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A BOOK REVIEW: SALT IN MY SOUL, AN UNFINISHED LIFE

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Salt in My Soul is not an easy book. Like every story of a life authentically lived, it is an alternation of joy and sorrow, expectation, and despair. It is, to borrow the title of another bestseller of years past, a book about the audacity of hope. How can one hope in the face of an inevitably terminal illness? Is such hope a necessary fiction that helps in the struggle of doing the day's work, a sort of optical illusion self-induced to prevent us from giving up prematurely? But what can "prematurely" even mean when the end is already living inside us, in our most intimate of organs, the channel of life's breath, consuming us from within? For CF is living death; CF is deathly living; CF is death and life interwoven — claspings, grappling, contending.

It is this question of hope that animates the entirety of Mallory Smith's life, and it is a question that anyone with CF will recognize as the central existential challenge of this disease. But, as Mallory so well understood, it is also the question put to any human spirit who will grace this earth for any period of time: "The question of how to meaningfully spend a life is not unique to those of us with health challenges. But for people with cystic fibrosis, or stage IV lung cancer, or any other life-limiting illness, there is a certainty that life will most likely be cut short to some extent. This certainty forces us to examine our values, prioritize our time, and search for meaning now rather than later" (185). CF as a crystallization of the human condition, as a window into the pain and suffering that all people know in their most intimate depths — this was the secret Mallory discovered, one that we learn along with her in the almost ten years these journals cover, from her high school days to her heart-rending death in young adulthood. "[CF] has given me the mountain that's been waiting for me all my life. The mountain we're all climbing, every day. It looks different for everyone, but we all have our own struggles, every person I see on the street. I have to remind myself not to envy those whose lives look normal, because their mountains do exist, even if they're less obvious than mine" (xiv).***

As this quote testifies, what slowly unfolds in Salt in My Soul is the growth of a soul learning self-transcendence. Concomitant with her struggle to hope in the face of almost certain loss was Mallory's confidence that life's time was given her precisely for the flourishing of others, for shared communion. She learned this truth in her childhood, from her family, especially her mother and father and brother, equally amazing characters in this story, who can be described no more perfectly than with the adjectives "always present" and "self-sacrificial." The joy in Mallory's soul we repeatedly encounter in the journals is joy with others, whether those others be her dear family or her beloved friends in her college years, or even — what is especially remarkable — her joy in this earth as it motivated her writing advocacy projects in post-graduate life. Her love for the planet, its history, its progression, its mystery, all shine a unique light on this woman who easily could have held a grudge against this world and its torturous evolution, producing, as it has, such vicious legions of disease and death as CF. But her overriding attitude to the planet's history and her own personal intersection with it was one of gratitude and wonder: "My life is a miracle. Life in general is a miracle" (111). In the journals we discover the moral pathos of Mallory's continual struggle between desiring the good for the whole and the good for herself as an individual. This contest plays out not only in her relationship with the earth, in her occasional ethically motivated vegetarianism, and in her desire to pass on genes the evolutionary process would consider "imperfect." It also manifests in her continual awareness of, and care for, the well-being of those around her. We read of her gratitude toward healthcare workers and her patience and compassion for those whose ignorance of CF causes them to treat her unjustly. We marvel at her solicitousness for the emotional lives of her parents, of the state of their marriage in the context of her illness, of how they are managing their grief over the deaths of their own parents. One of the greatest terrors that self-conscious CF patients experience is the fear of becoming trapped within the horizon of their own suffering; Mallory deftly avoids this snare with an almost preternatural ability to love, to care, to keep others in her heart. If Mallory's story says anything to CF patients in particular — and it says many things — it compellingly and movingly communicates the value of calculated risk-taking in a CF life. No choices are ever made with perfect knowledge of all variables and contingencies, and so the possibilities that so often present themselves to our healthier peers as pure opportunity appear to us as traps in disguise, as well as future sources of regret. This makes it all the more remarkable when we find Mallory, after agonizing over whether her time at college negatively and permanently impacted her health, coming to the conclusion that life is about quality, not quantity. "I sacrificed my health to go to Stanford — maybe I would have declined no matter what, but I definitely declined more by being away at college. It was worth it, 100 percent worth it, I wouldn't go back and change a thing, except maybe I would delete my period of depression" (140).

