabled people, mentally retarded people, and of course, Jews, Gypsies, and others—were life unworthy of life. At the same time, their first loyalty was to the state and not to individual patients. Forced sterilization of the “unfit” had become commonplace and popularly accepted. Physicians and midwives voluntarily reported every child born with disabilities to authorities. Binding’s and Hoche’s notions of killing as a “healing” practice were accepted widely as ethical and moral. Dr. Karl Brandt, whom Hitler had placed in charge of the euthanasia bureaucracy, had a plan of implementation firmly in place. The table was now set for the mass murder of hundreds of thousands of disabled people, an overture to the Holocaust.

Disabled infants became the first to suffer medical cleansing when Hitler signed a secret executive order in early 1939 permitting infanticide based on disability. No doctor was forced to kill patients, but the Hippocratic tradition had been so effectively undermined over several decades in Germany, that many physicians (as well as nurses,
and midwives) enthusiastically supported the policy, either directly by killing disabled babies, or indirectly, by referring them to “health centers,” which actually did the dirty work. The German medical establishment participated in the euthanasia Holocaust, not because they were Nazis, although many had joined the Party, but because they had convinced themselves that they were performing, in the words of Binding and Hoche, a “healing” service for the child, the family, and the Reich.

Hitler and Brandt were so pleased with the success of their infanticide program that Hitler next issued an executive order expanding the categories of those to be medically cleansed, to include disabled and mentally retarded adults. The order stated simply:

Reich Leader Bouhler and Dr. Brandt are charged with the responsibility for expanding the authority of physicians, to be designated by name, to the end that patients considered incurable according to the best available human judgment of their state of health, can be granted a mercy death.

—Adolf Hitler

This was the infamous “T-4 Program,” named after the address of the German Chancellery, Tiergarten 4. Killables included people with epilepsy, polio, schizophrenia, senile diseases, paralysis, and Huntington’s disease. As with the infanticide program, T-4 was officially a secret. Death certificates listed phony causes of death.

Adult euthanasia victims were sent to specially designated hospitals that had been converted into centers of mass murder. Like the later Jewish genocide, T-4 was highly bureaucratized. Government workers “coldly and calculatingly organized the murder of thousands of people” and kept meticulous records of what they were doing. Secretaries, for example, “shared their offices with jars of foul-smelling gold-filled teeth, listening to dictation which enumerated ‘bridge with three teeth,’ ‘a single tooth,’ and so on.” With so many people involved in the killing, it wasn’t long before much of Germany became aware of what was going on. There were some public protests. Archbishop Clems August, Graf von Galen, preached openly against the euthanasia policy, and dared the Gestapo to arrest him, stating that he would meet them in full regalia. Even some Party members objected, assuring themselves that the Führer must not know. Himmler soon recognized that the jig was up and pronounced euthanasia “a secret that is no longer a secret.”

Because of public pressure, Hitler rescinded the T-4 program, although not the infanticide directive. Nevertheless, German doctors continued to murder disabled and ill infants and adults in a freestyle process known as “wild euthanasia,” until stopped by the Allies at the end of World War II. The death toll is estimated to have been about 250,000 people. Every one of these deaths “required a physician’s review and order to determine that the individual’s life was not worth living.” Among those who participated in the killing programs were Dr. Ernst Wetzler, who ironically was the inventor of an incubator for prematurely born children, and Dr. Hans Joachim Sewerling, who was elected in the 1980s to the presidency of the World Medical Association but then forced to resign due to the efforts of Dr. Franzblau and the American Medical Association. Neither of these German doctors ever expressed remorse. Indeed, Dr. Wetzler called his participation in the murder of disabled infants “a small contribution to human progress.” Dr. Sewerling sought refuge in anti-Semitism, claiming his political troubles were the result of a “Jewish conspiracy.” Rather than receiving the calumny of his peers, Dr. Sewerling, after being forced to resign as president of the WMO, was named an honorary member of the German Medical Association’s board of trustees.

Immoral Medical Experiments

Adding to the infamy of German medicine were the SS physicians who engaged actively in genocide and human medical experimentation. For example, at Auschwitz doctors helped create “the murderous ecology” of the camp. They made selections and supervised the killing in the gas chambers. They determined when all of the gassed victims were dead. Doctors lethally injected debilitated inmates and helped work out details of body disposal.

A few SS doctors also carried out inhumane “medical” experiments
on people in concentration and death camps, during which inmates, almost all of them Jewish, were subjected to horrible crimes of bodily violation. Women had their cervixes injected with caustic substances in an attempt to invent sterilization by injection; men were subjected to intense X-ray exposure of their genitals to induce sterilization, with later castration to study the damage radiation caused to the testes; inmates were intentionally exposed to typhus contagion to determine the efficacy of various sera. At Auschwitz, Joseph Mengele engaged in a sadistic study of identical twins, including children whom he physically examined over several months, measuring every part of their body and taking their blood, and then lethally injecting them prior to dissection. “German physicians in the name of science,” Dr. Franzblau has stated, “froze people to death, asphyxiated them by denying them oxygen at high altitudes, forced them to drink seawater to the point of serious illness, injected them with tubercle bacilli, cut off arms and legs of war prisoners and attempted [tissue] grafting, and perfected the use of Zyklon B gas, the preferred method of death in the concentration camps.”

The depths to which some German physicians sank seems unthinkable to us today. But then, it was unthinkable when it happened, too. How could doctors, of all people, have gone so far astray? To blame the Nazis exclusively is not only to be historically inaccurate, but also to dodge the analogy between then and now. Adolf Hitler did not blaze the road to medical depravity. He just goose-stepped with full fascist regalia down the trail already blazed by Binding and Hoche, with their assertion that there is such a thing as a human life unworthy of life. Permission to Destroy Life Unworthy of Life gave the imprimatur of the academy to a subjective judgment of human life. Indeed, Binding and Hoche’s book is so important to an understanding of the evil that followed, that Robert J. Lifton calls it the “crucial work.” For as Dr. Franzblau sagely noted, “Once you breach the firewall of Hippocratic morality, only bad things can happen.”

A second fundamental lesson to be learned from the euthanasia Holocaust is that doctors must never allow themselves to be seduced into accepting dual loyalties. Subject to the rules protecting public health, the welfare of each individual patient—not that of society, the patient’s family, the finances of health insurance companies, or the doctor’s individual pocketbook—must be each physician’s unqualified concern. To place other agendas before the welfare of their patients is again to open the Pandora’s box we thought was sealed when Hitler died in the bunker and Dr. Brandt was hanged after the Nuremberg Trials.

Finally, it is important to heed the words of Dr. Leo Alexander, who served as an investigator in the Nuremberg Trials and became one of the world’s foremost experts on the medical aspects of the Holocaust. In 1949, Alexander attempted to summarize what he had so painfully learned through years of investigation. In the New England Journal of Medicine, he wrote:

Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitudes of physicians. It started with the acceptance of the attitude, basic to the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted, and finally all non-Germans.

Dr. Alexander then issued a prophetic warning:

In an increasingly utilitarian society these patients [with chronic diseases] are being looked down upon with increasing definiteness as unwanted ballast. A certain amount of rather open contempt for the people who cannot be rehabilitated ... has developed. This is probably due to a good deal of unconscious hostility, because these people for whom there seem to be no effective remedies have become a threat to newly acquired delusions of omnipotence.... At this point, Americans should remember that the enormity of the euthanasia movement is present in their own midst.

In today’s enlightened world, we comfort ourselves with the idea that the spirit of Binding and Hoche has been exorcised. But that is
CULTURE OF DEATH

self-deception. In fact, it still lurks in the dark shadows of hospital corridors, university seminars, medical school classrooms, legislative cloakrooms, and particularly, in the depth and breadth of bioethics advocacy. This is not to say, of course, that today's bioethicists are similar to Nazi doctors. (But remember, Binding and Hoche weren't Nazis either.) Nor is it to say that contemporary Western health policies are the same as those of fascist Germany. But we too are approaching a precipice where we see certain people as having expendable lives—although we are far too polite to use that term.

