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FINDING CONSCIOUSNESS

The Neuroscience, Ethics, and Law of Severe Brain Damage

EDITED BY

Walter Sinnott-Armstrong

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Finding Consciousness

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Finding Consciousness

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and Law of Severe Brain Damage*

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WALTER SINNOTT-ARMSTRONG

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PREFACE

As neuroscience gives us new abilities to do what we never dreamed possible, it also creates profound challenges in ethics and law. When we *cannot* do something, there is little or no point in asking whether we *should* do it. But when neuroscience (or any other science) makes it possible to do something novel, then we need to ask whether, when, why, and how we should exercise this ability.

One recent example of this trend is the ability to detect consciousness in patients who have suffered severe brain damage and show no outward sign of consciousness. In the past, families and doctors never imagined that they could communicate with these patients. Then, in 2006, a groundbreaking paper showed that an original method could be used to detect consciousness in patients who had previously been thought unconscious and unreachable. A follow-up paper in 2010 showed that such patients could even answer questions. One patient who had shown no outward sign of consciousness for 5 years answered five autobiographical questions correctly by thinking of motor imagery for “Yes” and spatial imagery for “No.” The answers could be detected by brain scanning, although it was impossible to communicate with the patient in any other way. These findings surprised and confused many readers.

The first confusion concerns the precise condition of these patients. We need to distinguish persistent and permanent vegetative states from death, coma, minimally conscious states, and locked-in syndrome. We also need to ask whether consciousness has been or is likely to be found in patients whose current condition is a result of anoxia, brain disease, or traumatic brain injury. The proper diagnosis of these conditions is a complex and uncertain medical issue.

These technical distinctions are crucial for avoiding overgeneralizations such as the conclusion that we should never give up on any patient, regardless of what condition they are in, because every one still might be conscious. That mistake would stand in the way of organ donation and all of its benefits. It would also lead to immense expenditures of resources on patients in hopeless conditions. Of course, we do need to think very carefully about which laws and

policies should govern the treatment of all of these patients, but that does not mean that we should treat them all the same regardless of whether they show any signs of consciousness. How we ought to treat various patients is a pressing issue in ethics, law, and policy, and there is no single, simple answer.

The fundamental philosophical question here is, What is it that gives people value and rights? Is consciousness what really matters? Some ethicists have argued that life has no moral status without consciousness, whereas others claim that membership in the human species is enough to confer value, or that pain is bad even when one is not conscious of it. These positions have radically different implications for how we ought to treat patients in whom we still find no signs of consciousness despite our best efforts.

Another complication is that every test of consciousness is imperfect. They all have the potential for false-positive or false-negative findings (cases, respectively, in which the test indicates consciousness where there is none or lack of consciousness where some exists). In the face of such uncertainties, we need to ask how likely these kinds of mistakes are, and which types of mistakes are the worst.

These uncertainties are difficult especially for caregivers, friends, and families of individuals with brain damage. What should they do when they do not know whether a loved one is conscious? And when neural methods detect consciousness, more personal questions are raised: What can caregivers do to improve these patients' lives? What is in their loved one's best interest?

Another issue is whether we should let these patients decide for themselves. If patients can answer questions, would it be more humane and respectful to ask them what they want to be done? This question is different from asking what is in their best interest, because the patient might prefer a course of action that we think is not in their interest. For example, we might think that a patient is better off alive even if severely disabled, but the patient might indicate that he or she does not want to be kept alive. Or the reverse: We might think that a patient's condition is so intolerable or meaningless that he or she would be better off if allowed to die, but the patient might express a preference to live. What should we do in such cases? Are the patient's decisions informed and rational? Are these patients competent?

Such challenging questions arise as neuroscience enables us to detect consciousness in more and more patients with severe brain damage, and all of these issues are discussed in this collection. Most of the prominent contributors met together at Duke University in January 2013 to share their views on these developments and controversies, and then they revised their talks in light of the intense discussions that followed. Three additional essays were added to fill out the picture. The resulting chapters describe the recently developed neural methods of detecting consciousness in patients with brain damage,

the contrasts among various conditions in which consciousness is affected by brain damage, the nature of consciousness and its value in determining the moral status of patients, lay attitudes toward letting these patients die, and the many moral, legal, and policy issues raised by these cases. The varied contributors looked at the issues from very different perspectives, informed by different disciplines and methods as well as different ethical and political assumptions. Still, they all agree that innovative methods of consciousness detection raise pressing, important, and fascinating questions about what it is to be human, what is the point of our lives, and which law, policy, and ethical norms should be adopted.

This collection should be of interest not only to academics in the fields of neuroscience, law, ethics, and philosophy but also to anyone with a friend or family member who has suffered brain damage or, indeed, anyone who might suffer brain damage in the future. That includes everyone, because we all have the potential to end up in the conditions that these chapters analyze.

