Why I Write About My Family [1]

May 5, 2014 Family Stories [2]
Illness [3]

Theme Essay by Ruth Carmel

Reporting from the War Zone—and Remembering Which Side You're On



“You shouldn’t have taken me to Petra’s class,” Nate says, apropos of nothing. His tone is querulous.

“How old were you?” It’s been a long time since we took that mommy-and-me music class.

“Five years old.” He’s thirteen.

“What didn’t you like at the class?” I say, though I know.

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“The music.”

Of course. I dimly remember Petra had a lovely voice. The music was innocuous, but I don’t pretend it sounded the same to his fight-or-flight, autism-spectrum-staticky brain.

It’s 7:46 a.m. We’re riding the elevator down in our apartment building, and we’re a minute late. Not optimal. If Nate misses his bus, we’re at the mercy of the New York City subway at rush hour.

In the next few seconds, I have three choices: (1) reason with him; (2) ignore him; or (3) agree that it was awful—and I was awful to do whatever I did.

The first choice is a nonstarter. His therapist (the one a couple of therapists ago) told me never to attempt to reason with Nate when he’s really upset. Ignoring him also won’t work; it’s not nice, and will make things worse. Three it is.

“You’re right, Nate,” I say, as we hit the lobby. “It must have been awful, and I know now that it made you feel sad, and I just didn’t realize it. I’m really sorry.”

“You shouldn’t have taken me there,” he says, but more calmly.

“I hope you forgive me.”

“Okay.” He runs to the bus, and I take the next elevator up. One crisis down. I still need to get my younger son to school.

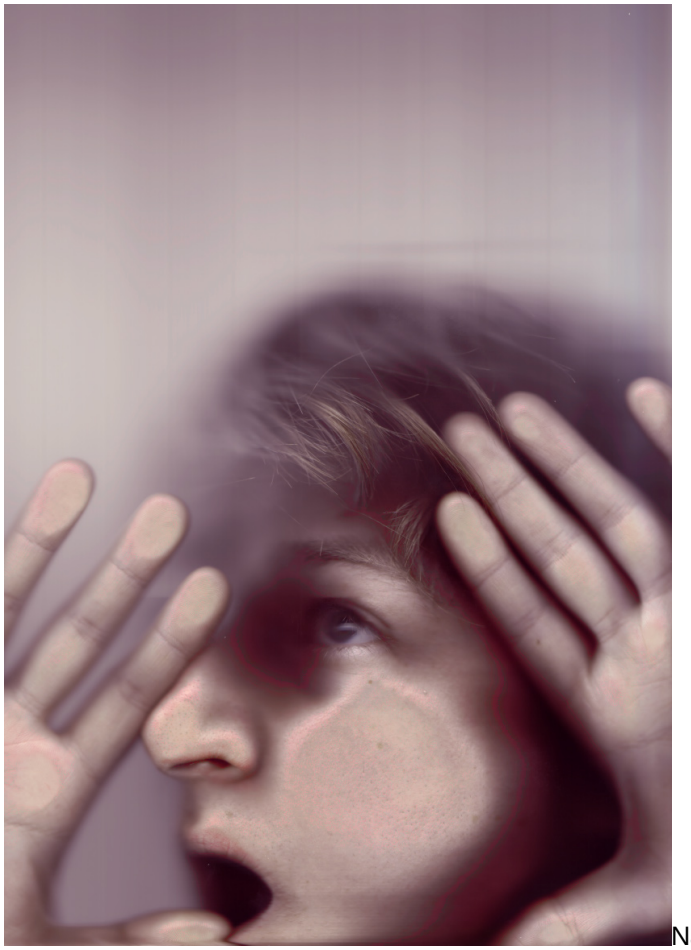
And then, another thing to write.

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I know there are problems with writing about family. What writer doesn’t know that? I grew up being told you don’t wash your dirty laundry in front of other people. Today’s world is a bit more...Kardashian? But while I don’t believe publicly airing family secrets is performance art, writing has helped me make sense of a life that's often blindsided me.

My younger son Sam is “neurotypical,” which translates as solid-mainstream-normal. Whatever normal is. That question can (and does) take up whole books, but normal doesn’t take up a lot of my writing. I’m pretty sure Sam doesn’t mind. He’s a slightly bookish nine-year-old who likes basketball, just learned to play chess, and really wishes—loudly—that his older brother was not autistic.

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Nate is dark-haired, thickly eyelashed, mischievous, and—well, I won't say "not normal." That's unkind and incomplete. How about extra-normal? As in extraterrestrial.

When he was around eighteen months old, my husband and I started noticing that something was wrong. Although we were idiot, first-time parents, we knew Nate wasn't acting the way a child his age should. He withdrew, didn't make eye contact, rarely used words.

At four, he was finally diagnosed with an autism spectrum disorder. I didn't tell my friends for a long time. It was too painful to admit to having so imperfect a child, as if I had the right to perfection, as if anyone does. The ensuing years involved a whirlwind of therapies, searching for the right school, searching for a better school. The therapies, need I add, were not just for him.

