

***Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness***, by Joseph J. Fins.  
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391 pp.

From a historical perspective, advocacy for the rights of patients is an uphill struggle in which comparatively few medical professionals have taken a vested interest, let alone an active role. In its scope, scholarly ambition, and humane vision, *Rights Come to Mind* is one of those rare works and may conceivably become an instant classic on the ethics of brain injury and disorders of consciousness.

The author, Joseph J. Fins, is currently the E. William Davis, Jr. M.D. Professor of Medical Ethics and Chief of the Division of Medical Ethics and Professor of Medicine at Weill Cornell Medical College, New York. For more than twenty years, he has been one of the most pre-eminent scholars on the ethics of brain injury and disorders of consciousness and has collaborated with Professor Dr. Nicholas Schiff, one of the most active researchers in studying disorders of consciousness at the Brain and Mind Research Institute at Weill Cornell Medical College.

Based on his extensive clinical experience and a trove of more than fifty interviews with families, Professor Fins delves deep into the lives of those stricken and afflicted by brain injury and into its traumatic ripple effects on the families. Creating a dense matrix that includes the voices of the affected families and his reflective observations, the book achieves what anthropologists sometimes call a *thick description*—looking at human behavior and suffering not in isolation but to contextualize and embed it into a wider perspective. With this

immersive narrative approach to medical ethnography, the book produces a cogent account of what it is like to be in the midst of the existential crisis that a brain injury often precipitates in the victims and their families.

In 22 evenly distributed chapters, the book interweaves four major threads into a coherent narrative of the ethics of brain injury and disorders of consciousness. One recurrent theme maps in great detail and empathy the often devastating experiences, hopes, and despairs of patients and their families as they navigate the healthcare system after a catastrophic brain injury.

Intertwined with these patient narratives, a second major theme emerges: the nosological history of disorders of consciousness as neurological diagnostic categories. Having had the privilege to work under the tutelage of the late Fred Plum, the founding father of the modern understanding and study of disorders of consciousness, Fins witnessed the gestation of the persistent vegetative state (PVS) and much later the minimally conscious state (MCS) as separate diagnostic categories. His vivid account of the inception of the PVS and later the MCS brings to life the controversy and the renitency with which these concepts were confronted over time. He illustrates the spillover of these debates from the medical community to the wider public consciousness along landmark medico-legal battles such as the case of Karen Quinlan (New Jersey Supreme Court, 1976) or Terry Schiavo (Florida Second District Court of Appeal, 2000–2003).

A third major thread in the book concerns the forays Professor Fins himself has undertaken in the scientific study of disorders of consciousness with neuroimaging and deep brain stimulation (DBS). In collaboration with Professor Schiff and others, he was engaged in designing a landmark clinical trial to use thalamic DBS as an experimental intervention in a patient with MCS. The author recounts the internal and external ethical tribulations of this endeavor with great candor. These chapters offer great guidance to any clinical researcher who is planning similarly experimental procedures with respect to the conscientiousness and prudence that is necessary in such invasive interventional trials.

The fourth, and by any measure most forceful, theme in the book is the author's uncompromising support and advocacy for the civil and fundamental rights of the marginalized patients who provide the core of the book's narrative. At the heart of these examinations lies the tension between the historic legacy of the right-to-die movement and the prerogative of the fundamental right for care, even in the direst of circumstances. The author repeatedly calls out important shortcomings of the current U.S. healthcare system that are responsible for the chronic underprovision of patients with brain injury. One fundamental flaw he exposes is the notion of medical necessity—that is, the idea that in order to qualify for state-based insurance in Medicare and Medicaid, patients need to demonstrate overt signs of steady improvement. Through his documentation of the bumpy journeys of patients and families through the system from acute care to rehabilitation to nursing homes (or home-based care), we learn that recovery from brain injury with a disorder of consciousness is nonlinear and cannot necessarily be accounted for through stepwise measures of improvement. Professor Fins does not stop short in exposing these

biases toward behavioral measures of improvement but makes a strong case that this state of affairs, in the final analysis, amounts to a systematic neglect and disregard of the needs of these patients and their families. This leads him to conclude that it is not just that these patients have slipped through cracks of the system; rather, this is a case of fundamental civil and human rights being violated. It is at this point at which the major themes of the book—its pervading empathy and humanity for the patients and their families, its diligent neurobiological understanding of brain injury, and its advocacy for fundamental rights—blend into a passionate plea against the marginalization and chronic neglect of these patients.

From the point of view of a clinical neuroscientist, *Rights Come to Mind* also demonstrates a deep understanding of the neurobiological intricacies (and uncertainties) of brain injury as well as a thorough appreciation of the possibilities and limits of modern neuroimaging techniques like positron emission tomography (PET) and functional magnetic resonance imaging (fMRI). As the scientific study of disorders of consciousness is still a nascent area of medical neuroscience, the number of research groups engaged in this field is comparatively small. Professor Fins duly acknowledges the contributions of other research groups, such as the team of Adrian Owen (formerly University of Cambridge, United Kingdom, now Western University, Canada) and the “Coma Science” group of Steven Laureys (Université de Liège, Belgium), who have demonstrated that there are indeed patients who are clinically diagnosed as being nonresponsive and thus would be categorized as being in a PVS, but whose minimal consciousness only becomes evident in fMRI experiments. The challenges that these findings provide for our deep-seated assumptions in medical neuroscience on what actually

constitutes behavior are mentioned by Professor Fins but would perhaps warrant further examination. One important consideration, for instance, is the possibility that these “nonbehavioral MCS” patients may benefit from brain-computer interface (BCI) technology based on electroencephalography (EEG) or even intracranial recordings with electrocorticography (ECoG)—techniques that are potentially much more flexible than fMRI and adaptable to a patient’s home environment.

The writing is limpid yet at the same time warm and engaging and pleasingly avoids repetitions, mannerisms, and jargon. Technical terms and definitions do occur when appropriate and necessary, without leading the lay reader astray or compromising on analytical sharpness for scholars versed in the field. The substantial intellectual grace and deep humanity that pervade every part of the book are a testimony

to the scholarly excellence and exceptional academic generosity of its author. The clarity of analysis and argument makes it also an important work of contemporary *critical* scholarship—in the best Kantian sense of *Kritik* (in English, “critique”) as the illumination, examination, and delineation of concepts. Overall, the narrative virtuosity of Professor Fins reminds one of the great cinematographers who are able to find depth and meaning in both close-ups and wide-angle panoramic shots.

To summarize, *Rights Come to Mind* marks a major milestone in the contemporary scholarship on the ethics of disorders of consciousness, in the narrative approach to medical ethnography, and in patients’ rights advocacy. It is safe to predict that it will become a work of reference and reverence for everyone who is interested in these topics for many years to come.

—Philipp Kellmeyer