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Finding Consciousness

An Introduction

MEGHAN BRAYTON AND WALTER SINNOTT-ARMSTRONG

Ken Diviney has been caring for his adult son, Ryan, for almost 5 years. A violent assault caused Ryan's traumatic brain injury and led to a severe disorder of consciousness. Ryan's injuries, however, affect far more than just his brain; every part of the body is affected. In caring for his son, Ken is in a constant battle against injury to Ryan's fragile bones, against infections such as those of the urinary tract and bloodstream, against kidney stones and muscular stiffness. Ryan has undergone nine operations, including one that removed a third of his skull. Based on his own reading and experimentation, Ken has transformed his basement into a sterile rehabilitation center containing a therapy area, hyperbaric chamber, hospital bed with percussion vest, shower, and kitchen, where he dispenses vitamins and medications, performs mouth care every 2 hours, and administers intensive physical therapy.

Ken had to figure out much of what he wanted to do on his own, because even medical professionals misunderstand Ryan's condition. For instance, Ken was treated with suspicion and questioned about potential abuse when he brought Ryan to the doctor for treatment of a broken arm. Because Ryan is bedridden, his fragile bones are prone to breaks and fractures, but so very little is commonly known about severe disorders of consciousness and their effects on the whole body that even many care workers do not know what to expect or how to treat Ryan. Where one specialist advises a particular medication, another warns of the disastrous effects of that medication. Without much communication among the many doctors who oversee the various aspects of his son's care, Ken wades through conflicting instructions and is left with tough choices

in deciding priorities for Ryan's care. The lack of shared knowledge among the many relevant people who care for his son is the highest hurdle in orchestrating proper care for Ryan.

Finding Consciousness opens with this real story of a father working to care for his son (Chapter 2) because the questions posed in this book, and their tentative answers, have real-life implications for the Diviney family. Thousands of families are dealing with these same issues. Although the exact number of patients with disorders of consciousness is unknown, it is estimated that as many as 15,000 patients in the United States have been diagnosed as being in a persistent vegetative state, and more than 100,000 others as being in a minimally conscious state (Hirsch, 2005). An estimated 5.3 million people in the United States live with some disability caused by a traumatic brain injury (Centers for Disease Control and Prevention, 1999).

Despite their prevalence, disorders of consciousness are widely misunderstood and difficult to accurately diagnose. Many people confuse these conditions:

- Coma—an acute, transitory condition in which the eyes remain closed
- Persistent or permanent vegetative state (PVS), also called unresponsive wakefulness syndrome (UWS)—a chronic or transitory condition in which the patient does not respond to commands even in the presence of eye opening
- Minimally conscious state (MCS)—a condition in which patients cannot communicate or manipulate tools but show more than reflex motor behavior
- Locked-in syndrome (LIS)—a condition characterized by complete immobility, without any required level of consciousness

Diagnosis of these conditions is discussed later, but first we need to contrast them with death. After all, a patient must be alive in order to have any disorder of consciousness.

CONCEPTS: DEATH AND CONSCIOUSNESS

To understand the new and confusing world of consciousness, it is crucial to review the history. Until the 1950s, cardiovascular, pulmonary, and brain functions were tightly woven together. The failure of one resulted in the failure of all, so the end of any single function simply meant death of the whole. With the introduction of positive-pressure mechanical ventilation, these three signs of life were pried apart. The criteria for death then needed to be re-evaluated,

because a person could continue to be alive in one or two functions while a third was supported mechanically. Disorders of consciousness such as PVS were particularly confusing, because in the course of human history there had never before been a way to keep someone alive for a long period absent some signs of consciousness. Doctors discovered a brand new frontier on the border of life and death.

Jeffrey Baker from Duke University begins the discussion (Chapter 3) by laying out the broad medical and cultural history that has informed existing beliefs about death and consciousness. He looks at current perspectives through the lens of the last few centuries: the enlightenment optimism that science could restore life, the fear of being buried alive enshrined in legend by Edgar Allen Poe, and the development of more sophisticated tools and technology for physicians which widened the gulf between them and lay diagnosticians, giving physicians greater authority in defining death.

One of the most significant of these tools began with the Dinkler respirators or “iron lungs” of the polio epidemic. Endotracheal positive-pressure ventilation was soon applied to other kinds of severe conditions in addition to polio, with differing degrees of success. Some patients did not recover consciousness, but their hearts kept circulating oxygenated blood throughout their bodies. As more patients were supported by long-term respiration while remaining unresponsive, doctors began to rethink the purpose of these extraordinary life-sustaining measures.