Now he's high-functioning, as the pros say, but he still can't be relied on to act normal or to see the value of acting normal. Some days, he's exploring uncharted territory. Like most adolescents, he can be anxious and sensitive to criticism, but his love/hate relationship with music is a particular wrench in the works.

When he was younger, he would get upset if anyone in the family tried to sing, unless it sounded exactly the way he thought it should. He'd scream uncontrollably if any music he heard didn't sound right, as if the pain this caused him amounted to what I'd feel if I were at the dentist and suddenly, without anesthesia, the guy started drilling.

Yet, Nate's sensitivity is part of his uncanny musical ability. When he started guitar lessons at age seven, I walked into his room one day and heard his instructor, tuning his guitar, asking Nate to sing an E. That's when I found out my son has perfect pitch.

So, okay. He used to throw hysterics when *The Sound of Music* came on because Julie Andrews sang "Doe, a deer" off key. These days, he's learning to simply leave the room. And there are times when he's singing a song I know, and I carefully ease into the harmony, and his shiny-eyed joy, his delight in the sheer, shocking rightness of the sound

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we make, is glorious.

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I've only been writing for a few years. Before that, I practiced law, but I lost my last job, and I found a writing class. On the first day of that class, we went around the room saying whether we were writing fiction or nonfiction. I felt buzzy as my turn neared; in law school, I did moot court before a crowd of hundreds, but I was no less nervous now. I told my instructor and the small group of students that I couldn't imagine writing about anything other than my life—mostly, my life with Nate. Maybe because it was so intense? Maybe because I lacked imagination.

I said the second part as a kind of joke—ha-ha. But really, I was writing about being the mother of this son because it still felt so all-consuming, the fear and love and grief and embarrassment and even, at times, hope. Being able to talk about it to a group of ten near-strangers was thrilling, cathartic.

Close on the heels of my euphoria, though, came the suspicion that writing about my family might have pitfalls.

The following week, as I was about to press "Send" on my first submission to the class about life with an autistic child, I finally addressed my nagging conscience and phoned my rabbi. As an observant Jew, I worried about violating the rules of *lashon hara*, the biblical proscription against gossip.

My rabbi—I'll call him Rabbi Epstein—is tall and has an old-school look, with his long graying beard and stark black suit. He's actually fairly young, around my age, and his imposing appearance is countered by an immense kindness and practicality. He's my touchstone for questions about so much, but especially about ethics.

I hoped that as long as I changed the names of my children, I'd be home free. So, I asked Rabbi Epstein, won't using pseudonyms solve the problem?

There was a pause on the other end of the phone. Then he spoke slowly and carefully, saying that writing about a child's difficulties means the child may later read what you wrote and feel awful.

I expected him to ask me how I would justify myself if that happened. But he didn't. He didn't have to. If I hurt Nate, there could be no justification. Rabbi Epstein only said: Be very careful.

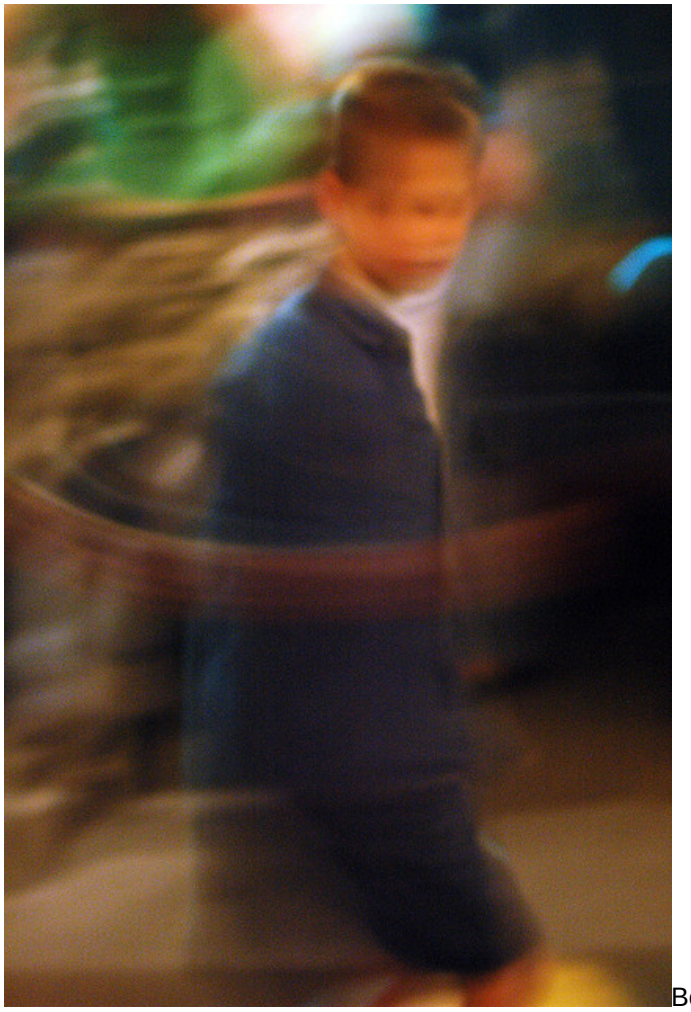
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So I'm trying to be careful. When I can get away with it, I write under a pseudonym, as I'm doing here. Though even that isn't a reliable defense against exposure. Put in too many identifying details, and it might as well be a neon signature. One woman in a writer's group I belong to said she once signed an article "Anonymous Mom," and the day after it came out, her husband's friend greeted him with "Hi, Mr. Anonymous."

