The Father, the Foreigner, and the Deep Wide Water: A Family History with Autism

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The story of parents of children with autism is one of people who do the right thing not because they receive any foreseeable reward, but simply because it is the right thing to do. In this regard, stories of autism have everything – everything essential – in common with the best and most timeless aspects of moral tales, and with India's oldest stories told and re-told. No parent chooses autism; rather, they are chosen, and this inexorable call to adventure presents an opportunity for parents – and families – to grow along with their children.

I could give you an explanation of autism from physiology; I could tell the story of what goes on amongst the neurones of an autistic brain, how the mind's steady, single ship launches into a flotilla of small craft each making its own course. But that isn't the story that you're after. What you want to know is, what is it like to live this? What does it do to the autistic person, and to the family? When sensation is loosed from control and soft caresses become a sandpaper brutality from which a child recoils, when action comes unfastened from emotion and a child seems not to recognise love, when attention unhinges from social reward and a a child seems not to notice or to value the people in his or her life, or when speech is divorced from thought and a child seems not to participate around the table – faced with all these obstacles, parents are left with little else but a faith that the attentions with which they shower their beloved children do sink in, and that still waters run deep.

Though I wasn't aware at the time – I had no other experience to compare – autism defined our family. I had never known anything else: for my entire life my elder brother John always was there, always John, always autistic, never speaking. Sure, I was jealous, as any child would be, of the transgressions that my brother could commit unpunished, whereas for me there was always the threat, and sometimes the reality, of my father's "heavy hand," as he called it. There was the time when John, having been taught and having newly mastered the motor ability of unscrewing lids, went through the pantry methodically and unscrewed every lid on every jar, dumping the contents: forgiven. There was the time when I, home alone, dad still at the office and mum shuttling John to one and another appointment, decided to do something nice for my mum by cleaning the living room carpet – with, alas, washing-up liquid from the kitchen: this evoked the "heavy hand" when my father reached home. We all were trying to help each other in ways that we thought might benefit, but none of us knew how.

My sister bore the worst of it: she shifted out of an elite school to enter the state-supported one, forwent a chance at an elite liberal-arts college to enter the state university, all because she thought that my parents could use the money. She never asked. The only result was my father's railing against her foolish decisions as she dropped out and back into university over eight years. Children need to be given space to take risks, whether to succeed and to win the self-confidence that they can navigate the world independently of their parents, or to fail and to receive the reassurance that the parents and the home always are there, unconditionally. My mum tells a story of how my sister was out one night with school friends and had said that she would be back by ten o'clock. She reached some half an hour late, bursting through the doorway bubbly and energised, only to confront a scared and desperately furious father's "Where have you been?!" My mum could see her wilt. My sister learnt to keep her head down, and moved through her later life silently caring for wayward creatures who couldn't look after themselves – a series of cats, husbands, and finally her own autistic daughter.

My father never did anything halfway: when he committed to a goal, he targeted it with a single-mindedness, a narrowness of field worthy of Arjun's arrow. My mother tells another story of their

meeting, on a tennis court in Phnomh Penh, when he slammed the ball towards her court with such ferocity that she dropped her racquet and crouched behind the net. He pursued her with the same single-minded vigour, and when he married her and pronounced the vow, "till death do us part," his voice cracked as he felt the depth of the promise that he was making.

His own parents had made the same promise to each other, and to a new country – forsaking Italy and arriving in New York (separately, later to find each other) filled with hope and determination. It's the immigrants, the people who explicitly commit to a new country, who feel most keenly their investment in this new culture – so my father was brought up to feel, first, American, and when he set foot in Cambodia it was as an American embassy press officer. To most Americans after two world wars – and still today, anachronistically – the world contained two types of people: Americans, and those who wished they were. To those of us who feel a disconnection or at least an ambivalence towards the United States this egocentrism is galling. To the Americans it feels natural. They have never known anything else.

There was no question, of course, but that my mother should marry him. Her own parents having expired at early ages, it was the aunties who evaluated him (a previous suitor having been chased away, a self-made man whose family were the wrong class, speaking with the wrong accent). All the boxes were ticked. He was eminently suitable: a professional, in the diplomatic corps, a good earner with family potential. The aunties never knew that dad's own father was an illiterate farmer and labourer; they never thought to ask. At the age of 28, mum was nearing the boundary of what was then considered spinsterhood. And when, all naïve, my mother agreed to travel with him to Scotland on a motoring holiday, her fate was sealed: the couple had booked separate rooms, but the aunties didn't know that, and immediately on their return to Hertfordshire the campaign to marry was mounted. A blameless Sita, my mother was exiled across the water to a rough and foreign place.