The possibility of organ procurement further complicated the issue. If the prognoses for these long-term patients were really hopeless, other lives could be saved by transplantation of organs from these healthy bodies uninhabited by any consciousness. The specter of the hopeless prognosis prompted Pope Pius XII to condone a balancing test: If the good that the life could experience were not at least equal to the burden of the “extraordinary” interventions, withdrawal of support was acceptable, but the question of whether the patient could be considered alive or dead was one for the medical profession. Soon afterward, doctors began to declare patients who remained unresponsive over the longer term despite artificial life support to be “brain dead.”

Important court cases followed. Guardian decision makers, believing that their loved ones would not have wanted to continue treatment, fought for the right to refuse unwanted medical intervention and won. Since 1990, all American citizens (or their surrogates) have had the right to refuse any treatment, even nutrition and hydration (*Cruzan v. Director, MDH*, 497 U.S. 261 (1990)). Some bioethicists fiercely debated the wisdom of this right, which was seen as passive euthanasia of those judged less valuable. They compared this situation with an imagined similar scenario for a child with a severe intellectual disability or an elderly parent in failing health: If family members believe

the future of the individual to be hopeless, is denial of food (e.g., removal of a feeding tube) permissible?

When surrogates disagree with the doctors or with each other, cases become more complicated, as was demonstrated very publicly in the Terri Schiavo case. After many years of therapy and seeing no improvement, Michael Schiavo, Terri's husband, decided that it would be best to end artificial hydration and nutrition for his wife. His decision created a national frenzy with years of legal hearings, protesters holding vigils outside Terri's hospital, and children being arrested for trespassing while bringing Terri symbolic cups of water.

Cases like this raise striking ethical questions that often hinge on uncertainty. At a certain point, diagnosis and prognosis rely on probability. For prognostic purposes, PVS is considered permanent if it persists longer than 12 months after a traumatic injury or 3 months after an anoxic event. Families often find these definitions arbitrary, and the many documented misdiagnoses enable them to retain hope in the possibility of the patient's regaining consciousness. On the other hand, there remains the fear of trapping a loved one too long in an unbearable condition that is much like being buried alive.

To quell these deep-seated cultural fears, a precise understanding of death is necessary. Probably the most widely accepted definition of death was developed by James L. Bernat from Dartmouth College, along with Bernard Gert and Charles Culver. Bernat's chapter in this volume (Chapter 4) outlines the components of brain death. This biological (as opposed to spiritual) paradigm is restricted to living organisms, specifically higher vertebrate species. This paradigm maintains the ordinary, everyday meaning of death, with the only options being dead or alive: Death is an irreversible event, not a process. The death of the organism as a whole is separate from the death of its parts, meaning that the parts can die while the whole remains, and vice versa. The essence of the concept is the "irreversible cessation of the functioning of the organism as a whole. Once an organism has irreversibly lost its totality, completion, indivisibility, self-reference, and identity, it no longer functions as a whole and is dead."

If a patient is not brain dead but is alive and has a disorder of consciousness, the next question that must be addressed is, "What is consciousness?" This question is bewildering because it is impossible to capture what consciousness is if we cannot imagine what it is to be without consciousness. We always imagine through the lens of our own conscious modes. Moreover, the word "consciousness" is used in so many ways, and its many distinct meanings are so often conflated in everyday usage, that it is no wonder most people find consciousness confusing. It is necessary to carefully analyze and distinguish the various meanings of consciousness in order to diagnose and understand disorders of consciousness.

This is the goal of philosophers Tim Bayne and Jakob Hohwy in Chapter 5. One central distinction that they draw is between global *modes of consciousness* and fine-grained *states of consciousness*. They describe a mode of consciousness as a global way of being conscious; waking, dreaming, seizures, and MCS are examples of modes. States of consciousness, in contrast, are content specific; examples include hearing music or feeling pain. Bayne and Hohwy also compare modes of consciousness with “levels of consciousness” in neurology and illustrate the difficulties with classifying degrees of consciousness, arousal, or wakefulness (orientation to the environment).

These authors then propose a unique framework, seeking to describe various modes of consciousness and distinguish their permutations from each other. They allow for ordering of modes, such as perceiving wakefulness as a higher-level mode of consciousness than sleep. Still, they recognize that a complete ranking (or a complete taxonomy) may be impossible to create and would be hard to apply in practice.

DIAGNOSIS

Once we understand the basic concept of consciousness and what is lacking in these patients, the next question to ask is how disorders of consciousness can be diagnosed in individuals. How can clinicians tell whether a patient is actually in PVS, MCS, LIS, UWS, or a coma? Caroline Schnakers from the University of Liège is known for her work validating the Coma Recovery Scale-Revised. In Chapter 6 in this volume, she gives a broad overview of the traditional bedside scales—the Glasgow Coma Scale, the Coma Recovery Scales, and the Nociception Coma Scale—and their various uses and challenges when detecting signs of consciousness. Because misdiagnosis has such serious consequences for the type of care available to the patient, including pain management and end-of-life decisions, Schnakers emphasizes reliance on objective, standardized, sensitive criteria and adherence to strict administration and scoring guidelines in order to avoid misdiagnosis.

