

Chapter 7

Other Parents of Autistic Kids



It's easy when sitting in your own house to think you are the only one with a problem. I remember overreacting to cold sores as a teenager, thinking I was singularly cursed in the history of mankind. A bit of perspective at times is no bad thing.

When Johnny was three we travelled to America to investigate a new way of approaching our situation and Angela and I found ourselves in a room with another forty parents of autistic kids from all over the world. Part of the first session involved feedback from the audience, which

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gave me time to understand who my fellow parents were. The man I remember most was a six-foot-seven African-American dad who said that he'd been an American football player. I wasn't about to argue with him on that, or anything else for that matter. He told a story of someone in a playground calling his kid an idiot. 'He's not an idiot,' the dad had said, 'he's autistic; you're the idiot.' Everyone laughed, even though the session leader was at pains to point out, that was definitely too aggressive an attitude.

We were then asked to turn to the stranger next to us and do an exercise. The small, older woman next to me was from India and spoke very good English. She was to imitate her daughter for two minutes while I had to try to interact with her. The exercise started and the woman proceeded to perform in character. She asked, 'When is Daddy coming home?' I was a little fazed from the off but tried to improvise. For the whole of the two minutes she just repeated the same phrase, 'When is Daddy coming home?' Whatever attempt I made to answer the question or change the subject, she'd come back with the question, 'When is Daddy coming home?' That was a very, very long two minutes and it upsets me now to think about what that quiet but determined woman was trying to cope with. Like me and the American footballer, she was here in search of something. I don't know the full extent of her struggle but my heart went out to her and I still wonder today how she's getting on.

Roles were then reversed and I had to imitate Johnny for two minutes while she tried to interact with me. It felt so strange trying to be Johnny even for those two minutes. It wasn't something I would have thought of doing before. It did have a profound effect. By trying to see the situation

from a different angle I realised it wasn't really about me. It was about how Johnny was going to interact with the world. I was just one part of that and it was up to me to decide whether I was going to be just part of the bigger problem or something more. *Something useful*. All around me people from all over the world were sharing this exercise. Angela was being Johnny to a fellow parent from yet another country with his own set of challenges. This was not just us with a singular problem in our house in Brighton. Looking around the room, there was a variety of people of all ages and backgrounds; we seemed to have little in common, and yet so much.

I thought of the American footballer again a year later when an incident occurred at our local garden centre. Johnny has always loved garden centres. They are usually spacious with high ceilings, and full of nature as well as the strange assortment of low-cost books, old-fashioned gifts and outdoor clothing that seems to have washed up on their shelves. The various seasonal fare always attracts Johnny. He likes the distinctive merchandise of Halloween, Bonfire Night and especially Christmas. An array of flashing lights, singing Santas, dancing reindeer, snow globes and glowing fairies adds a new level of attraction.

This was a normal summer's day though. Johnny was about four and he was standing with me in the queue to pay. He jumped about a bit at times around this age, rocking and moving his fingers – self-stimulation, or 'stimming', as it's sometimes called. Johnny must have invaded the space of the bloke behind us in the queue. The bloke spoke to him directly in a stern and abrupt voice. I confronted the 'idiot', as I'd now designated him. I explained Johnny was autistic and told the man in a similarly stern and abrupt voice to

back off. I don't know why at this particular moment the anger welled up inside me, as I've never been a violent person, but I was incensed. I berated him more than I should have. He was a solid-looking man who probably could have knocked me out with one blow, yet my dander was up. I think I was trying to pick a fight but the truth is it wasn't with him. It was with the world, perhaps, or maybe it was with God. I just needed someone to fight because this fight with autism was too hard.

Of course my anger was all futile and luckily Angela was there and soon calmed me down. Later in the car I realised I had gone too far and felt apologetic. I think I needed to reach the brink of such stupidity to realise that anger and violence would never solve this thing. That's not to say resolve, persistence, fortitude and downright stubbornness aren't useful; at times they are essential.

I've heard people say, 'I don't want your pity.' It's a loaded word, 'pity'. I looked it up on the wiki-dictionary and it means 'the feeling of sorrow and compassion caused by the sufferings and misfortunes of others. A cause for regret or disappointment.' There certainly was sorrow at first in our experience of Johnny's autism. We grieved for the boy we felt we'd lost. Even now, after so many years, there are times when I feel that sorrow and part of me still grieves. I'm not sure if I will ever lose that. I'd like to, and I can tell myself all the positives of our experience and that I'm grateful for the life we have, and that's true, but it is hard not to succumb every once in a while even though you know it may not be helpful.

It always sounds a little selfish to wish for more, and feels like some higher element of character is lacking in not being content with your lot. That said, you need ambition to drive

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progress so perhaps the trick is to achieve balance, or a kind of Orwellian double think. To be happy with what you have but want more. This is part of the thought process they were trying to advocate at the American training course we went to. I understand the merits of this seemingly contradictory logic on an intellectual level. If you can choose what you believe and how you feel then it will serve you well. Emotionally though, I lack consistency and no matter how much I tell myself what I should feel I do lapse occasionally. In a strange reverse of logic I have told myself it is OK to lapse once in a while.

Last year I was given an honorary degree as a Doctor of Letters by Nottingham Trent University and was invited to make a speech in front of over a thousand fellow graduates. Most of these young men and women were not much older than Johnny. While I felt sadness that my son would never have the kind of life these young adults had in store, I think knowing that made me appreciate in a more profound way what great potential lay before this new generation. I was moved seeing the parade of fresh faces, some filled with optimism and some with trepidation. My heart went out to all of them and to their proud parents. For me the occasion encapsulated that we are all on the same team, whether we see that as humanity, or life in general. I try to remember that day when I think about other people's thoughts and feelings towards Johnny.

'Compassion' is a more positive word. To feel empathy and compassion for others is not usually presented as a bad thing. So when I am talking or writing about Johnny, when we are out and about in public, I am never offended by other people's compassion. I can't say I've ever experienced any negativity from others in the form of pity. Maybe I choose not to see it or choose not to let it affect me. I feel that more

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compassion in the world is a good thing. I'm certainly conscious in this book that as part of telling our story I am trying to enlist empathy and compassion at times. It would be a strange human story if it didn't. I've read *The Outsider* by Albert Camus, possibly one of the bleakest books ever written, and even there I found it impossible not to empathise.

I have recently had strangers ask about Johnny, saying, 'What's wrong with him?' To which I always want to reply: 'Nothing's wrong with him, he's autistic. What's wrong with you?' I realise even now I'm still a work in progress.

Generally, though, I find Johnny brings out the best in people. I know he brings out the best in me.