

SCIENCE

Read An Excerpt From A Memoir Of A Young Woman Who Died Of A Superbug Infection

Salt in My Soul is a new memoir about a young woman's life with cystic fibrosis.

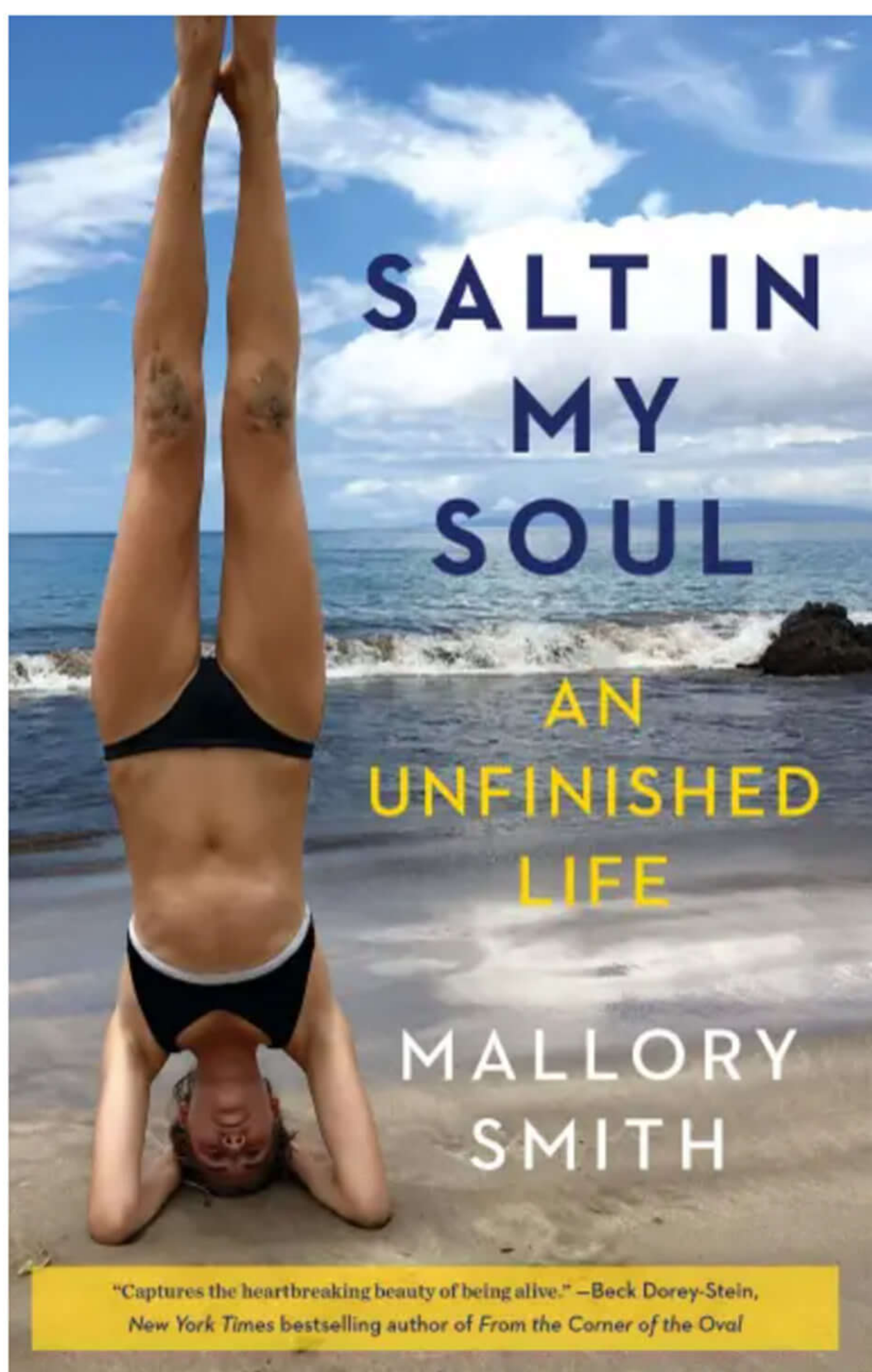


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Penguin Random House, Courtesy of Diane Shader Smith

Salt had always been a fundamental part of Mallory Smith's life. Like all babies born with cystic fibrosis, Mallory had inherited two defective copies of a gene responsible for balancing the salt and water in sweat. The disease caused a thick mucus to form in her lungs, trapping bacteria and triggering infections, and leaving her skin a little salty.