Exploiting Humans in Medical Research

When I asked former Surgeon General C. Everett Koop whether he agreed that medical experimenters in the United States often violated the Nuremberg Code, he barked back at me, "We shouldn't need the Nuremberg Code! We have the Hippocratic Oath." 41

Dr. Koop is right, of course. Unfortunately, the history of medicine and scientific research in the twentieth century—both pre- and post-World War II—demonstrates that too many doctors and medical researchers are willing to violate the Hippocratic Oath, either because of bigotry or from a willingness to sacrifice the weak in pursuit of a so-called greater good.

The Nuremberg Code recognized this and sought to add muscle to the "do no harm" ethos as it applied to medical research. Issued by the judges of the Nuremberg Medical Trials, the code established principles to apply universally in the treatment of human participants in medical experiments. To prevent experiments from being conducted on any unwilling human being, for example, the judges ruled that research subjects must give truly informed consent to be experimented upon. Equally important, in order to minimize the health dangers of experiments on humans, the code required that animal studies be conducted prior to commencing human trials. To ensure that any danger faced by subjects was proportionate to the benefit hoped for, the code decreed that the risks "never exceed . . . the humanitarian importance of the problem to be solved by the experiment." 42

Unfortunately, for all of its authority, idealism, profound resonance among the general public, and undeniable importance in promoting a humane and ethical approach to medical experiments on humans, the Nuremberg Code has never been strictly followed. Indeed, as David A. August has noted, "No country or international body has been willing to accept the necessity of absolutely voluntary informed consent as envisioned in the Nuremberg Code." 43

The Nazis may be the best known for exploiting humans in medical experimentation, but they by no means have a monopoly on this evil in the twentieth century. In the United States, for example, the infamous Tuskegee syphilis study, in which African-American men with untreated syphilis were studied for decades until they died, proved that immorality in research respects no national boundary. The Tuskegee "experiment" is now universally condemned, with President Clinton making a formal and necessary national apology, and compensation paid for redress of grievances.

But acknowledging past evils is far easier than recognizing abuses in the present. Informed critics worry that contemporary medical research is, once again, close to being out of control. According to Vera Hassner Sharav, director of the watchdog group Citizens for Responsible Care in Research (CRCRI, a nonprofit organization dedicated to protecting human subjects from unethical exploitation in medical experiments, "While America is certainly not Germany or the Soviet Union, our physicians and medical researchers are crossing lines that should not be crossed. There are substantial problems with [many researchers'] mindsets and inherent structural weaknesses in the system of checks and balances that permit terrible abuses." 44

Amil E. Shamoo, PhD, a biomedical ethicist at the Maryland School of Medicine and an internationally renowned critic of unethical experiments with human subjects, agrees with this view. He told me bluntly, "We in the United States don't have systemic atrocities, we have compartmentalized atrocities. But the intellectual underpinnings are the same as they once were in Germany: for the good of science; for the advancement of knowledge; for the benefit of society, for the national interest." 45

Canadian disability rights activist Mark Pickup, who has
Life Unworthy of Life

researchers from the University of Oklahoma Children's Memorial Hospital, in Oklahoma City. Spina bifida is a birth anomaly in which a child is born with an open wound on the back that exposes the spine, with hydrocephalus (water on the brain) a frequent accompanying malady. The proper treatment for infants with the condition generally includes surgery to close the wound and prevent infection to the spinal cord and brain, and inserting a shunt into the cranium to drain fluid if there is hydrocephalus. The prognosis for such babies varies from little impact to significant disability, especially paralysis in the legs, sometimes incontinence, and possibly mental retardation or early death.

The researchers at the University of Oklahoma intended to devise clinical criteria (which included socioeconomic factors) for use in separating spina bifida babies into two different categories: those who would receive treatment for their condition, and those who would go untreated because of the perception that their lives would be of insufficient quality to be worth living. In order to receive beneficial treatment in the experiment, the infant had to meet six standards, encompassing their likely mental and physical potential, and the socioeconomic status of their family. If the baby passed muster, aggressive treatment would be provided. However, if researchers deemed an infant’s potential for life to be of insufficient quality, his or her parents would be strongly advised against medical treatment.

Of the 69 infants involved in the study, 36 were recommended for aggressive treatment and 33 for “supportive care” only. None of the treated babies died of the condition (although one was killed in an auto accident). Not surprisingly, the 24 babies whose parents accepted the nontreatment recommendation (no surgery, no antibiotics to combat infection, no “sedatives”) all died at an average of 37 days old. Significantly, four of the six babies who were recommended for nontreatment but who received care because the parents refused to accede to the doctors’ recommendations lived—a 67 percent survival rate. Yet despite this statistic, the researchers concluded:

With the perspective gleaned from the long-term care of these children . . . valuable and pertinent information can be gathered within
a few days of birth to make a reasoned [treatment or nontreatment] decision—a decision that considers the perspective of both the baby and family. 49

Civil libertarian and syndicated columnist Nat Hentoff followed the case closely from the time it became a public controversy. He told me,

I was on this story for years and it was a horrifying case, one of the worst stories I ever covered. Here you had a group of physicians who violated their obligation to “do no harm” in the most egregious way. What were they going to prove? Did they need an MD license to tell them that children allowed to languish without necessary medical treatment would eventually die? This was the kind of experiment you would expect to read in the pulp magazines or in Lifton’s The Nazi Doctors. And these were reputable physicians! It was inexcusable and nothing was ever done about it. 50

This unconscionable research, clearly a nontherapeutic experiment on the babies who were not treated, profoundly violated the Nuremberg Code but apparently not the federal government’s regulations, since complaints to the appropriate authorities resulted in inquiry but no official action taken. Here, human infants were intentionally refused life-saving medical treatment with which they might have lived—as 67 percent of those whose parents refused the experimenters’ do-not-treat recommendations did—and instead allowed to die, due to what can only be categorized as medical neglect. Moreover, the purpose of the experiment was to determine bases upon which to similarly neglect other infants born with spina bifida. 51 And, apparently, it was perfectly legal and “ethical.”

Federal regulations for experimentation on humans, which were deeply influenced by bioethicists who served on the commissions that helped produce them, are now governed by a uniform multidepartmental set of standards known as “The Common Rule.” Because the government does not have the resources or personnel to oversee all experiments involving federal funding, the Common Rule delegates oversight to local committees of “experts” known as “Institutional

Review Boards” or IRBs. All experiments on human subjects using federal funds or requiring federal approval, such as a drug requires from the Food and Drug Administration [FDA], must be overseen by an IRB.

Unfortunately, too often the IRB system is often inadequate to its mandate, as demonstrated by the risky experiments carried out regularly upon people suffering from devastating mental illnesses. According to Dr. Amil Shamoo, perhaps the cruelest of these are “washout/relapse” studies, in which people with schizophrenia or other serious illness such as clinical depression are taken off their medication and intentionally allowed to relapse. 52 A story in the Boston Globe about such studies found that two thousand mentally ill patients over the last twenty-five years have been “ushered into a disturbing series of experiments by psychiatric researchers exploring the biology of psychosis.” Subjects have been injected with drugs designed to exacerbate their delusions and hallucinations and/or have had effective medications withheld to see how quickly they became sick again.

According to the Globe, these experiments were rife with ethical abuses. Repeatedly, researchers in charge of the experiments failed to “adequately disclose the risks and/or obscured their true purposes.” 53 The type of drug given to induce psychosis or the expected symptoms may also not be disclosed in these studies. 54 Moreover, “at least 850 patients seriously ill with schizophrenia were given dummy sugar pills [placebo] instead of medication known to work, as part of U.S. approved studies of experimental anti-psychotic drugs.” Seventy percent of the subjects became so ill that they had to withdraw from the study and at least one committed suicide. 55

In recent years a crescendo of media exposés has shown the degree to which the research enterprise is in serious ethical trouble:

- Eighteen-year-old Jesse Gelsinger was subjected to genetically engineered viruses to study the method as a potential cure for a sometimes-fatal liver disorder. Earlier tests of the experimental genetic treatment tried on monkeys had led universally to their deaths, and in humans, to severe toxic reactions. Despite this,
and despite Jesse’s not being sick at the time of the experiment, the research team at the University of Pennsylvania injected him with the trillions of genetically engineered viruses that thickened his blood “like jelly,” causing organ shutdown. The final version of the consent form signed by Jesse did not mention the monkey deaths or the previous toxic reactions in people. A preliminary FDA report criticized the experimenters for failing to report serious side effects suffered by two other patient/subjects prior to Jesse’s death. It is also worth noting that “the study was not designed to benefit people like Gelsinger; it was to test the safety of a treatment for babies with a fatal form of his disorder.” After Gelsinger’s death, the FDA found such glaring violations of experimental protocols in the case that it suspended the University of Pennsylvania’s gene therapy studies. Some might argue that the system worked since corrective action was taken. But at what cost? Rigorous oversight should not be an afterthought engaged in only after a research subject dies.

