



SALT IN MY SOUL: DIANE SHADER SMITH SHARES LESSONS FROM HER DAUGHTER MALLORY'S 'UNFINISHED LIFE'.



Diane Shader Smith holds her daughter Mallory Smith's book during a visit to the MCPHS Boston campus.

"If medicine is in the business of improving our health—human health, we ought to know what makes us humans," says Dien Ho, PhD, associate professor of Philosophy and Healthcare Ethics. He's speaking about the MCPHS Center for Health Humanities' ongoing series of lectures delivered by artists and writers exploring the patient condition. The Center brings around 4-5 speakers a year to campus; past visitors have included Kate Daniels, a poet and Bunting Fellow at Harvard; Peter Kramer, professor of Psychiatry at Brown University; and Jonathan Shay, a psychiatrist specializing in veterans PTSD and recipient of the MacArthur Genius Grant.

The primary purpose of these talks is to expose students to the idea that medicine involves far more than biochemistry and physiology," Ho says. "After all, the humanities have investigated these topics thousands of years before the advent of modern medicine." As part of this ongoing exploration of the human side of medicine, Diane Shader Smith visited MCPHS on April 11 to read from her daughter Mallory's book, *Salt in My Soul: An Unfinished Life*, and to share lessons from her life with an audience of students and faculty.

When Shader Smith looked through her daughter Mallory's possessions after the Stanford student's untimely death from complications of cystic fibrosis, she did not expect to find the complete makings of a book. But there it was: 2,500 pages of journal and blog pages containing both deeply personal musings on life and analysis of healthcare's big picture, with a particularly incisive focus on the cracks among hospitals, health insurers, and healthcare providers. Shader Smith, herself the author of the children's book Mallory's *65 Roses* (which explains cystic fibrosis in age-appropriate terms), arranged and published Mallory's writing in an effort to both honor her daughter's wishes and to communicate important truths about, and to, the American healthcare system.

"Mallory was closely attached to her healthcare providers and very good at articulating her condition," said Shader Smith. "The doctors considered her the poster child for compliance. I wasn't that. I was the 'bad cop' who would block the door of her hospital room at 5 a.m. when the janitors decided that they absolutely had to empty her trash can right then." Detailing the exhausting gauntlet of hospitalizations that monopolized Mallory's life, Shader Smith noted that her role as maternal protector often placed her at odds with her daughter's healthcare team. "I would sneak her out for walks, bar and lock the door to allow her to get uninterrupted sleep, and once I snuck her out of the room so she could attend a football game at Stanford," Shader Smith said. "It made me very unpopular [...] but you have to remember that Mallory was hospitalized *67 times*, with stays ranging from weeks to months."

The routine indignities and humiliations of hospitalization took an unseen toll: while Mallory adopted the slogan "Live happy" and projected an attitude of can-do cheer, her private writing reflected pain, anxiety, and forced contemplation of death. Additionally, her illness introduced a host of complications to her social life, such as the question of when to disclose her condition to new friends, dating partners, and employers. (The stakes were high: one employer withdrew a job offer upon Mallory's disclosure of her cystic fibrosis.) Shader Smith also detailed the strange limbo of waiting for a double-lung transplant for her daughter; Mallory needed to be "sick enough, but not too sick" to qualify for the surgery, and there were several false alarms before a viable set of lungs was procured.

Throughout her presentation, Shader Smith spoke with great candor about her struggle to advocate for her daughter, sharing her frank perspectives on how larger issues within the healthcare system, such as the opioid crisis, have affected individual patients caught within that system. "Fear of addiction must be better balanced with need when it comes to pain management," she stressed, pointing out that in the immediate aftermath of her lung transplant, Mallory was stranded for many hours with a chest incision, vocal cord paralysis, feeding tubes, and inadequate pain management.

MCPHS students, future healthcare providers, absorbed these harrowing details with rapt attention, nodding as Shader Smith re-emphasized the crucial nature the roles that they will play in making "the daily decisions that affect patients." By sharing the details of her daughter's "unfinished life," Shader Smith added both Mallory's incisive voice, and her own urgent message, to the education that those healthcare providers will carry into the future.