

## 28. Who Sings the Shower Song?

Tom Keating

“James, you need to take a shower today.”  
 “I can’t wanna take a shower.”  
 “You have to take a shower.”  
 “Why?”  
 “Because grown men start to smell bad if they don’t.”  
 “I’ll ring people’s door bells.”  
 “Knock it off and take the shower.”  
 “Who sings ‘The Shower Song’?”  
 “I don’t know who sings the freakin’ shower song. Just get in the damn shower.”  
 “Aah fucka.”

And so it would go. It wasn’t like James dislikes showering, really. He loves water and swimming, and really digs music. He actually seems to enjoy showers once he starts, and seems to like being clean afterward. I had to learn that it was really a dance about power and control. But it took me a long time to get that, and he knows the dance better than I do. I always feel like he’s a step ahead. “No flies on him,” Mom likes to say.

James has told me any number of times, “You don’t want to control me” and, “You can’t want to tell me what to do” in his own unique linguistic style. Maybe, using his Jamesian logic and knowledge of music, he figured that if it was important, someone would have done a song about it. And Bobby Darin may have sung about taking a bath, but he didn’t mention anything about showers, so James didn’t need to bother taking one. Hard to know. At the beginning I’m not sure I gave him full credit for having logic, intelligence, and emotions and being a full psychological being. The things he did were all just “behaviors” that I needed to deal with.

There was a lot I had yet to learn—who he is, how he thinks, what he needs—when we flew from the Bronx back to Oregon in the summer of ’81 at the beginning of this brotherly adventure of living together. We sat three across in our too-small airline seats—our brother Francis on the window, me on the aisle, and James wedged between us, eating our entrees. And then at 35,000 feet, for some reason, it seemed important to me that James eat his peas. Airline peas for chrissake. But dang it, this is where we start doing things differently. “James, why don’t you eat your peas?”

Wham, wham, wham, wham. A boxer-quick series of smacks to the seatback in front of him. Man, for a 225-pound guy with autism standing about 5’4”, he’s fast! Umm, yah, sorry about that, sir. Yup, everything’s okay here. (James, what the hell was *that* about?) Okaaay, so I guess we just won’t worry about the peas for now, but you wait. The times they are a changin’ my man.

The rest of the flight wasn’t really much better, and I was pretty fried when we landed in SF. Crisp is probably more like it. Rental car hassles were just another log on the fire, and I ended up sitting on James’s chest in a hotel room in Sacramento, ignorantly, primitively trying to establish the upper hand for the eight-hour ride up to Eugene. Fran looked on. Things were going to change. Power and control. What had I gotten myself into?

I had been shocked while staying at home that summer when I changed the channel on the TV and my brother growled at me like some feral dog. Okay, I admit it was rude of me to change the channel, but good grief! The people I worked with at my group home

work-study job in Eugene had way more severe disabilities and nobody communicated by growling.

“What would you think about James coming out to Eugene to live with Francis and me?” I asked my parents.

“Hey, Peg, did you hear that?” said Dad, with a nervous chuckle. “Thomas wants James to go to Oregon.”

“Fine,” said Mom, in her most stoic Irish manner.

Mom, you old softy. I know that game face. I don’t think they really thought I was serious at first, and my offer just kind of hung there for quite a few days. Then they asked me, “How serious are you about this?”

Well, I was pretty serious. And seriously clueless as well. I hadn’t given much thought to what a challenging change it would be for the folks. They loved the guy, and, whatever his challenges, they were used to having him around. But I had been thinking about it even before going back East the beginning of that summer. Serious enough that my super-literate friend Jay had loaned me a short story by Henry James, “The Pupil,” a cautionary tale of responsibility and commitment and getting in too deep. I actually read it. But I thought, hey, we’ll be in Eugene. You can’t throw a rock without hitting a world-class behavior management expert. We’ll figure it out.

But it was more than that. Since I had moved to Oregon in 1974, I don’t think I phoned the family even once that James didn’t ask in his idiosyncratic grammar, “When have I’m going to be moving to Oregon with you and Francis?” He wanted out. And once he got out, he never looked back.

In our Irish family of eight boys and two girls, I was number four, Francis was five, and James was six. We were a kind of distinct middle unit; always shared a bedroom in our cramped east Bronx housing project. Despite our protests and shamed by Mom’s tears and our own guilt, Fran and I were often responsible for looking out for James. Working to overcome our embarrassment, we’d sometimes take him along to Mary’s grocery store, the beach, or the park, and we’d stick up for him when Otis or some other clown told him to pull down his pants and sing the “Star Spangled Banner.” After the fights that would inevitably ensue, Mom would always say to us, “Don’t let

them get to you. James doesn’t understand that they’re teasing him. He likes the attention. Sticks and stones may break my bones....”

And I had to admit, James always could carry a tune, even with his pants at his knees. Hey, he had it better than Jackie. That poor guy. If we ever felt bad about James, there was always Jackie to consider. We would see him walking with his mother around the Throggs Neck Projects—she seeming older, him smiling a toothy exaggerated grin, and goose-stepping stiffly frog-footed behind her. The other kids would all run away shrieking, “Jackie’s coming! Jackie’s coming!” Man, if there’s a heaven somewhere, those two have front row reserved box seats.

