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AS GOOD AS DEAD

Is there really such a thing as brain death?

by Gary Greenberg

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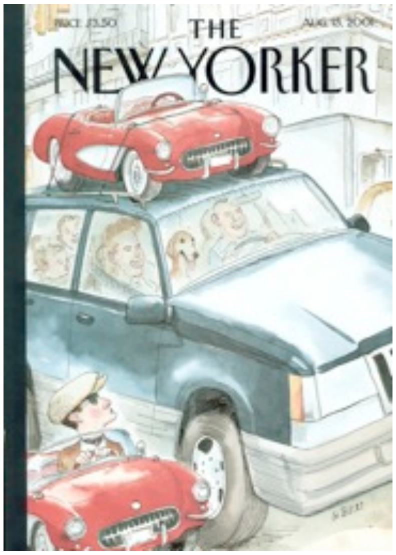

Just after a fourteen-year-old boy named Nicholas Breach learned that a tumor on his brain stem would be fatal, he told his parents, Rick and Kim Breach, that he wanted to be an organ donor. They respected his decision, and so did the boy's medical team at the Children's Hospital of Philadelphia. Bernadette Foley, Nick's social worker there, said that the decision reflected a "maturity and sensitivity" and a wish to help others—something Nick had shown throughout his eight-year battle with recurrent tumors. "I've never been to a meeting like this one," Foley said. "The peace that came over the family and Nick was remarkable, and once it was out that this was the end, and the decision was made about organ donation, Nick said he was happy. They all seemed to be happy." The decision was redemptive, she said. "In a way, it gave some meaning to his life."

By the time I met Nick, he was confined to a hospital bed that had been set up in the living room of the Breaches' house, a brick bungalow outside Harrisburg. It was difficult for him to speak, and we chatted only briefly—about his dog, Sarah; his brother, Nathan; and his hope that his heart, lungs, liver, kidneys, and pancreas might enable other people to live—and then he dozed off.

As Nick slept, his parents told me that, amid their other worries, they had run into unexpected problems with the donation. Nick had wanted to die at home, with only palliative care, but organ donation is a high-tech affair. In most cases, the donor is someone with brain damage so severe that he requires a respirator to breathe, even though his heart continues to work on its own. A neurologist determines that the patient's brain has been irreversibly and totally destroyed, and on this basis pronounces him dead. This condition is known as brain death. If the patient's family has consented to donation, he is left on the respirator, which, along with his still-beating heart, keeps his organs viable for transplant until they can be harvested. The Breaches accepted that Nick would now have to be hospitalized at the very end, but their insurance company balked at the change in plan—and the added expense—reminding them that they had already elected basic hospice care. Only after the family's state legislator and the regional organ-procurement organization got involved did the insurance company agree to pay. A plan was devised to keep Nick at home until the last possible moment and then to transport him to a hospital, where an informal protocol had been set up to help him become an organ donor.

Even with the logistical and financial arrangements in place, there was no guarantee that Nick would meet the criteria for brain death. Because the tumor was on his brain stem, which controls core physiological processes like breathing and body temperature, it was very likely that Nick's higher brain—the thinking part—would remain active until he died from respiratory or organ failure. (His oncologist told me, "In his condition, what happens is the body goes. He's a consciousness trapped inside.") This would probably rule him out as a donor.

When I spoke to Nick's parents, they still had trouble with the notion that, to become a donor, it was not enough for their son to die with his body more or less intact. He would have to have the right kind of death, with the systems in his body shutting down in a particular order. "I'm so confused about this part of it," his mother said. "I don't understand why, if his heart stops beating, they can't put him back on a respirator." Rick, too, was confused about the moment at which "the plug will be pulled." In reality, there is no moment when the plug is pulled; to keep the organs viable, the respirator is left operating—and the heart keeps beating—until the surgeon removes the organs.

Confusion about the concept of brain death is not unusual, even among the transplant professionals, surgeons, neurologists, and bioethicists who grapple with it regularly. Brain death is confusing because it's an artificial distinction constructed, more than thirty years ago, on a conceptual foundation that is unsound. Recently, some physicians have begun to suggest that brain-dead patients aren't really dead at all—that the concept is just the medical profession's way of dodging ethical questions about a practice that saves more than fifteen thousand lives a year.

