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Introducing Diane Shader Smith 00:55

My Opa, my father’s father, survived the Bergen-Belsen Concentration Camp. He also survived my dad’s death. He told me that he suffered more from losing a son than the concentration camp. I’m unhappy to say that I share the experience of losing a child with my Opa and Diane Shader Smith. Diane’s daughter, Mallory, kept extensive journals about her life with Cystic Fibrosis. Diane continued the bittersweet journey of shaping those journals into the book, Salt in my Soul, an Unfinished Life after Mallory died. I’m beginning and ending the conversations in this Young Adults with Complex Conditions series with solo parents - speaking with a parent and not their children - the first with Jill Woodworth and the last with Diane. I sought to provide a platform to share the stories of the young adults with perspective provided by parents, clinicians, and teachers. To hear Mallory’s story, please read the book. While Diane is engaging and well spoken, the meat is in Mallory’s book. A podcast can’t do justice to her story. While Diane and I were corresponding to set up the interview, she wrote, “Mallory told me that she didn't want us to be buried by grief if she didn't make it. I PROMISED her I'd live happy if anything happened - but only after I reassured her on many occasions, she had a lot of life left in her. I'm sure Mike wouldn't want you to suffer... I could never imagine life without Mallory, but now that it's here we are working hard to honor her memory by following her mantra, "Live Happy" ... it's not always easy, but it is important.” Yes, LIVE HAPPY.

Health Hats: Thank you so much for joining me. Salt in my Soul, an Unfinished Life is a book by Mallory Smith. Mallory lived with and died of cystic fibrosis. She strived to live the best life possible, given her genetics, her medical conditions, her social circumstances, and her physical environment. She was Captain of Her Own Ship. While her physical health was challenging at best, she grew into remarkable

spiritual strength that laid a foundation for her self-described variable mental health, and her deteriorating physical health. My son, Mike, who died at 26 of metastatic melanoma had the same health balance. He said he wasn't born with a tattoo on his ass telling him how long he had to live. I think he and Mallory would have found kindred spirits had they met. As a student of health, I value spiritual health over physical health any day. Because of that, Mallory seemed to die well; as did Mike. To hear it directly from Mallory, read her bittersweet book. I couldn't put it down. I selected it for my book club when it was my turn to choose. The book club is reading it as we speak. On the line with me, I have Diane Shader Smith, Mallory's mother. Welcome, Diane.

Diane: Hi. Thank you for having me.

Health IS fragile 04:40

Health Hats: Diane, where were you when you first realize that health was fragile?

Diane: Do you mean where was I physically or where was I emotionally?

Health Hats: Either one or both?

Diane: When Mallory was diagnosed at three, we didn't know what cystic fibrosis was. It was clear upon hearing the doctors' explanation and then when we did our own research, that life was going to change and that her life would be short. At that moment, everything changed, and every day became precious.

Health Hats: I'll say. Before you were a mother did was there a point in your life, you know as a child or as a young person when you realized that, maybe not to the extent that you did with Mallory, but to some extent.

Diane: Well, my mother would tell you that I lived my life every day from the time I was three myself, as if it was the last day. That I was running out of time because I was always wanting to do more in a day than could possibly be done. I don't know if it was conscious or subconscious, but I have always had that feeling that, as they say, shit happens. And you want to get it done when you can get it done.

Self-care. A common question. 06:05

Health Hats: Diane, in my series on young adults with complex conditions transitioning from pediatric to adult medical care, there's been a thread throughout all of the interviews that while the young adult with the complex medical conditions is the family's primary focus, we can't forget that tragedy affects everyone it touches. I'd like to focus this conversation on you and your family as you lived and breathed with Mallory. She was diagnosed, I think you had said, at three years old with cystic fibrosis. As a mother as a wife as a career person, you were all these years dealing with the health challenges in your family. How did you try to take care of yourself?