Errors do happen, however. Error can be introduced when the examiner samples too narrow a set of behaviors or does not properly define the criteria for intentional responses. The examinations could be too infrequent or the time windows too short, missing the desired behavior. Getting an appropriate sample is important. Timing matters because the patient’s ability can be affected by many factors that would have an effect on anyone’s ability, such as pain or discomfort, impairment from medications, or environmental disturbances. Poor conditions may decrease the probability of observing the signs of consciousness. To reduce such errors, Schnakers emphasizes reliance on the Nociception Coma Scale and careful monitoring to ensure that pain is being

properly managed. As her overview closes, Schnakers notes that advances in neuroimaging have been able to offer other insights into patient consciousness and should be considered as a complementary tool to distinguish patients with PVS from those with MCS.

These neuroimaging techniques add much more than merely a tool for distinguishing types of patients, however. Adrian Owen at the University of Western Ontario has really changed the game in understanding what is happening in some patients with disorders of consciousness. These new technological capacities, which were once only in the realm of science fiction, are summarized in the chapter by Owen along with Lorina Naci, also at the University of Western Ontario (Chapter 7). They take on the very real possibility that neuroimaging could be used to determine thoughts, intentions, and other mental states directly from brain responses without needing to rely on overt physical action.

Patients who had been classified as being in PVS for years have been studied with the use of functional magnetic resonance imaging (fMRI) to demonstrate the presence of conscious awareness and complex mental function. Revealing sessions have shown some patients' repeated brain responses to motor imagery tasks (e.g., imagining swinging a tennis racket) and spatial imagery tasks (e.g., imagining in detail walking through the rooms of your home); the responses clearly engage brain regions that are very close to the brain responses of healthy control subjects performing the same tasks. This difference allows patients to answer yes-or-no questions by mentally engaging in the various tasks in order to indicate different answers. Other mental tasks have also been effective in repeatedly generating consistent responses. Examples include answering questions about biographical information unknown to the researchers, such as the patient's father's name or a place where the patient had vacationed—answers that were subsequently verified.

These tools are supposed to do more than just demonstrate the presence of awareness in patients with disorders of consciousness. fMRI (and EEG in a separate report) can allow patients to engage in an activity (e.g., answering questions) that requires language (i.e., understanding the questions and the instructions for answering) as well as self-knowledge (e.g., their own father's name) and memory of the past (i.e., because they had not seen their father or been told his name in the years since the brain damage). These capabilities are amazingly advanced for anyone diagnosed as being in PVS. Some observers have concluded that such patients have some potential for competence in decision making, although this idea is controversial.

A healthy dose of skepticism is provided in the chapter by Will Davies and Neil Levy (Chapter 8). They argue that the experiments by Owen and others do not succeed in proving any significant intention, agency, or consciousness.

The ability to follow commands and answer questions shows only that these brain-damaged patients respond to external stimuli. These methods do not (yet) reveal any endogenous intentions of internal origin. They also do not (yet) reveal the kinds of connections among intentions that are required for plans, interests, or preferences about how life will proceed. Davies and Levy claim that patients who pass these recent tests still might have no more consciousness than patients with a different diagnosis: extreme akinetic mutism. They conclude that these tests do not demonstrate what is relevant to the moral status of being a person. That conclusion leads directly into the next set of chapters.

ETHICS: WHAT MATTERS?

The natural question to ask next is, “Given what we know and do not know about these patients, what should we do?” In particular, should we keep these patients alive or let them die? Any answer is bound to be controversial, but we can at least understand the issues better by considering conflicting arguments.

Jacob Gipson, Guy Kahane, and Julian Savulescu at the University of Oxford begin by outlining a general framework for addressing ethical issues (Chapter 9), applying Beauchamp and Childress’s principles of autonomy, beneficence, nonmaleficence, and justice. Then they report a survey of how everyday people rank these principles and reach overall judgments about whether patients with various disorders of consciousness should be allowed to die. The survey responses vary in fascinating ways depending on whether the question is asked abstractly or concerns an actual case and whether the question is about other people or asks whether the respondents would want to die if they were in such a conditions themselves. Gipson, Kahane, and Savulescu close by arguing that popular opinions about these matters have indirect relevance to normative issues regarding what should be done in specific instances.

Instead of appealing to surveys, most philosophers appeal to arguments and theories. The rest of this section of the book includes three such philosophers who suggest in various ways that both practitioners and the general public need to revise much of what they think about the ethics of these cases.