From the beginning, transplant practice has been governed by a simple, unwritten rule: no matter how extreme the circumstances, no matter how ill or injured the potential donor, he must die of some other cause before his vital organs can be removed; it would never be acceptable to kill someone for his organs. But, ideally, a donor would be alive at the time his organs were harvested, because as soon as the flow of oxygenated blood stops, a process called warm ischemia quickly begins to ruin them. By the nineteen-sixties, as doctors began to perfect techniques for transplanting livers and hearts, the medical establishment faced a paradox: the need for both a living body and a dead donor.

The profession was also struggling with questions posed by another new technology: respirators. These machines had become a fixture in hospitals in the nineteen-fifties, and at first their main purpose was to help children with polio breathe until they regained their strength. Doctors began to use them for patients with devastating brain injuries—the kind brought on by severe trauma or loss of oxygen as a result of stroke or cardiac arrest. Some of these people recovered sufficiently to be removed from the machines, but others lingered, unable to breathe on their own, inert and unresponsive even to the most noxious stimulus, and without any detectable electrical brain activity, until their hearts gave out—often a matter of hours, but sometimes of days or even weeks.

Physicians wondered what to do with these patients, whether removing the machines would be murder or mercy killing or simply a matter of letting nature take its course. At the same time, some noticed that the patients were perfect sources of viable organs for transplant, at least as long as their hearts kept beating. And then, in 1967, a Harvard anesthesiologist named Henry K. Beecher asked the dean of the medical school to form a committee to explore the issues of artificial life support and organ donation, which he believed were related. The Harvard committee, which Beecher chaired, included ten physicians, a lawyer, and a historian, and its report was published the following year in the *Journal of the American Medical Association*. "Responsible medical opinion," it announced, "is ready to adopt new criteria for pronouncing death to have occurred in an individual sustaining irreversible coma as a result of permanent brain damage." Heartbeat or no, the committee declared, patients whose brains no longer functioned and who had no prospect of recovering were not lingering but were already dead—brain dead.

This physician-assisted redefinition of death meant that removing life-support machinery from these patients was no longer ethically suspect. And, by creating a class of dead people whose hearts were still beating, the Harvard committee gave transplant surgeons a new potential supply of organs. In the nineteen-seventies, however, only twenty-seven states adopted brain death as a legal definition of death. Theoretically, this meant that someone who had been declared dead in North Carolina could be resurrected by transferring him to a hospital in South Carolina. Practically, it meant that a doctor procuring organs from a brain-dead person was not equally protected in all jurisdictions from the charge that he was killing his patient.

In 1980, a commission appointed by President Carter began to look at medical ethical questions, which included finding a definition of death that could serve as a model for state laws. The commission recommended that doctors be given the power to declare people dead based on the neurological criteria suggested by the Harvard committee.

Eventually, this recommendation was accepted in all fifty states.

The commission also wanted to convince the public that brain death was not just a legal fiction but the description of a biological truth. Two rationales were considered. In one, called the "higher-brain" formulation, a brain-dead person is alleged to be dead because his neocortex, the seat of consciousness, has been destroyed. He has thus lost the ability to think and feel—the capacity for personhood—that makes us who we are, and our lives worth living. But such "quality of life" criteria, the commission noted, raised uncomfortable ethical and political questions about the treatment of senile patients and how society valued the lives of the mentally impaired.

Instead, the commission chose to rely on what it called the "whole-brain" formulation. The brain, it was argued, directed and gave order and purpose to the different mechanical functions of our bodies. If both the neocortex and the brain stem (which regulates core physiological processes, such as breathing) stopped working, a person could be pronounced dead—not just because consciousness has disappeared but because, without the brain, nothing connects: there is no internal harmony, and the body no longer exists as an integrated whole.

When Nick Breach decided to become a donor, one of his first questions was whether he would be dead when his organs were taken. His parents told him that he would be, and, in a way, they saw this as one of the few things they could be sure about. Rick and Kim were more troubled by their son's next concern, that he might be taken from them prematurely. They began a vigil that took on a strange dual nature: keeping Nick company, making him comfortable, spending as much time as possible with him, and, at the same time, monitoring him for the signs—whatever they might be—that death had come so close that it was time to get him to the hospital so that he could become an organ donor.

