

# MY HEART CAN'T EVEN BELIEVE IT

## A STORY OF SCIENCE, LOVE AND DOWN SYNDROME.

BY AMY SILVERMAN



### READER'S GUIDE

#### QUESTIONS AND SUBJECTS FOR DISCUSSION AFTER READING "MY HEART CAN'T EVEN BELIEVE IT"

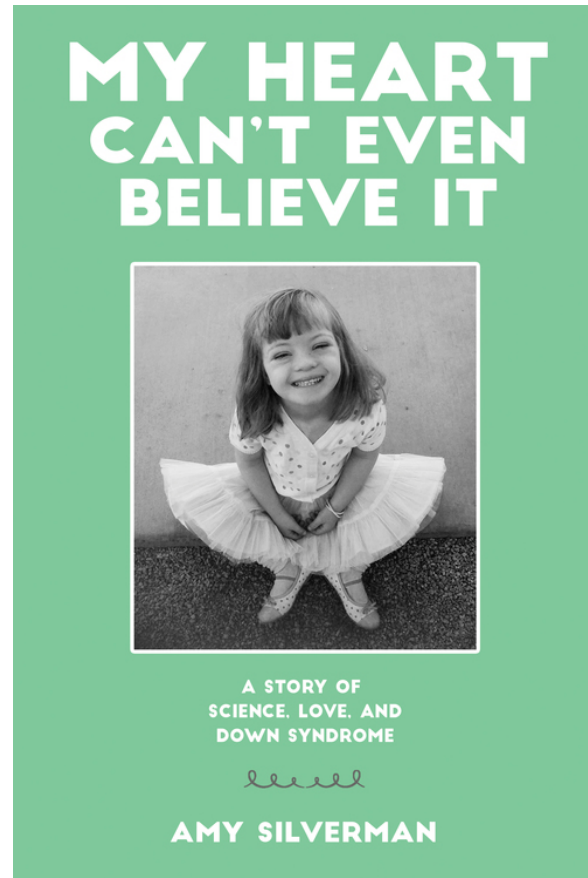
Amy admits in the book that Sophie was the first person with Down syndrome she had ever met. What about you? Do you have friends or family with intellectual or physical disabilities? Do you interact with people with disabilities in your daily life? If so, is that something you were uncomfortable with initially? Why or why not?

With the advent of prenatal testing, parents have the option of learning whether their child will have certain physical and mental disabilities. What is your opinion of prenatal testing? Do you think it's better to have access to the information as early as possible?

In the fairly recent past, children with Down syndrome and other intellectual disabilities were routinely institutionalized and sometimes kept a "family secret." How do you think the changes in how we approach Down syndrome and ID in general today have affected the children themselves, their families, and the larger society?

Mainstreaming children with disabilities can be challenging, as Amy discusses in the book. Is this something you have experience with, either personally or as an observer? What do you think the pros and cons of mainstreaming (as opposed to separate education) might be?

Amy discusses Unified Special Olympics as one way to integrate kids and adults with intellectual disabilities. Do you know of other ways, outside school?



How often do you see people with intellectual disabilities like Down syndrome depicted in pop culture? What about disability in general? Is the lack of this kind of diversity a problem and if so, what's the solution?

People commonly used the word "retarded" to mean "silly" or "ridiculous." Now there is the "Spread the Word to End the Word" campaign, the purpose of which is to make people aware of how hurtful the word "retarded" can be for someone like Sophie. Do you think changing our language can make a difference in our attitudes? Can you think of words you or your family once used that you no longer consider appropriate?

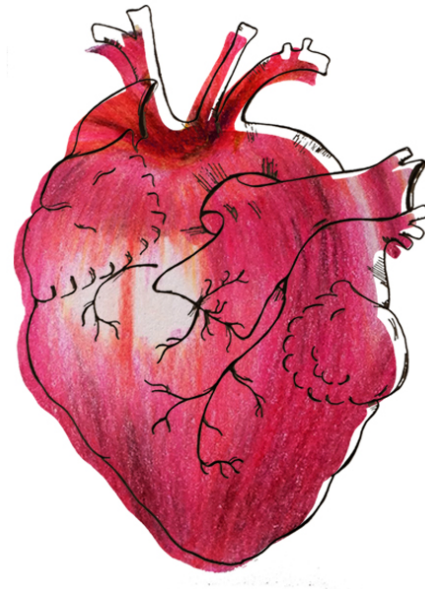
Writing about children with disabilities, particularly intellectual disabilities, raises ethical questions. Some argue that to do so is exploitative, partly because people with intellectual disabilities can't always advocate for themselves or understand what's being written about them. Some label writing about people with disabilities "inspiration porn." What's your opinion? When is it ok to write about someone with a disability and when is it not? Is there a line, and if so, where do you draw it?



