Two comatose teenage boys, 20 years and 200 miles apart, lead a noted ethicist and medical historian to ponder the nature of personhood—the nuances of determining if and when death is inevitable. This feature is excerpted from a new book by a DMS alumnus.

Story by Robert Martensen, M.D.
Illustration by Bert Dodson

Ryan: Boston, 1993

I was the staff emergency physician on duty one Saturday morning at a Boston-area hospital when an ambulance brought in an injured boy. Ryan, who was 17 and went to high school in Boston’s western suburbs, had woken up that morning eager to play soccer, which he did. On the way back from the game, a truck rammed the passenger side of the car in which he occupied the front seat. Now he lay motionless in the hospital’s trauma room. What I saw was this: a fair-haired, pale teenage boy of a slender and wiry build, about five feet eight inches tall, who weighed around 125 pounds. He had bruises on his right forehead and temple, and his right upper arm and leg showed obvious deformities, though the skin was not broken. Ryan’s airway, neck, chest, abdomen, and pelvis seemed normal on my emergency survey. Based on initial x-rays, Ryan’s cervical spine looked good to me, and the orthopedic resident said the fractures—of an arm and a leg—did not require surgery and should heal well. X-rays of his chest, abdomen, and pelvis suggested that they were not injured, as did the absence of blood in his urine.

It was Ryan’s brain that was the problem. Though his pupils responded normally to light, he...
moved his good arm in an uncoordinated way when his chest was pinched. Despite breathing on his own and maintaining a stable pulse and oxygen saturation, his mental state remained poor. Could—a mass lesion—a blow—have been causing Ryan’s unresponsiveness? CAT scans of his skull showed no pool of blood or clots for the neurosurgeons to remove. No ruptured veins or cisterns—the entities in the brain that contain cerebral spinal fluid—were not obliterated, though two might have been compressed. (Compression of the ventricles is an ominous sign, especially when it is not caused by a discrete mass. It can lead to increased ICP by causing the brain to swell. Too much swelling in a closed compartment like the skull frequently leads to irreversible brain damage or worse, the upper brain forcing the lower brain downward against bony protuberances inside the base of the skull, a situation that often leads to death if it is not halted promptly.)

Although Ryan was breathing on his own and maintaining a decerebrate level of blood oxygen, we intubated his trachea and put him on a ventilator in case his brain swelled. If the ventilator was set to stimulate his breathing slightly, the level of carbon dioxide in his blood would fall, and studies on patients with severe head injuries as well as animal studies suggest this would likely lower his intracranial pressure. We also elevated the head of Ryan’s bed 30 degrees, and I put an intravenous catheter in his left jugular vein to monitor his blood levels of carbon dioxide and oxygen. Our care was “supportive,” and we did not feel much like.

We speculated that Ryan’s brain had sustained a diffuse axonal injury. The bang-off-bang collision of his head into solid parts of the car had profoundly, if subtly, damaged his brain’s cortex, even as his brain stem was capable of functioning normally. MRI would be able to detect focal abnormalities in his frontal and temporal lobes as well as in the corpus callosum, the structure that connects the right and left cerebral hemispheres. Ryan’s family had not yet arrived, and as well as in the corpus callosum, the fact that the right and left cerebral hemispheres, Ryan’s family had not yet arrived, and I turned to other patients as he went for his MRI.

“He will recover?” I asked the neurological resident.

“Hard to say,” he responded. “He’s a teenager, so he’ll probably do better than an adult. And if he does well, he’ll make a fairly good recovery. It depends. His ventricles look a little compressed, not a good sign. About 40 percent with his injury die in the hospital.”

I knew that 40 percent of those with severe brain-injury people was that many apparent recoveries turned into tragedies, as about 40 percent end up in a persistent vegetative state (PVS), often after a prolonged coma 20 years earlier, while I was studying to become a doctor and “persistent vegetative state” was a new phrase in the medical vocabulary.