Diane: It's interesting, that question. It's a common question; I get asked all the time. Very interesting that you ask that. I'm a person who likes to exercise. So, if exercise is considered self-care, then I do that every day. I love my friends more than you could imagine and I make time for my friends. And so, I count spending time with friends as part of my self-care. I'm very attached to my family. Although it's

shrinking, as I lost my mother and my father and my daughter in a very short period. But I am extremely family-oriented, and we've adopted Jack, Mallory's boyfriend, and now consider him part of the family. I consider my close friends as part of my family. And my sister, my brother, who I'm very close to, don't live locally, so I don't get to see them very often, but we're all very close.

Managing and coordinating care 08:04

Health Hats: So, you have this extended family. How did you coordinate care over the years? It seemed like there were people stepping in and helping out, often.

Diane: Well, I made Mallory's situation public when I wrote [Mallory's 65 Roses](#) and started our annual fundraiser for Cystic Fibrosis research and had Mallory always stand before the community as somebody with a chronic illness. I never really understood the inclination people have to keep their personal problems private because I think that we live in a society where people can be kind. Knowledge is power. So early on I let people know what was going on, and I asked for help, and everybody stepped up.

Health Hats: When you ask for help, at least my experience, the managing of all that help was a job in and of itself. What's needed? When? Who can do what? Were you the person that that managed all that? Were you the project manager, so to speak, of all that? Or did that role shift or change from time to time? How did you manage that? How did you, as a team, manage that?

Diane: Well, I'm a control freak. I cared very deeply about Mallory's care and her social life, her family life, her friends, her academic life, and her sports life. I was very much of a scheduler and I'm a multitasker. I would just always make sure that if Mallory had a doctor's appointment, I brought my work with me or if she had a volleyball or water polo tournament, I would bring my work with me. I just made use of every minute of every hour of the day. At the risk of my own health, I probably didn't take the best care of myself. In terms of the sleep issue, because I've never really slept a lot. But I happen to be blessed with high energy and the ability to multitask. It's just easy for me and much more comfortable, emotionally, for me to know that I've planned everything out. When I say, I'm a control freak I would not have entrusted the day-to-day details of my children's life to anybody else. Not even my husband. He's an amazing dad, an amazing husband. But I'm very particular about the way things are done and I was known as the bitch in the house and he was Disneyland dad because he was the one always wanting to make sure they were having fun and I was the one to make sure everything got done.

Health Hats: Did you keep spreadsheets. Did you have conference calls? You know, I'm just picturing you, sitting there at a water polo match with either your calendar up on your whatever device or were you using pieces of paper?

Diane: I'm a list maker. I always insisted in my professional career on working at home, and my advice to anybody wanting to work at home is if you are good enough at your job, then you will be allowed to work at home. I just had to make sure that when Mallory was in the hospital and I wanted to disappear from the agency that I worked with for two weeks at a time, that I would make sure that the most important work happened when I wasn't in the office. So, I rewarded them by my working at home. I

think that a lot of it is about being organized. And you know, it's interesting because some people struggle with time management and organizational skills. I think there's a name for it now, executive function disorder and I sort of have the opposite. I'm blessed with high executive functioning skills. I'm not blessed with a lot of things, but that's one of the skills I do have, and it worked well for me to work take care of the kids and take care of myself.

Health Hats: Wow. That's a blessing having all that. You and I have had the conversation online a little bit about my son, who some of the time he was sick, he lived with us, and sometimes he lived near us, and sometimes he lived across the state. We lived in New York State at the time, and I got the sense from Mallory's book that there were the LA and other locations that you were managing. For us, it was before the internet, and we made heavy use of conference calls with Mike and his girlfriend and her parents and did a lot of scheduling of stuff. I have a pretty good executive function myself, probably not to your abilities. Did you, in terms of coordinating care, you're talking about coordinating lay people, friends, and community, and then all the professional stuff as well?

