

ESSAY

Inhumanity or In Humanity

Ann F. Beach, MD, FAAP

Edna Disher. I have never forgotten her name. She was my first patient who died.

It was 1977, and I was a third-year medical student, doing an oncology rotation. Mrs Disher was a frail, white-haired, once-beautiful Southern lady dying of cancer. I remember looking at her and realizing I was seeing the face of someone who wouldn't live to leave the hospital. Taking care of a terminal patient: it was a first for me then. She reminded me of my sweet grandmother, so entering her room led to tenderness, horror, angst, and a catch in my throat.

This was in the day of never-give-up cancer treatment. Hospice was a brand-new concept and unpopular with my attending physicians. Last-ditch efforts, surgical or pharmaceutical, were the norm. So, Edna, in her 80s and already frail with wide-spread metastatic cancer, was getting aggressive, hopeless chemotherapy. Her white blood cells had been wiped out, so she had no defense against infection and thus was in an isolation room. Because of this, the beautiful flowers sent by her church, neighbors and relatives were forbidden in her room; germs floating in the water or nesting in the flowers could be lethal to her. So, they sat in a forlorn cluster in the hall on the floor outside her room. Even sadder, all her get-well, we love you, and thinking of you cards were sterilized by autoclave before she got them. The heat and moisture of the autoclave made the ink run, so she never knew who her mail was from or what the loving letters said. My first terminal patient with cancer. New to the medical world, I thought this was how it was, and I just needed to steel myself and get accustomed to it.

Occasionally, I would hold up lovely flower arrangements at her opened door for her to catch a glimpse of. Her sad, tired husband would shuffle in, late at night, and try to decipher the blotchy ink in her sterilized mail. When I, the innocent medical student, the lowest person on the treatment team totem pole, asked the attending why she couldn't just have her mail and flowers since she was going to die anyway, I was shushed like an embarrassment.

It has been 45 years since I met Mrs Disher. I don't remember her cancer type, the treatment that was decided upon, or any of the medical facts I was supposed to learn while taking care of Mrs Disher. I remember the flowers and the inhumanity of what we did. I remember trying to learn what the attending was teaching; cancer and death are the enemies and must be fought until the bitter end. I was to learn that kindness and caring and gentleness were not important in the all-consuming battle against death.

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Address correspondence to Ann F. Beach, MD, 3325 Paces Ferry Rd, NW, Atlanta, GA 30327. E-mail: annbeach08@gmail.com

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Children's Healthcare of Atlanta at Scottish Rite, Atlanta, Georgia; Department of Pediatrics, Emory University School of Medicine, Atlanta, Georgia; and Department of Pediatrics, Morehouse School of Medicine, Atlanta, Georgia

1979. Jason Knight. The first patient I made a terrible misjudgment on. I was a pediatric intern on a rotation on the general pediatric wards. Jason was 8, had a profound immune deficiency for which there was no cure, and was hospitalized with pneumonia. He had been in the hospital for months. He seemed to be doing better. Late one afternoon, his weary mother asked me if it would be a good night for her to go home and see her other children. She hadn't been home in weeks. I told her he was stable and of course she could go home. I didn't think a thing of it. He was fine overnight and had an uneventful morning.

We, the team, were clustered outside his room making morning rounds when he unexpectedly stopped breathing. We were right there. We ran a full code for a long time, with excellent CPR, all the right code drugs, and all the best doctors. He died right in front of us, in spite of everything.

After the code was called, and he was pronounced dead, we all caught our breaths. We were shell-shocked, standing outside the room, debriefing, trying to figure out how we could have anticipated this. How we could have run a better code. How we could have saved him. I looked up as his mother rounded the corner at the end of the long hall. She saw us, saw my face, and knew. She dropped her bags, moaned, and ran for the room. The one night she had gone home, and I had told her to go. Her boy died without her. My fault.

I now know he would have died anyway. And I know it couldn't have been predicted. But I have not forgotten that her broken heart was worse because of my decision. A different kind of inhumanity. Inadvertent, but terrible, nonetheless. For my entire practice lifetime, much of it in a pediatric hospital, I thought of Jason when tired parents asked if it was a good night to go home.