My mother's life was defined by expectation and by social convention. It was not her own.

How she managed, in those days when the Americans were even more foreign than they are today, before global marketing had so homogenised the world – I can only imagine. Jet airliners remained the stuff of science fiction, transatlantic telephone calls were an expensive, rare occasion, and returning to her family remained, in any case, out of the question. Convinced to sign away her inheritance of the family firm by a husband who would brook no competition as a breadwinner, fast-tracked into an American citizenship oath before she had time to consider its implications practical and emotional, handed a US passport and congratulations on becoming *one of us (them),* she was cut off, in a country of 175 million people, all but one of whom had no idea who or what she was. She was trying hard to fill the role of homemaker but even buying groceries was a challenge when all the clerks spoke with the impenetrable accent of the American South. Over decades she adjusted practically, of course, but emotionally she – and I – always carried a sense of foreignness. Neither of us felt at home in America, and it always was when we escaped to England, on a summer break away from my father, that I felt most relaxed and closest to her.

England, though, was moving away from us. With every visit home it became less and less the land that my mother knew, and more some future world, foreign not in its spaces but in its time. The very familiarity of its cityscapes and country footpaths rendered the foreignness of a changed (and in many aspects globalised, Americanised) culture all the more uncanny. It was ghost land, where we ourselves were regarded as strangers. Even when I took a job at Cambridge, and bought my first house, the uncomprehending secretary in my laboratory kept asking "When are you going home?" as though I were a transient guest who were overstaying his welcome. At the elections my neighbours voted with ease, whilst I was asked to walk home to fetch my UK passport. To the British the moment I open my mouth I am labelled American, and to the Americans my speech with

my mother's dental 't's and anglicisms is an aberration to be corrected. For my mother and me both, no matter which side of the ocean we found ourselves on, we were the foreign, we were the other.

Such boundaries are human inventions: it is we who, as finite and limited beings trying to comprehend the sound and fury of an infinite universe, impose on that world a maya of categories and frontiers. People with autism, struck even more forcefully with this chaos of raw sense impressions, resort even more desperately to script, to ritual and to fetish in attempts to impose order and meaning (Belmonte, "The Yellow Raincoat," p. 74). In this sense they are the most human of all of us (Belmonte, "Human, but More So," p. 173). To the person with autism, the very world itself is a foreign place, always changing, never pinpointed, never the same river twice. Though my brother had no words to speak it, he and I understood this Heraclitean anxiety, this sense of the foreign outside one's body and outside one's control, which led to so many rituals of cause and effect: sometimes rocking back and forth to smash your head against the wall is the only way that you can create something loud enough, salient enough, to shout over the cacophony of the sense world (Belmonte, "Autism Connects Us," p. 101). The pain is at least a centre, a unifying Word.

I recall walking home from second-year primary school to the thud - thud - thud of my brother's head against the wall of his room, where my mother – and my father as soon as he reached home from work – would be trying to make him stop. My father reacted to my brother's behaviour with a sense of loss and anger. Having already suffered the loss of his first son at the age of one day ("The doctor told me, and I saw the floor coming up to hit me in the head," he would later say), my father wasn't ready to see another male heir slip away, this time into autism. His way of coping was to work hard, to provide for the family, to spend more time at the office. When no school would take my brother, my mother built a Montessori classroom in the basement of our house. Still uncertain how much was getting through, she taught him to use nouns and verbs in sign language, to point to pictures, to tie shoes. "Mrs Belmonte," scolded the white-coated physician who had been taught the dogma of the time, that autism was a psychogenic response to a mother's rejection of her child, "don't you feel *guilty?*"

When I first read the Ramayan I cried for Sita, who is all mothers, including mine. I remember sitting at my desk on a dark autumn afternoon, sobbing uncontrollably at the line in Ramesh Menon's lovely, lively prose translation, "it seemed the sky would shatter and time would end, for what had been done to that sinless woman" (Menon, p. 602). What makes these faces of God so compelling is that they are like us, they take on our frailties as a means of approaching us and reflecting to us an image of the divine, as Saint Paul observed "through a glass, darkly." This means that sometimes they fuck things up, just like we do – even though, somehow, it all works out in the end, and turns out to have been meant to happen that way.

