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Putting a face on the 'invisible threat' of antimicrobial resistance

Chris Dall, MA, Today at 5:59 a.m.

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Mallory Smith

Photo: Diane Shader Smith



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Mallory Smith was a young woman who, in her own words, had "big dreams and big goals."

When she was in high school, she set her sights on going to Stanford. After college, she hoped for a career where she could help people and "move the needle on something that's important." She wanted to write about the world and all its beauty. She wanted a life filled with travel and adventure. She wanted to fall in love.

But most of all, she just wanted to live a normal life. A life with normally functioning lungs that wouldn't hold her back from excelling at her favorite sports, volleyball and water polo, and from doing all the things that healthy teenagers and college kids get to do. A life without bouts of hemoptysis (coughing up blood), a peripherally inserted central catheter (PICC line), nebulizers, countless hospital stays, and the constant threat that *Burkholderia cepacia*—the family of deadly, antibiotic-resistant bacteria that clogged her lungs—would end her life before she could achieve those dreams.

Mallory was diagnosed as having cystic fibrosis (CF) at age 3, and like all CF patients, her lungs were vulnerable to bacterial infections that can exacerbate the condition and compromise lung function. That was enough of a challenge for any child to deal with. Then, at age 12, she found out her lungs had become colonized with *B cepacia*, which would substantially change the trajectory of her life.

Over the next 13 years, as the bacteria became resistant to every antibiotic Mallory's doctors tried, her lung capacity steadily diminished, and hospitalization became more frequent. For 10 of those years, she chronicled this experience—along with her frustrations, fears, hopes, and dreams—in her diary.

"I'm just sad and exhausted and drained and sick of being sick," she wrote on April 2, 2013. "I'm sick of what *B cepacia* is doing to me. It just doesn't want to cut me a break."

Mallory died in 2017 at age 25 following a double lung transplant and a last-ditch effort to save her life with bacteriophage therapy. But she never let CF and *B cepacia* prevent her from reaching for (and achieving) some of those dreams or from living a full and impactful life. In many ways, she used them as inspiration.

"Resistant bacteria does a lot of taking—of dreams, of time, of travel, of friendships, of freedoms, of potential, of plans, of lives," she wrote. "At the same time, it does give. It's given the creativity to reimagine my life, a skill that I wouldn't have needed to develop if everything had been easy and nothing was impossible."

Making the invisible visible

While it's a different type of crisis than the COVID-19 pandemic, antimicrobial resistance (AMR) is one of the most significant public health threats facing the world. The most widely cited [study](#), published in *The Lancet Infectious Diseases*, estimates that drug-resistant infections contributed to nearly 5 million deaths globally in 2019 and were directly responsible for 1.27 million.

With bacteria becoming increasingly resistant to the current arsenal of antibiotics, and few new antibiotics on the way, those numbers are likely to rise in the coming decades. Yet the wider public doesn't see most of those deaths. Many occur in children in low-resource countries or in hospital intensive care units among patients battling other conditions.

"It's kind of an invisible threat, and until it hits you personally in your own life, you're unlikely to realize how serious a problem it is," Steffanie Strathdee, PhD, associate dean of global health sciences at the University of California San Diego School of Medicine, told CIDRAP News.

Furthermore, AMR is a complex topic, filled with scientific jargon and an assortment of acronyms that can confuse even those who are experts.

These are among the reasons why there's hope that the story of Mallory Smith, and the stories of others whose lives have been upended by antibiotic-resistant bacterial infections, can help "move the needle" on AMR. Mallory's story was first captured in *Salt in My Soul*, a posthumously published collection of 10 years

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of diary entries edited by her mother, Diane Shader Smith, per Mallory's instructions. This spring, Shader Smith published [Diary of a Dying Girl](#), which contains more raw, unedited entries that provide a window into Mallory's emotional state and personal feelings about trying to live a normal life while fighting a deadly pathogen.

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—Steffanie Strathdee, PhD



Photo: Diane Shader Smith

Shader Smith, who has become a widely sought advocate and public speaker on AMR, says she thinks stories like her daughter's can help educate the public about AMR and motivate policy makers to do something about it in a way that mortality estimates and complex scientific reports and studies can't.

"People tend to respond to personal tragedies and personal stories," Shader Smith said. "And the single biggest reason to tell the stories is because it motivates people to action."