- Two-year-old Elsa MacEwen had cancer. The University of California at San Francisco physicians offered her parents two choices regarding her treatment: surgery followed by chemotherapy or new drugs that might cut Elsa’s tumor in half. Elsa’s parents consented to the drug treatment. However, the doctors failed to disclose two key factors that were highly relevant to obtaining informed consent: the surgery/chemotherapy approach, while difficult, was often successful, but the drugs in question were experimental and not approved by the FDA. The drugs led to a serious infection and Elsa died. UCSF officials labeled the failure to obtain truly informed consent a “regrettable lapse.”

- Susan Enderserbe of Minneapolis, a forty-one-year-old woman “struggling with schizophrenia and suicidal impulses,” was being treated with anti-psychotic medications and had her affliction under effective control. She was then referred to a psychiatrist who had a contract to conduct experimental drug trials. He entered her into his trial, he admitted, after ignoring the study’s criteria excluding suicidal people. As part of the trial, Susan was taken off the medication that was working for her and given no medicine for her disease for two weeks. Then, she was placed on the trial drugs. Susan quickly began to relapse, and threatened suicide. Despite this, the psychiatrist allowed her to leave the hospital when she requested permission to go to her home and pick up some things. Instead of going home, Susan killed herself by jumping into the Mississippi River.

- Joseph Santana, a New York psychiatric patient, died shortly after being “exposed to a deadly cocktail of anti-psychotic drugs,” which “triggered seizures that subsequently suffocated his brain.” His family claimed that he was unable to give informed consent to become a research subject and that they were informed of the experiment only after Joseph’s death.

Why is this happening? “The trouble with the IRB system,” Vera Sharav told me, “is that they represent the research center [more than they do human subjects]. Most of the members are employees of the research center and reflect the culture of the research center.” Sharav further believes that “too many universities have become places where they simply want more money. They don’t think enough about ethical issues. They don’t focus sufficiently on the advancement of knowledge. They really prostitute themselves for research funding.”

Sharav’s criticism is all the more credible when the tremendous stakes involved in the medical research enterprise are considered. Yes, there is certainly great potential for improving human health and welfare. But that is not all that drives the system. Researchers are often intensely competitive and may resent ethical constraints as obstacles that slow down their work and put them at a disadvantage. Entire university departments and research centers may depend on the tens of millions of dollars received in government grants and/or private contracts. Indeed, these funds may literally be an institutional lifeline. Moreover, for drug companies and other private enterprise participants in the health care industry, the development of a successful new medical procedure or drug may produce enormous profits, and for individual executives, large performance bonuses, stock options, and salary increases. Add to these potential conflicts of
interest the disregard that bioethics fosters for people deemed to have a low quality of life, and the potential for abuse and harm to vulnerable subjects becomes all too clear. These factors raise significant questions about the ability and perhaps desire of some IRBs to protect human subjects vigorously. Indeed, Sharav complains, “Some IRBs just don’t see that [independent oversight] as their role. They are there, above all, to approve research protocols. Too often, the system is a rubber stamp, a sham.” Adding weight to Sharav’s point: the chief federal official overseeing the safety and ethics of experiments using human subjects, Dr. Greg Koski, recently proclaimed that the research system may be “entirely out of control.”

Neglecting Disabled Infants to Death

In 1972, *Life* magazine reported on the celebrated case of Mrs. Phyllis Obernauer, whose daughter was born with Down’s syndrome. The girl’s condition was complicated by heart problems and an intestinal blockage, the latter a common occurrence with Down’s babies. The Obernauers decided they didn’t want a disabled baby and ordered their doctors not to perform surgery to clear up the intestinal blockage. Their intent was that their baby die by starvation. The doctors refused to deprive the child of life’s basic necessities and the baby lived.

Beginning at about the time of the Obernauer case—a mere fifty years after the publication of *Permission to Destroy Life Unworthy of Life*—some of the world’s most respected doctors and philosophers began again to suggest openly that it should be ethical to kill disabled babies or neglect them to death. Many of these death advocates were among the cream of the scientific community. For example, Harvard professor and Nobel Laureate James D. Watson, the co-discoverer of the genetic makeup of DNA, argued in reaction to the emergence of new reproductive technologies that “We have to reevaluate our basic assumptions about the meaning of life.” Analogizing to the ancient practice of exposing disabled infants on hills, Watson further declared, “No one should be thought of as alive until about three days after birth,” adding that parents would then “be allowed the choice” to keep their baby or “allow” their child to die. Similarly, the other Nobel Laureate involved in the discovery of DNA, Francis Crick, declared in 1978 that “no newborn should be declared human until it has passed certain tests regarding its genetic endowment and that if it fails these tests it forfeits the right to life.”

Demonstrating the prescience of Dr. Leo Alexander’s 1949 worries about American medical ethics, ideas like those of Crick and Watson took root. In 1982, there was another celebrated case—that of Baby Jane Doe, whose doctors engaged willingly in the very medical neglect that Baby Obernauer’s doctors refused to countenance only ten years before. Like the Obernauer infant, Baby Doe was born with Down’s syndrome and an intestinal blockage. Routine surgery to clear the blockage could have saved the baby’s life, but the mother’s ob/gyn told Jane’s parents they could refuse surgery. They decided that she—and they—would be better off if she died. They refused to consent to surgery and ordered the doctors to withhold food and fluids for their child, dooming her to death by dehydration.

When the news broke that Baby Jane was being neglected because she was disabled, several couples came forward asking, even begging, for the opportunity to adopt her. But Jane’s parents wanted their baby dead, not adopted. They refused to allow others to intervene. The matter was brought to court where a judge sided with Jane’s parents and against Jane’s equal moral status as a human being. She died six days after her birth. If a “normal” child were neglected to death in this way, the parents and doctors would be brought to the docket for child abuse; but because Jane was disabled, no legal sanctions were applied against either the parents or the participating doctors. This despite the fact that on her way to death, she became parched, dried out, and spit blood.

This is not the only case of parents or doctors choosing to let disabled babies die. In England, a woman gave birth to a Down’s baby who did not have an intestinal blockage. Upon learning that her baby was disabled, she said to her husband, “I don’t want it, Ducks.” Although the child had no physical abnormalities other than the genetic condition that causes Down’s, she ordered the doctors to withhold food. Dr. Leonard Arthur ordered the baby to be given morphine but not fed, and the baby died at the age of four days. Arthur was not
CULTURE OF DEATH

tried for homicide but, paradoxically, for “attempted murder.” Several of Arthur’s medical colleagues testified that such medical neglect of babies born with significant abnormalities is “normal medical practice.” Sir Douglas Black, president of the Royal College of Physicians, told the jury that he thought it ethical for a “rejected child” to be put “upon a course of management that would end in its death,” declaring “it is ethical that a child suffering from Down’s syndrome ... should not survive.” After only two hours, the jury decided the doctor was not guilty, causing rejoicing in the courtroom.69

Babies with spina bifida have suffered similar fates. Dr. John Lorber was once a leading proponent of treating babies with spina bifida, with surgery to close the wound in the back and a shunt to drain fluid from the brain. At some point, however, he had a change of heart and became a leading advocate for nontreatment, developing protocols for deciding which spina bifida babies to care for and which to abandon to death by neglect. He subsequently traveled the United States and Canada urging pediatricians not to operate on these helpless infants. His justification:

Humanity demands that such badly affected infants should not be put through such constant and severe punishment. Criteria had to be found, preferably on the first day of life which could reliably separate those infants who may die early but even more importantly those who would live but would suffer from severe multi-system handicaps and would be unable to live an independent and dignified existence in spite of the best possible treatment.... [In such cases,] nothing should be done to prolong life.70

What does this mean in actual practice? According to the approving Peter Singer, who interviewed Dr. Lorber, “The wound should be left open. If an infection develops, no antibiotics should be given. If excess fluid accumulated in the head, this should not be drained. If the babies did not eat and lost weight, they should not be tube-fed.... Few if any would live longer than six months.”71

Promoting Active Infanticide

In the 1970s, Joseph Fletcher, the patriarch of bioethics, advocated killing disabled children, an act he euphemistically called “post birth abortion,” dismissing the ethical and moral constraints against infanticide as a mere “taboo.”73 For Fletcher, the rightness of killing disabled babies could be determined through a simple utilitarian equation: if killing the baby increased happiness or reduced overall human suffering, then it should be done. “This view,” he wrote, “assigns value to human life rather than merely being alive and holds that it is better to be dead than to suffer too much or to endure too many deficits of human function” (emphasis in original).74

now too, disabled babies are identified from their earliest days as having an unworthy quality of life. Now as then, a decision is made to take action, or rather, not to act, thus ensuring that the babies die. As before, the physicians believe they are providing a service to their soon-to-be-dead patients, the families, and society.

