



JDAIM Reads!

**KETCHUP IS MY FAVORITE VEGETABLE:
A Family Grows Up With Autism
By Liane Kupferberg Carter
Reader's Guide**

QUESTIONS AND SUBJECTS FOR DISCUSSION AFTER READING

When Mickey was first diagnosed, Liane says she didn't know much about autism except from movies like "Rainman," or TV shows like "St. Elsewhere."

Do you know anyone with autism? Do you have family or friends with disabilities? Are there any similarities to your own family story? Did that make it easier or harder to connect to the Carter family? Do you think that having personal experiences with the issues she raises would make you enjoy the book more, or less?

Was there anything that surprised you in Liane's story?

What have you learned about autism, epilepsy, or disabilities in general?

Which aspects or scenes were the most poignant to you? What role does humor play in this book?

How often do you see people with autism or other developmental disabilities depicted in popular culture? Do you think these portrayals are accurate?

Liane was careful about respecting the dignity and privacy of family members. Do you think it's ok for parents to write about their children? Is it different writing about a child with a disability? What do you think the boundaries should be?

When Mickey is unable to learn in a traditional religious school class at her temple, Liane says to the school director, "The Torah says you're supposed to teach your children. It doesn't say some of your children. Isn't it a sacred obligation to teach all our children?" She says that although she could teach Mickey about Jewish holidays and observances at home, she also wanted him to have the experience of learning within their community to prepare for his bar mitzvah. How do you think a faith community can best support children with disabilities through the bar/bat mitzvah process, or other life cycle events?

Liane says that Mickey's bar mitzvah was a journey of faith and healing for her whole family. Why does she describe it that way? Have you attended or participated in the bar/bat mitzvahs of children with disabilities? What were those experiences like? What did you learn?

Interview with Liane Kupferberg Carter

What inspired you to write your new memoir?

Twenty-something years ago, Mickey's diagnosis was the earthquake at the center of our lives. I didn't know much about autism; not too many people did in those days. I was desperate to learn, but there was so little information out there. You couldn't go online to look things up, because the Internet didn't exist. There was no book on parenting called, "What to Expect When Your Child is Autistic."

I've been a journalist for many years, so I wrote the book I wish I'd had when my son was first diagnosed. I wanted to help other families avoid the mistakes we made, such as searching for miracle cures and falling prey to snake oil salesmen, and to mitigate some of the fear and isolation families feel. I wanted readers to see that it is possible to create a normal family life, even when you're dealing with the extraordinary needs of an autistic child. To not only survive, but to thrive.

What was it like to write a memoir about autism? What do you wish people knew that they don't?

It didn't feel like writing a memoir about "autism." I wanted to write about family upheaval and healing.

There's a popular saying: "If you've met one person with autism, you've met one person with autism." But here are four key things I hope readers take away from my story:

People with autism DO have empathy. Just because they may not have the social/cognitive skill to read someone else's feelings doesn't mean they can't feel someone else's pain. While it's true that autistic people often have a harder time reading social cues, it is quite a leap — and a dangerous one — to assume that a person's inability to interpret nonverbal cues means he doesn't care and has no empathy.

Presume competence. That doesn't mean that we think Mickey automatically gets everything, but we do assume he always wants and is able to learn. He's taking it all in, storing it, and processing it on his own timetable.

People with autism have sensory challenges. All of us have sensitivities. Maybe we don't like crowds, loud noises, flashing lights, or the feel of tags in our clothing. Autistic people experience the world more acutely. Trying to cope with these sensitivities takes a lot of physical and mental effort, which is exhausting. That's why trying new things makes Mickey anxious. He's not being difficult just to be difficult. It's genuinely challenging or even frightening to him. People on the

spectrum are wired differently. I'm a PC; Mickey is a Mac. Autism isn't a processing error; it's a different operating system.

Behavior is communication. My son is verbal, but many people on the spectrum aren't. With or without spoken language, all of us use behavior to communicate. Just because you can't speak doesn't mean you have nothing to say.

You had many legitimate fears for Mickey - for his physical health, his emotional development, and his ability to build independent life skills - how did you manage all the anxiety and not let it paralyze you?

When people ask, *how do you do it?* I always give the same answer: I wasn't given a choice. I knew I had to be my son's advocate. Most of his therapists and teachers were wonderful, but they went home every night. My husband and I were in it for the long haul. We did it because it had to be done. Those early years were difficult. I often thought of the poster that hung on my wall in college that said, "Feel the fear and do it anyway." I channeled my anxiety into actions: Deal with his dental phobia. Check out a social skills program. Set up a special needs trust. But don't try to boil the ocean – you can't do everything at once. Set priorities, and chunk the challenges into manageable tasks.

At the same time, I made sure I took the time to enjoy Mickey every day, just as I did his older brother Jonathan. We celebrated every one Mickey's accomplishments. Many of his milestones were hard-won, so we never took any of them for granted. I was determined not to let my fears of the future rob me of the pleasures of the present.