Since her daughter's death, Shader Smith has traveled the country and the world, telling her story, speaking to audiences ranging from high school students and Rotarians to members of Congress and NATO officials. A self-described "accidental expert" who never took a biology class in college, she now deftly weaves her daughter's (and her family's) personal experiences with the technical aspects of AMR to make people understand why they should care.

"It isn't just putting out the facts, because the facts don't necessarily tug on people's heartstrings," she said. "You have to create a story arc."

"Hearing Diane share the story of Mallory battling cystic fibrosis and ultimately succumbing to a resistant infection was completely crushing," said Emily Wheeler, director of infectious disease policy at the Biotechnology Innovation Organization (BIO), who invited Shader Smith to speak to AMR experts at BIO's international convention after hearing her presentation and reading *Salt in My Soul*. "You can't help, as a reader and a listener, but feel the emotion."

The realization that personal stories have an important role in AMR education and advocacy led Shader Smith, working with the Partnership to Fight Infectious Disease, to launch the [Global AMR Diary](#), a website that collects the stories of people who've had personal experiences with AMR, including patients, their families, and caregivers.

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—Diane Shader Smith

While Mallory had CF and was therefore more susceptible to antibiotic-resistant infections, her mother says that stories about otherwise healthy people who've had their lives upended by AMR are important because they illustrate that "no one is safe" in a world where antibiotics are losing their effectiveness.

"That's how you reach people," she said. "Nobody cares about the antibiotic pipeline that's not in that world, or about the research that's coming out. They just want to know that they're going to be safe when they go into the hospital for a hip replacement."

'I was like a sitting duck'

Vanessa Carter, executive director of the [AMR Narrative](#), is another person who understands deeply how a personal experience with an antibiotic-resistant infection can change the course of your life.

At age 25, Carter was in a severe car accident in Johannesburg, South Africa, which caused massive internal injuries and disfiguring facial wounds and fractures that would result in 10 years of facial reconstruction surgeries. During that period, one of the facial prosthetics that was implanted to rebuild the bones in her face became infected. But the antibiotics she took over the next several months failed to stop it.

Ultimately, doctors removed the prosthetic and found it was riddled with methicillin-resistant *Staphylococcus aureus* (MRSA). That MRSA infection would lead to more surgeries and antibiotics before doctors finally got it under control. And Carter still lives with the effects of that experience. Her face tells the story.

"The sections [of my face] that they had to remove, it was like amputating parts of my face, because this bacterium had eaten away so much skin," she said.

But the experience also launched Carter, who had a background in marketing, on a new career as an AMR patient advocate. Carter says that when she began this work in 2013, one of her biggest concerns was the lack of communication about AMR. And she still has that concern.

"There's still a huge problem with lack of communication about AMR," said Carter. "People don't know what it is."

But like Shader Smith, Carter thinks that personal stories about battles with drug-resistant infections can help. It's one of the reasons she started the AMR Narrative, which aims to promote public understanding of AMR and help patients share their stories and become advocates.



Vanessa Carter / The AMR Narrative

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"Sharing your story really brings to light what it feels like to be the person with the lived experience ... to show what is behind the statistics," she said. "When we talk about our experiences, we make it more relatable."

One of Carter's hopes is that these stories of real people will help educate other patients about AMR, so that they can have a conversation with their doctor if they've been on antibiotics and aren't getting any better—a conversation she wasn't able to have with the doctors who kept prescribing her amoxicillin.

"I knew nothing about AMR," Carter said. "I was like a sitting duck."

Shader Smith believes that if people can relate to those personal stories of lives upended by AMR, that could help them understand why they should care about the overuse of antibiotics, "or at least understand that every time you have a sore throat, you don't ask your doctor for an antibiotic."

Not just patients

Mallory Smith's story is just one of the entries you can find on the Global AMR Diary. Another is from [Areti](#), who became infected with *Klebsiella pneumoniae* during treatment for acute lymphoblastic leukemia and had to put her chemotherapy on hold. Former NFL player [Brandon Noble](#) shares the story of the MRSA infection that would end his career and nearly take his life.

But Shader Smith doesn't want to hear solely from patients who've been affected by AMR. She also wants to hear from the physicians who've lost patients to drug-resistant infections and the researchers who are "toiling behind the bench" to discover new antibiotics and alternative therapies.