## INTERVIEW WITH AMY SILVERMAN

### Q. What prompted you to write the book?

A. My short answer is that I wrote the book I wish I'd read before I had Sophie -- but really, that's the long answer, too. I didn't know anyone with Down syndrome before I had Sophie. I can barely recall a reference to Down syndrome beyond that show from the 80s with Corky. (It's called "Life Goes On" and ran for several seasons and I never watched it.) When Sophie was born I had no point of reference for what it meant to have this baby (and future child/adult) in my life. So the goal was to write a book that would give an honest portrayal of what being Sophie's mom has meant. This is by no means a parenting manual. I don't know any more than any other parent out there, and a lot less than many. But my goal was to make Down syndrome a little more accessible, and to explore it from the angle of a mom, journalist and American Studies major.



There ARE good books out there about Down syndrome. But many come from a religious perspective and others are very "how to." I wanted something a little more conversational.

**Q. You've been a journalist for many years. Have you written much about your personal life? If so, how was this book different from the other personal writing you've done?**

I had just dipped my toe into the memoir waters when Sophie was born -- I'd written a few personal essays for Salon and had just started co-teaching Mothers Who Write -- but really, I'd written almost nothing about my own life. Particularly when I was coming of age as a journalist in the early 90s, personal narrative was thought to have no role at all in straightforward journalism, and even in alternative journalism. I think social media and the storytelling trend have changed that -- but back then, it was forbidden. I had more than one editor tell me that "I" had no place in my work.

This brings up an interesting side issue for me, regarding the definition of objective journalism. I have never believed there's any such thing. If you and I are witnesses at a murder scene, and strive afterward to each write an objective account, try as we might, our stories will differ -- based on our physical location when we witnessed the event (perhaps you were on the roof of a building and I was across the street) but also on what we bring as people to the event -- our personal experiences, our training (maybe you know a lot about knives and I'm a pro at psychology) and a host of other things.

Right out of grad school, I was quickly drawn to the world of alternative journalism because I like the second-day story aspect to it -- not reporting on an event right when it happens, but giving it context after the fact, including an analysis of the way the media handled it.

To (finally) answer the question, this book (and the pieces that led to it) was different from other personal writing I've done because I incorporated my own experiences raising Sophie, trying to get her educated, exploring Special Olympics, etc., with some fairly involved reporting on the topics. It was a mix of memoir and journalism that really appeals to me.

**Q. Did you have a model for the book?**

A. Yes, several. I'm a huge fan of "Crazy: A Father's Search Through American's Mental Health Madness," by Pete Earley. He's a former long time reporter for the Washington Post who dove into the mental health care system after his adult son was diagnosed as seriously mentally ill. That's the closest model.

<http://www.petearley.com/books/crazy/>

I was also super inspired by Andrew Solomon's "The Noonday Demon: An Atlas of Depression" for similar reasons.

<http://andrewsolomon.com/books/the-noonday-demon/>

And "The Immortal Life of Henrietta Lacks" by Rebecca Skloot and "The Spirit Catches You and You Fall Down" by Anne Fadiman are tops on my list of books that incorporate great storytelling with science.

<http://rebeccaskloot.com/the-immortal-life/>

<http://www.indiebound.org/book/9780374533403>

**Q. Talk about the process of writing the book. How did you approach it? Was it difficult to juggle writing, plus your full-time job and your family?**

A. I had the idea for what feels like forever. I recall standing over Sophie's hospital bed after her first heart surgery (at four months) and reading Fadiman's "The Spirit Catches You and You Fall Down," which is about a lot of things, including how one family approached medical care for their daughter in a country that was foreign to them, and thought about how much I related, and I had the urge to explain the process we were undergoing, both in its specifics and generalities. Originally the book was designed to tell Sophie's story one body part at a time, and you can see some remnants of that original structure in the final project -- a chapter about her heart, one that begins with her ears, and of course several about the brain.

I had several false starts and more than one agent and finally got to what in journalism I call "the fuck it moment" -- when you procrastinate and quibble and over-report and finally stop one day and say, "Fuck it, I'm going to write this thing." And I sat down and wrote the proposal for the book I wanted to read.