Diane: Right now, we're working on the documentary about Mallory's life with this amazing award-winning team that did the documentaries, [The Invisible War](#) and [The Hunting Ground](#) and I do a lot of the logistics and the scheduling because it comes naturally to me. Whereas, my husband, who's the brains in the outfit and the scientific medical genius - the one who found [Phage therapy](#) for Mallory and the one who did all the research. That's his area of expertise. He understands medicine. He understands the research. He understands the treatment. So that was always his job was to research the best treatment. It was my job to make sure that we got it. The only thing that I didn't do that he did do a hundred percent of the time was fight with the insurance companies when they wanted to deny something. Because he's a lawyer and he can present the argument in a way that they had to say yes.

Who's doing what? Team roles. 14:40

Health Hats: Was there a period early on, as you were figuring out what it would take to manage all this, to figure out what your relative strengths were and then equilibrate to those strengths or was that something that you was pretty apparent immediately.

Diane: It was apparent immediately. I mean it's still even now Mallory's been gone a year and a half - a little more than a year and a half. Just in terms of our day-to-day life, I still manage all the logistics, the schedules. I still do all the same things I always did - keep the calendar, schedule all the appointments, nag everybody to death to make sure that they get what they need to be done. Whenever there's a medical condition that comes up, and there's been a bunch, I only call Mark and say, "okay, research this and figure out what kind of care we should get, whether it was for my mom or my dad or me or him or our son. His job was always to find out what was the best medical treatment, and my job is to do everything else.

Health Hats: Mmm. It's great that it was clear quickly. I think we had a similar experience. It didn't take long for us to figure out what our relative strengths were. And even now I have multiple sclerosis; it's my wife who does the research.

Diane: Wow, you have MS.

Health Hats: Yes. I have multiple sclerosis, and I'm a nurse, and I've been in health care for years and but when it comes to myself, you know, she's the one who does 90% of you know, figuring out, you know doing the research. It's. It says it to me. It's interesting about how we developed these roles.

Captain of her ship and the Control Freak 15:54

Health Hats: One of the things in the book, among many that I gravitated towards was Mallory talking about being captain of her own ship. You're a strong executive function person, and she's captain of her own ship. How did you balance that as she grew up and became more assertive herself?

Diane: Well, it's funny because she writes about the fact that I would turn her alarm clock off, so she wouldn't get up to go to school when I felt that she had gotten to bed too late or was under the weather and needed more sleep. So, I had my manipulative ways of getting her to do what I thought was in her best interest. But simultaneously, I would invite her entire team over for breakfast lunch or dinner at a moment's notice. And so, I think she recognized that I was happy to help, not just with a negative, but also with the positive. I often arranged for dinner parties here. We Sunday night dinner every Sunday so that she could participate in life with the easiest possible access to events. And that's why we did a lot of stuff in the home. I think that, for the most part, she understood that I was trying to make her life better. Once in a while, we would have our fights, and a very big fight happened when she was 16. Because she was walking around the streets of Santa Monica barefoot. I was freaking out thinking that if she happened to have cracks in her skin and bacteria from feces on the sidewalk would get in. I remember that period is being particularly difficult. Having a lot of tension between us. At that point, I asked Mark to intercede, and he didn't like to do that, but he did it on that occasion.

Unforgiving Cystic Fibrosis 18:40

Health Hats: Mark's your husband. Okay, uh-huh. I interviewed a friend of mine who has Sickle Cell and one of the things that her mother said was letting her daughters, who had Sickle Cell make their mistakes and live with the consequences. That in the long run that made them more fighters.

Diane: Well, CF is unforgiving and doesn't give second chances. That was not an option in our world.

Health Hats: Okay? Say more about that. This is something I don't know that much about.