In response to the Baby Doe tragedy, the federal government passed regulations to prevent medical discrimination based on disabilities, which unfortunately were invalidated by courts. Congress then passed amendments to federal child abuse statutes as they affect the laws of the states to prevent medically beneficial treatments from being withheld on the basis of quality-of-life criteria. The law permits the withholding of treatment for babies in irreversible comas if treatment would only prolong dying, if it would be virtually futile, and if it would be inhumane. But do these laws actually protect disabled infants? That is unclear. Former Surgeon General C. Everett Koop, who was instrumental in getting the Baby Doe laws enacted, has opined that they “are probably not legally effective” and that the “greatest protection that handicapped newborns have in the [United] States today is the concern on the part of physicians and surgeons who care for newborns that someone is watching.”72 Considering the increasingly utilitarian state of medical ethics and the pressures placed on doctors by managed care health insurance companies to cut the costs of health care, that protection may be scant indeed.

Life Unworthy of Life
What was shocking in the 1970s is shocking no longer. Arguing in favor of infanticide is now respectable and mainstream. Princeton's Peter Singer claims that infants have no moral right to live because, as discussed in the previous chapter, they are not "persons." He views infanticide at the request of parents as an ethical act so long as it will promote the overall interests of family or society. Singer originally suggested that parents have twenty-eight days within which to keep or kill their newborn child. More recently, he broadened this license, telling an interviewer, "I no longer think that will work. It's too arbitrary. I don't think you would get people to recognize that there's a big difference in the wrongfulness of killing a being at 27 or 29 days. So, what do you do? I think you need to look at it on a case-by-case basis given the seriousness of the problems and balance that against the age of the child." Earlier in the interview, Singer supposed that a child became a person "sometime during the first year of life," and thus his "case-by-case" approach could lead to killing a baby many months after birth.

When Singer's views are discussed in the media, he is often portrayed as "only" calling for the infanticide of "severely disabled" babies. This isn't true. Singer views not only disabled babies, but all infants as nonpersons who are replaceable... in much the same way as... non-self-conscious animals [e.g., bird and fish]." Since nonpersons have no right to life, there is nothing in his philosophy that explicitly limits infanticide to the killing of babies born with disabilities, so long as utilitarian principles are properly applied.

Singer knows that it would not pay for him to discuss the killing of healthy babies, and so he almost always addresses the issue in connection with disabled infants. But even here, the examples he gives are not infants who are "severely disabled." In Practical Ethics, for example, he supported infanticide of newborns with hemophilia, writing:

"When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of the happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if the killing of the hemophiliac infant has no adverse effect on others it would... be right to kill him." Singer reiterated his anti-disability bias in Rethinking Life and Death: The Collapse of Our Traditional Ethics, using a different type of disability as an illustration:

To have a child with Down syndrome is to have a very different experience from having a normal child. ... [W]e may not want a child to start on life's uncertain voyage if the prospects are clouded. When this can be known at a very early stage of the voyage we may be able to make a fresh start. ... Instead of going forward and putting all our efforts into making the best of the situation, we can still say no, and start again from the beginning.

Singer's advocacy of infanticide (and of euthanizing profoundly cognitively disabled people) caused a tremendous uproar in Europe, particularly in Germany and Austria, countries with an acute memory of the euthanasia Holocaust. Indeed, so many Germans and Austrians despise Singer's views that he is unable to lecture in those countries because of angry demonstrations that erupt whenever he appears to speak. These protests deeply disturb Singer. As a child of German/Austrian Jews who lost family members in the Holocaust, he resents his philosophy being linked in any way to the Nazis.

Singer defends himself by claiming that the acts he espouses, unlike those of the German doctors who participated in Nazi infanticide, are merely predicated upon "avoiding pointless suffering." But that was precisely what Binding and Hoche claimed when they labeled their proposal to kill disabled people a "healing process." Singer also says that the German doctors' motives in killing babies were different from the ones he espouses. That is not entirely true. Most German doctors who participated in killing babies believed fervently that they were benefiting all concerned. Singer attempts to distinguish himself further by claiming that he does not agree with racial hygiene theory. But whatever the supporting ideology, a murdered baby is a murdered baby. Another tack Singer takes to distance himself from the German experience is claiming that "Nazi euthanasia was never voluntary." Here, he is simply wrong.
The first known German government-approved infanticide, the killing of Baby Knauer, occurred in early 1939. The baby was blind at birth and had a leg and an arm missing. Baby Knauer's father was distraught at having a disabled child, so he wrote to Chancellor Hitler requesting permission to have the infant “put to sleep.” Hitler had been receiving many such requests from German parents of disabled babies over several years and had been waiting for just the right opportunity to launch his euthanasia plans. The Knauer case seemed the perfect test case. He sent one of his personal physicians, Karl Brandt, to investigate. Brandt's instructions were to verify the facts, and if the infant was disabled as described in the father's letter, he was to assure the doctors they could kill the child without legal consequence. Baby Knauer's doctors willingly murdered their patient at the request of his father. Brandt witnessed the killing and reported back to Hitler, who, pleased that all went as planned, signed the order permitting doctors to kill disabled infants.

The killing of Baby Knauer is precisely the kind of scenario Singer envisions when he argues that parents should be allowed to have their unwanted babies killed. Indeed, in *The Nazi Doctors*, Robert Lifton quoted Baby Knauer's father as stating in 1973 that Brandt had assured them “we wouldn't have to suffer from this terrible misfortune because the Führer had granted us the mercy killing of our son. Later, we could have other children, handsome and healthy, of whom the Reich could be proud.” Note the exact congruence between Brandt's justification for murder and Singer's philosophy.

It appears that the protesters in Germany and Austria who see a moral equivalence between Singer's utilitarianism and the German euthanasia Holocaust don't have it so wrong after all.

Peter Singer and Joseph Fletcher aren't the only ones who seriously advocate legalizing infanticide in some situations. An icon of bioethics in Britain, Jonathon Glover, wrote bluntly that infanticide is not morally wrong because babies are “replaceable.” Glover's reasoning, like Singer's, doesn't require that the killed baby be disabled:

It is wrong to kill a baby who has a good chance of having a worthwhile life, but ... it would not be wrong to kill him if the alternative to his existence was the existence of someone else with an equally good chance of a life at least as worthwhile.

Critics oppose infanticide because babies cannot choose to be killed—and autonomy, after all, is supposed to be an overarching value in bioethics. Glover casually dismissed this point:

This objection to killing provides no argument against infanticide, for newborn babies have no conception of death and so cannot have any preference for life over death.... The objection to infanticide is at most no stronger than the objection to frustrating a baby's current set of desires, say by leaving him to cry unattended for a longish period.

So much for the wrongness of giving birth and throwing the baby in the trash. After all, if the parents believe their lives and future families are best served by making the baby dead, according to Glover, no wrong was really done.

**Killing Babies in Holland**

Singer's infanticide philosophy is currently being carried out in the Netherlands under its euthanasia policy (to be discussed in the next chapter). A study published in the British medical journal *The Lancet* in 1997, which looked into the deaths of 338 Dutch infants between August and November 1995, found that approximately 8 percent were killed by doctors who administered drugs “with the explicit aim of hastening death.” If the study is accurate, with approximately 1000 infants dying in the Netherlands each year (1041 in 1995), about 80 babies are killed each year by their doctors—without legal consequence.

