

## **A Note from Diane Shader Smith, Mother of Mallory Smith**

**SALT IN MY SOUL: AN UNFINISHED LIFE** is not just a guide on how to live with an illness. It's a guide on how to live – and happens to be perfect for college students.

While Mallory's experiences are unique, the observations and conclusions she draws from those experiences are universal:

- How to deal with difficult body image issues.
- How to fall in love when you are afraid to make a commitment.
- How much and how soon to tell a new love interest – or new friends – about something deeply difficult or embarrassing to yourself.
- How to balance social life, academics and health.
- How to decide when it's time to change majors.
- How to figure out what you love to do... and how to give yourself the kind of schedule where you actually make sure you do it.
- How to find gratitude in every day no matter what challenges life is handing to you.
- How to be resilient.

My daughter started writing in her diary when she was 15. She wrote regularly and insightfully about the experience of being a girl growing up with the ups and downs and loves and losses that we all face – against a backdrop of a deadly illness. As Mallory wrote:

“Many of the feelings I write about are too difficult to share while I'm alive, so I am keeping everything in my journal password-protected until the end.”

What I came to understand after reading Mallory's journal is that it's full of wisdom we all yearn for:

- “I feel like people with CF are privy to secrets it takes most other people a lifetime to understand. How lucky we are to be alive.
- How lucky anyone is who has their health.
- How we should be appreciative of anything that's in our control since our health is not.
- That we can leave behind a legacy when we go that will impact others.
- That simple things are often the most beautiful.
- That love and happiness are the most important things to strive for.
- That ultimately, we shouldn't give a damn what other people think because everyone's making their own way and everyone's facing different struggles that others aren't aware of. “

### **MALLORY'S WORDS:**

#### **ON GRATITUDE**

CF is a disease that does a lot of taking: of dreams, of time, of travel, of freedom, of potential, of plans, of lives... At the same time it does give. It's given me the creativity to re-imagine my life,

a skill I wouldn't have needed to develop if everything had been easy and nothing was impossible. It's given me a community of men and women who astound me every day with the strength and endurance they use to ride through daily challenges and life or death struggles... It's given me a way to cut to the chase in my friendships and relationships... It's given me the mountain that been waiting for me all my life. The mountain we're all climbing every day.... It's given me empathy and gratitude and courage and humor and heartache and happiness."

### **ON WHY TO KEEP A JOURNAL**

"I've always wanted to be able to look back at some tangible body of writing and see the evolution of my outlook, how my beliefs and feelings and thoughts have changed over time in response to my life experiences."

### **ON MEMORY**

"I have an interest not only in legacy, but also memory... in how as time goes on, what was once vivid, real, present, becomes slippery and vague and trickles away like water cupped in your hands."

### **ON READING**

"I read a lot. I read because the vast wholeness of existence (the immeasurable, multifaceted beauty of what it means to be human) cannot be perceived through one life. I read because there are a lot of things I can't do. I'll never be like the characters of On The Road, picking up and hitchhiking across the country on a whim... But through the eyes of the character Sal I got to see the beauty of spontaneity and the sheer emptiness of wandering forever and never setting down roots."

### **ON BECOMING AN ADULT (written during Senior year of high school)**

I don't feel like an adult. I don't wanna act like an adult. Adult life seems so structured and tame. Adults have so many responsibilities, they lose their sense of humor. It seem like everything goes downhill from the time you're twenty-five, and especially once you get married. Maybe I just think this because I don't know anyone I would ever want to marry."

### **ON QUESTIONING IDENTITY**

Maybe this is why it's so hard for me to write a college essay, because you have to write about who you are and I have no idea who I am. I can't pick a college because I have no idea who I am. The qualities that people always say I have – the I'm persevering, positive, determined – I don't feel like I'm any of those things. I happen to have a disease and do what the doctors tell me to do so that I don't die. I don't call that persevering."