Joshua Shepherd at the University of Oxford begins his chapter (Chapter 10) with the assertion that consciousness is morally significant in itself, bringing with it its own ethical complications. Shepherd’s focus is on MCS, because patients with MCS show some degree of consciousness, even if their episodes of consciousness are unstable and intermittent. In order to specify more precisely what is morally important in cases of MCS, Shepherd discusses two distinct notions of consciousness: *access* consciousness and *phenomenal* consciousness. The possession of access consciousness entails abilities to

use information for reasoning or controlling behavior. In contrast, the possession of phenomenal consciousness entails that there is something “it is like” for the possessor (such as what it is like for a patient in a MCS). Shepherd argues that, if there is something that it is like to be in a MCS as opposed to a PVS, then MCS has a moral significance that PVS lacks, because phenomenal consciousness is required for the possession of some degree of subjective well-being.

However, if the MCS patient, when competent, clearly expressed a desire to die, then a difficult moral conflict may be posed between the values of autonomy and well-being. If autonomy is given priority, so that the desire to die is granted, then well-being and present and future enjoyment might be harmed. But if well-being is given priority, so that the remaining quality of life is preserved, then the patient’s right to determine his or her own life is violated. Shepherd finds that both autonomy and well-being need to be considered, along with other values such as distributive justice. That conflict of values explains why such cases are so difficult.

In contrast, Jennie Hawkins at Duke University (Chapter 11) asks whether the crucial question is what the patient wanted, or believed he would want, when writing an advance directive. At that past time, the patient had not yet experienced a disorder of consciousness. Therefore, instead of asking what the patient wanted, perhaps we should focus on what is in the best interests of the patient.

Hawkins distills the debate down to two questions that she believes are at the heart of making the ethical decision: whether patients suffer and whether they derive benefit from their lives. She ends up defending the choice to allow patients in PVS or MCS to die.

Hawkins relies on the concept of prudential value, rather than welfare or well-being, because there are times when people are struggling and suffering but continuing life might still be the best option. We need to look at which choice would be good relative to all other available options. For life to have value, in Hawkins’ view, one must have the capacity to form relationships and to value. Intermittent awareness and lack of communication would lead to such loneliness as to make death preferable.

For those with a disorder of consciousness, Hawkins believes that the benefits derived from life are small enough that suffering would clearly tip the balance toward death. Even if there were no suffering, she says, we ought not to assume that life is automatically preferable. Not having reason to die is not the same as having a reason to live. If a baby were born with neither consciousness nor capacity to develop it, then the child will derive no benefit from life and death is no harm, so the burdens of raising the child can tip the balance toward death.

Opponents are bound to object that patients should choose for themselves, because recent technological developments enable patients to communicate through fMRI or EEG. However, Hawkins questions the value of these messages. There is no way, she argues, to assess the quality of the decision making in such cases or the process behind it. Mere expression of preference does not sufficiently establish that the patient is competent to make decisions. Gaps in the scientific findings lead to doubts about how much to credit the communication that is currently possible.

Whereas both Shepherd and Hawkins assume that consciousness matters to morality, Valerie Gray Hardcastle at the University of Cincinnati (Chapter 12) questions this common assumption. Instead of consciousness, Hardcastle focuses on pain and uses studies of subliminal processing to argue that consciousness is not required in order to perceive pain. She reinforces this claim with evidence that there is a widely distributed neuromatrix for pain reception in the brain; it is not a highly localized process.

Hardcastle also questions whether consciousness determines how much we should care about a living being. Apparent expressions of pain from PVS patients, such as “grimacing, posturing, crying, even racing heartbeats and hormonal fluctuations,” could merely be autonomic and unconscious responses. But does that mean they do not matter? Moreover, unlike PVS patients, MCS patients have neural responses to pain that are similar to those of healthy controls, including responses in the thalamus, primary and somatosensory cortex, insula, and cingulate, as well as “the co-activation of specialized sensory cortices and frontoparietal areas.” This suggests conscious perception of the nociceptive stimuli.

Hardcastle posits that we do not know what it is like to be in such states of limited consciousness. In particular, it is difficult to establish the negative conclusion that any such patient really has no consciousness or perception of pain. And, as Schnakers and Owens demonstrated, there is a high number of misdiagnoses. For these reasons, an assumption that patients who have been diagnosed as being in PVS or MCS lack pain or consciousness seems reckless because it could result in extreme and extended suffering. The potential for awareness should prompt medical personnel to err on the side of pain management. We should assume that pain is possible and act to treat it.

□ PRACTICAL ISSUES: LAW AND MEDICINE

Each of the different perspectives articulated in this volume could arm policymakers with a good deal to think about. Some contributors who come at these issues with an eye toward making policy close this volume with practical considerations.

