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New Book Sheds Light on Life-and-Death Decisions in Intensive Care

CHICAGO, June 4, 2019 – A new book by sociologist and American Bar Foundation (ABF) Research Professor Susan P. Shapiro explores how loved ones make life-and-death medical decisions for patients who are unable to speak for themselves and what role law plays in their decision-making process. Speaking for the Dying: Life-and-Death Decisions in Intensive Care draws on daily observations over more than two years in two intensive care units in a diverse urban hospital to tell the story of how the end-of-life trajectories take shape and change course.

Seven in ten Americans over the age of sixty who require medical decisions in the final days of their life lack the capacity to make them. For many people, the biggest life-and-death decisions of their lives will be made by someone else. Loved ones will decide whether patients live or die; between long life and quality of life; whether patients receive heroic interventions in their final hours; and whether they die in a hospital or at home. They will determine whether wishes are honored and choose between fidelity to the patients’ interests and what is best for themselves or others. Yet despite their critical role, little is known about how these friends and family members make decisions for their loved ones.

From bedsides, hallways, and conference rooms, Speaking for the Dying reveals how physicians really talk to families and how they respond. The book uncovers how decision makers are selected, the interventions they weigh in on, the information they seek and evaluate, the values and memories they draw on, the criteria they weigh, the outcomes they choose, the conflicts they become embroiled in, and the challenges they face.

Observations also provide insight into why some decision makers authorize one aggressive intervention after the next while others do not—even on behalf of patients with similar problems and prospects. And they expose the limited role of advance directives in structuring the process decision makers follow or the outcomes that result.

“Professor Shapiro’s new book should be required reading for anyone interested in understanding the complex decision-making processes that families and friends go through in choosing among medical alternatives for their loved ones, and the role that law plays in shaping those decisions,” said ABF Executive Director Ajay K. Mehrotra. “It
exemplifies the type of innovative, rigorous empirical research that sets the American Bar Foundation apart.”

“This book is simply a tour de force,” said Kristi L. Kirschner, M.D., Clinical Professor at the University of Illinois College of Medicine. “Shapiro’s superb ethnographic research fills in the black box of what actually happens in the ICU setting when difficult decisions must be made for critically ill patients. It is a must-read for health professionals and for anyone likely to serve as a surrogate decision maker for a loved one at some point. In other words, for all of us.”

Research has consistently found that choosing life or death for another is one of the most challenging decisions anyone can face, sometimes haunting families for decades. Speaking for the Dying shines a light on a role few people will escape and offers steps that patients and loved ones, health care providers, lawyers, and policymakers can undertake before it is too late.

About Susan P. Shapiro

Susan P. Shapiro is a sociologist and research professor at the American Bar Foundation. Shapiro works at the intersection of law and relationships of trust in which one acts of behalf of a vulnerable other—for example, medical decision making for patients without capacity. Her publications examine the role of law at life’s end, ethics, agency theory, conflict of interest, the professions, securities fraud and regulation, and white-collar crime. She is the author of Tangled Loyalties: Conflict of Interest in Legal Practice and Wayward Capitalists: Target of the Securities and Exchange Commission.

About the American Bar Foundation

The American Bar Foundation (ABF) is among the world’s leading research institutes for the empirical and interdisciplinary study of law. The ABF seeks to expand knowledge and advance justice through innovative, interdisciplinary, and rigorous empirical research on law, legal processes, and legal institutions. To further this mission the ABF will produce timely, cutting-edge research of the highest quality to inform and guide the legal profession, the academy, and society in the United States and internationally. The ABF’s primary funding is provided by the American Bar Endowment and the Fellows of The American Bar Foundation.