

My Routine Life, by Steve K.

Thanks to JFGH, things are pretty routine for my family. In the mornings, my wife Sheryl and I hit the ground running at around 8:00. We wake up our three girls; rush them off to school; and spend a day at the office. Then we work in reverse as we pick up the girls and get them fed, washed up and tucked into bed. This has become our routine; it's what we do. Finally when the kids are down, the clock hits 9:30 at night, and sure as the sun rises in the east, the routine continues as Sheryl's cell phone rings.

Before I continue, let me provide a bit of context. My name is Steve, I grew up in Potomac, MD, son of Harold and Joan, and younger brother to twins Michael and Jeffrey. Growing up, there was never discussion about having a family member with special needs. Our needs weren't special; they were just part of our routine. My brother Jeffrey went to school, participated in extracurricular activities, hung out with friends and just like his brothers, shortly after high school, Jeffrey moved out of the house.

Jeffrey is a resident of 20+ years in JFGH's Mary and Charles Oshinsky Apartment Program (OAP). One thing I can tell you about Jeffrey is that he is a creature of habit. Jeffrey gets his Starbucks every morning, as he has for the better part of the past two decades. He has dinner with our parents every Friday and Sunday and loves to share his stories about skiing at Steamboat Springs. You might say Jeffrey also has his routine...which is where our worlds intersect. It's 9:30 on Tuesday evening and Sheryl has just put her feet up for the first time. Inevitably, within moments, the phone rings; it's Jeffrey with his evening phone call. Sometimes he calls with a story about another dramatic experience with a Starbucks barista who put either too much or not enough ice in his latte. Sometimes it's a juicy tidbit of gossip. Sometimes it's an update on the JGFH gala, or basically, anything going on in Jeffrey's world. You might say that some of the calls can be predictable.



Tonight's call was to discuss the plans for the family trip to Rehoboth Beach. This time the family includes Sheryl and our three girls, my parents, and of course Jeffrey. I'm expecting walks to Nicola Pizza, sandcastles with the girls, Jeffrey in his oversized "beach wheels," while drinking his Cherry Coke from Snyders Candy. For others with a family member with special needs, you may have similar experiences. In my case, my relationship with my other brother Michael is more traditional. Michael lives with his wife and daughter in Rockville, and we connect for family gatherings or the occasional get-together. Otherwise we live parallel lives, kind of just doing our own things.

Jeffrey, however, is definitely not traditional. Whether it's an evening check in call, weekend visit or family vacation, Jeffrey loves to spend his time being Uncle Jeffrey to his nieces. On the occasion that our parents are out of town, Jeffrey will lobby Sheryl for a Shabbat dinner at our place, and if he's feeling lucky, possibly another visit on Sunday to hang out with the girls. A few weeks ago, our steady routine actually evolved a little bit. Instead of his usual trip on Metro Access to spend a few hours hanging out at Montgomery Mall by himself, Jeffrey spent the evening cruising the mall with my nine year old daughter, Alexa. While I wasn't there, I'm guessing that Alexa experienced many of the same things I experienced growing up beside Jeffrey. I'm sure she observed as others in the mall stared at Uncle Jeffrey. I'm guessing there was a little boy or girl pointing, and asking, "Why's that boy in a wheelchair?" and I know this because that's just part of having someone with special needs in your family. So as they say, the more things change, the more they stay the same.

For me, while the dynamics have changed over the years, it seems the routine remains mostly unchanged. While Jeffrey is and always will be part of our routine, there is no part of our relationship that is burdensome or challenging. Sheryl is more generous with her time with Jeffrey than I ever have been. He knows who to talk to if he wants an invite to the house or if he needs to confirm what time to meet up at Starbucks. After the recent outing at the mall, I can imagine many future dates for Jeffrey and my girls, enjoying dinner in the food court, and the girls convincing Uncle Jeffrey for a few new pieces of jewelry. So while I can tell you what it was like growing up with a brother with special needs, it seems that I'm still learning what it's like to be grown up with one.



As I write this essay, I find myself thinking about the differences and similarities between the family I grew up with and the family I'm grown up with. Over the years people have asked me what it's like to grow up with a brother with special needs. It wasn't until this essay that I had ever pondered what it's like to be a grown up with a brother with special needs. I guess the reason I've never thought about it is because I've never needed to think about it. Since Jeffrey was never treated differently in our house growing up, he never had a reason to consider himself to be different, and still doesn't. On top of that, we are blessed to have our parents who are healthy and still live in the area. Also, our brother Michael, sister-in-law Lauren and niece Gillian live nearby and also spend time with Jeffrey. Mainly, we don't need to think about it because Jeffrey has his own life. He has a job, his health and lives independently in an apartment with a roommate and generally takes care of his own needs. So, thanks to JFGH, our needs aren't really all that special; they're actually pretty routine. And that's just the way we like it.