### **ON AMBIVALENCE ABOUT GOING AWAY TO COLLEGE**

I know that college will be amazing, but I haven't had enough of what my life is now... moving out? I'm a CHILD. It's a joke to think that I could live on my own. I sit in my bed that is ten feet from the kitchen and ask my mom to bring me green beans. I ask my mom to email my teachers when I get too sick to finish an assignment on time... and I ask my dad for tutoring constantly... I just wish my family could come with me to college."

### **ON GETTING INTO HER TOP CHOICE COLLEGE**

“I GOT INTO STANFORD!!!!!!!!!! I can’t believe it. I’m so happy!!! The hard work that I’ve done my ENTIRE LIFE has paid off. I no longer have to have perfect grades. What was it about me that made them accept me??? I’m just in shock.”

### **ON WORKING WITH THE OFFICE OF ACCESSIBLE EDUCATION (OAE)**

“I went to my meeting with Teri Adams, who works for the OAE, which basically helps people with medical conditions and disabilities.... After dinner they broke us into groups for a scavenger hunt.”

### **ON MOVING INTO DORM LIFE**

“Moved into my dorm yesterday and spent my first night here! ... I’m also soooo happy with who they picked as my roommates. Sabrina and Adelle are supportive of me and my special needs... We had dinner and a dorm meeting where we went over rules and polices and did an icebreaker. I did ataluren and inhaled meds while the RA was talking and this guy came over to me and asked what I was doing, why I was using a nebulizer, what my health condition was, whether it was mild, moderate, or severe, whether I would die soon, how I felt about it all and whether I believed in God.... People looked over and clearly wondered what was going on. It was a little off-putting at first, but I told myself to get use to people staring.”

### **ON PANIC ATTACKS – SOPHOMORE YEAR**

Had a couple of crazy breakdowns and panic attacks. I’ve been on an emotional roller coaster for weeks. It’s my fifteenth day in Stanford Hospital... The night of Nov. 3 I broke down and... was just sobbing in the lounge, thinking nobody would understand.”

### **ON FEAR**

“I don’t know why I’m so afraid of EVERYTHING. All of a sudden. I’m afraid of being myself, I think (which makes me worry too much about how people perceive me). I worry that no one will ever love me (which may seem ridiculous but if I can’t love myself how could someone else?). I worry that I’m losing who I am and losing the ability to have fun. I fear that I’m succumbing to depression... I fear that the choices I make are going to cut my life short. Would I rather live a long life and modify my expectations for how that life will look? Or would I rather have the “go hard or go home” mentality and go all-out, love life, have fun, live like everyone else, not look back and accept that what happens, happens?”

### **ON FRIENDSHIPS**

“Developing friendships was such a huge goal of mine for this year, branching out, making new friends that aren’t just acquaintances. When I’m stuck in the hospital I can’t meet anyone new. I can’t participate in campus life, I feel like I’m going to fade away and be forgotten.”

### **ON WISHES**

“It’s funny how over the years my wishes have evolved, like what I say in my head when my eyes are closed and I’m blowing out the candles... When I was young I wished for specific things: for someone to have a crush on me, to get to go on a trip,... Then I would just wish to be health, nice and simple. Then it was, “I wish to be health and happy.” The second half was added

on because that was starting to feel unobtainable. Now it's just "I wish to be happy." The most achievable of all, something I used to wake up feeling and take for granted."

### **ON DIETING**

"I'm going on a permanent diet starting today. I'm going to eat less and absolutely no sugar. I probably won't be able to follow the zero sugar thing but I'm going to try really, really hard.... I just want to be skinny and feel good internally and good about my body and right now I'm none of those things."

### **ON DIVULGING ILLNESS**

"With a burgeoning relationship, I wonder how much to divulge to Jack about the possibility that dire things could happen to me, and my fears that they will. My physical fragility and my underlying emotional anxiety. Will he run away? Will he view me as too fragile and stop seeing me as an equal, a partner? Will he want to go the long course with someone who might not be able to make it to the finish line? Or will he make up some excuse and duck out once he realizes the reality of this fucked up, shitty, relentless, unforgiving, merciless disease?"