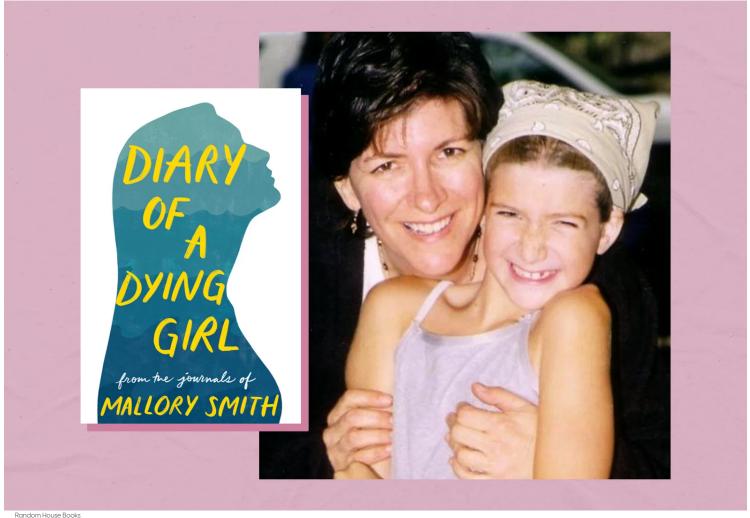
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## Her Daughter Died From a Chronic Illness – Now, She's Sharing Her Diary

By Alexis Jones

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Random House Books Diane Shader Smith

Diane Shader Smith was at a bris ceremony celebrating the birth of her friend's baby boy when she got the call that her then 3-year-old daughter Mallory had been diagnosed with cystic fibrosis.

"We were in the middle of celebrating and I got a 911 — I was wearing a pager at the time, and so I ran upstairs to call [Cedars-Sinai Medical Center]. When they told me Mallory was diagnosed, I remember moaning and screaming and noises coming out of my body and having heart failure," Smith recalls.

Cystic fibrosis is a progressive condition that causes mucus to build up in the organs, including the lungs and pancreas, per Cleveland Clinic. Complications of the disease can include chronic infections, coughing up blood, chest pain and breathlessness, <u>nutritional deficiencies</u>, and respiratory failure in which the lungs no longer function.

Over the next two decades, Mallory would work tirelessly to prolong her life, undergoing countless CF treatments and hospitalizations, all while documenting her experiences and unfiltered thoughts in a diary.

"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," she wrote in a 2014 entry.

Mallory lived by that kind of thinking, Shader Smith explains, detailing her daughter's refusal to be overcome by the disease. She continued playing sports, like swimming and volleyball, fell in love, forged new friendships, went to Stanford, navigated hookups, and found her passion in environmental activism and storytelling.

It wasn't until after college graduation in 2017 that Mallory would lose the fight, falling victim to antibiotic-resistant bacteria that ate away at her lungs just two months after a successful double lung transplant — something Shader Smith has become adamant about closing the knowledge and funding gap around. Shortly after Mallory's death, her grieving mother read the thousands of diary entries in Mallory's computer. Shader Smith would posthumously publish the entries as "Salt in My Soul: An Unfinished Life" in 2019 and the not-yet-released "Diary of a Dying Girl" on May 7.

"[Finding the entries] was really devastating," Shader Smith says. The more she read, the more she realized that her daughter was suffering as much as she was living. The brave face Mallory put on, adopting the mantra "live happy," was just one side of her lived experience. These entries were the space where she told it all — as Mallory wrote, "the letdowns, the uncertainties, the anxieties, the loneliness."

Shader Smith admits to having left a lot of that out of that first book. "It was too painful. I just couldn't do it," she tells PS. Now, six years later, she's ready to share the full breadth of Mallory's raw and inspiring insights.

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The biggest takeaway Shader Smith has learned throughout the process: don't waste a single day. "You won't hear me complain a lot about anything," she says. "I don't sweat the small stuff. I fully engage in life and I realize that it's a gift — every breath I take. You learn that when you live with somebody who has struggled with a debilitating chronic illness."

"Diary of a Dying Girl" will be released on May 7 on Amazon.

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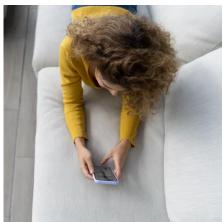
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