At that point, several years had passed and I'd amassed some rough material in the form of blog posts, newspaper articles and radio essays. Once I sold the book I made many lists and outlines of which chapters I had nailed down and what reporting was left to do for each. (Reporting is my favorite part, so that was fun -- and a great way to procrastinate even more!) And then I sat down and wrote through each chapter (again and again).

The ending was the most difficult part -- since of course the story goes on. I decided to end at the brink of puberty, which is where we were last summer when I was wrapping it up.

In terms of the logistics, that was tough. (Let me add that it's tough for all writers -- if you're doing it right!) To overcome abject fear and writer's block, I relied on rituals -- a pink straw in my hibiscus iced tea, the same room at my favorite coffee

shop, and friends by my side, both literally (at our so-called Secret Writing Parties) and figuratively as I tossed them chapters to read as I completed drafts. I wrote before and after work, at the coffee shop and the kitchen table. I did a lot of reporting from my phone in the parking lot of the girls' ballet studio. I didn't sleep much for a while.

Was it hard? Yes, every drop of it. Really hard.

**Q. Did you have any qualms about writing about Sophie?**



Absolutely. Like many parents, my attitude about writing about my kids has changed as they've gotten older and more self-aware. When Annabelle was about 11, I started backing off writing about her -- she made it clear she didn't like it.

Sophie doesn't mind. As Annabelle has observed, Sophie likes the attention -- so the whole book project works. There is a line of thinking that says that parents of kids with special needs (and really, parents in general) don't own their kids' stories and don't have the right to tell them. I disagree. I do think this

has the potential to be the most dangerous kind of writing, and I take the telling of Sophie's story very seriously (even when I try to be funny), but at the end of the day I feel really strongly that what will serve Sophie and the community of people with intellectual disabilities is to be pulled out of the shadows. Maybe it's not a perfect scenario for me to tell her story, but hey, at least it's a fucking scenario. So often we ignore this community in an effort to protect them, and our good intentions have resulted in society's ignorance.

But still, I self-edit -- a lot. I always have but find myself doing it more so as Sophie gets older. It's funny because one of the first things many people say after they read the book is, "Oh my god, it's so honest!" And I want to say, "How would you know?"

Seriously, though, it is honest. It all happened. But a lot happened that isn't in the book -- that goes back to my position that there's no such thing as objective storytelling. I hope that what I left out doesn't change the story in a substantive way -- I don't think it did, although I'll admit I'm pretty close to it. But I did self-edit as I went along, and it was as it regarded just about all of us in the book. My goal was always to be the hardest on myself, I think that's a rule for memoir writing. Do not

let yourself off the hook! (Although I'm sure I did in some instances I didn't recognize.)

But yes, I was very aware the entire time that I was writing about my family, the people most important to me. And there's the thing that might sound weird to you: I did it without a net, in that I did not ask anyone in the family to read any part of the book before it was published. I did not even tell them about the book before I signed the contract to write. I think that's my journalism background -- you do not ask your subjects for permission. I feel like operating that way gave me some really strict parameters that I hope helped to shape the final product in a good way. I had to be super accountable and yet I wasn't being asked to sugarcoat anything or edit it.

**Q. What does Sophie think of the book?**

A. Sophie totally gets that she's the topic of the book, and she loves that. When I handed her a copy, she immediately flipped through it to look for the word "cuddle," her favorite word. I think she understands a lot more than she lets on -- but I also know she hasn't really attempted to read the book. (She adores books but more the thought of them than the actual action of reading, which I'll admit to relating to at some level.)

**Q. How did your family react to the book?**

A. Of course I don't know what has been said privately, but the response I know about has been really wonderful. Word has it that there were tears (in a good way) from more than one family member, not counting my mother, who cries happy tears at most everything I write and was incredibly supportive as expected. (We should all have a mother like mine!) My father bestowed a rare compliment. My typically reserved sister had kind words. All of that was incredibly important to me.

No one's opinion means more, though, than Ray's. Not only is he my husband, Sophie's father and the closest person to the story after her -- he is a journalist, too, and a wicked good one. After all my bravado about not showing the book to him ahead of time, I held my breath till he had finished. That really was a huge gamble. He claims to love the book, and has even taken to Facebook to praise it. I'm really pleased.

**Q. Are you thinking about writing a follow-up?**

A. If I do, it won't be for a long time. This book spans almost 13 years. But I am tempted to document Sophie's teen years and all that entails.





## **AUTHOR BIO**

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**Publication Date:** 282 pages

**Paperback:** 400 pages

**Publisher:** Woodbine House

**ISBN-10:** 1606132741

**ISBN-13:** 978-1606132746