Salt, she knew, would eventually cut her life short: The average life expectancy of a person with cystic fibrosis in the US is just 38 years. As she wrote in her diary shortly before she died at age 25, "My disease erodes the life blueprint I drew as a kid."

Her mom, Diane Shader Smith, told BuzzFeed News that early on in Mallory's life, she and her husband, Mark, decided to push for "a sense of normalcy," despite frequent doctor visits and a shifting cocktail of antibiotics to quell the infections that would flare up in her lungs. Part of this turned out to involve more salt: When Mallory was a toddler, Mark read a scientific paper about inhaled saltwater's positive effects in clearing the mucus in the lungs. So the family began taking regular vacations to Hawaii, where Mallory became an avid surfer. At home in Los Angeles, tumbling in the waves of the Pacific Ocean, she found it easier to breathe.

That sense of normalcy, her parents said, extended into her life as a young woman with big dreams. She went to college at Stanford, where she played club volleyball and studied biology. During this time, she also kept diaries to chronicle not only her love life and frustrations at school, but dozens of long hospital stays and her ever-deteriorating health.

When Mallory was 24, an infection in her lungs caused by a bacteria called *Burkholderia cepacia* became resistant to all of the antibiotics available to treat it, turning into what's known as a "superbug." In September 2017, she was lucky enough to get a double-lung transplant. When Mallory's new lungs became reinfected with *B. cepacia*, Mallory's parents pushed her doctors to consider an experimental treatment they'd wanted to try for years: phage therapy. That approach, which involves hunting down specific viruses that can kill bacteria, has led to some remarkable success stories fighting superbug infections in the past few years.

With the help of the US Navy's phage therapy research group, the Smiths found two phages that could kill Mallory's bacteria. The viruses were helicoptered to the hospital and pumped into Mallory's body. Although the phages did begin to attack the bacteria in her lungs, it was too late. On Nov. 15, 2017, she died of pneumonia.

Mark and Diane Smith have since become big advocates for phage therapy, which they and others think has the potential to turn cystic fibrosis into a chronic condition instead of a death sentence. They've also collected excerpts from the diary Mallory kept for more than a decade, which will be published tomorrow as *Salt in My Soul*. Diane told me she wants Mallory's experience to inspire other people, and even save lives. "She knew that she had something to share, and I wanted to honor her wishes," Diane said. "She will live on because of her words."

Here's an excerpt from that memoir.

10/16/14

When I was young, I learned about the selfish gene.

Lying in bed at night, cuddled beneath the covers, my dad's voice would soothe me to sleep with talk about the complexity of the human genome, the spiral shape of a DNA helix, the way forces of natural selection would make harmful mutations die out with their host, but allow random beneficial mutations to proliferate and spread through a population, causing such changes within a species that one common ancestor could play grandfather to a bonobo, a rhesus monkey, and a human, or a Brussels sprout, mustard seed, and stalk of broccoli.

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Every night, as he'd wax poetic about the marvels of evolutionary biology, only taking a break to throw in some astrophysics and history, I'd fall asleep to the letters A, T, C, and G, amazed at this world we live in, developing this *profound love* for the theory of evolution, for the belief that random chance and probability could shape a planet composed of rock, water, and protozoa into the beautifully varied community of life that exists today, from the highest peaks of the Himalayas to the lush richness of the Amazon to the eerie black depths of the dark ocean floor.