Diane: If you have an exacerbation and you don't take care of yourself, your lung function can go down and not necessarily go back up. And since it's a progressive disease, you can't afford to take chances and the people who have not been compliant don't do as well. It's been documented, well documented in fact. So, fortunately, because my husband and I do have an education and we have access to good health care. We were able to impose a sense of family order, for lack of a better way to describe it, early on. There was zero tolerance for non-compliance. Health came first. Fun came second. School came third. And then at one point, sports became, other than treatment, the single most important thing and that dominated the household. Because when you have CF, you have thick sticky mucus. If you exercise, it helps dislodge the mucus, which helps prevent or at least lessen some of the exacerbations. So, I was

not the mom that was saying I want A's on your report card. I was the mom saying I don't care if you get C's but you're going to go play sports and sports wasn't optional. I took her out of dance and ballet and music and painting and party girl stuff when she was three when I understood that her life would be better if she was an athlete. I imposed that on her. Initially, I think she was, "why can't I take a ballet class? Why do I have to go play volleyball?" But over time, it became her identity and I know that she came to appreciate it. And it's why she, I believe, writes so positively about our relationship. I think ultimately, she knew at the end of the day every single decision that I made was about her and her health and her happiness.

Health Hats: I love the picture on the website. There's a picture on the website of Mallory with her breathing equipment. She's working at the computer. It looks like she's quite engrossed in her work while in the middle of treatment. It seemed like the multitasking to maintain both her health and her actions really came out in that photo.

Diane: Well, one of the things I used to say to her is if you need to study, get it on audio and do it while you're on the treadmill. Or while you're doing treatment, get your homework done, so you can go out and play after whatever it was. She was unbelievably focused and very luckily naturally gifted in terms of her intelligence. Things did come easy to her other than her health, which is the tragedy but everything else. She excelled at sports. She excelled in academics. She was beloved by her friends. She was beloved by her doctor. She was beloved by her family. As they say, you don't get it all.

Gifts and superpowers 22:24

Health Hats: You were listing some of her strengths. In my family, we talked about superpowers when Mike was sick and dying. We would sit around the kitchen table and think about what superpowers were, which helped him draw on those. Was that something that that you guys did? How did you help her identify and capitalize on her strengths?

Diane: How did we identify them, or how did we get her to recognize them?

Health Hats: How did well how did she come to know what they were and use them as part of her toolkit in terms of managing everything?

Diane: I think she was just somebody who recognized early on that life was short and that there was a sense of urgency to everything and she didn't waste any time on drama with friends or sweating the small stuff. She had a unique ability, in my opinion, to understand what it was she was dealing with and recognizing what the priorities were.

Health Hats: That is a gift. For my son, he identified that his strength was accepting what is and for him that was "I wasn't born with a tattoo on my ass telling me how long I had to live." Here I am. What am I going to do now? How am I going to live this life that I have left?

Diane: Well, I think most people with a chronic illness that are smart, recognize that life is short and that it's a gift and don't let the small things get in the way. I certainly see that in the CF population. I've never

met such an outstanding group of people as CF patients who if they get to take a breath and it doesn't hurt, it's a good day.

See the show notes or my website www.health-hats.com for more information, to subscribe or contribute. If you like it, share it. Thanks.

The ship reflects its Captain 25:24

Health Hats: What what'd what advice would you give to other families that are dealing with these devastating chronic illnesses in their families?

Diane: Well, I do say that a ship reflects its captain and if you look put out, unhappy, stressed out, aggravated, imposed upon in any way because you have extra responsibilities and challenges because of your child, they will feel that, and they will know that. I think it's the responsibility of the parents to follow Mallory's mantra to live happy. I used to say no pity party, and my goal was to find the joy in every day. And Mallory had the mantra, live happy. I think that none of us know how long we have and I as somebody who has had 67 hospitalizations with Mallory each one ranging from weeks to months. I was very aware that there were a lot of people in the hospital that were not there because of a chronic illness. They were there because of a car accident or an accidental overdose from drinking. A college kid drinking and then for no reason at all they vomited aspirated and died. Just a bad set of circumstances. I do think that that changes who you are. I think if you're a wise parent, you recognize that you want to make your child have a happy life. You want to do whatever you can to make sure that their life is happy despite whatever their challenges.