The organ-procurement agency that worked with the Breaches during those months was called Gift of Life. In 2000, Gift of Life, which is based in Philadelphia and has a staff of a hundred, helped manage more than eight hundred organ donations at a hundred and sixty-two member hospitals in Pennsylvania, New Jersey, and Delaware—five per cent of the total organs removed in the country.

The agency's mission is to "positively predispose all members of the community to organ and tissue donation so that donation is viewed as a fundamental human responsibility." Public-service ads, a pamphlet featuring Michael Jordan, and bumper stickers that say "Don't take your organs to Heaven—Heaven knows we need them here" are all promoting an attitude about how, as Howard M. Nathan, the bearded, energetic forty-seven-year-old who heads Gift of Life, put it, "society should feel about this subject." Because of the drama and human interest of Nick Breach's case, the agency was naturally eager to publicize it: "Here's a young man who is awake and aware, contemplating his death, and he becomes a donor," Kevin Sparkman, the agency's director of community relations, explained. "What a great example of what we want families to do!"

When a person is identified as a potential organ donor—generally, when he is about to be pronounced brain dead—Gift of Life dispatches a transplant coördinator to the hospital to try to obtain the family's consent. (An organ-donor card is merely an indication of a patient's wishes; the family has the final word.) "The first thing we do is insure that the family understands and acknowledges that their loved one is dead," Linda Herzog, a senior hospital-services coördinator, told me.

Consent rates are tied directly to knowledge of brain death: families who think that donation is actually going to kill the patient refuse more often than families who believe that their relative is already dead. This is not as straightforward as it may seem, largely because of the lifelike appearance of the brain dead, whose skin is still warm to the touch and who are known within the industry as "heart-beating cadavers." Gift of Life has developed a program that trains hospital staffs to explain the phenomenon to families. I watched in a darkened conference room as Herzog reviewed the program for two transplant coördinators, who were scheduled to present it later that afternoon in a Philadelphia hospital.

Using slides, Herzog ran through the process by which brain death is established. A neurologist performs a series of tests at the bedside—checking for such things as pupillary reflexes, response to pain, and the ability to breathe spontaneously. (If the patient is entirely unresponsive during two such examinations, the doctor concludes that his whole brain—cortex and brain stem—has been destroyed.) This is not a terribly sophisticated procedure, but it's far more complicated than, say, ascertaining that a person has no pulse, and far less self-evident. Even when the tests are conducted or reënacted in front of family members, they often rely on their intuitions and insist that the patient is still alive. This failure to accept the truth is a function of denial, Herzog said, and she went on to note, with some dismay, that even highly trained professionals who fully accept the concept sometimes talk to brain-dead patients.

”It took us years to get the public to understand what brain death was," Nathan said. "We had to train people in how to talk about it. Not that they're brain dead, but they're dead: 'What you see is the machine artificially keeping the body alive . . .' " He stopped and pointed to my notebook. "No, don't even use that. Say 'keeping the organs functioning.' "

Virtually every expert I spoke with about brain death was tripped up by its semantic trickiness. "Even I get this wrong," said one physician and bioethicist who has written extensively on the subject, after making a similar slip. Stuart Youngner, the director of the Center for Biomedical Ethics at Case Western Reserve University, thinks that the need for linguistic vigilance indicates a problem with the concept itself. "The organ-procurement people and transplant activists say you've got to stop saying things like that because that promulgates the idea that the patients are not really dead. The language is a symptom not of stupidity but of how people experience these 'dead' people—as not exactly dead."

Last year, I went to Havana for the Third International Symposium on Coma and Death, a conference held every four years and attended primarily by neurologists and bioethicists, joined by lawyers, anthropologists, and members of the clergy. At one session, I watched as a videotape of a recumbent adolescent boy, his feet toward the camera, his legs bowed, almost froglike, played on a television monitor in a corner of the room. He wore shorts, and there were two tubes entering his body, one in his abdomen, the other in his throat. The boy's chest rose and fell to the whir and click of the respirator, but otherwise he was perfectly still.