We worshipped Dawkins and Dennett, the unusual versions of childhood heroes my brother and I clung to, and they illuminated if not the why, then at least the how of human existence. Evolution seemed like a religion, but it wasn't one because it does not require faith, it encourages you to question, to dig, literally, to understand the origin of our species and the complex history of the genetic matter that existed, mutated, and evolved to construct this current world of ours. This community of species we share the planet with, a community that has lost members like the dodo, the Kauai o'o bird, the Caribbean monk seal, the Baiji white dolphin.

We read *God's Debris* and *The God Delusion*, debunked the logical proof of God's existence put forth by Aquinas, read the Bible as literature, and occasionally laughed at the more outlandish elements of certain stories — Lot's wife turning to a pillar of salt for looking over her shoulder, Joseph's brothers' inability to recognize him when he became pharaoh of Egypt, Noah's Ark and the idea that two of every species alive today could fit into one boat without all eating each other, the blood in the river and the frogs and the leeches; but we learned some lessons anyway, in Sunday school and in discussions at the dinner table, what my parents called the "point" of their atheist version of Judaism.

But one day, I realized that evolution, the almighty natural force that I revered with the core of my being ... *evolution isn't acting on me.*

I'm exempt.

If natural selection were happening unhindered, I would be dead. There would be no Mallory Smith, age 22, Stanford graduate living and breathing, making friends and reflecting on the origins of the universe. There would just be some ashes scattered in the Pacific Ocean, or however my family would choose to honor a life that had no chance to ripen.



Courtesy of Diane Shader Smith

I was born with two defective copies of the CFTR gene, one mutated copy from each parent. You have one copy of the gene, and you get a heterozygote advantage, an increased fitness because of a lower likelihood of dying of cholera. But with two copies of the gene, you're salty. The old adage goes, "The child will soon die whose brow tastes salty when kissed."

At this point, keeping myself alive is a full-fledged mission, enlisting all of my energy and hours of my day, every day, as I need 9 to 10 hours of sleep, 16 pills with a hearty breakfast, packing extra calories to overcome malnutrition caused by pancreatic insufficiency. Vitamins and minerals, probiotics and antibiotics, gastrointestinal medications, sinus rinses with saline, steroids and antibiotics, lengthy CPT treatments. All to reduce inflammation and fight the chronic deadly infection eating away at my fragile, scarred lungs.

And that's just the morning.

Throughout the day, more pills four times a day. Some three times a day, some every time I eat, some 30 minutes before eating. Another round of CPT/vest midday, more breathing treatments. Then the entire morning routine again at night.

About four hours a day I dedicate to the simple act of taking a breath, fighting the billions of bacteria overtaking my lungs and clearing out the mucus so I don't feel like I'm breathing through a straw with a boulder weighing on my chest. Staying alive, for someone with CF, requires active and constant effort *against* natural selection, requires a grand *fuck you* to that force which, left to its own devices, would have us suffocated from respiratory failure before adolescence.

What does my survival come down to, what is responsible for my ability to trump natural selection? Medicine. Medicine gives me the gift of life. Medicine exempts me from the forces that paved the way for humanity to emerge, that shaped life on Earth for millions of years, since the very first cell sprung to life in the primordial soup.

How is that fair? Why do we, today, get to override evolution? What will that do for the future of our species? More important, what does that mean for the millions of other species on this planet who don't have that unfair advantage, who still exist at evolution's mercy?

I want to live and I want people the world over affected with illness, ridden with deadly diseases, to live, to survive, to *thrive*, and to reproduce, creating imperfect little perfects. I want us to be viewed as worthy enough to pass on our genes, even if we'd be outcompeted by those whose genome is "better" in a world where natural selection still reigned supreme.

My life is a miracle. Life in general is a miracle. Our existence is the result of stars exploding, solar systems forming, our Earth having an environment hospitable to life, and then, finally, millions of highly improbable events accumulating over millions of years to bring us, a capable and conscious bag of stardust, to the here and now.

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