

Looking Through the Album

By Martha Nance

After my son's wedding last summer, I found myself thinking back over his childhood. I succumbed to my urge to reminisce, and sat down to page through our photo albums, filled with his life and growth and my joy and pride. But, as sometimes happens when I thumb through my happy memories, a second set of images intruded into my consciousness. The Album of my Patients' Deaths is as dark as the Album of my Children's Lives is bright, although at times surprisingly beautiful.

The first image in the album is a faded, black and white, often-thumbed view of an empty bed, dating back over half my life ago to my days in medical school. I was assigned to the care of Miss Olive ---, an elderly spinster with uterine cancer (note: names and non-essential details of this patient's history and others' have been altered to preserve some degree of privacy). She was receiving chemotherapy, and it fell to me to extract blood from her femoral vein every day because the veins in her arms were dried up.

"Looking good," I would say.

"I feel so tired," she would answer.

"Don't worry," I would say encouragingly, speaking, as I thought I was, for the whole medical team. "We're working hard. I'm sure the chemotherapy will help."

"How much longer will this take?"

"I'll be done in just a minute!"

And the conversation would go on for about as long as it took me to draw the blood, encouraging her all the while with hopeful thoughts of improved blood counts and next week's CT scan. Then I would move on to my next patient and my next task.

One day I came in to work and Miss Olive's bed was empty. Surprised, I double-checked to see if I had gone into the wrong room. No, it was the right room number. The bed was empty, the pillow fluffed and the corners crisp. She was dead, and gone. I was first bewildered, then silently tremendously embarrassed, as it dawned on me how misguided my interactions with her had been, and how alone she had been with her coming death. I waited for a debriefing to occur on rounds that day, perhaps even to be berated for failing to recognize her incipient death, or to hear about the on-call team's heroic attempts to resuscitate her during the night. But what has stuck with me for over a quarter century is this: not another word was ever spoken by anyone on the medical team about Miss Olive. No recognition that she had lived, no acknowledgement that she had died. Not a word. I was alone like Miss Olive, baffled, saddened, and humbled by her death.

My life went on. I became an intern, a neurology resident, and eventually a specialist in neurodegenerative movement disorders. Blurry images of a decade or two pass by.

The smell of Alvin floats into my consciousness. Alvin was a mischievous chipmunk in a children's song, and a patient of mine with Huntington's disease. He came of age in an era when he and many young men in America grew their hair long, smoked marijuana, and protested. Eventually he settled down, cut his hair, married, and worked at the state

(psychiatric) hospital in the scenic northern part of the state, along the banks of a river. I suspect he was one of those “nice aides” who would slip a “special” smoke or two to the residents now and again, with a twinkle in his eye. After he developed Huntington’s disease, his wife divorced him and took the children, leaving him to fend for himself. His anxiety, impaired coordination, and chorea (involuntary movements that can range from fidgety to flailing) became increasingly severe as the disease progressed, and both were particularly bad one time when he was hospitalized in his home town for an infection. He was malnourished because he would forget to eat, and exceptionally anxious because he was deprived in the hospital of his habitual weed. The hospital sent him down to my clinic, a wild man, sticky, matted hair pointing in all directions, dirty and disheveled. “Is this due to Huntington’s disease?” the physician’s note asked. “You are the Huntington’s disease expert, tell us what to do!”

“Discharge him from the hospital as soon as his infection treatment allows, to a place where his meals are provided and clothes washed,” I responded, “preferably in a location where he can sit on the banks of the river” (and have a nice aide slip him a special smoke or two, I didn’t add).

Alvin lived on for several years in a group home by the river. I looked forward to his 6-month visits; we would talk about his children, now teenagers, whom his ex-wife (remarried) would bring around periodically, or music, or who had moved in or out of the residence. We could usually find some way to make each other laugh. The last time I saw him, though, he had changed dramatically. His teeth, bad for years, had been pulled, so his cheeks were sunken. He had lost 20 pounds that he could not afford to lose. His speech was quite hard to understand, he was incontinent and could no longer stand. The twinkle in his eyes had burned out.

“Oh, Alvin,” I said. “Are you getting tired of this disease?”

“Yhuumph. I gmnnna diiiy.”

