

THE NIGHTMARE OF SUCCOTH

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1.

The Washington Square Park rangers were hammering away at beige boards near the famous arch, as I pushed my older daughter Anna through the park in her new, brightly colored wheelchair. In the months since my wife Kate died, in March 2012, the park was my family's refuge. We went there almost every day, even on a gray fall afternoon like this one, to listen to "the piano guy," as Anna called him, or watch her little sister Jane careen around the park, something Anna had not been able to do for many years.

"Look, Daddy..." Anna gestured at the ramshackle structure being flung up in the park.

I knew what she was thinking. "It can't be!" I said, loudly. "It's too early!"

She beamed at me with her glorious smile. She would have bellowed the words herself but she had already begun losing her verbal ability, eaten away by the dreadful genetic disease which would soon take her from us.

"Daddy . . ." she managed. She wanted me to say it. So, I did, because I could rarely deny that sweet child anything.

I bent down and whispered in her ear, "It's the . . . *nightmare of Succoth!*"

She laughed hysterically. Her raucous laughter was one of the last things to go.

Jane slowed her dash around the arch to a canter. "What's all that hammering about?"

"They're building a succah," I told her. "For people in the neighborhood to eat in. It's part of those crazy crazy Jewish holidays,"

"Crazy crazy!" Anna echoed.



2.

Anna was adopted from Hangzhou, China in 1995. She was seven months old when Kate and I got her, the most beautiful baby anyone had seen. Strangers would stop us on the streets of Manhattan to exclaim at her loveliness.

At four, after a freak accident, which landed her in the grim emergency room of St. Vincent's Hospital, she was found to have an enlarged liver and spleen. This was followed by stressful visits to seven specialists over seven months, at last leading us to the Mayo Clinic, in May 2000, where she was diagnosed with the horrifying degenerative neuromuscular disease Niemann-Pick Type C.

Only about 500 people in the world are known to suffer from NPC. Partially, that's because the disease is notoriously hard to diagnose. Although both of Anna's birth parents had to carry the gene, no one in China in 1995 would have recognized this. The symptoms in children born with this disease are rarely detected until something else brings them to a hospital.

But also—let's be blunt—the reason there are so few cases is that kids with Niemann-Pick C almost never make it to adulthood.

3.

Succoth and *nightmare* have, perhaps, never been used before in the same sentence.

It's difficult to think of a more anodyne holiday than Succoth, which is either a harvest fest or a commemoration of the Hebrews being protected by Yahweh in small shelters during their inexplicable 40 year sojourn in Sinai. But the holiday lasts for seven days then seeps into two more obscure Jewish Holidays, Shemini Atzeret and Simcha Torah. Only deeply devout Jews take all of that time off. But Anna's school, the Hebrew Academy for Special Children (HASC), was run by deeply devout Jews, and every one of those holidays was a day off from school for Anna. Coupled with the High Holy Days of Rosh Hashanna and Yom Kippur, this meant that the beginning of each school year was pocked with almost 3 weeks of days off. Days off for Anna but not for me.

Thus, the Nightmare of Succoth.

HASC was not a school I had ever imagined my daughter attending. But on her twelfth birthday, as in some dark fairytale, she began having seizures. The principal of the Special Ed school which Anna had attended since first grade—who swore to us that Anna would always have a place there—became alarmed, then outright hostile about the malign cloud of seizures which descended upon Anna. She made it very clear that Anna was no longer welcome there.

I spent 2007 slogging through the outer boroughs of New York, where all of the schools which might better handle Anna's neurological needs were located. I was so desperate to find a place for my affable yet profoundly disabled child that HASC, which occupied a rather dingy old building in a rather dingy part of Brooklyn, appeared as a shining beacon in our lives.

My Chinese Catholic daughter in an Orthodox Jewish school?

I imagined my secular humanist dad glowering somewhere, while his devout father was high-fiving other Orthodox souls in whatever annex of the afterlife they might occupy.

Yet however unlikely a placement HASC was for my daughter, Anna loved that place immediately. Her teacher assured us that Anna was a perfect fit for HASC. “Many of our students have seizures,” she told us, “and many of them are lonely. Anna is so friendly; she makes everyone in the school happier.”

Also, as HASC’s principal pointed out, the school was one of those strange NYC admixtures, a publically funded private school, required by state law to be diverse. Anna tripled HASC’s diversity just by showing up. She began attending HASC in September of 2007. “She’ll be safe, active and well taken care of here. But the Fall holidays can be a trial,” the principal shrugged.