"Everybody understands we need patient stories," she said. "But we also need provider stories and biotech innovator stories... because many times these people have a personal story to tell."

Wheeler agrees. "I think that's what is unique about the Global AMR Diary, and we're really thrilled to help amplify that message and encourage the small biotech innovators that are doing the lion's share of research in this space to contribute their stories and voices to this effort," she said.

I knew nothing about AMR...I was like a sitting duck.

—Vanessa Carter

Strathdee approaches the issue from both sides—as a scientist and the spouse of a person who almost died from an antibiotic-resistant infection. In 2019, Strathdee and her husband, Tom Patterson, PhD, published [The Perfect Predator](#), which told the story of Tom's life-threatening infection with multidrug-resistant *Acinetobacter baumannii* and the bacteriophage therapy that saved his life.

Strathdee, who's authored or coauthored scores of published scientific papers, has long valued the importance of communicating science to the public and had always wanted to write a book. With *Perfect Predator*, she and Tom wanted to tell a highly complex, highly scientific story in a way that would put a human face on AMR and make it much more accessible to the general public than a paper in a scientific journal.

"I wanted to tell the story to raise awareness about AMR and about this 100-year-old forgotten cure of phage therapy, which I felt really deserved to have its fair shake in clinical trials," she said.

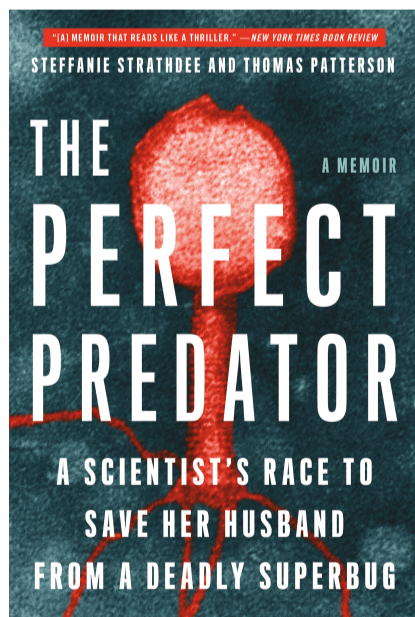
But she also had a "secret desire": to inspire young people go into science or public health careers.

"I thought that if one person ends up writing me and tells me that this book helped them make a decision about their career, then I'd feel like it was a success," she said. "And that happened almost immediately."

Can stories move the needle on policy?

The big question is whether personal stories and storytelling can help motivate the people who have the power to make policies that can mitigate AMR and bolster the weak antibiotic pipeline, which experts have said is insufficient to address the rise in the type of multidrug-resistant pathogens that infected Mallory Smith, Vanessa Carter, and Tom Patterson.

Wheeler, who heads up BIO's AMR legislative and regulatory policy efforts and is among those advocating for Congress to pass a bill that could help fix the antibiotic pipeline (the [PASTEUR Act](#)), thinks they can.



"The power of storytelling really transcends all audiences," Wheeler said, adding that stories like those of Smith and Patterson are "critical as a part of the community that is advocating for urgent action in this space."

Personal stories can certainly help you get a foot in the door, says Shader Smith, who's been invited to tell her daughter's story on Capitol Hill and at the White House.

"There are not a lot of people like me in the room with the big boys and girls, but I have now been invited into many rooms, at the highest level," she said.

Strathdee notes that her personal experience has also enabled her to reach and educate policy makers with whom she might have very little in common. She recalls how Rep. Morgan Griffith (R-VA) held up a copy of *The Perfect Predator* during a Congressional subcommittee hearing and told attendees that it was how he learned about AMR and phage therapy.

"Here's a guy that I don't share very many political views with at all... but it shows you that through storytelling, you can reach across the aisle and you can make an impact on people's education and awareness," she said.

None of this, of course, will bring Mallory Smith back. But just by telling her story, she's already achieved one of her biggest goals. "I always envisioned myself making positive change in the world," she wrote in her diary on December 14, 2013.

More than a decade later, that vision has come to fruition.

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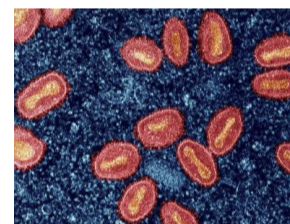
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