According to this study, 45 percent of surveyed neonatologists and 31 percent of surveyed pediatricians had “given drugs explicitly to end life.” Most of the babies were killed because the doctors believed they would not survive, but 18 percent of the killings were due merely to “a poor prognosis,” meaning disabilities. Life was shortened by *more than 5 years* in 16 percent of the cases. Some of
the killed babies hadn’t even required life support to survive; “a drug was given to hasten death to neonates not dependent on life-sustaining treatment in 1 percent of all death cases” which “represents 10–15 deaths of this type per year in the Netherlands.”88 Most—but not all—of the killings were at the request of parents, as per the Peter Singer formula.89 Despite legal requirements that euthanasia deaths be disclosed to the coroner’s office for review, “physician-assisted deaths for neonates is ... virtually never reported.”90

Few instances of infanticide have been prosecuted in the Netherlands. Those cases that have been brought were primarily efforts to establish a “precedent.” [Dutch prosecutions are not necessarily adversarial in nature, particularly as they involve physicians implicated in euthanasia. As Dutch lawyer and euthanasia proponent Eugene Sutorious told me, “The public prosecution, as a body, sees that this is not criminality in the normal sense... So, even the prosecutor, while bringing the case, he’s more interested in making sure that we have strict definitions and order than he is in punishing the professional. He’s trying to create a precedent.”91]

The first case in which infanticide precedent went formally unpunished involved a Dutch gynecologist named Henk Prins, who killed a three-day-old infant born with spina bifida, hydrocephalus, and leg deformities. When prosecuted (in order to create a precedent), Doctor Prins testified that he killed the girl with her parents’ permission because of her poor prognosis and because she screamed in pain when touched. Yet the child was in agony primarily because she was neglected medically. The open wound in her back had not been closed, nor had the fluid been drained from her head, although these treatments are standard in spina bifida cases and would have substantially reduced the infant’s pain.

The trial court refused to punish Dr. Prins for killing the baby. Indeed, the judge praised him for “his integrity and courage” and wished him well in any further legal proceedings he might face.92

The Royal Dutch Medical Association [KNMG] published a report in 1990 setting forth guidelines for killing incompetent patients, including infants. The standard for pediatric euthanasia is what is called “a livable life.”93 According to Dutch medical ethics, and

echoing Fletcher’s “humanhood” concept described in the last chapter, the “livableness” of an infant’s life depends on a combination of factors, including:

- the expected measure of suffering (not only physical but emotional).
- the expected potential for communication and human relations, independence (ability to move, to care for oneself, to live independently).
- the child’s life expectancy.

If the infant’s prospects don’t measure up to what the doctor and parents believe is a life worth living, the child can be medically neglected to death, or if that doesn’t work, killed by the doctor via lethal injection.94

Partial Birth Abortion

It could certainly be argued that one form of infanticide is also legal in the United States. “Partial birth abortion” is a legal/political term applied to the act of killing a late-term fetus that goes by the medical name “intact dilation and extraction” [D&X].

D&X is not really an “abortion” at all. Williams Obstetrics, a premier medical textbook, defines abortion as occurring prior to the twentieth week.95 [Some other medical texts extend that time to the twenty-fourth week.] Since most partial birth abortions occur after the twentieth week, it is accurate to describe a D&X as an induced premature labor, followed by a partial delivery, and then the killing of the almost-born child. As some critics claim—including the pro-abortion rights New York senator Daniel Patrick Moynihan—that makes the procedure an infanticide.

During a D&X, the doctor gives the pregnant woman drugs to dilate her cervix prematurely. When the time comes for the induced delivery, the doctor reaches in, turns the baby so it will come out feet first, and delivers all but the head, which is left inside the mother’s body. The doctor then pierces the skull with a sharp instrument and suctions out the brain, collapsing the skull so the head can be pulled completely out.96
Supporters of this procedure claim that “only” a “few hundred” are performed each year, and only when the baby has a hopeless physical anomaly inconsistent with life, or when it threatens the life or health of the mother. They have claimed that the baby doesn’t feel pain, but dies from the anesthesia given to the mother. Relying on these assurances, President Clinton twice vetoed legislation to ban the procedure passed overwhelmingly in both houses of Congress. The House of Representatives voted both times to override, but the Senate twice barely failed to achieve the necessary two-thirds vote to pass the ban into law over the president’s objections.

In fact, as opponents of D&X have proved:

- The procedure isn’t rare. Between 3,000 and 5,000 are performed each year, more than ten each day.
- Most of the fetuses killed are healthy.
- Most of the mothers are not endangered by their pregnancies; approximately 80 percent of partial birth abortions are purely elective.
- Only a miniscule number of partial birth abortions are undertaken for purely medical reasons.
- The fetus is usually alive when the partial birth abortion takes place. It is not killed by the anesthesia. At twenty weeks or higher gestation period, the unborn child may feel the pain of being killed.
- The American College of Obstetricians and Gynecologists could identify no circumstances where a partial birth abortion “would be the only option” to save or preserve the health of the woman.

The American Medical Association found that “there does not appear to be any identical situation in which intact D&X is the only appropriate procedure to induce abortion.”

At present, more than half the states have passed bans on D&X, all of which were attacked in the courts as unduly limiting a woman’s right to an abortion. In June 2000, the United States Supreme Court ruled that Nebraska’s law proscribing the procedure was unconstitutional because it did not provide an exception for the health of the mother. Expect more moral wrestling over partial birth abortion in the years ahead.

Dehydrating Cognitively Disabled People

Disabled infants are not the only ones at risk of medical cleansing. Today in the United States, almost as a matter of medical routine, cognitively disabled people who receive their food and fluids medically through a “feeding tube” are intentionally dehydrated and starved to death, and it is deemed ethical and moral.

In few areas of modern medicine have bioethicists been more influential than in attitudes toward brain-damaged, cognitively disabled people. First, they “dehumanized” them. Next, they gave moral permission to families and physicians to withdraw basic sustenance. Then they urged legal authorities in court cases and in statute writing to make dehydration a matter of the legal “right to die.” Today, causing death by dehydration to cognitively disabled people who receive their sustenance medically is legal in all fifty states.

The first people to be targeted for death by dehydration were those diagnosed as persistently unconscious. The medical term for this condition (coined in 1972) is “persistent vegetative state,” a medical diagnosis involving violence of logic and language (human being = vegetable). PVS is "a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him or herself or the environment." People in PVS are not terminally ill. What they need to survive is simply what every other human being does: food, water, warmth, shelter, cleanliness, and movement (in their case, by way of turning). With one crucial exception, these services are considered humane care that can never be withdrawn ethically.

That exception is food and water when it is delivered via a feeding tube, which is considered a medical treatment, not a basic human requirement. Defining “artificial nutrition” as a treatment instead of humane care was a crucial step in the development of the culture of death. As I will describe in more detail later on, medical treatment, unlike humane care, can be withdrawn or withheld from patients legally and ethically as a matter of respecting the patient’s personal autonomy—even if the decision is expected to lead to death.

Not too many years ago, it was considered unethical, indeed, potentially a criminal act, to stop feeding and hydrating an
incompetent patient. Then, beginning roughly in the early 1980s, some bioethicists began to wonder out loud whether profoundly disabled and frail elderly people were living too long. At that time society would not have accepted outright euthanasia. A consensus solution was required to this newly emerging "ethical problem." Bioethicists found it in intentional dehydration. Thus, in 1983 Daniel Callahan wrote, "a denial of nutrition may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die. Given the increasingly large pool of superannuated, chronically ill, physically marginalized elderly it could well become the non treatment of choice."109

For several years the debate raged among bioethicists as to the appropriateness of pulling feeding tubes from people diagnosed as persistently unconscious, who after all are not terminally ill. A few resisted the rising tide. Paul Ramsey, for instance, argued that only the "objective medical condition of the patient" should be considered when determining whether to cut off treatment, "not the subjective, capricious, and often selfish evaluations of the quality of future life that are often to the detriment of the most vulnerable and voiceless."110 Ramsey's point—a good one—was that when a patient is actively dying and can no longer assimilate food and water, then it is humane to desist from providing such care; indeed, the practice is a proper and compassionate component of good end-of-life care in some circumstances. However, withholding sustenance from an aged or disabled person in order to cause death is simply wrong, because it is based not on the patient's actual medical needs, but rather on the perceived moral worth of a human life.