“Yeah. I know. It’s okay. It’ll come, Alvin. It won’t be too much longer. Are you having any pain?” We talked about death for a while. The group home was uncomfortable addressing his terminal needs, so after several phone calls we arranged a spot for him at the state hospital he knew so well, which had morphed into a nursing home since he retired.

I knew I would never see Alvin again, as did he, so the customary end-of-appointment hug would be our last. And that day, the hug was filled with the smells of institution and illness, an unpleasant mixture of urine, bleach, greasy hair, sweat, last week’s dinner embedded in the joints of the wheelchair, and the distinctive aroma of that special smoke the nice van driver must have provided on the trip down. This peculiar mixture of odors lives on in my memory. Alvin died comfortably a few weeks later.

Cinders. Another terrible, terrible Huntington’s disease odor. Karl was a successful young businessman until he developed Huntington’s disease. He and his wife were thinking of adopting a child when his disease-fueled paranoia began to escalate, leading to a confusing jumble of thoughts and events. “She’s having an affair. She wants to lock me up and put me away.” He would take refuge in their cabin, an hour or two from the city. There was a trip to the Crisis Center, where he was judged not a risk to self or others, prescribed a medication, and sent home. One day he left, no coat, just the clothes on his back, and ended up at his brother’s house 500 miles away. He stayed there a while, but then returned to my clinic one day as abruptly as he had left, agitated, angry, and paranoid. Apparently his wife was out of town, and he couldn’t get into the house. Afraid of his return, it turned out, she had changed the locks on

the doors and retreated to the safety of her family. The social worker found him a temporary shelter. Family members were contacted, medications prescribed but not taken. His wife returned. His brother came. Her sister came. Karl was given permission to spend some time up at the cabin while the family sorted things out and made a more definite plan. He would return next week for follow up.

A few mornings later I saw Karl's name in the obituaries in the newspaper. Stunned, I called his wife.

"The cabin burned down Sunday night, and Karl was in it."

Accident? Suicide? It could truly have been either. (And I confess with embarrassment, the possibility of homicide even fleetingly came to mind.) I will never know. But I do know that I smell the acrid odor of cinders whenever the ghostly shade of Karl passes through my head. Is there a universe, somewhere, in which Karl's life did not spin so rapidly out of control, the resulting friction creating the spark and fire that consumed him? Could I have steered him to that other universe?

I turned more pages in the Album of my Patients' Deaths. On the last page was a recent handshake. When I was on call, we admitted an elderly gentleman who had suffered an out-of-hospital cardiac arrest. He was nearly dead when he came in, and after a couple days of repeated exams and discussions with the family, who had arrived from various corners of the country, when there was no hint of a neurological improvement, the family made the decision to disconnect the ventilator. The eldest son came up to me after their decision, and said, "I can't thank you enough for all that you and your staff have done for my father and for our family."

(I haven't done anything at all except wait the requisite number of hours, perform the required exam, and tell you what you already knew), I thought to myself. Then Miss Olive floated by to remind me that having family at your bedside, and nurses and doctors who predict day-by-day as best they can what is *really* going to happen, and then stay to answer questions about it, perhaps does constitute cause for thanks. I stammered something or other (how do you thank someone who is thanking *you* as their loved one dies?), and we shook hands. Surrounded by family, the elderly gentleman breathed his last a few hours later.

It was time to close the album and return to today. Three closing thoughts rushed to my fingers.

To my patients: O patient, please know that your life has meaning to me, that your death leaves a hole in my soul, and that your spirit swirls about in my brain, informing me and—I truly believe—improving me.

To my medical colleagues: I hope we do better now at 'teaching about death' than we did when I was in medical school. I still struggle to guide my patients through to their ends, and often feel quite alone as I do so.

Lastly, a plea that comes jointly from the doctor and mother who share my voice: death is such a difficult thing. Let us, please, as individuals, a country, a world, do the best we can to celebrate and improve the short lives that we have, and to preserve the world around us so that we all may live without regret, knowing that just as surely as our own moons will inevitably set when it is time, the suns of our loved ones will rise again the next morning.

Martha Nance is a neurologist in Minnesota who specializes in neurodegenerative disorders such as Parkinson's disease and Huntington's disease. She has published many scientific research articles in journals with long, scary names, but is new to literary writing. She had one essay, "What it mean(s)(t) to be a doctor" published earlier this year in Dreamers Creative Writing.