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978-0-521-88750-2 - Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness

Joseph J. Fins

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## Rights Come to Mind

Through the sobering story of Maggie Worthen and her mother Nancy, this book tells of one family's struggle with severe brain injury and how developments in neuroscience call for a reconsideration of what society owes patients at the edge of consciousness. Drawing on more than fifty in-depth family interviews, the history of severe brain injury from Quinlan to Schiavo, and his participation in landmark clinical trials such as the first use of deep brain stimulation in the minimally conscious state, Joseph J. Fins captures the paradox of medical and societal neglect even as advances in neuroscience suggest new ways to mend the broken brain. Responding to the dire care provided to these marginalized patients, after heroically being saved, Fins places society's obligations to patients with severe injury within the historical legacy of the civil and disability rights movements, offering a stirring synthesis of public policy and physician advocacy.

JOSEPH J. FINS, M.D., M.A.C.P., is the E. William Davis Jr., M.D., Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medical College where he also serves as Professor of Medicine, Professor of Health Care Policy and Research, and Professor of Medicine in Psychiatry. He is the founding chair of the Ethics Committee of New York–Presbyterian Weill Cornell Medical Center where he is an attending physician and Director of Medical Ethics. Dr. Fins co-directs the Consortium for the Advanced Study of Brain Injury and is an adjunct faculty member and senior attending physician at Rockefeller University and Rockefeller University Hospital. The author of more than 250 publications, Fins is a co-author of the landmark 2007 *Nature* paper describing the first use of deep brain stimulation in the minimally conscious state. He is an elected Member of the Institute of Medicine of the National Academy of Sciences, a Fellow of the American Academy of Arts and Sciences, and an *Academico de Honor* of the Royal National Academy of Medicine of Spain.

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# Rights Come to Mind

Brain Injury, Ethics, and the Struggle  
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JOSEPH J. FINS

*Weill Cornell Medical College*

*Cornell University*



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*To the Memory of Drs. John L. Battenfeld, Martin Gardy, and Fred Plum,  
who left legacies;  
and Robin Heller Moss and Jerold B. Katz, who sustain our scholarship.  
For Ruth and Hank Fins, who made everything possible,  
and  
Amy Ehrlich and Harrison Ehrlich Fins, who make it all worthwhile.*

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“But it’s not about pity, it’s about courage. . . . Here’s a real person and  
here’s what happened to her.”

*Nancy Worthen*

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Unless otherwise noted with an asterisk\*, permission to use family names and other identifiable information has been given through a formal consent process for narrative interviews approved by the Weill Cornell Medical College Institutional Review Board.

\* Names in this book, first identified by an asterisk, are not the individual's real name but pseudonyms.

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