Dr. Fred Rosner, director of medicine at Queens Hospital Center, also argued strenuously, if in vain, against countenancing intentional dehydration as an ethical medical act. Denial of food and fluids is different from other forms of care, he wrote in the New York State Journal of Medicine, because it is "biologically final," that is, it can have only one result: death. Second, unlike surgery or other forms of treatment, "food and fluids are universal human needs." Rosner worried that for physicians to remove food and fluids "attacks the very foundation of medicine as a profession." He further suggested that just because nutrition is delivered through a tube, it "does not change into an exotic medical substance"; food and fluids do not become medical therapy simply because another person is needed to provide them.111

Ramsey, Rosner, and the relatively few others who fought against redefining "artificial nutrition" from humane care to medical treatment were unable to staunch the fast-running tide. And although Ramsey had been one of the first bioethicists to defend ceasing life-supporting medical treatment at the patient's request, few of his colleagues were swayed by his doubts about this new, more radical position.

The advocacy of bioethicists profoundly influenced court decisions and legislation on the issue of removing food and fluids from people in PVS. In a 1983 California case, for example, an appeals court refused to sustain an indictment of doctors who had withdrawn food and fluids from an unconscious patient, citing bioethics literature as having helped the court in its reasoning.112 That case was soon followed by another appeals court decision overturning a trial judge's refusal to permit the dehydration of another man in PVS at the family's request. Indeed, the court ruled, families can order doctors to pull feeding tubes from people in PVS without asking a supervising court's permission.113

At about the same time, in 1986, the American Medical Association issued a momentous ethical opinion. While asserting that doctors should never "intentionally cause death," the AMA's committee with jurisdiction over ethics issues opined that it was ethical to terminate life support, even if "death is not imminent but a patient's coma is beyond doubt irreversible." In and of itself, that wasn't big news. What was significant was that for the first time, the AMA listed "artificially supplied ... nutrition and hydration" as a form of medical treatment.114

The ultimate legal blow to the severely disabled came in the landmark United States Supreme Court case of Nancy Beth Cruzan who on January 11, 1983, lost control of her car on an icy road in Missouri and crashed. She was thrown from the vehicle and landed face down in a water-filled ditch. Cruzan's heart stopped, but paramedics revived
CULTURE OF DEATH

her. Her injuries included profound cognitive disability, resulting in a diagnosis of PVS. While that diagnosis is disputed in some circles, there is no contradicting the fact that her care did not require “high tech” medicine. She was not on a respirator. She did not need kidney dialysis. She was not terminally ill.

In May 1987, the Cruzan family filed suit in Missouri seeking to force the hospital employees where Nancy resided to remove their daughter’s food and fluids. Hospital administrators and especially nurses who treated her daily, and saw her as a living, breathing human being deserving of respect and proper care, resisted the request. The trial judge disagreed. Nancy Cruzan was ordered to be dehydrated.

The State of Missouri appealed, basing its disagreement on state law requiring clear and convincing evidence that a patient would want life support removed before allowing it to be done. On this basis, the Missouri Supreme Court reversed the trial judge, ruling, “This is not a case in which we are asked to let someone die. . . . This is a case in which we are asked to allow the medical professional to make Nancy die by starvation and dehydration.”

The Cruzans appealed to the United States Supreme Court. But the court affirmed the lower ruling, finding the evidentiary standard constitutional, and ruling that such a strict standard was properly in keeping with the state’s obligation to protect the lives of its citizens. Since no clear and convincing evidence had been offered at trial that removing food and fluids was what Nancy would have wanted—as opposed to what her parents wanted for her—Missouri could properly require her life support to continue.

Then, those who opposed Nancy Cruzan’s dehydration saw this “victory” morph into a slow-motion defeat. First, it soon became clear that the Supreme Court, between the lines of its decision, had agreed that tube-supplied food and water were a medical treatment that could be withdrawn. The Cruzans went back to court in front of the same trial judge who had originally ordered Nancy dehydrated, this time bringing with them testimony from two of Nancy’s former co-workers relating a few vague conversations in which she had said that she would not want to live in a coma. Nancy’s exact words could not be described, nor whether she made the statement or simply agreed with someone else’s opinion. But that sparse testimony was all the judge needed to rationalize doing what he had wanted to do all along. Once again he ordered Nancy dehydrated. This time Missouri did not appeal the decision, and none of the many opponents of Nancy’s killing had legal standing to enter the case. Nancy died on December 26, 1990, twelve days after the removal of her feeding tube.

The death of Nancy Cruzan was a true watershed moment in bioethics, demonstrating the power of philosophers and activist physicians to redefine medical ethics, public policy, and popular opinion. With the Cruzan case, virtually all institutional and legal opposition to dehydrating people in a PVS at the request of caregivers collapsed. Such people can now be dehydrated in all fifty states. If other family members dispute the caregiver’s decision, it will rarely be to any avail. Indeed, they will often be accused of bad faith meddling and roundly castigated in the media. And it only took about ten years from the beginning of the bioethics debate about dehydration for people in PVS to be viewed in medicine, law, theology, and among the general public as Joseph Fletcher hoped they would eventually be: as “objects,” “vegetables,” “mere biological life,” a disposable caste whose intentional killing is proper and compassionate.

The attitude that it is better to die than to live cognitively disabled has triumphed so completely in our medical culture that some doctors now report a rush to write off newly unconscious patients as disposable, and consign them to death by cutting off life support before they have a chance to recover.

Dr. Vincent Fortanasce, a board-certified neurologist and psychiatrist, told me that many doctors make diagnoses of permanent unconsciousness after only a few days or weeks, although it takes at least three to six months to make a proper medical determination. Dr. Fortanasce gave me an example from his own medical practice. A sixty-year-old patient collapsed and became unconscious. He was diagnosed as PVS by his internist, who strongly urged the family to continue life support, including nutrition. The family was reluctant, so they brought in Dr. Fortanasce to give a second opinion. “I came in and gave the appropriate tests,” he told me. “I discovered
that the patient wasn't PVS but had experienced a brain seizure. I prescribed continued life support and medication. A week later, the patient walked out of the hospital in full possession of his faculties. Had the family listened to the internist, the man would be dead today.\textsuperscript{116}

Such cases occasionally make the news (almost always as “man bites dog” stories). In Los Angeles, Maria Lidia Lopez, six months pregnant, collapsed from a blood vessel disorder in the brain and entered a coma. After only three weeks waiting for her to awaken, doctors declared that her brain was so injured that she could not survive. All life support was about to be discontinued, which would have caused not only her own death, but that of her twin unborn children—but Maria awakened, and slowly improved to the point that the doctors were able to deliver her two healthy babies by Caesarian section.\textsuperscript{117}

**Targeting the Conscious**

The culture of death is never static; it ever seeks to occupy new philosophical space. Thus, it wasn't long before bioethicists moved to expand the category of those who can be dehydrated to include brain-damaged conscious people who need feeding tubes, as well as those in an unconscious condition.

A disturbing example is that of Marjorie Nighbert, a successful Ohio businesswoman who was visiting her family in Alabama when she was felled by a stroke. Marjorie was quickly stabilized, and she was not terminally ill. Somewhat disabled by the stroke, she was expected to benefit from rehabilitation. Accordingly, she was moved to the Crestview Nursing and Convalescent Home in Florida, where everyone hoped that she could relearn how to chew and swallow without danger of asphyxiation. To ensure that she was nourished, Marjorie was provided a feeding tube.

This presented an excruciating quandary for Marjorie’s brother Maynard, who, because of a power of attorney, was now the medical decision maker in charge of her care. Marjorie had once told him she didn’t want a feeding tube if she became terminally ill. He interpreted that statement as indicating that if she was unable to be weaned off the tube, she would have wanted doctors to remove it; so finally, when she did not improve, he ordered the tube removed. Marjorie was expected to die within three weeks.