Nita Farahany and Rachel Zacharias from Duke University address many of the same questions about consciousness, death, and pain from a legal perspective (Chapter 13). They introduce a theoretical framework by which to define legal life and death in terms of consciousness. The legal standard for death has implications for tort, estate, organ donation, and criminal law (e.g., whether a crime is homicide or assault). They call this framework “the legal circle of life.”

Farahany and Zacharias suggest that a legal standard should hold based on its purpose, regardless of the technologies available now or in a few years. Consciousness has had and continues to have value in the life of the individual. The belief that life ends with the end of consciousness is controversial, but not so controversial as the application of this principle to the abortion question. When viability also depends on technology, consciousness may be the more important question. Many lawmakers have tried to use nociception as the guideline for when a fetus begins to feel, or be aware, or be conscious, but responses to unpleasant stimuli are not the same as processing pain. Consciousness of pain “requires a somatosensory cortex,” and “that signal must come through a functioning thalamus.” Even though there may be cortical activation, there cannot be conscious perception of pain. These issues lie at the intersection of law with neurology and philosophy.

In the final chapter, Joseph Fins brings us back to the issues raised by Ken Diviney at the beginning of this book. Many of the real decisions about treatment fall into the hands of the patient’s guardian. Guardians aid patients in many essential ways. They advocate, protect the patients’ interests, seek treatment in facilities that might not have offered it, and affirm the right to care. Still, there is a potential for infringing on a patient’s civil liberties or limiting self-determination, because guardianship is assumed to be permanent. Because increasing numbers of these patients will regain consciousness and independence, however, it is essential to structure guardianship to protect patients both when they are incompetent and when there is a possibility for regaining competence.

For example, how does guardianship come to an end when it is no longer needed? Most guardianship situations either have a specific termination date (e.g., when the ward reaches 18 years old) or are considered indefinite. If the patient can contribute to decisions about his or her own care, an overzealous guardian may hamper the patient’s agency. When a guardian is appointed by a court from outside the family, his or her decisions might not reflect the patient’s true wishes and could strain relations within the family. A distributive justice question also comes into play when long-term care and rehabilitation facilities require guardians for all their patients. Patients with no relatives and fewer resources may not be able to secure a guardian and may have worse outcomes than more connected and wealthy patients.

Fins recommends that close family members be privileged in guardianship because they tend to have the greatest knowledge of, and respect for, the wishes of that individual patient. Guardianship is especially important when there is a need to establish a trust and prepare for spending over the life of the patient. Diagnostic errors are always possible, and the outcome may differ greatly from the expected course of the patient's disorder of consciousness. For this reason, guardians must, above all, be wary of the existing cultural nihilism toward those with disorders of consciousness. Any guardian who neglects to aid recovery of consciousness and ability is abusing the position and infringing on the rights of the patient. Much like Shepherd, Fins speaks of weighing the expressed interests of patients alongside their present and future well-being in order to properly represent those patients who do not have the ability to advocate for themselves.

For the tens of thousands of guardians like Ken Diviney, who are trying to work through the ins and outs of how to help loved ones with disorders of consciousness, and for those of us who are looking to understand what our own consciousness means, these real questions hold important meaning. They also raise profound issues for courts and policymakers and will stimulate much debate both inside and outside of academia for decades to come. We all might end up in with a disorder of consciousness or with a close relative or friend who has a disorder of consciousness, so we all need to think through these difficult questions.

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Discussion with a Caring Father

KEN DIVINEY AND KATHERINE GRICHNIK

The following is an edited, transcribed audiotape of an interview performed during the Finding Consciousness workshop at Duke University, January 24, 2013. The participants are Katherine Grichnik, MD, MS, FASE (KG) and Ken Diviney, father and caregiver from Ashburn, Virginia (KD).

KG: This is Ken Diviney. . . Ken's son, Ryan, is . . . 23. Three years ago, he was walking to a convenience store behind his college house and there was some verbal exchange that took place between Ryan and his group of friends and a second group of friends—of young people over sports. . . . Actually, why don't you tell the story? Because I think you'd be better to explain it. . . .

KD: So the short end of it is that he was blindsided by a sucker punch, went to the ground, hit his head on a raised grate, was unconscious, and another kid kicked him. So his injury is diffused.

Before I get into all that, what you guys are doing here today . . . is right on the mark. Now, we need to bring you all together and get a solution because I see there might not be the connection between the philosophical and the legal and the neurological and the countless other disciplines that are involved in brain injury. Somewhere, that's got to come together so it can be practically applied at the patient level. Now I've been able to track with all of you, from the wonderful keynote last night and the Coma Recovery Scale this morning. I have sleep studies I can pass off to you.

