

# Joseph J. Fins' *Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness*

By Arthur L Caplan, Ph.D.



## Rights Come to Mind

Brain Injury, Ethics, and the  
Struggle for Consciousness

**JOSEPH J. FINS**

Cover/Courtesy of Cambridge University Press

*Editor's Note: The book reflects Fins' role as co-director of the Consortium for the Advanced Study of Brain Injury at Weill Cornell Medicine and the Rockefeller University and his struggle to answer the kinds of questions that stand to shape how society treats people with brain injuries. What is the capacity of brains to recover? What are the mechanisms of that recovery? How do we know that our assessments are accurately describing what's going on in a patient's mind? And what does society morally owe these patients and families?*

I need to make two things clear at the start of this review. One is about conflict of interest: Joe Fins is a good friend of mine. So why would I review the book of a good friend? That leads to the second thing: *Rights Come to Mind* is a wonderful book; perhaps the best book ever to emerge from the young field of neuroethics. By any criteria, the book is an inspiring exemplar of how to integrate ethics and medicine. When a book is so manifestly outstanding, the reviewer's conflicts of interest wither away.

What makes the book so good? To start, Fins writes clearly and in an orderly, organized manner. From chapter to chapter he tells you what he is going to do, does it, and then recapitulates what he did and why.

Fins studied with giants like Fred Plum, a neurologist whose pioneering research advanced the understanding and care of comatose patients. (Plum coined the term "persistent vegetative state.") As a result of his training, Fins knows his way around the injured brain and is a thoughtful guide to those who do not.

The book starts with a thorough, insightful examination of the history of medicine's and science's understanding of brain function and brain injury. It progresses to a series of cases, some in depth, others in snippets, all engaging and illuminating as they reveal the struggle those caring for their loved ones have had and continue to have in trying to do what is best for the severely brain injured.

Fins is the motive force behind the notion that the permanent vegetative state includes less irreversible and impairing variants, which he terms 'minimally conscious.' He builds on recent advances in imaging, in the understanding of brain injury etiology and effects, and in deep brain stimulation to make a case that not all non-responsive comatose patients are alike. He argues that 'prognostic pessimism' and 'therapeutic nihilism' in the face of non-responsiveness need to be replaced with more patience, better care, and more intense

efforts to determine if an individual capable of thought and perception still resides inside a damaged brain.

Which leads to the ethical heart of this important book: Fins wants to return rights to brain injured individuals once thought to be permanently vegetative but who may well be minimally conscious. He argues that recovery from a terrible brain injury may need both better rehabilitative settings and more time. He proposes that drugs or neuromodulation by direct brain stimulus may lead to either brain cell regeneration or the activation of other pathways that might permit more integrated brain activity and patient communication. In other words, he wants us to view the minimally conscious as a new category of patient who merit both research funding and resources for clinical care.

His convincing case leaves me worried.

While being minimally conscious may allow more cognition of some sort than being irreversibly comatose and unconscious, it is far from clear that this is a better state to be in. Finding out that one is at best dimly aware of one's surroundings and cannot communicate to anyone, and that one's body is unable to perform any but autonomic tasks might well fill a person with dread. The understandable sense of horrific dread many people feel in thinking about finding themselves or a loved one possibly facing end-stage ALS or locked-in syndrome, in which a stroke or aneurysm leaves a person fully aware but unable move or communicate due to complete paralysis, may not lead them to demand better clinical care in a specialized setting but rather to demand that care be ended.

What those who complete advanced directives will say they want done—given the current state of knowledge about the minimally conscious state—is not necessarily what Fins deems appropriate. Nor is it clear from his argument what clinicians ought to say to a patient's loved ones, or even to a patient who they suspect might be minimally conscious, in terms of the continuation of care.

And while research to reverse the effects of brain injury is progressing, and new tools to control the problem have emerged, in fact we neither understand the brain well enough to truly know what we are doing in this area nor have any idea how long effects induced by research interventions will last. Calls for research are likely to be heard by desperate families as opportunities for novel therapies. Before venturing further down the research path, it is important to call more loudly than Fins does for sound clinical trials, competent investigators, national and international registries, diagnostic homogeneity, conflict of interest management, and rigorous Institutional Review Board examination.

And then there is the question of the right to health care for the minimally conscious in a nation like the United States, where the *fully* conscious cannot be assured of life-saving or disability preventing care. Justice may forbid discrimination against those with even severely incapacitating neurological conditions. But if there is no publicly funded long-term care insurance and no budget for home health assistance, and co-pays for rehabilitation services or novel treatments are prohibitive, then it is not likely that affording the minimally conscious the same rights as others will do them much good.

Like any provocative book, Fins' work offers plenty to argue about. What ought to be the consequence of acknowledging that thousands, maybe tens of thousands of people around the world may be in a minimally conscious state? My hunch is that it will take decades to figure out exactly who they are and how best to treat them. Fins wants a faster timetable. I may well be wrong, but without this thoughtful, compassionate, and principled book, I would never have realized my obligation to worry about who is right.

### **Bio**

**Arthur L. Caplan**, Ph.D., is the Mitty Professor and founding head of the Division of Medical Ethics at New York University Langone Medical Center. He is the co-founder and Dean of Research of the NYU Sports and Society Program and the head of the ethics program in the Global Institute for Public Health at NYU. Previously, he was the Caplan Professor of Bioethics at the University of Pennsylvania Perelman School of Medicine, where he created the Center for Bioethics and the Department of Medical Ethics. Caplan has also taught at

the University of Minnesota, the University of Pittsburgh, and Columbia University. Caplan's most recent book is *The Ethics of Sport* (Oxford University Press, 2016). He has served as the chair of the National Cancer Institute Biobanking Ethics Working Group, the advisory committee to the United Nations on Human Cloning; and the advisory committee to the Department of Health and Human Services on Blood Safety and Availability. Caplan was a *USA Today* 2001 "Person of the Year" and was described as one of the ten most influential people in science by *Discover* magazine in 2008. He received his Ph.D. from Columbia University.