So often have I post factum berated myself for ventures and adventures that came with unexpected health repercussions; sharing in Mallory's own self-questioning and, in her ultimate affirmation of the value of embracing thoughtful risk, I find some solace that I am not alone. These mental and emotional exercises in second-guessing our choices point to another key value of the book for those with CF: its clear depiction of the mental health struggles built into this devastating illness. To name just a few: the constant shifting of goal posts as our health outlook improves or reverses; the unceasing, low-grade anxiety of the "ticking time bomb" of hemoptysis ready to explode at any moment; the responsibilities of daily adult life packed on top of the complicated medical regimens we need to keep us going; the challenge of being one's own advocate toward medical professionals and occasionally morally corrupt insurance companies; the need to make weighty medical decisions in the face of conflicting expert advice; the navigation of family relationships and natural growing pains made more complex by CF; the fears of rejection in intimate romantic relationships; the burden of being an inspiration to those who would consume our life stories in a superficial manner; the terror of watching others with CF reach the end of their journeys before we do, often in tragedy, and wondering how long we have until we fill their shoes and become a spectacle of suffering for the CF patients coming behind us. All these realities are endemic to a life with CF, and no one can bear them alone. Mallory's incredible community and resilient spirit helped keep her afloat, but her recognition near the end of her life of a need for psychological therapy reminds those of us with CF to seek professional help as we navigate this path strewn with physical obstacles and emotional land mines.

You may know of the Catholic practice of venerating saints. In that tradition (which is my own), saints are people who have lived their lives with such intensity and transparency to Ultimate Reality — what believers call God — that their lives become examples to follow as we make our own journey through the wilderness of existence, so terrifying and so unknown. How can we live in love toward others and toward life itself in the face of so much suffering, bewilderment, and disappointing heartbreak? We need guideposts. Saints, with their lives of self-sacrifice, devotion, and care for others, mark a path for us, teaching us and encouraging us; they don't impart a message so much as they themselves, through their lives, become the message.

I thought of the saints as I read Mallory Smith's journals in *Salt in My Soul*. Her remarkable story, so vulnerably on display in these pages, reminded me of the many saints' lives I have read, stories lovingly transmitted from generation to generation by those touched and changed by them. Every year in the CF community we learn the tragic news of the beloved people this disease has taken from us. They pass on, leaving behind an imprint of love on the hearts of those near them, and their memory emerges suddenly as a vulnerable treasure to be cherished and kept, cultivated and handed on. To that end of preserving a life in the heart's memory, few means are more powerful than the written word. It is our good fortune that the written word was Mallory's exquisite gift, and that her family saw fit to share her life with us so that her wisdom might spread, and that she might live on in the memory of hearts she never knew but will nonetheless intimately befriend the moment her words are read. I conclude by noting that this extraordinary memoir bears the subtitle "An Unfinished Life." While such a description is eminently understandable from the perspective of those who knew Mallory and loved her, of those whose lives are irrevocably altered by her death, I wonder whether another subtitle might have been equally apt: "A Perfected Life." In the Greek language, the word for "end," *telos*, means both "end" and "goal" — to reach one's end is to reach the purpose, the aim, the reason one set out on a journey in the first place. In spite of all the beautiful things in life her CF took away from her, Mallory nonetheless felt she had achieved something precisely through her CF: "I feel like people with CF are privy secrets it takes most other people a lifetime to understand. How lucky we are to be alive. How lucky anyone is who has their health. How we should be appreciative of anything that's in our control since our health is not. That we can leave behind a legacy when we go that will impact others. That simple things are often the most beautiful. That love and happiness are the most important things to strive for...CF has given me my value system and ultimately, no matter how hard it is, I'm grateful for it" (236). Mallory's life as told in *Salt in My Soul* was a life replete with love, as saturated by it as her soul was with the salt of suffering. Only such a soul could say with sincerity that the love of her family had taught her to feel, despite her illness, that "the world is a good place" (294). That love could make this vale of tears we inhabit a good place is the most realistic of hopes for enduring the unpredictable and ruthless sufferings of life; whatever our circumstances, and however much time we may have, we are always being gifted with the possibility of allowing love at work in us to make others feel that life is worth the living. Any who read Mallory's story, told here in her precious words, will learn something of how to live with that hope, so that no matter how their days may end, ripened or premature, theirs will be a life unfinished only in time, not in love.