Regardless, I use pseudonyms for my family members. I call my husband "Michael." I keep changing the names I pick for the kids; these days, it's "Nate" and "Sam." But I doubt that's enough to secure their anonymity. It's up to me and my best intentions.

In my head I can just hear Rabbi Epstein: *What if your best intentions aren't good enough? If there are risks to your family's privacy, risks that can't be completely eliminated, why do it?*

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Because when I'm besieged by autism, writing helps. When Nate's said or done something outrageous, like yelling at me in the street, and I'm humiliated and hopeless—or, worse still, when I lose patience and yell until my throat is raw—writing helps.

Because writing reminds me of the good stuff, too. I forget the good stuff. Writing makes me focus on Nate's progress—his increasing ability to control himself, his love for guitar—the same way I need to see the cuffs of his pants inching farther and farther from his ankles before I realize just how much he's grown.

Because someday, I tell my rabbi—and myself—maybe another mother or father of an autism-spectrum kid will read my work and say, *that's right, that's me, too.* And feel less alone.

One of the first pieces I read about autism after Nate's diagnosis was the 1987 essay "Welcome to Holland" by Emily Perl Kingsley. She likens hearing the bad news about your kid to planning a vacation trip to Italy and arriving somewhere else:

> And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very very significant loss. But…if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

I needed her words then; they made me realize the future was brighter than it seemed. But by the time Nate was a few years older, I'd also found "Welcome to Beirut" by Susan F. Rzucidlo, her refutation of Kingsley's optimistic essay:

> There you are in Beirut, dropped in the middle of a war. You don't know the language and you don't know what

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> is going on. Bombs are dropping ‘life-long diagnosis’ and ‘neurologically impaired.’ Bullets whiz by ‘refrigerator mother,’ ‘a good smack is all HE needs to straighten up.’

That helped, too. Rzucidlo made me realize that despair is a perfectly acceptable response to having an autistic son.

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Ever since I started writing, I’ve looked at my family differently. I’m not just a wife and mom now; I’m an observer. I’ve wondered if that makes me too uninvolved. I want to be objective enough to write effectively, but I don’t want that to affect how I act with my kids—to make me less loving because I’m analyzing what they’re doing.

Except I’m not standing behind a one-way mirror. The glory and heartache of having your own family is there’s no possibility of staying out of the mess. So, a little distance makes it easier to cope. I’m better when I can slip into observer mode instead of being the harried mother who’s so in the thick of it she can’t get out mentally.

I actually tried blogging for a couple of weeks, but it felt too dangerous. I tend to talk fast, and sometimes my brain is a beat behind, and while I generally get away with it in person (it helps that I’m a truly skilled apologizer), peppering the Web with bon mots about my daily life and the dubious joys of motherhood ran the risk of exposing way more than I would choose to tell if I gave myself enough time to think about it.

So, I observe from the middle of the fray. I scribble the words in notebooks or files not meant for public consumption or dictate into my smartphone, sometimes as tears are rolling down my cheeks, after I’ve dispatched my husband to deal with what I can’t. And I let the words marinate until I’m ready to craft a family story that’s true to all I’ve witnessed and felt.

When I took that first writing class, I had so much pent up inside. The more I wrote, the calmer I felt. It was like turning the light on and discovering that the thing in the dark was just a shadow. Okay, not a shadow—but not a monster, either.

The more I write about dealing with Nate’s challenges, the less fearsome they are. I still have my 2 a.m. moments of lying awake, terrified of the future. But the writing allows me to shape my fears, making them coherent and, possibly, conquerable.

I know, Rabbi Epstein. It’s in my self-interest to find justifications for writing about my family. Writing about the people I love is a walk between the battle lines of truth and recklessness. But I don’t think I’m self-deluded in saying that writing makes me happy, too—and that such happiness helps my family. I know how I felt before I started and how I feel now.

Now is better.

Publishing Information

- “Welcome to Holland” [4] by Emily Perl Kingsley (self-published, 1987).
- “Welcome to Beirut (Beginner’s Guide to Autism)” [5] by Susan F. Rzucidlo (self-published, no date).

Art Information

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Ruth Carmel—a pseudonym—is a lawyer who recently began writing. She's working on a memoir about life with a child on the autism spectrum. Because of the privacy concerns addressed in this article, Ruth is writing under a pseudonym to protect her family. A few small factual details have also been changed in the piece to preserve anonymity.

Her pseudonym is based on biblical references. Of it, she says:

> *Ruth* because of what she said to Naomi: 'whither thou goest'—and I've got to follow my kids before they'll take my lead. And *Carmel* because a little wine, on occasion, gives a stressful situation a pleasant haze.

Source URL: https://mail.talkingwriting.com/why-i-write-about-my-family

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