Lessons from Mallory 26:45

Health Hats: Yeah, absolutely. When you look back on the various 67 hospitalizations? I can't imagine. When you look back on your interactions with the medical system, do you have recommendations that you would make that would have made your experiences easier?

Diane: Definitely. I mean hindsight's 20/20. I wish I had Mallory's book, Salt in My Soul, to hand to every caretaker that we were going to come in contact with because I think she does such a great job of articulating what it is that a patient needs and wants. But for example, one of Mallory's biggest complaints was when a nurse or a doctor would ask her about her bowel habits in front of one of her friends. No matter how many times I told them they'd never to get that. In retrospect, I wish I had a primer to hand to healthcare professionals. As I speak around the country that's the job I've undertaken. I wish I had done it when she was alive instead of waiting until she had passed away. But I was honestly too busy taking care of her to be thinking about educating a larger population. To honor her memory, that's what I'm doing.

Health Hats: It sounds like a question of dignity.

Diane: Absolutely.

Health Hats: What do you think? I should be asking you that I'm not.

Diane: Well, I think you should be asking me about Mallory's insights that she shares in the book. Okay, so you want to ask me, or should I just ask myself?

Health Hats: Tell me about Mallory's insights.

Diane: Well, when I when, I tour I've done the talk that I gave 59 times, and I have at least 30 more talks ahead. I share six insights, and I think the insights that she has related in her writing are worth mentioning every possible opportunity. One of them is about the need for balance with opioids and with pain management in this era of the opioid epidemic in terms of under- and over-medicating because Mallory writes about the fact that when she was in the most excruciating pain of her life, she was undertreated out of doctors fears of creating an addict in her. She wasn't at risk of addiction, and she was carefully monitored, and she was in serious pain. But she also writes about her fears about getting addicted. I think it's really important that pain management is taken seriously and addressed. They talk about personal this era of personalized medicine. But in fact, these guidelines are created, and they don't work for everybody. And so, I think that's one important insight that she shares. She also taught me and helped me understand that when you have a chronic illness, you become an accidental expert not in the beginning but over some time. And that in fact doctors should be looking to patients and their families for insights. Again, I refer people back to Salt in My Soul because Mallory's done such a magnificent job of explaining it. But I think that the healthcare professional would do well to listen to more patient studies and patient case studies and parent advocates. I think they do know a lot. It's not what you find in the textbook, but it's what you experience on a day-to-day basis. One of the things I talked a lot about - and ironically there was just an op-ed in the New York Times a few weeks ago - is about how underrated sleep is in the hospital. I do think it's starting to change. But one of the things that made me most unpopular in my hospital stays was the fight about sleep. When they would want to come in to empty the trash, or they want to come in and write on the board the daily goals. Or when they would want to have somebody that was a young student or resident come in and do a whole intake at seven in the morning when Mallory had been up till really late past midnight. I became a very unkind unpleasant person when they would not accept the first no; you can't come in. So, I would hope that people would read her book and understand that sleep is a vital part of medicine. Now the ironic part of all this is that every day in the news now you see about how we're not getting enough sleep and it's causing dementia. But for some reason, they fail to remember that when we're dealing with chronically ill patients. The reason I think the op-ed was so dramatic was that it was written by a young doctor who has a child, who said that for the first time when her child, who has a chronic illness, was in the hospital. She understood that the medical teams didn't take sleep seriously enough. She was going to work to address that, and that's something I think needs to be talked about much more openly. So, there's pain management, there's sleep. There's becoming an accidental expert. Another thing that Mallory writes about that I think is worth sharing is that doctors and caregivers should favor giving more information than less. The anecdote I use is when Mallory was called in for transplant the first time and we waited 24 hours and they didn't tell us until the morning after 24 hours of being up all night that the lungs that she had been called in for we're going to somebody else because she was a backup candidate. If they had told us that in the first place, it would have managed our expectations, as a result, it was

devastating, and it didn't need to be it could have been, "hey, this is a dry run. You're probably not going to get them. Come on in. Hangout, listen to music. But you know just in case they don't work then you'll get them." So, I do feel strongly that Mallory taught me that giving more information is very important rather than giving less information. There's just a number of things that you can learn from somebody who has had a chronic illness who then takes the time to talk about it or write about it or sing about it or draw about it. It doesn't matter what the medium is. But we should look to patients for what it is that they can share with the rest of us because they often times do know way more than we do because they have that innate understanding that life is short and what's most important.

