Mother publishes daughter’s diary after her untimely death from cystic fibrosis

By Jane Ridley

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DianeShaderSmith is shown with her daughter Mallory at a San Francisco Giants game. Shader Smith has published a memoir culled from her daughter’s diaries that document the younger Smith’s battle with cystic fibrosis and a double-lung transplant.

Courtesy of Diane Shader Smith

There was a brief window of hope — lasting about six weeks — when Mallory Smith’s long-awaited double-lung transplant appeared to have been a success.

Only then did the cystic fibrosis sufferer and her mom, Diane Shader Smith, seriously discuss turning her journal into a memoir.

“I don’t think I have enough to say to sustain a whole book,” the 25-year-old Ivy League graduate told her mother.

As usual, Mallory underestimated herself. Following her daughter’s tragic death on Nov. 15, 2017, Shader Smith found no fewer than 2,500 pages of notes she had typed on her laptop over the past 10 years.

Determined for Mallory’s voice to be heard from beyond the grave, the veteran Los Angeles publicist edited the diary and published “Salt in My Soul: An Unfinished Life” (Spiegel & Grau).
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“I think Mallory was and continues to be the most inspiring person people know,” Shader Smith, 59, tells The Post. “My feeling is that it’s time to introduce Mallory to the world because she has so many life lessons to share.”

The athletic young woman was first diagnosed with the deadly genetic respiratory and digestive disease at the age of 3. Then, as Shader Smith describes, Mallory had a “chronic runny nose and cough” and was frequently sent home from pre-school.

Among other symptoms, the condition — which, in Mallory’s case, was complicated by a superbug bacteria — causes persistent lung infections and the coughing up of mucus. Over time, it limits the ability to breathe. More than 30,000 Americans are diagnosed with CF, and the disease’s life expectancy is just 37.5 years.

As Mallory poignantly writes in her memoir: “Cystic fibrosis is a disease that does a lot of taking — of dreams, of time, of friendships, of freedom, of potential, of lives.”

Despite the grueling CF treatments she underwent — she was hospitalized nearly 70 times, hooked up to IVs and various machines — the passionate environmentalist, sports enthusiast and champion of universal health care maintained an optimistic outlook. Her mantra was “live happy,” because she wanted to make the most of her short time on Earth.

“My life is a miracle,” Mallory writes. “Life in general is a miracle.”

Shader Smith maintains that, from the outset, even during her toughest times, her daughter was encouraged to think of others who were worse off than her. She rarely felt dejected for long.

“I would always say, ‘No pity party,’ ” says Shader Smith. “I definitely set the tone in the house that we’re not going to be crying and would find the joy in every day.

“Mallory knew she had to make the choice whether to let the disease swallow her up or whether she was going to move forward and have a happy life.”

She achieved much in her quarter century, including graduating Phi Beta Kappa from Stanford University with a major in human biology, rallying her community to raise more than $5 million for cystic fibrosis and pursuing her love of sports, especially water polo, volleyball and surfing.

As her health declined, she became increasingly devoted to yoga. “She fell in love with yoga because she felt it was forgiving,” says Shader Smith. “She wrote a lot in her journal about

Diane Shader Smith with her daughter Mallory during a hospital stay

Courtesy of Diane Shader Smith
how important it is to continue your practice no matter what you are going through.”

Other topics she chronicles range from body image, self-esteem and anxiety to the need for balance with pain management during the opioid epidemic. At one point, she describes her constant pain as “torture” because of limits on the amount of medication she could receive.

“She had an ability to communicate in such a sophisticated and accessible way,” says Shader Smith, who is embarking on a nationwide speaking tour to spread the word about her daughter’s book.

To the very end, Mallory remained convinced that she would survive following her double-lung transplant on Sept. 11, 2017, despite her body eventually starting to reject the new organs and contracting pneumonia.

In the final stages of her illness, she pinned her hopes on a groundbreaking treatment called phage therapy, which might have helped as an alternative to antibiotics. Sadly, she passed away before the treatment could be started.

Mallory’s relatives made the decision not to tell her that the end was near.

“We didn’t want her to be afraid,” says Shader Smith. “The reason the doctors ask you to tell patients they are dying is so people can unburden themselves.

“But we’d always been a close family and said everything that needed to be said. We had been so involved in each other’s lives. Mallory knew she was loved. We knew she loved us.”