To My Young Sons

BY CHRIS FEUDTNER

Someday I suspect you’ll ask me what I do. You’ll ask, “What is pediatric palliative care?” I wonder what I’ll say, whether I’ll try to explain the important yet difficult truths of this job or simply recollect the encounters of that day. This morning, for instance, having gently knocked, I step into a patient room and close the door, leaving behind the hospital hubbub. The mother sits on a blue sofa by the window at the far end of the room, her baby in her arms, wrapped in a white blanket. Standing next to her is her own mother, hands on her daughter’s shoulders. I approach, passing the empty crib, the tray of medical supplies, the silent monitors, and I sit at the edge of the sofa. Midmorning sunlight cascades through the window, enveloping us. The mother looks at me, tears on her cheeks. We say nothing. Then, after a while, she says, “It happened so peaceful. I never knew someone could die so peacefully.”

Several hours later, in another hospital room, bending over to examine a teenage boy, I see a maroon line of dried blood where his teeth meet his gums. Pale lips open, sallow eyelids closed, the sound of his unconscious breathing fills the otherwise quiet room, his chest rising and falling conspicuously yet adagio. His bedside is ringed with family. One holds his limp hand; another strokes his black hair. I check the doses on the medication pumps infusing drugs through the IV line. The father steadies his gaze on me, and I ask him the question that we agreed earlier was, at this juncture, the most important question: “Do you think your son is comfortable?” He nods.

The final patient I visit today is, at that moment, alone. The mother and nurse had just bathed the child. Even at some distance, she smelled like lavender, her brown hair combed and tied back with a purple ribbon. Propped up in bed, pillows supporting her twisted limbs and back, she is looking in the direction of the TV, which plays her favorite video. I greet her but expect no response. With the odor of illness absent from the room, I know immediately that she has improved. Glancing at the record of her temperature, I see further confirmation of this impression. Then the mother re-enters the room, and from the look on her face, I am sure that this crisis has ebbed, even as we both know that, like the ocean tides, the physical havoc wrought by the illness will someday flow again. “Hi, doc,” she says. “Well, this is a much better day. … This is what I was hoping for … just to get her back to that place where she’s stable enough to go home, at least for a while, and do the few things that she really loves to do.”

In the car driving home, I weave through the traffic. So many thoughts, feelings, images, decisions from work clutter my mind. Navigating is always a challenge. I pull into the driveway, stopping short of the yellow kickball and red tricycle. Walking toward the door, I ready myself, trying to be as present and mindful as possible. From the foyer, I hear both of you shout out, “Daddy!” and come tearing around the corner, running up to me with your arms outstretched. Walking toward the door, I ready myself, trying to be as present and mindful as possible. From the foyer, I hear both of you shout out, “Daddy!” and come tearing around the corner, running up to me with your arms outstretched. Savoring my favorite part of the day, I pick each of you up and jostle you around in the physical play of love.

Just how I will answer your questions about my job is not for now, but for another day – a day I look toward with uncertainty, yet with conviction that, despite the inscrutable and often cruel workings of fate, we must work to create our hope.

Chris Feudtner, G’89, Gr’95, M’95, is a pediatrician specializing in complex chronic conditions and palliative care at the Children’s Hospital of Philadelphia and in the Division of General Pediatrics at the University of Pennsylvania. He lives with his wife, Lynda Bascelli, a family-medicine physician, and their sons, Jack (3 years old) and Hank (2).