

# New book examines consciousness in brain injury patients

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The medical community needs a better understanding of people suffering from severe brain injuries, argues a Weill Cornell Medicine professor of medical ethics, whose new book calls for advocacy and awareness.

"Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness," by Dr. Joseph J. Fins, the E. William Davis Jr., M.D., Professor of Medical Ethics and chief of the Division of Medical Ethics at Weill Cornell Medicine, chronicles the evolution of the medical classification of [severe brain injury](#) while presenting the stories of what he calls "a deeply marginalized class" of society.

Through interviews with 53 families of people with brain injuries identified as in a [minimally conscious state](#) – or having partial conscious responsiveness or awareness to the world around them – Fins reveals that [patients](#) are often incorrectly categorized as in a vegetative state – or having an absence of responsiveness or awareness. In fact, Fins said up to 40 percent of nursing home patients with [traumatic brain injury](#) diagnosed as vegetative are actually minimally conscious. As a result, care options for these patients lessen, and society, he said, tends to neglect them.

"The thing that really keeps me awake at night is people who are conscious have been erroneously labeled as unconscious at an alarmingly high rate," said Fins, who gave the David Kopf Lecture on Neuroethics, titled "Giving Voice to Consciousness: Neuroethics, Human Rights and

the Indispensability of Neuroscience" for the Society for Neuroscience's annual meeting Oct. 19. "If you're aware of the moral significance of the state of classification, and why it matters, you'd be sure to have more diagnostic vigilance. It's a question of depriving a highly vulnerable group of patients their civil rights."

The book centers on Margaret Worthen, who in 2006 suffered a severe brain injury. Worthen initially was diagnosed as vegetative, but thanks in part to her mother's perseverance and physicians who argued Margaret may have shown signs of consciousness, she was found to be minimally conscious.

Though Worthen died in August at age 31, the final years of her life included remarkable milestones such as recognition of family members and communication through eye movement. The hope of continued progress remained for Worthen's family, knowing that Margaret was responding to her environment. Fins argues in "Rights Come to Mind" that the restoration of functional communication leads to the reintegration of these patients into their community and is consistent with the goals of the Americans with Disability Act.

"They still revel in having their loved ones there, and once they're there it can be quite a remarkable epiphany to learn that your loved one who you thought was irretrievably gone is still there," said Fins, who is also a professor of medicine, of medicine in psychiatry, of health care policy and research and of [medical ethics](#) in neurology at Weill Cornell Medicine. Fins was recently named the Solomon Center Distinguished Scholar in Medicine, Bioethics and the Law at the Yale Law School, where he lectures about bioethical and legal issues related to patients with severe brain injuries.

While "Rights Come to Mind" details Worthen's progress, and the progress of other minimally conscious patients, it also chronicles

advances in treating severe brain injury. One such emerging treatment, deep brain stimulation, was pioneered by Dr. Nicholas Schiff, the Jerold B. Katz Professor of Neurology and Neuroscience in the Feil Family Brain and Mind Research Institute at Weill Cornell Medicine. Fins was a co-investigator on that trial. Schiff and Fins co-direct the Consortium for the Advanced Study of Brain Injury at Weill Cornell Medicine and The Rockefeller University, which is dedicated to understanding mechanisms of recovery following severe brain injury and affirming the rights of these patients through public policy engagement.

"I think the technology and neuroscience is advancing," Fins said. "There's really been a radical evolution of what we know about these conditions."

Much of the evolution in understanding traumatic [brain injury](#) is rooted at Weill Cornell Medicine. Fins acknowledges his colleague, Schiff, and their mentor, former chairman of neurology Dr. Fred Plum, as groundbreaking physicians in the fight for patients' rights and pioneering neuroscience.

"It really is a product of Weill Cornell Medicine," Fins said. "I'm proud to be part of that tradition."

Provided by Cornell University

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