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Learning to Say Goodbye

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“It’s no surprise you don’t sleep at night,” said the therapist. I had just told him that I care for children with epidermolysis bullosa, a rare and life-limiting genetic skin disorder often called “the worst disease you’ve never heard of.”¹ In children with this disease, the slightest shear force causes their fragile “butterfly” skin to separate from the dermis below, leaving behind a battlefield of open wounds.² Over the past 15 years, I have stood guard from birth to death over so many butterfly children. To carry on, I separated myself from the stories of their deaths, storing those hardest moments in the recesses of my mind. Yet in the quiet of the night, memories of their faces and voices often visited me.

The therapist nodded, pausing, before saying, “I think it might be time for you to figure out how to say a proper goodbye.”

I remember the first time I didn’t say goodbye. I had been working for the previous year with Steve Berman in the country’s largest epidermolysis bullosa clinic. Well into his 60s, Steve possessed an energy unparalleled by that of anyone I had ever met. So I wasn’t completely surprised to be jolted out of sleep at 2 a.m. one night to find his name lit up

on my phone. “Jamie, I’ll stop by to pick you up on our way to the hospital. Hannah is dying.” Twenty minutes later, we walked into a quiet intensive care unit (ICU) bay. Steve had known Hannah since her birth, and she had just celebrated her 16th birthday. Now she lay there unconscious, septic, her eyes closed, her face swollen from kidney failure.

I stood silent and motionless, a young attending, not wanting to do anything that took the focus off Hannah and her family. Throughout my medical training, I had been told (or perhaps had told myself) that a patient’s death was not supposed to be about me.³ I needed to be present for the medical needs while being invisible for everything else. So it surprised me when Steve bent over Hannah and gently placed a kiss on a small patch of unaffected skin on her forehead. “I am so proud of you,” he whispered to her. “It’s OK to rest.” Later, Steve pulled me aside. “They are my family,” Steve said. “I’ve been with these kids and their parents for their entire lives. I can’t walk away without kissing them goodbye.”

It took me several more years of visiting bedsides and attending funerals with Steve before I took his advice.⁴ The night I finally did, I was standing guard

in the hallway outside the hospital room of Rahm, a 7-year-old with a severe form of epidermolysis bullosa that resulted in heart failure. Steve was out of the country, but I knew that he would want to know that Rahm was dying. When Steve’s name finally lit up on my phone, I explained the situation. “Will you make sure to tell Rahm that I’m proud of him?” he asked from the other side of the world. I assured him I would, although I didn’t know quite how. Steve and I had both taken care of Rahm since his birth, but Steve was his family’s anchor. Now I was the one standing in the hallway escalating the pain medications, and with each increase I felt like I was stealing time from his parents.

Working up the courage to ask for time with Rahm, I quietly entered the room. “Dr. Berman asked me if I could say goodbye to Rahm for him.”

They nodded, then added, “Dr. Feinstein, thank you for being a part of our family. Rahm has always loved you.”

I walked over to the little boy, who was snuggled into a fleecy orange blanket. His eyes were closed. “Rahm, it’s Dr. Feinstein. Dr. Berman wanted me to tell you he’s proud of you,” I said. “I’m proud of you, too.” Then, I did something I had never done

before. I bent over Rahm's face and lightly kissed a soft patch of perfect skin on his forehead. "It's OK to rest," I said.

When I pronounced Rahm dead an hour later, I knew that I had wanted and needed to say goodbye and that I almost hadn't done it.

It was now becoming clear to me that at the end of life, I was part of each child's story and — equally important — the child was part of mine. And when I stopped insisting on separating my patients' stories from my own, I began to acknowledge that I, too, needed certain things in order to find a sense of peace. My work with the therapist was helping me understand why Steve needed to kiss his butterfly children goodbye. Although I would have been content to end the life lesson there, I remember the moment when the world decided to come full circle.

I was on the indoor rower in my icy garage when Steve's name lit up on my phone. A nagging worry that I had been suppressing set in at full force. I hadn't seen or heard from Steve in the several weeks since he had finished immunotherapy for an indolent lymphoma. When I answered the phone, a soft, unfamiliar voice asked, "Could you come to the ICU to see Steve? He's asking for you." Twenty minutes later, I walked into the

adult hospital, which was strikingly devoid of the balloons and flowers that were painted on the walls of the children's hospital next door where Steve and I had worked together for nearly 15 years. I arrived at the ICU bay where Steve lay. Behind the dialysis catheters and jugular lines, his wiry white hair was unmistakable. I felt a quivering start from somewhere deep in my body.

"Who is that?" he asked.

"Hi, Steve, it's Jamie," I replied.

I leaned in, and his crystalline eyes focused directly on mine. Never one to skirt the truth, Steve said, "Jamie, I'm dying. I wanted to say goodbye."

"I know, Steve. I want to say goodbye, too."

We spoke for several minutes. Steve asked me if I would give a eulogy at his funeral. Then he beat me to the words that were on the tip of my tongue.

"I am so proud of you," he said.

Still up close where he could see me, I hovered over him. I touched my lips lightly to his brow with the weight of a butterfly landing on a branch. I didn't want to cause any more pain, but I wanted him to know I was there. His skin was soft and warm.

"It's OK to rest," I said.

But I knew I needed one more thing for myself.

"I love you, Steve."

"I love you, too, Jamie."

I turned and walked peacefully away.

In the year since Steve died, I have also started to say proper goodbyes to the many children who used to keep me awake in the darkness of night. Now when their faces appear in my mind, I take the opportunity to remember their stories. I think about the parts they have played in shaping my own story. And — a little late, but better than never — I tell them out loud that I love them. Then, having returned the energy of those memories back into the world, I finally sleep.

The patients' names and other identifying details have been changed or omitted to protect their families' privacy.

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