What does healthy look like now? 33:23

Health Hats: Yes, so now that you've been through all of this do feel like your view of what healthy is has changed?

Diane: I think it's become honed as opposed to changed. I think I always knew. I mean I grew up in a family where my dad in his 50s, when I was in high school, went in for a routine checkup and the doctor said if you don't have five bypasses in the next 24 hours, you're going to be dead in a week of a heart attack, and he went in the next day. We were going on vacation my parents sent us away without them so that they could get my dad the surgery that he needed, and we wouldn't be around to distract as we were old enough at that point to take care of ourselves. Definitely taught me that early detection and taking care of yourself is your responsibility and that in fact, my dad lived to be 93. He died last year right after Mallory did. But he had a bad heart. He had five bypasses, and then he had four bypasses, and then he had electrical Pacemaker, and he had all kinds of pride. Had a hip replacement. He had Retinitis Pigmentosa. He was almost blind at the end. He had a million things wrong with him, but he got up every single day and exercised watch for an hour until his hips wouldn't allow that, and then he brought a rode his bike every day for an hour. So, he taught me a sense of responsibility in terms of taking care of your health. Between that and what I learned taking care of Mallory; I have come to understand that one of the biggest societal problems we have now. And you see it every day in the headlines is diabetes, which is related to lifestyle choices. And a lot of that is about education because those of us who are lucky enough to live a life of privilege, it's very easy to get the information, but there are many underserved communities that don't have that access. They don't know or aren't able to get fresh vegetables or go to the gym or do all the things that we do, and I don't think for me that I've changed. I think I've just become more intense about taking care of myself and imposing that on the people that I am able to exert some influence over.

Health Hats: Yes, well, thank you. I appreciate that. I appreciate your time. I look forward to seeing you at Boston Children's Hospital on July 11th. Is your MS at a point where it's debilitating or is it just an inconvenience?

Health Hats: I think it's seriously annoying. I'm a two cane and electric wheelchair guy, but I'm very active, and I lead a full life. Nothing like what Mallory went through. That's for sure.

Diane: Well, you've lost a child and you have MS and you're in a wheelchair. I think you have a lot to teach people, as well.

Health Hats: Thank you. I look forward to meeting you in person.

Diane: Thank you and thank you for having Salt in My Soul as your book club book. That's very meaningful.

Health Hats: Well good.

Diane: When are you all meeting?

Health Hats: I think about three weeks. I will send you an e-mail with the highlights.

Diane: I'd love to hear about it.

Sure. Thank you so much. Thank you. Bye. Bye.

Reflection 38:37

So much to reflect on.

Lessons from Mallory are profound. Dignity, privacy, sharing information, pain management, accidental expert, Live Happy.

I love how sports became #1 for Mallory – good for the lungs and good for the soul. A few years before Mike died, he said to me “If you want to be a musician, you gotta play.” I've been playing bari sax now for 20 years 4-6 hours a week. The neurologist says that's better than the infusions I get. It's good for my lungs and keeps my breathing muscles strong. It's a big horn with big keys and keeps up my dexterity in my fingers. Music creates new pathways in the brain. Plus good for the soul. I thank Mike every day for the push.

I will publish one more episode of this series next week. I think it will include clips of all 14 interviews and further reflections. Then it's time to move on to new topics. OK, my readers, listeners, and lurkers take it from Mallory and Diane, Live Happy!