
POETRY/FICTION

Little boy blue

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He was slim in build, and even as he sat in his wheelchair, you could see that he was tall. Infected, he claimed, by a serious bout of sexual promiscuity with women and too much alcohol. He gave me an overenthusiastic grin, trying just a bit too hard to be nonchalant, and said “Hey good-looking, coming to see me next?” I nodded absent-mindedly, trying to get through the note I was writing and simultaneously fending off the 20-odd patients clamoring the halls, all keen to get a word in with the doctor before their chance at an intervention disappeared for another week. Even though we frequented the nursing home far more often than mandated by state regulations, there still seemed to be so much to do and such little time to do it in. I told Mr. J I’d be with him in a minute, and he smiled affably. “I’ll be waiting in my room,” he said pointedly, knowing full well it would take me too long to get to him.

The AIDS unit was a chaotic, fragmented, and sometimes miraculous place, but more often than not the distinct smell of antiseptic lingered with overly done mashed meals and various bodily excreta. The walls were pale with occasional pictures situated by the elevators, and a medication cart was usually anchored down one of the two hallways, making its slow transit from patient to patient. The people housed here reflected every disease, from the short-term shooters in for a quick fix of IV antibiotics for one abscess or another to the intractably ill who were minimally aware of their whereabouts. The bed-bound and incontinent patients were interspersed by the wandering addicts, trying hard not to look for that next fix, which was probably more accessible here than on the outside. Visitors could be sparse, our patients having burned their bridges many times over, and we struggled to

hang on to the “placement issues,” people we knew had few external supports and who would crash and burn with surprising speed in the real world. It may not have been home, but it was better than much that they had known.

I stacked the charts on the unit clerk’s desk, trying to gently draw her attention to what needed relatively urgent input, then skittered down a back hallway to see Mr. J, avoiding the barrage of patients waiting at the nurse’s station. I had touched base with the seriously ill patients earlier, Mr. J was last on my list, but the needy ones waited still, seeking one more day pass, an extra dose of painkiller, any assurance that today would be better than yesterday. There were never enough counselors, volunteers, or peer groups to hold the “walky-talkies,” those that were not ill enough to be in bed but unwell enough to be at home. By and large, these patients were left to fend for themselves, and this often involved prolonged contact with a large-screen TV in the rec room at the end of the unit.

“Hi Mr. J!” I said, with considerably more cheer than I felt as I entered the door to yet another institutionally scented room. “How are things today?”

He looked at me conspiratorially. “That nurse, she doesn’t listen to me. I need my Motrin 20 minutes before the oxycodone or it doesn’t take. Will you say something to her?” Despite his boyish looks and easy-going demeanor, I knew Mr. J could give the short-staffed nurses a run for their money, and he could be very demanding. His somewhat meticulous nature added to his need for control over an unforgiving illness, and the fact that he was in his early thirties and functionally hemiplegic only added to his frustrations. I could not imagine the loss that he felt, the anger at HIV for robbing him of movement, and I softened as I leaned up on the edge of his mattress. “I’ll mention it to her. How are the plans coming for going home?”

Unlike most of my patients, Mr. J still had a home of sorts to go to, and currently all of our

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energies were focused on getting him there before the virus threw us another curveball.

