

GRAND ROUNDS

Thursday, March 2, 2023

4:30pm- 6:00pm EST; Location: Zoom

Please RSVP [here](#) for link or to

bioethics@stonybrookmedicine.edu

Dementia Man: An Existential Journey

Samuel A. Simon

Samuel A (Sam) Simon's distinguished career is exemplary by any standards as a writer, TV personality, and disability activist. In 2018 Sam was diagnosed with MCI (Mild Cognitive Impairment), which lies between significant but normal age-related forgetfulness and a diagnosis of dementia. In 2021 Sam was diagnosed with early Alzheimer's disease. Always highly creative, resilient, and determined, Sam began writing a new play, *Dementia Man, An Existential Journey*, which was showcased in January of 2023 in New York at the highly selective Association of Performing Arts Professional Conference. One of Sam's most important goals is to change the narrative around cognitive impairment and its underlying causes such as Alzheimer's, Parkinson's, and Lewy Body.

In this presentation, Sam will read aloud a 15-minute excerpt from his play, followed by a five-minute commentary from Stony Brook Medical School's physician-poet Dr. Maria Basile MD, President of the Suffolk Academy of Medicine and Vice Speaker for the Medical Society of the State of New York.

Part Two: An Ethical and Spiritual Dialogue on the Challenges of Alzheimer Disease with Questions for Sam A. Simon from Stephen G. Post, author of *"Dignity for Deeply Forgetful People"* (Hopkins 2022) followed by Q & A from our audience:

1. How did you experience your diagnosis and do you have any recommendations for aspiring neurologists and other physicians as they learn to communicate with patients such as yourself?
2. What do you think of the word "dementia"?
3. What is the right balance between freedom and safety?
4. Where do you find hope? Where does your wife find hope?
5. Are you on a drug study now? Why?
6. What is unique about the dementia alliance? How is a "care partner" different from a "caregiver"?
7. What does it mean to be treated with dignity as a person with dementia?
8. Do you worry about being overtreated?
9. Do you ever think that a person with dementia is "gone," or "vanished"?
10. What are your thoughts on pre-emptive assisted suicide as a response to the diagnosis of dementia?
11. What do you think of Amy Bloom's memoir, *In Love*, about her husband's trip to end his life through legal suicide at Dignitas in Switzerland?
12. Do we place too much value in linear rationality? Do "hypercognitive values" bias us against the people with dementia?
13. Do you enjoy nature? Your dog Sparky? Music? Beautiful art? Poetry?



Samuel A (Sam) Simon is an unlikely playwright, author, and performer. He describes his work as his "fourth age." He comes to it after a career as a prominent member of America's consumer movement. Trained as a lawyer, he started his career as one of the original members of Ralph Nader's first legal advocacy group in Washington, DC in 1970. Early in his career, his leadership was recognized through a profile in the New York Times. (NY Times, Jan 29, 1971, p. B1). After a stint in the US Army as a JAG Captain, Sam returned to work for Ralph Nader. He then started his own consulting firm. During that time, Sam became a regular in the national news, appearing on programs such as Face the Nation, The Today Show, Good Morning America, CBS Morning News, The Nightly News, Phil Donahue Show, and the Oprah Winfrey Show. Sam has also been a leading advocate for inclusion and served for 15 years on the board of the World Institute on Disability, and was awarded the Frank Bowe Award for Disability Advocacy by Hofstra University.