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When I left New York to move to Oregon, I was twenty-one and James was seventeen. By the summer of ’81, he was twenty-four, and capable of taking a bus from Co-Op City in the northeast Bronx to the Pelham Bay Subway, catching the local train for a forty-minute ride to 125<sup>th</sup> St., switching to the express two levels down, riding that to 14<sup>th</sup>, walking across town to a sheltered workshop on the West Side, and doing it all in reverse going home in the afternoon. He’s great at using transit systems and loves doing it. He got all the rope he needed from Mom and Dad to develop his independence that way. They were into family and community inclusion way ahead of their time. They rejected the recommendation to place James in an institution, helped start a parents’ group in the Bronx, and worked to create opportunities for him.

They didn’t have to worry too much about James learning his way around. He’s always had that autistic memory thing going for him, and still does. He has precise videographic memories of events in his life, which he frequently plays back out loud. I’d love to record him and then get all his old special education teachers in one room to listen. They’re all immortalized in verbatim neural movies, for better or worse: Mrs. Russo, Mr. Karen, Mr. Newman, and the others along with his friends. Some of the tapes are happy, but a bunch are about getting busted for hitting someone, cutting up, or what have you. Because he had that autistic behavior thing too.

James is severely patience-challenged, and has never suffered fools gladly. Tell him to quiet down once too often when he's talking to himself and you might want to duck. He was downgraded from "educably mentally retarded" to "trainably mentally retarded" pretty much after he hit early puberty, but it was just the behavior doing the talking. It still does. He likes his own space, likes to run his own show, and doesn't like it when anyone tries to deter him from his appointed rounds. I'm kind of hoping old age slows him down before he gets permanently banned from the buses or the library, but he's still going strong.

Mom likes to tell the story of how James would leave really early in the morning from the north Bronx to get to a workshop in lower Manhattan, even earlier than Dad did to get out to work. The whole behavior thing was in full gear at that point, and Dad would have to roust James out of bed with great difficulty, and, with this threat and that, get him out of the house on time.

One morning after the usual tussling, Dad had chased him down the stairs to the townhouse foyer. With one foot out the door, James turned around, looked up the stairs at the old man still in his underwear, said "Fuck you" as clear as day, and ran to the bus. Power and control. As the late tennis champion Arthur Ashe said, "Start where you are. Use what you have. Do what you can." It must be hard always being on the short end of the stick. You've got to pick your spots; use what you have. James picked a good spot that morning.

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James is a lot different now. And a lot the same. Me too. He doesn't punch out windows when he's angry, and I don't ask him to eat airline peas, or do other arbitrary things he doesn't want to do. He still gets into trouble for occasionally pushing or bopping people who bug him, and earns extended breaks from the library, buses, or stores where these events occur. My fights on his behalf have moved from the Otises of the world to the systems in our community that just don't seem to get what cognitive disabilities are really about and what it takes to make an inclusive community for people with marginal behavior. This is all much more stressful for me than it is for

him. He still has a wonderful head of fine brown and gray hair. Me, not so much.

I'm happy to say we've shared many pleasantly uneventful airline flights since that fateful first outing. He's even traveled on his own once or twice. He, Francis, and I shared a house for a while, then an apartment, another house, and then separate apartments in a duplex. I got my special education degree. Francis moved away and came back. I got married. Francis shared the duplex for a while, but he moved on, and James has been on his own now in that same duplex for almost fifteen years. He does okay, with a lot of support from us still, and a lot of burned microwave popcorn, but he manages. If future archeologists should by chance pick his apartment site to excavate, they'd likely conclude that people of our era in fact lived primarily on burnt microwave popcorn and frozen dinners. Sometimes I think he needs a change, more support, but it's not like there are lots of options out there, and I don't think he'd do well in a foster home or group home.

I do worry about his nutrition. One time after he got home from an independent grocery-shopping trip, I noticed that a package of pork chops was open and it didn't look quite full.

"James, where's the missing pork chop?"

"I ate it."

"Where?"

"On the bus."

Picture yourself sitting on a bus and the guy next to you starts gnawing and gnashing on a raw pork chop. To say he likes meat is like saying fish like water. He's a certified carnivorous maximus and knows the best butchers in town on a first name basis. Unfortunately, he doesn't play by all the food safety rules and he likes to create dining room sculptures consisting of pretty much all the leftovers in his refrigerator piled on one plate. I've got pictures of some them.

James gets a lot of understanding—and sometimes party invitations—from many of the young university students, artists, and natural food store workers who come and go in the larger ten-unit development that his duplex is in. Some new people don't understand why he feels compelled to deliver their mail from the box to their

door, but the veteran neighbors fill them in and usually they're okay with it. Like the rest of the world, some are put off or fearful, and they stay that way.

