

Brave

My daughter's coming of age with Down syndrome.



BY AMY SILVERMAN JAN 25, 2017



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My thirteen-year-old daughter, Sophie, has Down syndrome. With some assistance, she's kept up with her typical peers and is currently included in regular classrooms in eighth grade. Sophie's speech is really good, but she has fine motor challenges. Handwriting is tough for her; she still can't tie her shoes or ride a bike. She also can't button her skinny jeans, or do the buckle on her strappy wedge heels. Thank goodness for jeggings (although she'll only wear the expensive Lucky ones that look like real jeans). And those strappy wedges have a zipper down the back for easy off-on, which is convenient since Sophie insists on wearing them to school every day.

She wants to impress her boyfriend.

My teenage daughter still sucks her thumb and refuses to brush her hair, but she spends half an hour in the bathroom each morning with a giant leopard-print box full of makeup. She watches Peppa Pig and Saturday Night Live with equal enthusiasm, although her favorites are the YouTube tutorials about choosing just the right back-to-school supplies. Even though high school doesn't start for nine months, Sophie's ready.

Of all the things that have gone down with this Down-syndrome business — the surgeries, the orthotics, potty training at age five, hours of meetings to put her in regular classes at school and keep it that way — nothing has confounded me more than puberty, which has arrived right on schedule, and which Sophie has embraced with gusto.

Perhaps this is because of my own arrested development. I do not recall having a real conversation with a boy 'til graduate school. Wallflower was putting it mildly, and I was keenly aware of my status. I wore a frumpy, pale-brown shirtdress and clunky, wooden, it-was-the-end-of-the-'70s sandals to the eighth-grade graduation dance at my school, and I can still feel my heart pounding as I watched one of the cutest, most popular boys cross the room and stop in front of me (ME!) and ask me to dance. It was one of those slow-motion, underwater moments that seemed to last for days and that I'll remember forever. I said no thanks, positive it was a prank. I never did know for sure, and that's OK with me.

Contrast this with Sophie, who has no problem FaceTiming a boy fourteen times even after he's broken up with her. And get this — it works. The other day we were out running errands, and she looked at her phone, sighed happily, and said, "Sam texted me. He loves me and we're back together."

(By the way, Sam does not have Down syndrome. He's a pretty typical kid with a soft spot for mine. I'd be worried, except their time together is limited to lunch in the crowded cafeteria, or "dates" at Peter Piper Pizza, chaperoned by both his mom and me.)

I reached for the phone and confirmed:

Sophie: Boyfriend and girlfriend?

Sam: Sorry, I can't talk right now.

Sophie: It is fine. Boyfriend and girlfriend?

Sam: I do love u so much be my girlfriend.

Sophie: Yay.

It's like she's a witch (in the best possible sense).

Sophie's older sister shares my awe. Annabelle, 15, goes to a fancy charter school where she dances en pointe and reads *The Iliad* and Howard Zinn. Her idea of a fashion risk is pink Converse instead of white. On Saturday nights she stays home and bakes cookies, and at this rate is probably not going to have a serious conversation with a boy 'til she's in her twenties. Annabelle and I are constantly shaking our heads with envy at Sophie's ability to navigate her social world in ways neither of us can.

Most nights, Sophie falls asleep next to me on the living-room couch, and I stare at her long eyelashes and tangled hair and wonder how this tiny kid is doing so well. Sophie was born with the heart defect that about half the people with Down syndrome have, and she rocks the giant scar that makes its way halfway down her chest. She's hypertonic, meaning she's too flexible, and also meaning she's able to do the splits anywhere, anytime. (And she does.) She's often totally socially inappropriate — she has no

problem marching into the nail salon with a ukulele, ready to serenade the other customers, or picking and choosing who she'll sit with at lunch in the school cafeteria. After much speculation, I've decided it's simple: Sophie does not give a shit what anyone thinks of her.

At a time where other kids are self-conscious and miserable in their own skin, the teachers report that Sophie's got her hand up in every class, ready to take a stab at the answer. I sent her nanny as a spy to the first junior-high-school dance; word came back that Sophie was the only girl dancing, out there boogying with several guys she knew from math class. The other girls stood against the wall, glaring, but guess who was dancing with boys? Sophie had the last laugh — even if she didn't realize it — because Sophie doesn't care. She doesn't know enough to.

Sophie sees what she wants — a spot on the cheer squad, a position in student government, first place in line for lunch — and she goes for it. Tell her no, and she'll just keep asking, until fourteen FaceTimes and who knows how many texts later, you're her boyfriend again.

Long after I've peeled her off me and shoved her in the direction of her bedroom each night, I stay up and worry about Sophie. What if she decides she wants to have sex? She's pretty sheltered; there's almost always an adult with her. But where there's a will there's a way. What happens when her boyfriend really is done being her boyfriend; will there be another one? Will Sophie hit a glass ceiling — maybe in high school, maybe before that — where the other kids won't talk to her, even if she's wearing a cheer uniform? Even if she calls a dozen times?

Turns out, Sophie worries, too. "Mama, I don't want to have Down syndrome," she told me the other night as we pulled up to our favorite Chinese restaurant. I turned off the car and we sat for a few minutes.

"Oh, Soph, I know, sweetie," I said. She's been saying this since she was eight. The first time happened to coincide with her introduction to Special Olympics. Sophie had never spent much time around adults with developmental disabilities; I think she had culture shock — her own culture — and started wondering what it meant to belong to this club. Over the years, she's mentioned it from time to time, and I've struggled to respond, wondering when it will officially be time for therapy. "Can you tell me why?"

"No," she said, dipping her head shyly. "I wanna be like you."

"No, you don't," I thought to myself, fighting the urge to say it out loud. I've learned that it doesn't work to tell Sophie that I get where she's coming from, that I don't like being short or bad at sports. This is different.

For the gazillionth time, sitting there in the car, I wondered what it would be like to be in that body, in that brain, to see the world how Sophie sees it. Sophie looks for the good in people — and finds it. When the rest of our family is fed up with my curmudgeonly father, she's still climbing up on his lap, looking for a cuddle. "You picked the best husband," she tells me often. "You are the best sister I ever had," she tells Annabelle. She's right. She also asks for what she wants — and she usually gets it, whether it's a solo in choir class or a bagel that's toasted just enough. I wish I could give her the one thing she wants most of all. But I can't. I looked her in the eye and told her I wished I could be like her, explained why — that she is brave and real. She smiled and reached out for a hug; I know she didn't believe me.

Amy Silverman is a Phoenix-based journalist and the author of My Heart Can't Even Believe It: A Story of Science, Love and Down Syndrome, published in spring 2016 by Woodbine House. Find her at myheartcanevenbelieveit.com.

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