Of Angst And Acceptance

Rozanna Lilley initially resisted the diagnosis of her son’s autism.

Last December my son, Ewan, wept because it was my birthday. I explained that I had been 45 and now I was 46. “I don’t want you to change numbers. I want everything to stay the same,” he sobbed, vehemently.

Ewan has a very limited tolerance of change. He is extremely anxious, for instance, about holidays. Once, on a drive to a coastal town, he muttered darkly the whole trip: “This is not a good day for me; this is not a good day for me.”

About four years ago, we moved from a cottage to a large terrace. Ewan still refers to it as “the new house”. For years, we have been visiting video-rental stores. Ewan has a passion for PlayStation. More importantly, he finds going to the stores and checking all the items soothing. It gives him something to look forward to after school each day. We still visit the ‘old’ video store in our old suburb. But since our move, we have expanded our options and now also sometimes visit the ‘new’ video store nearby. Things do change and sometimes even Ewan becomes familiar with those changes.

Ewan has a diagnosis of autism and is currently categorised as having a borderline intellectual disability. This year he turns eight.

Like many mothers of children with autism, I initially resisted his placement in that diagnostic category. My own stereotypes of autism (a sullen and sometimes aggressive child silently hunched in the corner of a bare room, endlessly fidgeting with a ball of string) meant I literally could not recognise my child as autistic. “But he laughs,” I remonstrated with the paediatrician. “He loves to be tickled. He enjoys so much!” Of course, I could have added other characteristics to this list: he
doesn’t speak; he runs away from me and seems oblivious to danger, as though that astonishing invisible thread that connects mother and child had been severed; he climbs up into the supermarket shelf and lies there, surprising people scanning the shelves for groceries; if he falls and hits his head very hard on concrete, he just stands up and walks away; when a child of the same age or younger is nearby, he shakes uncontrollably and hides underneath furniture, refusing to come out.

Ewan was on the path to diagnosis long before he turned three. I invented many ways of avoiding that seeming finality. I did my best to act like a good middle-class mum. I took him to kindergym. Indifferent to the gym component, he fixated on a toy fire engine. I had to carry him out screaming because he could not keep it. I took him to Montessori play sessions. The instructor suggested that I needed to give him different toys at home, so that he could take his aggression out in the safe confines of a domestic environment. Ewan and I went to the train station and watched the trains go by instead.

At one point, I asked a former child-health nurse who had started her own consultancy to visit us at home and tell me whether or not she thought Ewan was autistic. A GP told me that the nurse was not qualified to make that call. I didn’t care. She had seen Ewan when he was a baby; she had recorded his growth on charts. She was from a familiar, safe world of neighbourhood health and the seemingly certain regularities of child development. She asked me whether Ewan had any “German blood” in him. When I confirmed that this was, indeed, the case, she assured me that he was simply more intelligent than other children – a leader not a follower. She pointed to his very large head as evidence for her eugenicist fantasies. Despite realising this woman was, at a minimum, racist, I chose to believe her, delaying the cold fact of diagnosis for another few months.

Ewan is often much smarter than I am. When he was three, for months he would place a face washer in my handbag before we went out. I had no idea why. One day I noticed that the washer had a label with a Target logo. I realised that this boy who could not speak had been entreating me to take him to the toy department at Target. No wonder he wailed in despair when we ended up elsewhere!

The moment of diagnosis was, for me, a moment of black despair. My world contracted, literally. I no longer wanted to leave the house. I found watching other women’s ‘normal’ children incredibly painful.
I am not religious. Nevertheless… I made a bargain with a higher power. I promised that if Ewan ever spoke, I would never wish for anything more. He began talking at three-and-a-half, and these days is rarely quiet. It turns out that I am greedy. I’ve moved my sights to literacy now.