I see James most every day and he comes over for dinner on Sundays. He likes eating my wife Janet's Italian cooking, and he likes being Uncle James to Sean and Ryan, our seven-year-old boys, sharing with them his love of the Three Stooges. You just haven't lived until you've watched the Stooges with James a few hundred times. I'm not kidding. We've had a lot of fun, and shared a lot of challenges. Every so often he'll come up and get his nose right up close to me and say, "Big Thomas" with a huge grin on his face. "Big Jim," I say in return. Francis actually gets more of those moments than I do. He's more of the brother and I'm more of the heavy, but it doesn't take too many of those to light up your world.

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James is a computer guy. He maintains infinite lists of everything he'd like to buy, places he wants to go, things he wants to do, and, dead people he has known. We all need hobbies. He loves videos and viewing animated storybooks too, and has learned how to use a scanner to digitize photos. Technology is important to James and it's also brought about some major transformations in how I'm able to support him. If I don't have time to stop by his apartment, or he doesn't want me to bug him, I can drop in from home or work via computer to see how things are going. We also have a video link. But most important, James has played an important role in helping me to understand how the computers, sensors, and software used in home automation can help me do a better job of helping him. Let me explain.

Our venture in technology-based caregiving began one day about six or seven years or so ago when James wasn't feeling well. We went to the doctor, who asked some pretty typical questions. How is he sleeping? Is he getting up a lot at night? Is he using the bathroom more often? James isn't good at answering questions like that, and I told the doc that I didn't know either, because we didn't live together. Even if we did live together, I might not be able to answer accurately.

Not long after that, I became familiar with home automation systems and installed a network of motion sensors in his apartment. Thus began the process of learning how I could get more information about how James was getting along in his home. I didn't realize then how I would come to rely on these systems, and how profoundly it would change how I care for James and how he cares for himself. I've always been James's big brother. Now I was his Big Brother.

Scary, right? But it's funny how it's worked out. Something that looks at first glance as though it would be intrusive actually functions paradoxically to enhance independence. James likes having his own space and not having his pain-in-the-butt brother checking up on him in person all the time. I now have enormous peace of mind in knowing whether or not he's home at night, how he's sleeping, what kind of hours he's keeping, whether he's spending inordinate amounts of time in bed or in the bathroom, and whether he's carrying out key personal care routines like showering.

Maybe the biggest thing that's changed is that we don't fight so much about showers any more, because the system tells me when they happen. As noted at the beginning of this essay, as recently as a couple of years ago, our interactions around showers were a major source of tension. I had to make sure he took some every week, and he frequently resisted taking them. I think resisting showering served as an important way for him to assert control in his life, a behavioral tool he learned he could use long ago with our folks to compensate for being on the short end of the stick. Power and control. Use what you have.

Even cash incentives wouldn't do the trick because I never knew whether he had actually taken a shower unless I went to his apartment, and I couldn't always do that. For a while, he would actually honestly tell me whether or not he had taken one, and I'd pay him. Then he apparently had a head-smacking epiphany of some sort (Duh!) because he got way normal and always told me he had showered whether he really had or not, and I'd still pay him! When I found out the truth I'd often have to go to his house, and tell him that I wasn't going to leave until he took a shower, and that I might also eat all his potato chips if it took too long.

This routine changed when it became possible to have the sensors detect when showers had been taken and to have that information easily accessible via web page and email notification wherever I happened to be. Once I was able to know when showers really occurred, I could be consistent in working with James to earn cash or other incentives for taking regular showers. After a very short while, he “got” it. It has become now more of a straightforward, almost business-like affair and the tense, coercive element of the interaction has virtually been eliminated. But more than that, James has taken on more responsibility for taking showers without reminders and big payoffs from me.

We’ve come a long way, and the technology is powerful, but it’s just a tool. Teaching and caregiving is still more than anything about relationships, a dance with a lot more footwork to figure out. I love the guy and I respect the hell out of him for trying to live his life the way he wants—even when it makes me crazy. We’re both still learning as we go, and with luck we always will. But James no longer has to ask, “Who sings the shower song?” It’s a tune he’s learning to carry pretty well himself.

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## 29. My Sister, My Daughter

Maryjane Westra

When my parents brought my newborn sister home on March 26, 1962, Martha was a tiny five pounds and fit perfectly in my nine-year-old arms. It was the first time I had ever held a newborn and I walked around our home, rocking her gently and speaking to her softly. I made my sister many promises that night. I promised to help her with her hair and make-up the night of her senior prom. I promised to be the Maid of Honor at her wedding. I promised exciting activities for the dozens of children we were going to have. I promised to share deep, sisterly secrets. But most of all, I promised to love her deeply, passionately, and forever. The final promise is the only one I have been able to keep.

At the age of three, Martha talked and remembered amazing things like birthdays and all the verses to familiar Christmas carols. However, her language had an odd tone and her eyes had a strange piercing quality. She amused herself for hours by dangling strings or rocking rhythmically. She would fly into rages which lasted for hours, all because the furniture had been rearranged or Dad wasn’t