And Ram, the father: what of him? His despondence and anger at Sita's final return to her mother Bhumi devi (a return trip that my own mother was never able to make, in this life) mirror those of my father when he knew that he had done wrong, and his sorrow and regret are genuine even if, like most men, he's unable to voice them, unable even to allow himself to admit his fault. He was doing the job that he thought he had to do, fulfilling the role that he had been taught within a South Italian ethos in which wives, daughters and families in general were things to be possessed and protected. My father, like all of us, was following a script. We didn't have the same script, but can I blame him?

It was a November day in 1977 when I had come home from year 3 of primary school to find mum collapsed and sobbing at the top of the stairs. A late afternoon sunbeam splashed golden across the deep red carpet, as my mother explained how people change and my father was no longer the man whom she had married. I had thought then that we would leave, and as she explained to me twenty

years later, she had had a flat for us all selected, but couldn't go through with it as she felt that we needed a father. She had been handed a script.

When I first came to India, Chitrakoot was at the top of my itinerary. The irony of the present-day rural Uttar Pradesh with which the legend was surrounded and instantiated, it was palpable. Half the population were missing from the discourse: men did the talking, women served chai. (I once made the mistake of saying hello to one of them. "Acha, he's single!" one of the young men chimed in as the young woman melted away in shame.) Boys spilled from a schoolyard all keen to practise their English; girls sat by themselves and gazed out of the corners of their eyes. "Come back and visit us!" the boys exclaimed. "With a beautiful wife, and two sons!" I would indeed like to come back someday to Chitrakoot, to step again into the Mandakini at Janki Kund alongside a self-assured wife who buoys herself as much as her husband, and with two confident, venturesome daughters who splash into deep waters, laughing at boys who can't swim.

On another autumn morning, thirty-three years after that day in 1977, I awoke amid the mass-produced apartment towers and shopping malls of Gurgaon to email from my sister: "Mom just called to let me know that Dad died earlier this evening." Plans were made, flights were booked. Over a few jet-lagged early mornings I wrote a eulogy (below, unedited), and realised that after three decades we had at last made peace, and that dad had chosen the right time to go. There isn't much to add, in this brief space, other than that this strange family over its generations has known the privations of war, the hardship of caring for the disabled and the ailing, but also the prosperity of good times and the contentment of love.

My father waded into a pushbutton-activated river of fire half a world away, in a kingdom that I had run away from and thought that I would not be seeing so soon. I was handed ashes in a plastic box. "Are you carrying human remains?" quizzed the airport security man, gaze flitting from the X-ray console to my face. I suppose this happens all the time for them. What do I say? I am flying home with my father? "Yes." When I poured his life and my thoughts into the water I snapped a photograph for my brother. The earthen pot bubbled into the mud, the garland snaked across the glassy surface. Ganga ma's strong fingers pulled at my clothes, wanting to carry me away, too. Still waters run deep.

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Celebration of the life of Joe Belmonte, 8 September 1927 – 1 October 2010
Greenspring Retirement Community, Springfield, Virginia, 31 October 2010, 2-4pm
Remarks by Matthew Belmonte

The task and privilege of speaking of our father's life belong properly to my brother John. Today I speak in his place, and I hope that I can express what he and I both would say.

My father's eighty-three years of life spanned more than a third of the history of the young country that his parents adopted. Dad liked to observe that the year he was born Charles Lindbergh flew across the Atlantic Ocean, whereas the year I his youngest son was born, people flew to the moon. His upbringing was a pragmatic one, and his parents instilled in him a desire to work for the betterment of his country and its people, rather than dwelling on, and being consumed by, the unfairness and prejudice that always are a product of ignorance. My Calabrese-speaking grandmother, always preparing her son for life as an American, used to ask him, "How do you say this word in your language?"

His family bore many injustices with grace and acceptance: Even when they were maliciously burnt out of their home, the loss of material possessions could not touch their spiritual wealth. Till the day my father died he carried in his memory an image of his own father, labouring to demolish a brick wall, sweat beading on his dust-covered face as he strained against a rope. Dad observed to me many times that for him this iconic memory of his father was the very image of dignity.