Caleb: Dartmouth, 1973

Caleb was a teenager and breathing on a ventilator and I was a 26-year-old Dartmouth medical student on my pediatrics rotation when we first encountered each other in August 1973. He looked as though he were ceasing, and he had been that way for almost three months. His eyes used to open and close spontaneously two months earlier. But no movement since, just a flaccid paralysis. All Caleb’s deep tendon reflexes—the doctor’s tap below the kneecup—were gone. Talking to him or pinching him or giving him a whiff of ammonia elicited nothing. Indeed, only his pupils responded reflexively: when one shined a light in one pupil, it contracted, and so did the other.

But, that, and the fact that his pupils maintained normal diameters, were probably the only good news about the course, in that they showed his midbrain was working. In every way possible, though, he depended on critical care nurses, doctors, and machines. In the meantime, he was excreting and even growing. Caleb’s puberty had just kicked in.

He was a big-boned youth, about six feet tall and 175 pounds, and I considered him relatively unmarked except for the forehead and temporal pinnacles on his puffy face. Whenever I saw Caleb, I also saw his parents. He was their only child. Day in and day out on most nights, one or the other stayed by his side in the small ICU room where Caleb now lived. Their names where Stephan and Sofia, and, like their sons, they were big and fair and had flat skin and dark hair and eyes. They might have been brother and sister, so alike did they look.

Originality from Hungary, they had come to this country with the promise of a good life and work. And, dissatisfied with the Russians, Caleb was conceived shortly after they arrived in Boston, which was why they had given him a New England-style name, not a Hungarian one. He would be a “true American.” Since Caleb had been in the ICU, they had watched around their jobs—aah with a nearby fire department and hers with the hospital food service department—so that one or the other, and ideally both, could be with their son. What else could they do?

So, in the ICU, they sat around planning what to tell Caleb’s parents. They did not know when Caleb would come out of the coma—in fact he was in a coma and maintaining a stable pulse and oxygen saturation, his doctors told his parents and the nurses that they should just talk to him in ordinary ways. This meant having technical discussions out of Caleb’s earshot on the off chance that he might hear them, or at least understand them.

Sofia and Stephan took this mean to they should keep Caleb up on his regular interests—What’s on TV? What’s the weather like? What’s the Boston Globe—these to him think he is and most of the principal ones. They turned on the TV and radio when either was being broadcast, and they read him the sports and the New York Times, and the Boston Globe. The National Geographic, Sports Illustrated, spiced with Popular Mechanics and the occasional car magazine. Caleb’s best friend from school came by often and told him jokes. He saw his parents, his dealer and his grandfather, who was a suburban house owner, every few weeks passed. As the summer flowed on and Caleb remained in a coma, his parents would start talking about Caleb finishing high school and assure their friends that they would their friends that they would soon talk to Caleb in their own words, and the coma would reenter the regular world. When Caleb wake up? became, without anyone ever mentioning it,
Will Caleb wake up? No one wanted to put the question in words, but one could see the shift in everyone’s face. By September, the question of his future had become acute.

Neurologists were and are brilliant examiners, but before CAT scans (and then MRIs and PET scans), they gained most of their knowledge from the “use of functioning brains, but there was little close observation of people’s exteriors, awareness, and capacities. Simple x-rays have never been very good for delineating subtle aspects of soft tissues, especially when a process is diffuse. Unlike today, when a PET scan can light up exactly which part of the brain is active in a Buddha doing a specific type of meditation, neurologists then had no way of directly visualizing what brains are doing. For generations they relied instead on questions and tests of individuals’ motor and sensory functions and mental states to correlate seemingly tiny signs of neurological dysfunction with diseases whose outer signs might otherwise have remained obscure. Autopsies, not images of living brains, provided the diagnostic confirmation.

Although Dartmouth was then about to install a CAT scanner, one of the nation’s first, we could not have slid Caleb into its narrow chamber because we could not have maintained his ventilation while he was inside it. Electrical recordings—EEGs—of the brain’s activity often provided useful information, but their analysis then was not as refined as it is today, especially in comatose states that had been going on for a while. We performed EEGs on Caleb regularly, but they were not specific for anything, only displaying diffuse slowing and dampened amplitudes consistent with someone on sedatives. Caleb’s neurologists talked about doing a brain biopsy on him but ruled it out because of the risks. Was his brain functioning or not? And if so, was there any indication of the causes of his dysfunction?