She was, and they were.

4.

I am pretty sure that I never sat inside a succah in all my life. Even my grandfather did not actually construct a mini-tabernacle in their scraggly backyard in Richmond, Virginia.

Or maybe he did, and my sister and I weren’t allowed in it? That is very possible. My dad, who was embarrassed by his old world, not-entirely-competent father, did not need much persuading by my outright-hostile-to-religiosity mother to keep my sister and I at arm’s length from my father’s family.

In the brief periods when my parents were involved with an ultra-liberal Reform Temple in Albany, New York, where I grew up, Succoth seemed like a minor-league Thanksgiving. Gourds and pumpkins and grapes bedecked the little hut near the altar, and children were asked to bring a can of food to distribute to the poor. I had no idea that you were supposed to eat in the succah, that it was a place for prayer and reflection. But then, I thought Christmas was a Jewish holiday until I was eleven.

My mother’s family, deeply assimilated German Jews, sometimes lit Sabbath candles on Friday nights but also had the grandchildren over for elaborate Christmas Eve present dispersal, complete with festive tree; we even had Easter egg hunts on their manicured lawn. They were Jewish in the most remote way possible—my mother, to this day, will inquire if someone is Jewish or not, as if this were an insight into their value as human beings. But she has just as often loudly proclaimed that she hates *all that religious stuff*. When my dad died—in an airport on their way home from a New Year’s Eve trip to Reno—she declined to have a funeral for him. No one even knows what became of his ashes.

She also had a rather snobbish contempt for my father’s Russian immigrant parents, who never spoke good English. A classic escapee from the Lower East Side, my grandmother worked in a sweatshop on Delancey Street until she met my grandfather. The youngest of 10 children scattered across the U.S., he spent the Great Depression drifting from sibling to sibling, trying to make a go of it. They ended up in Richmond, Virginia, with a little grocery store in a bad part of town, which my sister and I were not allowed to visit.

Although my father was among the first Jewish medical students admitted to University of Richmond Medical College—his dean actually warned him that he and his cohorts were a test case, and had better perform well—he never spoke about being Jewish. My parents almost exclusively socialized with other Jewish couples, but almost all of these people also celebrated Christmas. There was never a discussion about my having a bar mitzvah, and this was not just our quirky family. Perhaps, it was something in the air in 1960s Albany, or because the congregation my parents occasionally pretended to belong to might well have passed for Unitarian, but the year I turned 13, not one of my friends had a bar mitzvah. This was a source of unending grievance to my father’s father; maybe that was the idea.

In one of the few conversations I ever had with my grandfather, when I was about 14, he asked me, “Do you hope and pray for a blessing from God?”

The words *blessing* and *God* were so rarely heard in our household that they might as well have been the words of an alien being. “Sure,” I managed. “Sure, I do.”

Eventually, a few friends delved back into Jewish rituals, in search of their roots. This never crossed my mind. I was never interested in roots. I never felt like a branch on that tree.

My almost complete lack of interest in my heritage barely impinged on my life. Now and then, some acquaintance might ask me when the Jewish holidays were. Until Anna attended HASC, I never knew. There was one cousin in my late wife’s vast Irish Catholic family who liked to point out that I was Jewish. His remarks weren’t insults, or even inappropriate jokes. He was just always finding ways to note that I was Jewish. If a Jewish actor or celebrity came up in conversation, he would inevitably say, “One of your people.” If it was December, he would ask, “Getting out the old menorah?”

“Is he anti-Semitic?” I asked Kate one Christmas.

“Maybe,” she said. “Or maybe he’s just an asshole?”

That’s about as close as I ever came to feeling discriminated against. But once, many years ago now, I got into a heated discussion with an old high school friend, who expressed shock that my children were being raised (sort of) as Catholics. I pointed out that religion meant nothing to me but did to my wife.

“You are just one of those self-hating Jews,” he snarled.

I was taken aback. Not only that someone who once knew me well might think this of me, but also, upon thinking it, that he would lapse into such a desiccated gibe, like someone in a story by a second-rate Philip Roth.

I shrugged him off. I have plenty of reasons to hate myself, but being Jewish isn’t one of them. As that self-hating Jew Kafka notes, “What have I in common with Jews? I have nothing in common with myself . . . ”

5.