My father learnt this dignity of hard work first-hand when he took a summer job on the railroad as a boy, working doggedly side by side with older men. He would come home aching, exhausted, longing for the start of the school year in September, and gained all the more respect for working people when he realised, as he said, "For these guys, September never comes." So it was that when he graduated from Herkimer High School as an honours student, my father ensured that his beaming mother was seated front and centre in the auditorium.

Dad joined the army because it was the way out and up. Though he often kept it well hidden, my father always was a sentimentalist at heart, and was torn up by long goodbyes. For the rest of his life he remembered the ticking of the clock as he waited for that taxi to come to take him to the station and the army, away from one life and into another, far away. This theme was to be repeated in his life and death.

A buddy told him that the army always allowed an extra day for travel delay to the port of embarkation. So he took that extra day before leaving home. Reaching the port a day late, Dad found that the troop ship had already sailed to join the occupation of Japan. So instead he was sent to Adak, a frozen island in Alaska.

Dad's intellect, his sensibility, and his capacity to teach and to mentor his peers impressed his commanding officer so much that he rapidly rose to the rank of sergeant, and was asked whether he wanted an appointment to West Point. His path, though, pointed in a different direction. He mustered out with the GI Bill, joined the forestry school at Syracuse University, and in that typically creative and synthetic, uniquely American style of liberal education – one that he would represent during his later work abroad and at home – he discovered political science and international relations, and switched his major. When he took a job teaching high school social studies, his mother presented him with a new fountain pen and brimmed, "My teacher needs a good pen."

It was in teaching and mentoring that Dad always shined. He loved to see people realise their potential, and to feel that he had had some role in enabling their successes. One of his proudest achievements was exactly reversing his predecessor's poor passing rate on the New York State Regents Exam, not by rote instruction but by challenging his students to think and to write. In the midst of the red scares of the 1950s, he asked his students in a state-funded high school, rhetorically, "How do you think it would be if we had a socialised system of education?" Later, in his work in foreign language and area studies in the US Department of Education, one of his favourite parts of the job was meeting the Fulbright grantees and chatting about what they were doing.

Some years ago, after my father had retired, I was visiting my parents and we were sitting round the dinner table when my father received a phone call from one of those Fulbright scholars, Les Hook. Decades before this call, Les had been passing through Washington and had stopped in at my father's office just to say thanks for a small grant that he had received. My father hadn't been at his desk, so Les left his regards and went for a taxi. My father dashed after him and caught up just as a cab was pulling to the kerb. Dad took time for a long conversation with Les, convincing him to apply for a year-long Fulbright grant to go to Japan. Les did that, where, in an echo of my father's own experience in Phnomh Penh, he met the woman who would become his wife. Les had called just to remind my father of this story, and to say thanks for changing his life. I will always remember my father, turning to us after hanging up the phone, choking back tears. This was the sort of decades-long loyalty that my father inspired, and the emotion with which he responded to people whose lives he touched so deeply.

Even – and perhaps especially – after the challenge of raising a son with autism, my mother maintains a faith that events happen for reasons. I'm inclined to agree with her, even if those reasons may be up to us to realise, or to construct, after the fact. Often we recognise only in hindsight that events seem to have been leading towards a theme or a conclusion, and that the world has been conspiring in our favour. Many of you will recall my father's trove of oral stories of his Italian-American childhood. Some years ago, before he began to lose control of his voice, I sat with him for about a week and audio-recorded those stories – all of them. Then just this past July I had the opportunity to drive him, along with my mother, back for a five-day visit to his old home town

where those tales had played out. He was happy, and as we drove away he said, “The book closes for everyone sooner or later. I wanted to see all those people again because it might be the last time.”

I saw him again on his birthday this past 8 September, when we spent the whole day together. We disagreed politically, as we often have done, but we didn't dwell on argument. Leaving for the airport the next morning, I said goodbye, kissed him, touched his feet. In my mind, and in his too I am certain, was the thought that this might be our last goodbye so we had better make it a good one. And it was good. All that we needed to do had been finished, and he was ready to go.