And that's one of the problems of being the caregiver in all this. I don't have a centralized source. So I'm going out, I'm trying to get information because, if there is a medical breakthrough . . . or some sort of discovery, I need this data because you guys need this data. And that's the only reason. And it doesn't matter what I see, because it's not real until you see it. . . .

KG: . . . I have a set of questions that I had shared earlier and I was going to walk through. But I think it would be more important that, as I ask the questions, for you to participate and ask as well. Because this conversation can go anywhere we want. I don't want to prescribe it, and I would like us to have a two-way conversation.

So, first I want to ask about making that transition from an interoperative setting . . . to just taking care of Ryan at home. When he was first injured, what did you understand from the medical team about what was likely in the future? How were they able to talk to you? Or what could you hear?

KD: Exactly. Because when you walk into that sort of situation, I don't know your language. I think I've learned it well now. So what it got down to is one doctor saying he's in grave condition and another one saying [otherwise]. . . .

So finally I got a hold of Julian Bales, who was at Ruby Memorial. He's with the NFL now. . . . We actually are friends with Sanjay Gupta, so he called Bales and brought him in. And my only question to Bales, was: Is there no reason to hope? I didn't care about anything else, and that answer was going to dictate where we went next. Because the summer before, my son, my wife, and I were all talking and it all came out of my wife saying, Did you ever fall asleep and you wake up and you feel like you're in a coma? And we got on that sort of discussion. My son specifically said you have to do everything if I'm ever there. So I knew, going in. But if there's no hope, then there's no reason.

KG: So Dr. Fontes just said we always try to convey hope. Is that reasonable?

KD: It's reasonable, as long as it's realistic.

AUDIENCE MEMBER: I don't mean to interrupt.

KG: No, please. We would like a discussion.

AUDIENCE MEMBER: I have a hard time dealing with the whole process when I'm the intensivist—and I have clinicians, physicians, caretakers—and I'm offering hope when I feel strongly there's no hope. What does one do at that point? Clearly you don't want to complicate the situation more. But it is not to say that they're wrong either, because they've told you there was one patient that he or she had so-and-so who was comatose for 2 months in the ICU and they walked out of there. I've had such experience.

KD: Remember the mine collapse in West Virginia that was 4 years ago? Julian Bales' patient was the one that walked out. He was the one that walked out of there. What do you do? When you don't have the information, you default to the decision that we're going to continue. The default decision is never "Let's go ahead and terminate now." It's never that.

KG: . . . So the decision was made to go ahead and operate and to relieve the pressure and allow his brain to swell in reaction to the injury. But that was clearly an operative procedure that you had to have consented for. And so

you gave consent, I think maybe knowing that that triggered the rest of this series of events.

KD: It was the decision of a lifetime.

KG: But you probably didn't quite know where that was going at that point.

KD: Oh, no. There's no way. I'm telling you this has to be the worst injury that a person can have inflicted upon them because it hurts them everywhere. It touches every part of the body, right down to the cellular level. I mean UTIs and it's a constant battle. Things that you wouldn't even associate with it. . . .

KG: Again, I just want to ground us in what reality is now. So we were talking about what happened at the time that Ryan was first injured. He's still in the hospital transitioning to the skilled-care facility. Just give me a snapshot. Has he woken up today?

KD: Well, I think I'm kind of in agreement with everyone here. I don't know. It's possible. There's been imaging that shows brain activity and we use—every 3 months we do QEEGs, MRIs. Things light up. Ask him questions, this and that. Is he awake? Not like you and I are. Sometimes he's purposeful. Then it goes days, weeks, months, and I'm like, oh, maybe I was just imagining that.

AUDIENCE MEMBER: Is he getting treatment?

KD: He gets a lot of treatment.

KG: You do it.

KD: Yes.

AUDIENCE MEMBER: Is he getting any medications?

KD: He does. Well, we use a lot of off-label type of stuff. Depending what sort of region of the globe you come from, it's tiracetam/piracetam. We have amantadine, bromocriptine, cardidopa, levodopa, Ritalin . . .

AUDIENCE MEMBER: So you're managing all the dosing?

KD: Yes, exactly. And then things to boost the immune system, nutraceuticals. At one point, I counted. It's like 40.

KG: Every day. Well, not all at one time. Spread out.

KD: Yes, spread out, spread out throughout the day. And then I retract him from that and see what happens. You know, give him a holiday from this one. It's very complicated.

KG: So, I'm going to bring us from today back to the skilled-nursing facility. When you transitioned to that time period, was there any one person or setting that was particularly helpful—or not—in helping you to understand, to project out what your life was going to look like here?

KD: No.

KG: What was your understanding at that point of what was going on?

KD: Well, that he was medically stable.

KG: Well, we've used that term, haven't we?