What the staff at HASC made of the *mélange* of our family, I was never sure. Loving and attentive to Anna, they could have been Wiccan missionaries for all I cared. There were some awkward moments. After we signed the agreement to have Anna attend HASC, I reached out to shake the principal’s hand; she smiled wanly. Kate, who worked for Panasonic and dealt with many ultra-Orthodox electronics dealers (yes, this is a thing), hissed at me, “She can’t shake a man’s hand.”

I beamed boyishly and thrust my hand behind my back like I had just touched a hot stove.

And that first year, after the Nightmare of Succoth, when the school began in earnest with its annual Parent Teacher Day, I was surprised to see that I was the only father at the event, and that many of the mothers were dressed up as if going to the opera: heavy necklaces, furs, hats, their finest wigs. They looked me up and down, in my black jeans and battered leather jacket, as if I had just popped in from a distant planet.

But Anna exuberantly embraced all the complexities of the HASC connection—she came home one December singing *dreidel dreidel dreidelover* and over again; she proudly played Queen Esther in the Purim Parade, and once,

on some spring afternoon, got off the school bus, looked up at me, and asked in her slightly fractured speech, *Why this night different from other nights?*

I laughed. "I guess that means it's almost Passover?"

Mostly, she loved the other children, many of whose bodies were far more ravaged than hers. She felt at home with them, even if none of them looked or dressed anything like her. She loved the endless bus rides to and from Borough Park, where she chatted, and sang, and where all the little boys with their peyos chimed, "We love Anna!" whenever I got on the bus to help her off.

Each school day, we would lean against the large window in our living room, listening to her favorite tunes, waiting for her bus to appear, and watching all the children up and down Bleecker Street, heading to school. "There the PS 41 bus!" Anna would exclaim. "Look, that girl always running for the UNIS bus . . ." As she got older and her speech started to falter, I would do the narration. "Look, Anna, there goes the trio of girls in school uniforms heading to the subway. Look, there's Tiffany waiting for a ride downtown . . ."

And on the many autumn days when Anna had no school, we would still look at all the children and all the buses, and she would say, "Daddy, why no school for Anna?"

And when I murmured, "Those crazy crazy Jewish holidays," she would cackle like I had never uttered that phrase before.

6.

Soon after she turned twenty, Anna's health began its precipitous descent. She struggled with pneumonia three times between September 2014 and May 2015, and I spent much of that year going back and forth to NYU Langone Medical Center, where Anna was sad and agitated and repeatedly asked, "When I go back to my HASC?"

The students and teachers at HASC sent Anna loving cards and drawings; the social worker called weekly to check on Anna's progress. When Anna died, in June 2015, we were inundated with calls and messages and postings on Facebook. "May her memory be a blessing to you," her teacher wrote, a traditional Jewish offering to mourners.

For a long time, I was not sure that could ever be true; for a long time I could only think of the unfairness of losing her. I was borne down by sorrow. Although she was funny, affectionate, never complained about her lot in life, brought great joy into many people's lives, it was difficult to remember the happy times without immediately plunging down a rabbit hole of grief.

But recently, in early October, I was walking back through Washington Square Park, toward my apartment. It is the apartment where I lived with and lost both Kate and Anna, and which now, with Jane in college, seems eerily empty, not so much like home. It was one of those humid fall days, when it seems summer will never recede. As I lumbered through the park, I heard a loud banging, and I jerked my head back, thinking someone might be in trouble. But it was just the park rangers, hammering away at their yearly task of constructing a slapdash succah.

I slumped, saddened again at the memory of losing Anna. Then, I thought of her merry eyes, and how she loved words even when she could no longer speak them. "Hey sweetheart," I murmured, as if we were walking through the park together again. "Look, it's the . . . *Nightmare of Succoth.*"

I straightened up. I could almost hear the peals of her laughter, and just for a moment this memory lit up my smile, and that was all the blessing I needed to get me home.

Stephen Policoff's first novel, *Beautiful Somewhere Else*, won the James Jones Award, and was published by Carroll & Graf in 2004. His essay, "Music Today?" about his disabled daughter's experience in music therapy, won the Fish Short Memoir Award, and was published in *Fish Anthology 2012* (West Cork University Press, Ireland), and widely reprinted elsewhere. His second novel, *Come Away*, won the Dzanc Author Award, and was published by Dzanc Books in 2014. He is currently Clinical Professor of Writing in Global Liberal Studies at NYU. This essay is an excerpt from a longer work about his daughter's struggle with Niemann-Pick Disease.

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