On the tape, a trim, balding man named Alan Shewmon, a pediatric neurologist at U.C.L.A., stood near the bed and conducted a medical examination. He looked into the boy's eyes, shook maracas next to his head, inserted a swab in a nostril, dropped cold water into the ears and lemon on the tongue, pinched and palpated and inspected. None of these actions drew a response from the boy, whom I will call Matthew.

Shewmon was also standing next to the monitor in Havana, offering additional commentary. He has been thinking about death for most of his career. A practicing Catholic, he has made contesting the concept of brain death a specialty, and has served on a Pontifical Academy of Sciences task force on the subject. Shewmon's inquiry has led him from the higher-brain rationale through the whole-brain rationale to his current position: a strong conviction that brain death, while a severe disability, even severe enough to warrant discontinuing life support, is not truly death.

Although Matthew didn't seem dead, it was hard to think of him as alive. On the monitor, a nurse removed the upper tube, suctioned the small hole in the boy's throat, noted that he did not cough, and continued the routine of the exam. Then something different happened: some ice water trickled onto the boy's shoulder, and it twitched. And though the screen was too small to see this, Shewmon told us that Matthew sprouted goose bumps, that his flesh was mottling and flushing with the stress of the exam. He was showing signs, that is, of precisely the kind of systemic functioning that the brain dead would generally be expected to lack.

In the video, Shewmon lifted Matthew's arm by the wrist, and the hand sprang to life with a small spasm. A woman's voice—Matthew's mother, we learned—said, "When he knows what you're going to do, he stops that." Shewmon described what was going on in medical terms—clonus, an involuntary contraction and release of nerves. He was making his main point: that this boy—who at age four was struck with meningitis that swelled his brain and split his skull, who would probably have been pronounced brain dead had he not been too young under the statutes of the time, whose mother refused to discontinue life support and ultimately took her son home on a ventilator and a feeding tube, who had persisted in this twilight condition for thirteen years, healing from wounds and illness, growing—was alive. Not by virtue of intention or will, as his mother has implied, but because he had maintained a somatic integrated unity—the internal harmony, and the overarching coördination of his body's functions—which, if the whole-brain rationale is correct, he simply should not have been able to do.

After the presentation ended, I spoke to Ronald Cranford, a professor of neurology and bioethics at the University of Minnesota, who is one of Shewmon's critics. He argued that Matthew's case was only an unusually prolonged example of the normal course brain death takes. "Any patient you keep alive, or dead, longer than a few days will develop spinal-cord reflexes," he said, recalling a case in which the doctor said, "Yes, she's been getting better ever since she died."

In a question-and-answer session with Shewmon the next day, after an address in which he drew parallels between the brain dead and people who are conscious but have been paralyzed by injuries to the upper spinal cord, no one really took issue with his science. At the same time, none of the physicians would accept what Shewmon was really saying: that the brain dead are not dead. "The main philosophical question is, Is this a body or is this a person?" said Calixto Machado, the Cuban neurologist who organized the symposium. Fred Plum, the chairman emeritus of the Department of Neurology at Cornell University's Weill Medical College, had positioned himself directly in front of the podium for the talk, and shot his hand in the air as soon as Shewmon was finished. "This is anti-Darwinism," Plum said. "The brain is the person, the evolved person, not the machine person. Consciousness is the ultimate. We are not one living cell. We are the evolution of a very large group of systems into the awareness of self and the environment, and that is the production of the civilization in which any of us lives."

Shewmon had laid a trap for his audience, he later told me. He had hoped to break down the pretense that anyone subscribed to the whole-brain rationale. He wanted to show that the higher-brain rationale, which holds that living without consciousness is not really living—and which the President's commission rejected because it raised questions about quality of life which science can never settle—was the sub-rosa justification for deciding to call a brain-dead person dead. He wanted to make it clear that these doctors were not making a straightforward medical judgment but, rather, a moral judgment that people like Matthew were so devastated that they had lost their claim on existence. And, at least in his own view, the comments he'd provoked meant that he had succeeded.