KD: I'm telling you, medically stable was not what I envisioned at that point because when he went over to this rehabilitation facility, he was still having

neurological storms and, second night in there, his temperature going up and up and up. We can't get a doctor in. All we want to do is ask: Is this normal? Is this something that happens? How should we deal with it? I mean, I've never left him and we could not get a doctor in the room. You know how we resolved that problem? We called 911 on the ICU.

Yes, that was an interesting night. And we had plenty of doctors in the room after that. They were all interested.

AUDIENCE: [Laughter].

KD: So then the center we took him to was Shepherd's Center in Atlanta, which is very good for spinal cord injury. And they're just starting to get it together for the brain injury. But they were the only facility on the East Coast that had an ICU in their rehabilitation facility. And in their facility was a tunnel to Piedmont Hospital. Without that Center, we would have had nowhere to take him. We didn't know what to do. So we considered that a short-term relief. He stayed there until February, and every 10 days they would come in and say, well, we're going through the insurance process, duh-duh-duh-duh. . . . And they got to February and I said stop it. Just stop it. We're going home. I know what I'm doing now. I can give a clinic on respiratory care. And if you need, I can suction you.

AUDIENCE: [Laughter].

KD: So we took him home and we read a study about a new treatment. By the way, I've probably read everybody's studies in here. And I probably emailed you too. So we took him to Kessler Center in New Jersey because they were doing some protocols that we liked, and they came out in an article in *Newsweek* that was called "Waking the Dead," I believe it was. They were using some interesting things. But by September nothing was really different, so I brought him home.

I've been tending to him ever since. Converted the entire basement. And fortunately we had a fairly big house, so I had about 1600 or 1800 square feet I could work with. Put in a huge bathroom with a shower. I tell people you could have a Roman orgy in the shower. It's just like that. Basically a hospital room, a therapy area, a prep area with a kitchenette, and then just an area to get away from everything. Had to put all new ramping in. We probably bought so many yards of concrete that we could have done two tennis courts with the amount we bought. We brought in—I know it's highly controversial—hyperbaric oxygen. Bought the chamber. I have a chamber in my house. He gets it on/off—30 days on, 30 days off—3 hours a day sessions. Functional electrical stimulation on a bicycle. Every morning, I hook him up to electrodes. His muscles are doing the work. It's involuntary, but they're doing the work.

KG: Who helps you? Who is the physician who helps you? One of you asked how many medications and who manages that. I mean, you seem so capable. Now, you've got to have a partner in this.

KD: No. The way it works is neurologists will prescribe the ones that they prescribe and then the urologists, you know, we want to put him on low-dose Macrobid, prophylactically we want to give him oxybutynin to take the muscle tension off his bladder. But then this one could affect brain awareness here. So, what I do is I manage all the doctors. You've got urologists, you've got neurologists, you've got all the "-ologists" out there. And then you've just got to make decisions on your own. They gave him a baclofen pump, which helps with spasticity on some patients. And he was getting something like 700 micrograms to start this about a year or two years ago. I thought, you know, I'm just going to start dropping this. And nobody questioned me. So, slowly we started weaning him down. The pump was removed in October.

KG: That's less infection.

KD: Exactly.

KG: Jeff, you had a question?

JEFF BAKER: Some of my patients who have been in very tough situations, their families will express how, when they're in the hospital, they can't really tell who is in charge. . . . Sometimes one person doesn't take charge when you're in the ICU.

KD: One time his bone density was going down, and fast. And he actually did completely break the ulna and fractured the radius during therapy. And I take him to the hospital. And this is the crap that we have to deal with as caregivers. I take him to the hospital after calling up my physician and they're saying, yes, you should probably take him in. And pretty soon some guy is walking in asking me a bunch of questions. And then it dawns on me. I'm like, wait. Where are you from? Who are you? And he was adult protective services.

KG: Oh, my gosh.

KD: So, this is all the fallout from that. His bone density has decreased, he's in physical therapy, and he sustains an injury. And all of a sudden the caregiver, the best caregiver that any patient could have, is suspect. That's being pissed off. But you can't act that way because then you feed into it.

KG: Oh my goodness. So, you've actually touched on some things that I wanted to bring up that I think are sensitive. And it's not only about caring for your loved one in this situation where it's 24/7, but it's also the financial pressures that go along with this, and I'm going to say the emotional pressures.

KD: Let me talk about financial pressure. Brain injury touches every part of the body. Does anyone disagree with that? Insurance doesn't understand that. So, I go out and I try to get a therapy table and they think, well, you can just do that in bed. But I have him up at 5:00 a.m. every morning and he doesn't go to bed until 9:00 p.m. They don't understand that if you leave him in bed, it just contributes to the injury. And this is what happened. I was looking at some of these pictures of the contractures. My son is as loose as can be. He