Caleb’s injury was a kind of cosmic affront. Neurologists have a way of directly visualizing what brains are doing. For generations they have x-rays have never been very good for delineating subtle aspects of soft tissues, especially when a process is diffuse. Unlike today, when a PET scan can light up exactly which part of the brain is active in a Buddha doing a specific type of meditation, neurologists then had no way of directly visualizing what brains are doing. For generations they relied instead on questions and tests of individuals’ motor and sensory functions and mental states to correlate seemingly tiny signs of neurological dysfunction with diseases whose outer signs might otherwise have remained obscure. Autopsies, not images of living brains, provided the diagnostic confirmation.

Although Dartmouth was then about to install a CAT scanner, one of the nation’s first, we could not have slid Caleb into its narrow chamber because we could not have maintained his ventilation while he was inside it. Electrical recordings—EEGs—of the brain’s activity often provided useful information, but their analysis then was not as refined as it is today, especially in comatose states that had been going on for a while. We performed EEGs on Caleb regularly, but they were not specific for anything, only displaying diffuse slowing and dampened amplitudes consistent with someone on sedatives. Caleb’s neurologists talked about doing a brain biopsy on him but ruled it out because of the risks. Was his brain functioning or not? And if so, was there any indication of the causes of his dysfunction?

Caleb’s injury was a kind of cosmic affront. Neurologists have a way of directly visualizing what brains are doing. For generations they have x-rays have never been very good for delineating subtle aspects of soft tissues, especially when a process is diffuse. Unlike today, when a PET scan can light up exactly which part of the brain is active in a Buddha doing a specific type of meditation, neurologists then had no way of directly visualizing what brains are doing. For generations they relied instead on questions and tests of individuals’ motor and sensory functions and mental states to correlate seemingly tiny signs of neurological dysfunction with diseases whose outer signs might otherwise have remained obscure. Autopsies, not images of living brains, provided the diagnostic confirmation.

Although Dartmouth was then about to install a CAT scanner, one of the nation’s first, we could not have slid Caleb into its narrow chamber because we could not have maintained his ventilation while he was inside it. Electrical recordings—EEGs—of the brain’s activity often provided useful information, but their analysis then was not as refined as it is today, especially in comatose states that had been going on for a while. We performed EEGs on Caleb regularly, but they were not specific for anything, only displaying diffuse slowing and dampened amplitudes consistent with someone on sedatives. Caleb’s neurologists talked about doing a brain biopsy on him but ruled it out because of the risks. Was his brain functioning or not? And if so, was there any indication of the causes of his dysfunction?

Caleb’s injury was a kind of cosmic affront. Neurologists have a way of directly visualizing what brains are doing. For generations they have x-rays have never been very good for delineating subtle aspects of soft tissues, especially when a process is diffuse. Unlike today, when a PET scan can light up exactly which part of the brain is active in a Buddha doing a specific type of meditation, neurologists then had no way of directly visualizing what brains are doing. For generations they relied instead on questions and tests of individuals’ motor and sensory functions and mental states to correlate seemingly tiny signs of neurological dysfunction with diseases whose outer signs might otherwise have remained obscure. Autopsies, not images of living brains, provided the diagnostic confirmation.

Although Dartmouth was then about to install a CAT scanner, one of the nation’s first, we could not have slid Caleb into its narrow chamber because we could not have maintained his ventilation while he was inside it. Electrical recordings—EEGs—of the brain’s activity often provided useful information, but their analysis then was not as refined as it is today, especially in comatose states that had been going on for a while. We performed EEGs on Caleb regularly, but they were not specific for anything, only displaying diffuse slowing and dampened amplitudes consistent with someone on sedatives. Caleb’s neurologists talked about doing a brain biopsy on him but ruled it out because of the risks. Was his brain functioning or not? And if so, was there any indication of the causes of his dysfunction?

Caleb’s injury was a kind of cosmic affront. Neurologists have a way of directly visualizing what brains are doing. For generations they have
datures—and nothing surpasses major organ transplants in this regard—
can mean the difference between red and black on a hospital's annu-
ral report. A successful program can fill up surgical ICUs and even sup-
port the development of new ones.