When we grieve for a soul that is no longer manifest amongst us, we're grieving not for the dead but for the living; we're feeling sorry for ourselves. There perhaps were things that we wanted to do or to say, opportunities that we wanted to take, advice and physical comforts of which we now feel deprived. But if we have lived correctly then we find within ourselves the spirit of those who are not longer manifest here physically. In this regard we may take solace in Krishna's speech to Arjun, who despairs at the prospect of the deaths of his seniors and friends. Krishna says, in chapter two of the *Bhagavad Gita,*

> You speak sincerely, but your sorrow has no cause. The wise grieve neither for the living, nor for the dead. There has never been a time when you and I and the kings gathered here have not existed, nor will there be a time when we will cease to exist. . . .
>
> The body is mortal, but that which dwells in the body is immortal and immeasurable. . . .
>
> You were never born; you will never die. You have never changed; you can never change. Unborn, eternal, immutable, immemorial, you do not die when the body dies.
>
> As one abandons worn-out clothes and acquires new ones, so when the body is worn out a new one is acquired by the soul, who lives within.
>
> Every creature is unmanifested at first and then attains manifestation. When its end has come, it once again becomes unmanifested. What is there to lament in this?
>
> The glory of the soul is beheld by a few, and a few describe it; a few listen, but many without understanding. The soul of all beings, living within the body, is eternal and cannot be harmed. Therefore, do not grieve.

When a person leaves this world we can take a lesson not only from the right ways in which they lived but also from the things that they still have to work out. These aspects of karma are always two sides of the same coin, and we would fail to honour my father's teaching if we were to overlook that here:

We all have faults, else we wouldn't be here – and my father's faults were bound up with his virtues: he wanted so strongly, and pursued so single-mindedly (just as he did on that tennis court with my mother), the things that he believed would be good for the people whom he loved or cared for. In the days before autism services were available, he made countless trips to the state capital to press

for education and other rights for people with disabilities, and it was his very tenacity that began to achieve those rights.

My father shouldered these burdens because he had to. At his best, he acted not because he expected any personal reward but simply because he knew that what he was doing was the right thing to do. And at moments of weakness, as we all do, he wondered at his torment. Paradoxically, it was his deep love for us, his intensity of desire for good things, that drove him to such frustration when the things that he believed best for us did not immediately happen. His very attachment to these outcomes sometimes got in the way of their fulfilment. Krishna warned Arjun against this attachment, and the anxiety that it breeds. He said:

> Those who are motivated only by desire for the fruits of action are. . . constantly anxious about the results of what they do.
>
> When consciousness is unified, however, all vain anxiety is left behind. There is no cause for worry, whether things go well or ill.
>
> When you keep thinking about things in the world, attachment comes. Attachment breeds desire, the lust of possession that burns to anger. Anger clouds the judgement; you can no longer learn from past mistakes. Lost is the power to choose between what is wise and what is unwise. . . . But when you move amidst the world free from attachment and aversion alike, there comes the peace in which all sorrows end, and you live in the wisdom of the soul.
>
> When you let your mind follow the call of the senses, they carry away your better judgement as storms drive a boat off its charted course on the sea. . . .

This metaphor of steadying a boat on the sea is one that my brother John has often used to describe the calm that flows from love.

Even the Parkinson's disease that progressively consumed my father's control of his body during his final eighteen years had a purpose: it forced him to admit that he could not hope to control the world around him, or even, finally, his own body.

I remember exactly when I first glimpsed the symptoms of the disease that would take his life: it was June 1992, and Dad and I were driving across the continent to deliver me to graduate school in San Diego. We had stopped at a motel in New Mexico, enveloped in a surreal desert twilight the likes of which I had never before seen. I wanted to walk out to a mesa a mile or so distant. Dad insisted on coming along, but he was shuffling, couldn't seem to pick his feet up. I suggested maybe he should turn round and I'd meet him back at the room. “I'll follow you anywhere,” he shot back. So after a few minutes we <u>both</u> turned round, and we passed the evening trading stories with each other in the plastic-and-neon motel bar.

With Parkinson's disease my father began to learn detachment. He became more benign, more able to demonstrate readily the deep compassion that he always had possessed and kept bottled within. My father and I are alike in more ways than perhaps he or I would openly admit, and in his reflection I've been able to learn about him and about myself.

During the very challenging years of the 1970s in which families dealing with autism had so little help, my father in doubt and despair like Arjun would exclaim, “Why was I ever born?!”

Decades later, when my brother learnt to say things by typing, one of the first messages that he gave us was “I love you dad I am glad you are born.” I couldn't agree more, and I know that the soul that was manifest in my father will continue its journey.

Let us take a lesson from my father's life, by finding the strength to work for what we believe is right, and to accept victory and defeat with equanimity and with the faith that such events are parts of a story whose full extent we cannot yet perceive.

Thank you for honouring my father with your presence here, and with your good works that he has helped inspire.

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