“My dad’s putting the ramp into the basement, the dog’s gonna stay downstairs with me, I cannot wait. But we have to get all this stuff in place first: the home care nurse, physiotherapy, a commode. And my sister cannot, under any circumstances, know about the HIV. She couldn’t handle it.” Mr. J’s plans to get home to die were paramount in his life, and I supported his desire to be out of the nursing home, although I had some reservations about his living situation. He would be in the basement of the family home, pretty much isolated by a flight of stairs, with a mentally ill sister and a largely absent father. His mom had died some years ago of breast cancer, and Mr. J felt he was a large part of the glue holding his teetering family unit together. The fact that he was an adopted child seemed trivial in the face of his devastating battle with AIDS, which currently was ahead in the race with its latest weapon: vacuolar myelopathy. Although Mr. J had come to us from the prison system on compassionate release, a definitive diagnosis had not been made. It was not until the AIDS-neurologist saw him and ran multiple tests, including pretty frequent lumbar punctures, that Mr. J realized how bad his situation was. He openly talked about dying, drew up an advanced directive (referring to himself as “little boy blue”) and explicitly articulated his wishes for no advanced life-support. His “overpreparedness” for bad news took me aback at times, but he seemed to have thought through his wishes pretty well. Nevertheless, I was concerned about his risk for depression and asked the unit’s psychiatrist to come and assess him. The psychiatrist concurred that Mr. J was certainly at high risk for impulsive behavior, and that he intellectualized away some of his fears and emotions. Not entirely a bad way to deal with it, I thought, and certainly easier to manage than the hysterically weepy or uncompromisingly demanding patients I was more accustomed to.

Mr. J agreed to take HIV meds, hoping for some improved quality of life and perhaps even a remission of his myelopathy, and he actively participated in research studies, but underneath it all he knew his time was limited.

“I think the meds are helping,” Mr. J said, referring to yet another study trial he was enrolled in. “This morning I moved my bowels all on my own!” I gave him a wry smile, happy for him yet casting a somewhat jaded eye on his assessment.

“Let’s set up a meeting with your dad, tie up some of the loose strings, and try to get you home in the next week or so. Deal?” He smiled, and I gathered up my stethoscope, had a quick listen to his

chest and set up an agreeable meeting time. He patted my hand companionably. “See you Tuesday!” and he was wheeling out the door, eager to make up time in the sunny courtyard, chatting up the other patients, avoiding his own thoughts.

The meeting with Mr. J and his father went smoothly, all the necessary supports fell into place, and he was ready to make the transition home. He gave me a quick hug, told me he’d see me in clinic and was off in his state-arranged wheelchair-friendly transportation. The nursing staff was not entirely sad to see him go, for despite his amiability, he could give them a time of it.

It was another month or so before I saw Mr. J again, although the home care nurse kept me updated regularly, and I often would field “urgent” calls, triaged through the clinic or my private office, whose number he had somehow wheedled. It wasn’t until I saw him in the clinic, somehow smaller and less potent, that I realized how hard the move home had been for him. He told me things were great, and he was so happy to be home with his dog, but something in his eyes refuted his words. I drew his blood, asked if he would consider some ongoing support in the form of a therapist (which he promptly brushed off), and rewrote his scripts. Superficially, things were great, and rushing about in my busy clinic there was not way to pry beneath the surface with any efficiency.

Shortly after the New Year, I received another urgent call from Mr. J. “I’ve got to see you—I need to go back to the nursing home,” his voice was hoarse and desperate.

“What’s going on Mr. J?” His last set of blood work had shown a viral load of less than 50, the golden utopia toward which all HIV physicians strive.

“Please, it’s so important . . .” We set up a time, my accessibility being somewhat limited by my newborn baby. “Thank you,” he warbled, in a voice so small it made me feel petty for not being more available to my patients.

The clinic that day was half full, and I had slipped Mr. J into the patient roster of my mentor physician, knowing she would allow me to spend time with him and help me out in a pinch if postpartum dementia had seriously diminished my brain capacity, as I strongly suspected. Mr. J looked thinner and gaunter, and the scruffy beard he now assumed did not hide the angles of his face. On the palmer aspect of his left wrist was a large Band-Aid, clumsily applied and pitifully in need of a change.

“What happened?” I asked him gently, as I undressed the wound, clean but deep to the tendons and just starting to scar down.

