

FIELD NOTES | SPRING 2023

On Hope

By Denise Napoli Long

My patient, D., was young for hospice, in her late 60s, with cancer that had spread everywhere —brain, bone, lung. It was close to eight years ago, now, when she died, and I've forgotten a lot of the details.

I had been trying to become pregnant for a few years when I left the ICU and took a job as a visiting home hospice nurse. By the time I began to care for D., I'd started seeing a fertility specialist, Dr. Scholl, who was tough, and busy. He had no time to hold my hand, tell me to be hopeful. And maybe he knew it didn't matter, anyway: my husband and I were taking hope out of the equation. We were putting life, the life we hoped to create, into the hands of the Modern Medical Machine, and it was the functionality of that machine that would determine whether life was created. Or not.

Hospice nursing, on the other hand, was a purposeful withdrawal from the Modern Medical Machine. Hospice was putting hope back into the equation: not for life, but for a good death. "Letting nature take its course," I told my patients.

My nature would not take its course, and I was running out of time. My nature—my desire to be a mother—would have to be forced.

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D. did not have time, either. And like Dr. Scholl, D. was tough. She rolled her eyes when I visited and refused to answer my questions about pain, and nausea, and weakness. She'd tell me I didn't need to come next week, or ever again. She refused aides to help her shower, refused a hospital bed, refused to take any morphine. In the kitchen, her husband pleaded with me: make her take the medicine, make her accept the help. What he wanted to know was, When would the anger pass?

I had no idea. I was still relatively new to hospice, and I was used to being showered with gratitude. Wherever I went, patients and families clasped my hands and said, *You're an angel.* D., on the other hand, seemed to blame her diagnosis on me, personally, as if all the trouble had begun with my arrival. I dreaded my weekly visits.

I also dreaded my weekly visits with Dr. Scholl. One week he performed a hysterosalpingogram, to see whether my fallopian tubes were open. They were, he reported, distractedly, making notes in my file as I sat across from him, crampy and leaking dye into a sanitary napkin his nurse had given me. Another week he chastised me for not following up with an endocrinologist to check my thyroid. My frustration made me bold: Was he not a reproductive endocrinologist, I asked? Did he not have a lab right here, in this very building, with which he could check and recheck my TSH to his heart's content?

"If your thyroid is off, it could cause a miscarriage," he intoned, giving me one hard look before his gaze fixed itself over my shoulder at the next woman who had chosen to put her faith in science over prayer, medicine over mystics.

I went to an endocrinologist. I took the medicine.

Meanwhile, D. began to decline more swiftly. Sometimes I'd walk in the house and find her asleep, and her husband would say that finally she had taken a few drops of the liquid morphine after being awake all night in pain. Sometimes she would become confused about who I was, believing I was her friend who was also a nurse. Sometimes she would smile and let me give her a compliment. "What a beautiful pedicure!" I'd say, kneeling while I ran my hands over her swollen calves, pressing my fingers into the top of her cool, pitted feet, mottled on the underside, where she couldn't see. "I did it myself," she'd say, dreamily, from a morphine haze. Her husband shook his head, N_0 , behind her. He'd done it, because she always liked to have them painted.

As D. began to slow, things began to speed up for me. The all-consuming Cycle was upon us. First there were the clomid pills, taken on days one through five. Then there was an ultrasound, to check my follicles, followed by a trigger shot of human chorionic gonadotropin, so that they would burst. Another day my husband generated the sperm sample, with many jokes, and brought it to the office where it was prepared. A few hours later, it was injected into my cervix. I sat in my car in the parking lot with my legs up on the dash for an hour, after.

It worked. The next visit to Dr. Scholl's was a happy one. I should come back in two weeks, he said, to check the progress of the developing embryo.

But a lot can change in a week. I knew that. I had only to look to D.

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Summer turned into fall. D. had a bed sore, now, a stage 4 sacral wound. It bore into her backside, its own kind of womb.

"Thank you," she whispered, on her side, facing the wall, while I dressed the wound, making breezy, distracting chatter while I calculated my due date, again and again, in my head. She was crying. She was weak. The anger was gone at last, and she had begun to hope, again. Not for life. Not for healing. For a good death. That it would come, and soon.

I will name this child after D., I thought. To honor her.

At first, D's bedsore had been manageable at home, between my visits and her husband's daily care. But in that interval between my clomid pills and my positive test I'd begun seeing her her twice a week, then three times, for dressing changes. Her friend the nurse started coming, too, when the dressing was too soaked with exudate, or soiled with stool. We used Dakins to pack it, Flagyl to irrigate it. No one expected it to heal; D. was taking no more than a few bites of food each day, and was constantly in bed, and would not tolerate lying on her side. She still refused a hospital bed, with a high-quality pressure-relief mattress. It wouldn't have done much good, anyway. Her body, like all bodies, had begun to break down.

"I think we should bring her into the hospice house," I said to the husband. "I think we need to let the nurses there take care of this wound for you. This is too much."

But she wouldn't go. Not yet. And he wouldn't send her.

And then Dr. Scholl had time for me, at last. The sac was there, on ultrasound, but whatever was inside was not the right size. He calculated it again and again...I'd been inseminated on day X, and today was X + Y, and therefore it should be so many millimeters. X, plus Y, equals...not big enough. My husband and I listened with sinking hearts. "Time will tell," he said. "See you next week."

The next week, Thanksgiving week, we watched the flickering heartbeat start and stop, start and stop, flashes fading into blackness. Dr. Scholl held my hand. "We are witnessing a miscarriage in progress," he said.

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In the end, it was another nurse who persuaded D. and her husband to go to the hospice house. This other nurse, more experienced than I, older, with a doctor husband and four boys in college, knew how to make herself heard, and understood. I didn't know that, yet. I didn't have those skills. I'm better at those things now. But maybe some of us will only ever go so far.

I can't remember whether I saw D. again. Sometimes I did visit patients in the hospice house, at the end. It seems that I would have. But no image of her in that setting comes to me. I can see her in her living room at home. I can see her with her eyes closed, half asleep, her face drooping. I can see her husband, tall and thin, hollow-eyed, smoking on the front stoop. And I can see myself, sitting in my car in her driveway, wishing I wouldn't have to visit her anymore, though of course that would only be possible when she was no longer there to visit. When she died.

I had a son almost exactly a year later, after another round of IUI, and another two and a half years after that, also courtesy of the good Dr. Scholl. I went back to hospice nursing after they were born, and I am still a hospice nurse today. I hold my patients' hands when I meet them, when they let me. I tell them, We will let nature take its course.

As D. did. And as I, thankfully, did not. Both of us hopeful, in our own ways. Both our hopes gratified.

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