The neurologist James Bernat, a professor at Dartmouth Medical School and the author of the chapters on brain death in several neurology textbooks, is one of the defenders of the whole-brain concept. Like Shewmon, Bernat served on the Pontifical Academy of Sciences task force. And, last August, his position appeared to prevail when Pope John Paul II, speaking before an international transplantation congress, said that "the complete and irreversible cessation of all brain activity, if rigorously applied," along with the family's consent, gave a "moral right" to remove organs for transplant—thus resolving an ambiguity in the Church as to whether Catholics should become donors. (Orthodox Jewish and other theologians continue to debate whether a brain-dead person is truly dead.) But even Bernat sees the problem he's up against. "Brain death was accepted before it was conceptually sound," he told me on the telephone from his office in New Hampshire. He readily admits that no one has yet explained scientifically why the destruction of the brain is the death of the person, rather than an extreme injury. "I'm being driven by an intuition that the brain-centered concept of death is sound," he said. "Death is a biological function. Death is an event."

Stuart Youngner, of Case Western, however, rails against what he sees as bad faith in the way brain death came to be defined. Youngner, a white-bearded, avuncular fifty-six-year-old, calls the Harvard committee's work "conceptual gerrymandering," a redrawing of the line between life and death which was determined by something other than science. "What if the Harvard committee, instead of saying, 'Let's call them dead,' had said, 'Let's have a discussion in our society about whether there are circumstances in which people's organs can be taken without sacrificing freedom, without harming people.' Would it be better?"

The problem, as Youngner sees it, is that the veneer of scientific truth attached to the concept of brain death conceals the fact that the lives of brain-dead people have ended only by virtue of what amounts to a social agreement. According to Youngner, this means that the brain dead are really just "as good as dead," but, he is quick to add, this doesn't mean that they shouldn't be organ donors. Instead, he suggests that "as good as dead" be recognized as a special status, one that many people, brain dead or not, may achieve at the end of life."I'm willing to point out the ambiguities and inconsistencies in the notion, and I actually think that acknowledging them may in the long run be better," he told me.

During the last decade, Youngner and other doctors and ethicists have developed protocols to allow critically ill or injured people who have no hope of recovery, but who are unlikely to become brain dead, to donate their organs after they have been declared dead by the traditional cardiopulmonary criteria. This procedure, which is known as non-heart-beating-cadaver donation and requires extremely rapid intervention and newly developed techniques, may make it possible to salvage viable organs in a wider range of cases.

As it happened, Nick Breach was a candidate for this procedure. If he was brought to the hospital, placed on a respirator, and then languished, without ever meeting the criteria for brain death—a likely scenario, given the course of his disease—only a tight orchestration of his death could conceivably give him a chance of becoming a donor. According to Gift of Life's protocol, Nick's parents would first have to decide to remove life support. Nick would then be taken to an operating room, where he would be taken off the ventilator, and the doctors would wait for his heart to stop. If that took more than an hour, warm ischemia would set in (as his breathing would be too compromised to supply oxygen to his organs), the donation would be aborted, and Nick would be returned to a hospital room to die. But if cardiac arrest came in time, a five-minute count would begin, at the end of which Nick would be declared dead. A transplant team standing by in an anteroom would immediately harvest his organs and rush them to their recipients. (Even with this alternative, the window for success was fairly narrow. "All we're trying to do," Howard Nathan acknowledged, "is give it a shot.")

Non-heart-beating protocols have the potential to increase donation by as much as twenty-five per cent. But, as Youngner points out, the five-minute waiting period (it ranges from two minutes in some protocols to ten minutes in others) is really just a decent interval, a more or less arbitrary marker of the passage from life to death, whose significance is far more symbolic than scientific.

Robert Truog, a professor of medical ethics and anesthesiology at Harvard Medical School, is even more critical of the protocol. “Non-heart-beating protocols are a dance we do so that people can comply with the dead-donor rule,” he told me. “It seems silly that we hang on to this façade. It’s a bizarre way of practice, to be unwilling to say what you are doing”—that is, identifying a person as an organ donor when he is still alive and then declaring him dead by a process tailored to keep up appearances and which, in the bargain, might not best meet the requirements of transplant. In Truog’s view, a better approach would be to remove these patients’ organs while they are still on life support, as is done with brain-dead donors. “If they have detectable brain activity, then they should be given anesthetic,” he said, but there is no reason to continue to conceal what is happening by waiting for their hearts to stop beating.