As she slowly dehydrated, Marjorie began to ask the staff for food. “She was saying things like, 'Please feed me.... I'm hungry, I'm thirsty, and I want food',” says attorney William F. Stone, who briefly represented Marjorie as a court-appointed guardian.\textsuperscript{118} In response to her pleas, members of the nursing staff surreptitiously gave her small amounts of food and water. One eventually blew the whistle on the death watch, leading to a state investigation and a brief restraining order requiring that Marjorie Nighbert be nourished.

Stone was appointed Marjorie’s temporary guardian by Circuit Court Judge Jere Tolton, who instructed the lawyer to conduct a twenty-four-hour inquiry, the sole issue being whether Marjorie was competent to rescind her power of attorney and make her own decisions. After the rushed investigation, Stone was forced to report to the judge that she was not competent at that time. She had, after all, been intentionally malnourished for several weeks. Stone particularly noted that he had been unable to determine whether she was competent when the dehydration commenced.

With this report in hand, the judge decided to allow the dehydration to be completed, apparently on the bizarre theory that Marjorie was not competent when she requested the “medical treatment” of food and water. Nighbert died on April 6, 1995.

The dehydration bandwagon usually runs smoothly, but there have been a few potholes along the way. A recent Wisconsin Supreme Court decision, for instance, refused to allow a cognitively disabled, conscious Alzheimer’s patient to be dehydrated at the request of her sister/caregiver, ruling that they had established a “bright-line rule” limiting dehydration to people who are PVS, partly because conscious people might feel the agony of dehydration, and partly to prevent Wisconsin from falling down a “slippery slope for the consequences may be great.”\textsuperscript{119} Wisconsin, however, is the exception.

Two other notable court cases that have slowed the drive to move dehydration of conscious, cognitively disabled people from the “justifiable” to the “unexceptional” are the Michael Martin case in
Michigan and the Robert Wendland case in California. These cases are strikingly similar. Both involve the wife of a disabled, middle-aged man, brain-damaged in an auto accident, who decided to dehydrate her husband based on the belief that he would prefer being dead to being profoundly disabled. In both cases, the mother and sister of the disabled patient opposed dehydration. Because Michael Martin and Robert Wendland have relatively high levels of functioning, both cases were long, bitter, and emotionally traumatic for all concerned.

Michael Martin was interactive with caregivers. He enjoyed watching television and listening to country-and-western music. He was also able to nod his head yes and no and respond to simple requests. In April 1992, he learned how to use a communication augmentation system in which he pointed to letters to express himself. Through the system, he was able to communicate, "My name is Mike." According to the therapist's report, when asked to spell a word, Mike spelled out the word [water]. When asked to find the character to clear this page, Mike was able to do it independently. Mike also indicated to us in response to a yes/no question, that the scanning device was too slow for him and he wanted it a little faster. When directed to the feelings page, Mike responded to the question of how he was feeling by indicating happy.

In October 1992, as part of the court case then ongoing, Dr. Robert K. Krietsch, a board-certified physician specializing in physical medicine and rehabilitation, evaluated Martin and reported:

When I first entered the room his radio was on and he agreed to allow it to be turned off. When asked if he is able to see television and follow some shows, he indicates with an affirmative and also again, with a 'yes' head nod when asked if he likes certain shows. He brightened up with a large grin when asked if he liked cartoons.... When shown his poster with country western music stars, he again became quite animated with his expression, using a large grin, and was very cooperative in identifying by head nod and attempted to point with his right hand on questioning who were the different stars that I pointed to.... He was 100% accurate on identifying all of these.

Dr. Krietsch also reported that when asked if he felt at any time it was not worth going on, Michael indicated "No."

The principle expert on the dehydration side of the case was Dr. Ronald Cranford, a neurologist and bioethicist, who came to national attention when he became the star "expert witness" advocating the dehydration of Nancy Cruzan. Cranford reported that Martin's left side was completely paralyzed and his right side had limited movement. He was unable to speak or swallow. His ability to answer yes and no questions was "consistently inconsistent." He got some answers wrong, such as whether he wears diapers or whether he is disabled. Moreover, of key concern to Cranford were Michael's pre-injury statements indicating that he would not want to live with profound cognitive disability. According to Cranford, Michael smiled when told his daughter had been killed in the accident that caused his own injuries, indicating he didn't understand what he was hearing. Cranford later wrote, "The horror in this case is that you don't know what he is thinking for sure, you don't know what he's feeling." Martin's wife, Mary, joined Cranford in believing fervently that it was in her husband's best interests to be dehydrated. On the other side were Martin's mother and sister, who stood up for his right to live. While his current life was certainly not the life Michael would have chosen for himself before he was injured, that did not mean his alleged pre-injury statements about not wanting to live with cognitive disabilities reflected his current wishes or that his life should be ended by slow dehydration.

The trial court and the court of appeals sided with the wife and against the mother and sister. But the Michigan Supreme Court ruled 6-1 that a conscious, cognitively disabled person can be dehydrated only if it can be demonstrated by clear and convincing evidence—the most stringent standard in civil court—that he or she would not want to live with their disability, but would prefer to die in the manner that removing food and fluids would cause. The court ruled wisely, "If we are to err ... we must err in preserving life."

It wasn't long before a similar struggle was unfolding in Stockton, California. Like Michael Martin, Robert Wendland was in an
automobile accident that left him physically and cognitively disabled and dependent on others for his care. Like Martin, he was not terminally ill, nor was he hooked up to machines, although he did require a feeding tube because he couldn't swallow well enough to eat.

Wendland's wife wanted to dehydrate her husband, primarily because of statements she said he had made in the aftermath of her father's death, three months before Robert's injury, to the effect that he would not want to live if he could not "be a husband, father, and provider." It is pertinent that the last time Robert made such a statement, one week before his accident, he and Rose were arguing over his heavy alcoholism and repeated drunk driving. Indeed, Robert's mood was so sour, according to Rose, that he claimed his death or incapacitation would have no impact on the family—"as much an indication of depression as a clear, reasoned statement about life.

Wendland's mother and half-sister, Florence Wendland and Rebekah Vinson, were warned by an anonymous call from a hospital nurse of the wife's plan to dehydrate her husband. They sued to save Robert's life.

Wendland was indisputably not PVS and his ability to perform some activities could not be denied. Nonetheless, his wife's attorney and the San Joaquin deputy public defender appointed to represent Robert in the trial, Doran Berg (who decided that her own client should die) tried to convince Judge Bob McNatt to permit his dehydration. Once again Dr. Cranford came to court to testify, as did other bioethicists and physicians, in favor of ending Wendland's life. They claimed that his abilities meant little, amounting to mere "training," rather than truly human behavior. Some of the witnesses even likened his activities to that of trained animals. One went so far as to claim that Robert "is unable to think at all in the manner we conceive humans do." Similarly, the appellate attorney retained by the County of San Joaquin to represent Robert after the trial, following in Berg's footsteps, argued that his own client should be dehydrated, maintaining that Robert "can respond to simple stimuli somewhat in the manner that an animal might.

What these so-called experts and advocates saw as demeaning and akin to animal behavior could also be described as wonderful victories for someone who progressed from sixteen months of total unconsciousness to the point where he could:

- maneuver a manual wheelchair down a corridor.
- drive an electronic wheelchair down a hospital corridor.
- retrieve and return colored pegs into a peg-board when asked.
- take and return a ball when asked.
- write the letter "R" of his first name when asked as well as some other letters of his name.
- use buttons to accurately answer yes and no questions some of the time. (Is your name Robert? Yes. Is your name Michael? No.)

Robert could also feel pain. This is significant, considering the agony that dehydration can cause to conscious people. A recent article on palliative medicine makes all too clear what this suffering entails:

Confusion and restlessness; dry mouth, impaired speech, thirst, increased risk of bedsores, circulatory failure, renal failure, ... cardiac arrest, ... confusion, constipation, nausea, myoclonus [rapid, uncontrollable muscle spasms], seizures.

Dr. William Burke, a professor of neurology at St. Louis University Medical Center, has summarized the suffering caused by dehydration in conscious, nondying people in even blunter terms:

A conscious person would feel it [dehydration] just as you or I would. They will go into seizures. Their skin cracks, their tongue cracks, their lips crack. They may have nosebleeds because of the dryness of the mucus membranes and heaving and vomiting might ensue because of the drying out of the stomach lining. They feel the pangs of hunger and thirst. Imagine going one day without a glass of water! Death by dehydration takes ten to fourteen days. It is an extremely agonizing death.