The hallway scuttlebutt was that the hospital was experiencing
operating losses and dipping into capital for the first time to make
ends meet. Which was why the hospital was undertaking "marketing
initiatives" in many areas, with increased performance of major organ
transplants at the top of the list.

During our annual reviews that year from Dr. Meldrum, a number
of us ER doctors heard that we were not being sufficiently supportive
of the hospital, especially in marketing. In our individual meeting,
Meldrum told me to "get with the program." "Really?" I responded. My
feedback from patients had been pretty good, I reminded him, not to
mention feedback from fellow physicians. I had also managed to pub-
lish quite a bit. "That's not what I'm talking about," he said.

We physicians work with patients one at a time, and in the ER we
do so in a unique moral space—24/7, with no questions asked
about immigration status, nor any requirement for ability to pay, and
with every effort made for the well-being of that individual. Serving
emergency patients is our end; for us they are not a means to some-
thing else. To consider an emergency patient in the context of a finan-
cial or utilitarian calculus regarding the transplant potential of his or
her organs is not for the treating physicians to do. Moreover, at
the time of severe brain injury of metabolic insults—the two general con-
ditions that may lead to PVS—medical science has no reliably predic-
tive tools to determine who may or may not end up in PVS or a min-
imally conscious state. Whatever we know about these conditions,
we do not know this; they only become apparent after months have
elapsed, and even then physicians cannot definitively say who is veg-
etative and who is minimally conscious.

As PVS has become more common and the demand for organs
from living donors grows, a number of bioethicists, notably those con-
nected with active transplant programs, have argued that the defini-
tion of brain death should be expanded to include PVS. The critical
biological feature of personhood, they maintain, is a functioning cere-
bral cortex. Absent that—as is the case by definition in PVS—they
assume a person is alive in name only and would be better off dead.

So how was I to respond to Ryan's father as he contemplated his
son's fate? We sat down together in the lobby, and I told him what I
knew of the science at that time. If Ryan was in PVS, which could not
be so in a unique moral space—24/7, with no questions asked
about immigration status, nor any requirement for ability to pay, and
with every effort made for the well-being of that individual. Serving
emergency patients is our end; for us they are not a means to some-
thing else. To consider an emergency patient in the context of a finan-
cial or utilitarian calculus regarding the transplant potential of his or
her organs is not for the treating physicians to do. Moreover, at
the time of severe brain injury of metabolic insults—the two general con-
ditions that may lead to PVS—medical science has no reliably predic-
tive tools to determine who may or may not end up in PVS or a min-
imally conscious state. Whatever we know about these conditions,
we do not know this; they only become apparent after months have
elapsed, and even then physicians cannot definitively say who is veg-
etative and who is minimally conscious.

As a society we need to engage in reasonable discussions about
how we respond ethically, legally, and financially to the challenges
posed by PVS and minimally conscious states. At a minimum, the
interested parties, especially the transplant lobby, should candidly
disclose their philosophical assumptions, financial interests, and
lack of scientific understanding of brain death, cortical and
whole. Organ transplantation is an invaluable way to extend life. But
constructing fictions about its underlying realities renders someth-
what ought to be resolved in clear light. 

A British anesthesiologist faced the issue head-on in a 1999 letter
to the Journal of the Royal Society of Medicine: “The greatest miscon-
ception is that the donor will be dead in any ordinary sense of the
word.” As the anthropologist Lesley Sharp recently noted (and as I
have witnessed): “A brain-dead body [that has not been anesthetized]
will move in a life-like way when nerves are pinched or cut. [It] may
seem to shudder or kick or even signal.”

As a society we need to engage in reasonable discussions about
how we respond ethically, legally, and financially to the challenges
posed by PVS and minimally conscious states. At a minimum, the
interested parties, especially the transplant lobby, should candidly
disclose their philosophical assumptions, financial interests, and
lack of scientific understanding of brain death, cortical and
whole. Organ transplantation is an invaluable way to extend life. But
constructing fictions about its underlying realities renders someth-
what ought to be resolved in clear light.