

FIELD NOTES | SPRING 2018

Lily Darwin

By Elizabeth Lahti

Lily Darwin slumps in her hospital bed. Her legs are doughy and her temples wasted. She has fleshy bags under her eyes and her spine curves like a tree after an ice storm, but her voice is clear. I have come to talk to her about how she wants to die.

"I wanna live to be eighty-eight," she says. "That's how old my mother was." Lily has mentioned this before.

"Did I tell you they found a brain tumor when she was thirty-five? They told her she had six months. She lived another thirty years."

I do the math in my head. It doesn't check; when you are eighty-seven years old, memory and magical thinking often overlap.

"When is your birthday, Lily?" I ask.

"December."

I look at my watch, a reflex when I don't know the date. I silently hope Lily doesn't think I am looking at the time. She is my favorite ward patient and when I sit at her bedside, I enjoy our time together. Then I remember it is only January.

"You just turned eighty-seven." I say. I count the months till December in my head. Lily slumps forward again.

Over the past week, I have gotten to know Lily. Though her body fails her, she tells the stories of her life with vigor. The first day I meet Lily she tells me she joined the army at age twenty-two. She recounts leaving her sister and mother behind, putting on her uniform and reporting for duty.

"I wanted something more," she said.

The second day I see Lily, I ask if she has a photograph of when she was in the service. She nods and the edges of her mouth turn up in a flash of a smile.

"I'll ask Michael to bring one in," she says.

On the third day, Lily's son brings a framed photograph to the hospital room and hangs it on the wall between the bedside commode and the oxygen tank. The photograph looks out of place, like it should be in a living room, not hanging askew in a hospital room. In the photograph, Lily comes alive. I see a young woman with smooth skin and dark eyes. Her hair is pulled back from her face, and it falls in waves under her uniform cap.

"What do you see when you look at that girl?" I ask.

"I was never very pretty, you know. And I didn't think I was very smart either."

She tells me about a time she worked the night duty. She found personnel files of all the girls in her unit. She didn't hesitate; she peeked in every single one.

"I'd always thought I was stupid," she says. "But when I looked in those files, I saw I had the highest IQ of any of the girls."

Lily's secret changed her. Her love of science and new found confidence led her to assignments in hospitals. She left the service and worked in a lab. One day Lily accompanied her mother to a neurology appointment and asked to see their EEG machine. By the end of

the afternoon, she had been hired to reconfigure the equipment and coordinate the lab. A few years later, she co-founded a technology school for women.

After one story, I laugh and say to her, "Lily, you have lived such a full life." She is quiet for a moment. Then she takes her hand from mine, looks away.

"But I've never been in love." She tells me she never loved her husband. She only wanted children.

"Back then, the only way to have children was to be married."

Listening to Lily's stories gives me a window into who she is. She is not an eighty-seven year old with critical aortic stenosis, a rising creatinine, and debilitating neuropathy, but Lily, the young woman who peeked in the files, the girl who left home, the daughter who cared for her mother, the scientist and teacher, the mother who beams at the mention of her childrens' names. Each story tells me something new about her.

A friend once asked me how I get to know someone during a short hospital stay. How can I make potentially life-changing decisions when I've only just met someone? In the question, I believe my friend longs for an ideal: a doctor who knows a patient from the time she is born until the time she dies. Those doctors are out there, but in our current health care system, they are few and far between. And often the primary care physician is not the one caring for a patient in the hospital setting. Although many hospitalists meet their patients for the first time during an acute illness, there are many opportunities to know the patient.

I tell my friend, "I listen to their stories. Not just what they are about, but how they tell them. What do they include, what do they leave out?" I look for an invitation to join them in their illness. The invitation might be subtle and often requires prompting, like asking to see a photograph or recall a favorite memory. I rarely start a conversation with, "Do you want to be resuscitated?" Instead I ask questions about who my patients are, what is important to them. With Lily, I ask her to look back before she looks forward. I don't know what details will surface, but I listen to her stories and how they are built. Where does the narrative start? Who are the characters? Some questions lead only to awkward silence. But others light up the storyteller in ways I couldn't anticipate. Some questions prompt family members to chime in or pull me aside when we meet in the hallway or the cafeteria.

After hearing the stories, I frame my questions and responses in the context of my patient's life. I talk about the mechanics of her failing heart and kidneys differently with Lily than I would with a ship's captain, a biology teacher, a poet, or a mother who has lost a child. The stories of my patients' lives give their illness meaning.

For Lily, her story is about regret. But it is also about family. And love.

"She lived to be eighty-eight, so I want to be eighty-eight."

But time is running out for Lily. She might not make it to eighty-eight.

"Lily, do you want to die in the hospital or at home?"

"I don't want to die," she says.

We pause. In the silence, we let the words sit between us.

"You know your heart is sick. And we can't make it better," I say.

Did I ever tell you about my mother?" she asks.

"Yes," I say. And I wait because I know Lily has more to tell about her mother.

"We were all at home that day. My sister, my aunt, and my mother. She was in bed, you know. Her breathing was funny. My aunt said to take her to the hospital, but I knew the hospital couldn't do anything. I was with her in the room. Her lips turned blue. And then she reached out to me with her hand. I took it and I crawled into the bed next to her. She looked

at me and closed her eyes. I said to her, 'Mama. I love you so much Mama.' And then she died."

In telling me of her mother's death, Lily cracks open the door and invites me in. That afternoon we talk mostly about the day her mother died, and Lily inches toward connections between her mother and herself.

The next day Lily chooses to go home. She chooses to take a medicine that helps the terrible pain in her feet, even though it might make her kidneys worse. Lily chooses to check the "DNR" box on the pink form that accompanies her chart. For others who do not know Lily, that checked box might only mean the difference between calling 911 or not. But for Lily, and for me, that little box represents a giant window through which her whole life shines. Hearing the stories of Lily's life, the stories that make her who she is, is what guides me to check that box with her. The stories Lily shares with me show me not how Lily chooses to die, but how she chooses to live.

Elizabeth Lahti is a teaching hospitalist and Director of Narrative Medicine at Oregon Health & Science University in Portland, Oregon. She writes poetry, short fiction, and creative non-fiction, with a focus on the experience of illness from multiple perspectives. In 2015 she co-founded the Northwest Narrative Medicine Collaborative, an organization dedicated to bringing healthcare providers, patients, caregivers, and artists together to better understand the multiple perspectives of health and illness through narrative. Her work has been featured in the Journal of General Internal Medicine, the Annals of Internal Medicine, and the Elohi Gadugi Journal. Two of her short stories have received honorable mention from Glimmer Train.