Abandoning the dead-donor convention—which is an inevitable consequence of Youngner’s and Truog’s positions—may, however, cause other problems. It awakens the same sort of fears that Nick Breach himself had about the premature removal of his organs. It raises vexing legal questions, because, as Truog bluntly told me, without the rule “taking organs is a form of killing”—killing that he thinks is justified, and that Youngner and others would argue is already happening. He added that repealing the rule risks “making physicians seem like a bunch of vultures.”

In return, Truog points out, patients would gain more control over the end of their lives: they would no longer have to wait until they crossed over that gerrymandered border and, instead, could specify at what point they would like to be declared dead so that they could donate their organs. This, however, might not be adequate consolation for those who fear that the need for organs might create a perverse incentive for doctors to give up on them, after weighing their lives against those of others who may be more worthy or less damaged. Youngner expressed reservations about how his position would sound to other doctors and, most important, to potential donors. “I think that stridently advocating the abandonment of the dead-donor rule would be a mistake,” he said. He worried, he told me, that religious conservatives and others might “seize on it as a violation of the right to life,” thus turning transplant into another medical practice—like abortion or fetal stem-cell research—that’s bogged down in intractable political wrangling.

As Nick Breach thought about his death, he made some additional last wishes that were easier to satisfy than his desire to become a donor: Ronald McDonald came to visit; so did Weird Al Yankovic, one of Nick’s idols. When Yankovic pulled up to the Breaches’ house in a bus, the neighbors moved their cars to accommodate him. Yankovic came inside and sat for a while with Nick, who was bedridden by then. Nick told him, “I really love all your CDs, Weird Al.”

Six days later, at 11:45 P.M., Nick stopped breathing. Rick, who was taking his turn by the bedside, summoned Kim, who called an ambulance and began to administer CPR. The plan was to revive Nick so that he could be brought to a hospital and placed on a ventilator. But his mother’s efforts, and those of the paramedics in the ambulance and the staff in the emergency room, failed. Nick’s heart had stopped too soon, and ischemia had set in. In the end, the only organs he was able to donate were his eyes.

It is tempting to wish that death weren’t so complicated. Had Nick and his parents realized how alive he still needed to be in order to donate his vital organs successfully, they could have been given an honest choice between having Nick remain at home until the end and giving up on his goal of becoming a donor, and going to the hospital much earlier and staying until he could be declared “as good as dead.”

Over and over again at the conference in Havana, I heard ambivalence and anxiety about “the public” knowing what doctors already know. “These things ought to be worked out in the medical profession, to some extent, before you go to the public,” Shewmon told me. “Because if you go public right away, it could just put the kibosh on the whole thing, because people get hysterical and misunderstand things.” He paused and looked at me. “These are complex issues. You can’t expect the public to understand these things in sound bites, which is what they usually get. So I’m reluctant to talk to reporters about this stuff.”

During a break between sessions, I got into a conversation with a philosopher. He told me that he had been talking about this subject with a colleague, and that they’d found themselves calling brain death a “noble lie.” Later, as the conference reconvened, I asked him if we could talk some more about that idea. He was visibly upset. “Listen, I’m not sure about that comment,” he said. “It’s inflammatory. It’s too strong.” Among his concerns, he explained, was the possibility that his words might discourage people from becoming organ donors.

It may be too much to say that the concept of brain death is an outright lie, but it is certainly less than the truth. Like many of technology’s sublime achievements, organ transplant, for all its promise, also has an unavoidable aspect of horror

—the horror of rendering a human being into raw materials, of turning death into life, of harvesting organs from an undead boy. Should a practice, however noble, be able to hold truth hostage? Perhaps the medical profession should embrace the obvious: to be an organ donor is to choose a particular way to finish our dying, at the hands of a surgeon, after some uncertain border has been crossed—a line that will change with time and circumstance, and one that science will never be able to draw with precision. ♦