Is there anything you feared that you now wish you hadn't wasted energy on?

When I was a kid, one of my favorite books was *The Emerald City of Oz*. The Wizard shows Dorothy a town called Flutterbudget Center, where people worry constantly. They begin every statement with "if." It's filled with people who let their nerves and the "what ifs" run away with them. As the parent of a special needs child, it's very easy to set up permanent residence in Flutterbudget Center. I could be the town's mayor.

One of the many things I obsessed over for years was how to make him indistinguishable from other kids his age. I just wanted so badly for him to fit in. Therapists urged us to encourage Mickey to have more age-appropriate interests. "Make him look as normal as possible," they urged. And today he does have what you'd consider some "appropriate" interests: for example, he's an avid sports fan. He reads the sports standings in the *New York Times* every morning. But he still watches Nickelodeon shows and Sesame Street. I wish now I hadn't invested so much energy in trying to change him. Maybe wanting him to be more age-appropriate said more about my own comfort level than about Mickey's development. So what if his interests don't fit someone else's

idea of appropriate? If carrying a small Sesame Street Grover beanie in his pocket makes him feel safe, why shouldn't he? I'll choose "happy" over "normal" any day.

Like many parents of kids with disabilities you also had a fear of something bad happening to you, because then who would take care of Mickey? "I have to live forever" became your mantra. Did this fear motivate you in positive ways to take care of yourself for the long haul?

Absolutely. You know how on airplane, the flight attendant tells you that if the oxygen mask drops down, to put on your own oxygen mask first before putting it on your child? Otherwise you risk blacking out before you can help anyone else. I learned early on that I was no good to my kids if I didn't stay healthy and strong. That didn't mean indulgent trips to Canyon Ranch, it was basic stuff. Making time to exercise. Eat better. Sleep more than six hours a night. Schedule date nights with my husband. There was a study several years ago in the [Journal of Autism and Developmental Disorders](#) that found that mothers of adolescents and adults with autism experience chronic stress levels comparable to that of combat soldiers. Self-care is imperative.

You were brave in speaking out against the link others were making between autism and vaccines, and now you've written a memoir that is very open and honest. Did you have fears in going public with your thoughts and feelings? What were your boundaries?

Just before the book was published, I had a wave of cognitive dissonance. I believed our story would be helpful or healing to others traveling the same path. But suddenly I found myself seriously questioning the wisdom of what I'd set in motion. Had I been an emotional flasher? Revealed too much about my family? Was I making myself too vulnerable? I'd been publishing personal essays for years, so I'd experienced how it feels to be the target of Internet trolls. Why was I opening myself up for more of that?

It's a balancing act to share your family's story while protecting your family's privacy. I wanted to explore the hardships and high points in raising a child with special needs. At the same time I was clear that I wouldn't write anything that might embarrass or blame anyone in the family. Again and again I checked in with myself: what were my motives in telling a particular incident? How would I have felt at the age of 15, if my mother had written something like that about me? If the thought made me squirm, the details or scene didn't belong. It was ok to out myself, but my kids were off limits. Anne Lamott is lauded all the time for saying, "You own everything that happened to you. Tell your stories. If people wanted you to write warmly about them, they should have behaved better." That's a bit glib. Yes, you own what happened to you, and you're free to write about it. But children can't defend themselves. They certainly didn't ask for a mother who's a writer!

Any advice to writers working on memoirs?

Come from a place of integrity. Are you writing to get even? Don't. You aren't the victim of your story, or the hero. Be clear that this is your version of the story. Others might tell it very differently. Remember you aren't sharing your diary. You don't have to reveal all. One of my windows. After all, we can't look out of all the windows at once, can we? We choose a view. We pick a story to tell. We shift through the ever-changing sands of memory, and in so doing create something hopefully beautiful, by which I mean universal."

Writing about yourself can be therapeutic, but unless it moves other people you haven't done your job. My best bit of advice for someone feeling blocked is this: a first draft doesn't have to be perfect. It just has to be written.

Can you talk about the difference between writing memoir and fiction?

With memoir, as opposed to fiction, you are more bound by the "truth" – well, "a" truth, anyway. But it's my truth, not necessarily anyone else's.

When you write memoir, you still use the techniques of fiction. The facts of my story provided the scaffolding for the book. But when it came to the writing, it was still all about voice, scene, dialogue, characters, pacing, and finding the narrative arc. When readers tell me the book reads like fiction, I take it as a compliment.

AUTHOR BIO



Liane Kupferberg Carter is a nationally known writer, journalist and advocate for the autism community. Her work has been published in the *New York Times*, *Chicago Tribune*, *Parents Magazine*, PBS's *Next Avenue*, *Brain*, *Child Magazine*, and numerous literary journals, blogs and book anthologies. She has a master's in journalism from New York University and a B.A. in English from Brandeis University. She lives with her family in New York.

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