"I did it a while ago . . . I'm okay now, really . . . just feeling down one day . . ." he brushed a lock of hair out of his eyes, avoidant and needy all at once for both his self-inflicted wound and his troubled soul. I went through the standard suicidal screen, and he contracted for safety, promising to reach out before he acted impulsively again. We both knew it was a pretense, and that his time was drawing near. "I need to get out of the house for a while . . . I can't do this with my sister, my dad . . ."

He had been living in the basement throughout the winter, no sunlight and few windows. He was largely isolated it turned out, his dad struggling to keep the family together financially and his sister attending one day program or another. His days consisted of visits from the physiotherapist (a highlight), the home care nurse (when approved of by the HMO gods of the day), and the odd drive-by buddy from days of yore. By and large he was alone, and that gave him time to berate himself, mull over his progressive loss of form and function, sink into the ever murkier waters of grief. Things had not been going well with neurology, meaning that his prognosis was becoming more and more obviously grim, and the long shots with experimental therapies were failing. He was angry at the doctors, angry at the virus, and angry with himself. It was so unfair, all of it.

I examined him, did the paperwork, got him in the nursing home for a respite admission as soon as possible. He thrived there, blooming in the presence of other patients, sunlight, and wheelchair accessibility. At the end of the week, he came to a decision.

"No more meds, doc, not for the HIV. Just the pain pills, the Motrin, the stool softeners. This isn't the kind of life I want to lead anymore."

"Are you sure?" Although the psychiatrist had seen him again and cleared him from a risk-of-suicide perspective, I was still uncertain about his frame of mind.

"I'm sure. You know what? I'm gay," he blurted out, relief and exhilaration flooding his face. "Did you know? Could you tell? I've always been gay, which is how I got the virus. I've known for years and years, just didn't do anything about it. Didn't want my folks to know, didn't want to disappoint them." The tears were flowing now. "I drank to cover it up, partied with the boys on the beach, you name it, I've done it."

"Do you want to tell anyone? Your dad?" I questioned softly, holding his hand.

"Someday maybe. . . . It's such a relief just to say it out loud. I've fought for so long, I'm so very tired." He slumped forward in his chair. "I'll give my brain to science, my spinal cord—that will help the fight against HIV won't it?"

"It's up to you. Whatever you need to do, we'll support you. We've talked about hospice before—what do you think? It will take the pressure off your dad, your sister. There's a beautiful place up at the north end of the city." We talked, ironed out details; more paperwork, more transfer forms, and soon Mr. J was installed at one of the nicer hospices in town. The staff loved him, and he made a point of visiting with the other patients, cheering them up as much as he could. With each inevitable death though, his animation seemed duller, his spirit more weighted. I swung by to visit him, a few weeks before he died as it turned out. We meandered over to the cafeteria in the adjacent hospital where, ironically enough, he had been born and given up as an infant.

"Teenage mom," he wisecracked to me. We coasted out onto the smoking patio, Mr. J seeming somehow harder and yet more accepting of his fate all at once. He had tried to tell his father about his sexuality, but felt by and large his dad was unprepared or unable to hear it despite how much Mr. J wanted to tell. He had started to write his memoirs, something to leave behind, and he gave me an unfinished copy before I left. He gave me a kiss, thanked me for everything, and escorted me out of the building.

"I'll watch out for you and your baby," he promised me. "From heaven, you know. I'll make sure she's ok . . ." The inexplicable humanity and sadness of his words tugged at me, and I leaned over his chair to tell him goodbye.

That was the last time I ever saw Mr. J. He died a "good death": no pain, on morphine, in a beautiful calm hospice with loving, caring staff. His wishes were respected, and he clearly marked out his last days, fighting to be heard above the din of medical-ese that often afflicts health care professionals. His unfinished memoirs sit in my office still, a reminder of a life robbed short by the virus and of human dignity and courage triumphing over anguish. The first lines of Mr. J's writings remain poignant and compelling, and act as a reminder to me in my own life:

I shall pass this way but once. Any good that I can do, or any kindness that I can show, let me do it now. For I shall not pass this way again.