1981. Timmy Smith. When I met Timmy, he was 13 years old and had been in the hospital for over a year. He'd gotten a routine Strep throat infection, and then developed the rare complication of

glomerulonephritis, which led to eventual kidney failure. He had been on dialysis, received 2 kidney transplants (1 from each parent) and rejected them both. He'd had every complication imaginable. It took me an entire afternoon to read his multivolume chart and understand everything that had gone on with him.

He was sick of it all. He hated the hospital. He was weary of feeling bad, taking pills, having blood drawn, and spending long dreary hours in the dialysis center. He mostly rebelled against his restricted renal diet: low salt, low protein, and carefully calculated calories and fluid intake.

But I was a junior resident now, halfway through my pediatric training, and had learned a few things. I got permission, after lots of begging to the head nephrologist, to take Timmy out of the hospital for a day. I cajoled the dialysis nurse into "running him dry" during his dialysis session, taking off extra fluid from his body. We packed a bag with all his routine and emergency medicines. Then he and I, along with a couple of other residents, piled into a car and took off to Ringling Brother's Circus! We ate hot dogs, peanuts, popcorn, French fries, ice cream, and cotton candy: all the forbidden foods. We guzzled sodas. We watched the high wire act, the trained elephants, the contortionist, and the trained monkeys. We threw darts and won stuffed animals. We did everything Timmy wanted to do that day! By the end of the day, Timmy was exhausted and, for the first time in a long time, happy. We arrived back at the hospital late, didn't tell anyone where we'd been, and bundled him off to bed. His blood pressure and fluid status were hard to control for the next few days and his nephrologist wondered why. None of us said a word.

Timmy's hospitalization lasted longer and was still hard and discouraging. But because of the League of Funsters, as we came to be known, there were occasional trips outside the hospital. Timmy got to do things 13-year-old boys should be doing, like going to concerts, learning to drive a car in an empty parking lot, and holding hands with his girlfriend in the movies. Many years later, I

learned that Timmy's nephrologist knew exactly what we were up to. He was turning a blind eye and had sternly warned all the nursing staff to make sure no one "caught" the League of Funsters in action. He knew what was important and was happy to see us learning as well.

Perhaps I was learning how to be humane.

1982. Jamie Fuller. Jamie, a beautiful red-headed 4-year-old, had acute myelogenous leukemia. I'm a red-head and I imagined I would one day have children who looked like her. She had been in and out of the hospital during my 3 years of residency, and now there were no more chemotherapies to try. She and her family had gone home to their cozy house at the end of a gravel road in the North Carolina mountains. They had no phone, so we didn't hear from them often. Pediatric Hospice did not exist there, so family and friends were helping out as much as they could.

One day, on a whim, I went to visit. Her mom ushered me into the quiet living room, where relatives sat in uneasy silence, watching Jamie. Barely conscious, she was propped up in her little kid rocking chair, cushioned with pillows. Her eyes were swollen shut, her skin a ghastly gray, her stertorous breathing filled the room. I touched her and realized she was profoundly bradycardic. I retreated to the kitchen with her mom and warned her Jamie wouldn't last much longer. She looked relieved and told me none of them could take much more. Finally, at dusk, the struggle ended, and Jamie died. As I helped her mom bathe her limp body and put on clean comfy pajamas, she said to me, "You are an answer to prayer. I didn't want a stranger pronouncing my baby dead, and I asked God to send me someone who knew Jamie. And here you are."

Why had I chosen that random day to go visit? I suppose I was meant to be there: someone who loved Jamie, who could pronounce her dead, just what her mom had prayed for. I was part of a much bigger, extended family of care for Jamie.

And that terrible day was much more humane because I happened to be there.

We must teach residents, and learn ourselves, that medicine doesn't have to be inhumane. We need to change the focus

from prolonging life at all costs to really living it. How can each day be the best possible day? Can we make sure that patients can smell the flowers, read the notes from loved ones, cuddle with their

mom, go to the circus and act like a normal kid? Can we make sure our patients can die in comfort? You won't find any of these things written on prescription pads, but they may be the most important medicine of all.