Even Dr. Cranford admitted during the trial that the lips, eyes, and tongue of a person being dehydrated "get extremely dry," but claimed it is rare for them to crack and bleed, while acknowledging that "anything that is dry for a long period of time may crack. And
CULTURE OF DEATH

anything that may crack may bleed." He also testified that it is rare for dehydrating patients to go into seizures. Still, Cranford's description of the dehydration process, which he testified usually takes between ten and fourteen days but in some cases up to twenty-one, reveals its awfulness:

After seven to nine days [from commencing dehydration] they begin to lose all fluids in the body, a lot of fluids in the body. And their blood pressure starts to go down.

When their blood pressure goes down, their heart rate goes up. Their respiration may increase and then the patient experiences what's called a mammalian's diver's reflex where the blood is shunted to the central part of the body from the periphery of the body. So, that usually two to three days prior to death, sometimes four days, the hands and the feet become extremely cold. They become mottled. That is you look at the hands and they have a bluish appearance. And the mouth dries a great deal, and the eyes dry a great deal and other parts of the body become mottled. And that is because the blood is now so low in the system it's shunted to the heart and other visceral organs and away from the periphery of the body.131

Proponents of dehydration claim that these symptoms can be palliated by the proper use of eye drops and ice chips for dryness, and morphine for pain; Cranford also testified that he sometimes puts his dehydrating patients into a coma. But theirs is a circular, not to mention deeply ironic, argument. The patient would not require strong drugs to palliate suffering except for being denied the basic humane provision of food and water.

And do attempts at palliation really control the suffering? In Robert Wendland's case, Dr. Cranford testified that the amount of morphine he would be given would be "arbitrary" because it would "be hard to tell whether he's suffering or not," due to Robert's inability to communicate effectively. If that is true for Robert Wendland, it is also true for other conscious, cognitively disabled people who are dehydrated in nursing homes and hospitals throughout this country.

When dealing with these food and fluids cases, bioethicists often describe dehydration as being "in the best interests of the patient."

But that is questionable. What is actually behind many of these decisions is a utilitarian view that some lives are simply not worth living. The testimony of Dr. Cranford in this regard shows who is intended to benefit from his death:

MS. SIESS [Florence and Rebekah's lawyer, Janie Siess]: Why in your opinion as a clinical ethicist should . . . the error not be on the side of caution . . . and just let Robert [Wendland] live?

[Objection and the Court's overrule omitted]

THE WITNESS [Dr. Cranford]: The harm to continuing treatment . . . is, first of all, there wouldn't be a lot of harm per se as he is now because he has a minimal level of cognition. It's hard to talk about harm although he has some suffering.

It's harmful to the family because . . . they know his wishes are not being observed. They know he is in limbo or living death if you want to call it that. That's not what they want for Robert.

I think it's very harmful for a family to again feel like they're prisoners of medical technology about his treatment. So—you can go on and on about the psychological harm to the family. I think the family should be able to go through the grieving process. Four years is enough.

And so I think for people to start functioning again—because it is really harmful to families when you get into a situation like this—that the family should be allowed to live their lives.

They can still love Robert and remember Robert, but Robert should be allowed to die so the family can grieve and go through the normal grieving and knowing that Robert's wishes were respected....

I think it is counterproductive to what medicine should be doing in an era where we have to look at resources. Not just money and everything, but to give futile treatment like we do in the United States in situations like this which doesn't benefit the patient and doesn't benefit the family is one major problem for health care costs. So, I think it is harmful to society to do it.

I think there's a lot of harm that's done by erring on the side of caution. I think it's ridiculous to err on the side of caution when
there’s [no] doubt in my mind and any reputable person will say he’s never going to recover. He’s beyond that point. [emphasis added]\(^{32}\) 

Judge McNatt did not go along with this argument; he refused to permit Rose Wendland to dehydrate her husband. Following the “clear and convincing evidence” standard set forth in *Martin*, McNatt ruled: 

In our society, the rules under which Rose must make surrogate decisions are the same ones that someone less compassionate, less ethical would also operate… To allow termination of Robert’s life over the objections of other family members and on the legal basis of the evidence presented would allow the opening of a door that other families with less noble motives might follow through… To allow it would be to start down a treacherous road.\(^ {133}\) 

Rose Wendland and the public defender appealed. The appellate court, applying a California statute, reversed Judge McNatt. Making the shocking ruling that “there should be no presumption in favor of continued existence” in California law, the appeals court ordered the trial to continue and be decided upon a determination of whether Rose made her decision in “good faith.”\(^ {134}\) Janie Siess next petitioned the California Supreme Court to review the appellate decision. In a clear indication of the case’s import, the high court agreed. Thus, nearly five years after Robert Wendland awakened and relearned how to use his body in limited ways, the basic issue of whether he will be allowed to live out his life or be dehydrated to death remains up in the air. His ultimate fate might be determined by the United States Supreme Court.

### Protecting Animals versus Protecting Cognitively Disabled People

We are already farther down the “treacherous road” described by Judge McNatt than most people realize. So far, in fact, that animals receive greater protection from being dehydrated than do cognitively disabled people. There have been many cases in the United States in which people who allowed animals to go without food and water were jailed or otherwise punished in criminal court. In 1985, someone called the Sulpher Springs Police Department in Arkansas to report two horses that were starving to death. One was so malnourished it had to be shot. A veterinarian testified that one of the primary causes of the horses’ poor condition was malnutrition (in addition to exposure). A horse trainer testified that he had seen the horses and they were literally “starving to death.”

Under Arkansas law, a person commits the offense of “cruelty to animals if” he or she “knowingly” subjects “any animal to cruel mistreatment” or “cruel neglect.” Such cruelty is defined: “every act, omission, or neglect whereby unjustifiable physical pain, suffering or death is caused or permitted.” Based on this law, the owner of the horses was convicted of a misdemeanor, fined $1,000, and sentenced to thirty days in jail, which were suspended on the condition that there be no further cruelty violations within one year.\(^ {135}\) 

Then there was the Nebraska case of the cattle that died because of pronounced dehydration and malnutrition. The animals’ owner was charged with “cruelty to animals,” which under Nebraska law includes “failure to provide food and water.” Malnutrition causes “pain to animals,” the appellate court noted in reviewing the rancher’s conviction. “Absence of food produces abdominal cramping.” The conviction of the rancher on a misdemeanor was upheld, subjecting the defendant to a maximum term of six months in jail, a fine of $1,000, or both.\(^ {136}\) 

In Arizona, where abuse of animals recently became a felony, a man was arrested for the starvation death of a horse. The Maricopa County Sheriff was quoted as applauding the pending prosecution because the law holds that “We have to treat our animals well. Excuses don’t cut the mustard.” As of this writing, the arrested man faces a maximum penalty of a year in jail and a $150,000 fine.\(^ {137}\) 

I could fill several pages with descriptions of cases where people have been convicted of starving and dehydrating animals. I find these crimes appalling, but obviously I mention them to make a larger point: If such mistreatment is enough to bring jail time when it is inflicted on animals, why is essentially the same act considered moral and
legal when done to a cognitively disabled human being? The bioethicist's answer—that the existence of a feeding tube makes all the difference—simply won't do.

The Price of Autonomy

"I don't want to be hooked up to medical machines when I am dying."

How often we hear those words. People's fear of being forced to live against their will by medical means is persistent and consistent across the entire political, religious, and moral spectra of American life. Pro-lifers are as concerned as pro-choice, conservatives as liberals, the young as the elderly. Indeed, if I were asked to choose the most common worry people have about dying, I would not hesitate to say it is being tethered to high-tech medical machines and kept alive against their will.

Doctors once believed they were duty-bound to use every weapon in medicine's armamentarium to prevent death. But in the postwar years, as medical advances led to ever more grandiose expectations, the goal became more an obsession. Consequently, people were hooked up to machines, in part because of the erroneous belief that Hippocratic ethics required doctors to keep their patients alive as long as possible in virtually every case. But the existence of the machines themselves also contributed to the problem. Technology exists to be used. Innovations such as kidney dialysis machines, modern respirators, and the electrical heart defibrillator all have helped people to live who only a few years previously would almost surely have died.