

# Leaving Normal

the journey of a mother and son with autism

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## ***Dedication***

**T**o my wonderful husband who embarked on this journey of care-giving later on down the road but has been willing to adjust to the unexpected and unfamiliar demands of the journey, and is committed to the many twists and turns yet to emerge in this difficult terrain. You have been my ardent and able spokesperson at times when I have been too wearied or emotional to talk.

To my loving parents, Sir Richard Cheltenham and Dr. Hazel Cheltenham, who have modelled to me what dedicated parenthood means. Thank you for your material and moral support as I have looked after Fela over the years.

To my beloved brother, Chris, whose wonderful selection of gifts have helped to stimulate Fela's brain and keep him amused. Thank you for always checking up on Fela's well-being and sending helpful articles on breakthroughs in autism research.

This book is dedicated to all those care workers, teachers and health care practitioners who have supported our family over the years. You are too numerous to mention by name, but your tireless and patient interaction with Fela have enabled him to learn skills and remain safe and well, not to mention the respite you have afforded me to be able to focus on other life challenges and interests.

To all readers who also care for loved ones in their

homes; many of you have willingly and lovingly sacrificed huge portions of your lives to look after loved ones who are chronically ill and disabled. I know some of this heroic band, and salute you for your courage and faithfulness. It is hoped that this book will encourage you to press on in faith with your necessary and noble efforts until such a time when capable others can take over your responsibilities or they are no longer needed.

Last but not least, to my darling son Fela who has extracted from me blood, sweat and tears<sup>1</sup> but has made my life all the sweeter for showing me what true love entails. I look forward to what the next chapter of our thrilling adventure has in store.

Additional photographs and information about Carla and Fela's journey, also about autism and the strategies Carla considered can be found at:

[www.leavingnormal.co.uk](http://www.leavingnormal.co.uk)

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<sup>1</sup> "Measure thy life by loss and not by gain, not by wine drunk, but by the wine poured forth, for love's strength standeth in love's sacrifice and he who suffers most has most to give." [Love's Paradox by Harriet Eleanor Hamilton Smith]

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## ***Prologue***

**W**elcome to the world of weirdness. My son and I inhabit this world on a daily basis. We are amongst those who are forced to leave the land of normal. We think it will be a temporary sojourn, but then we find we are permanently banished. It is at first a crushing blow, but over time we begin to see that the land of 'normal' is not always as wonderful as it is cracked up to be. Normal people are killing one another, living with fear, anxiety and depression, and struggling with a sense of hopelessness and purposelessness. Normal people are frenetically striving for the world's measure of success – money, popularity/fame and power. Insofar as my son has not lived a normal life thus far, he has managed to avoid these pitfalls and hollow ambitions. Still, deep down inside, I pine for normal.

Autism is a brain disorder which affects communication and behaviour. Prevalence has been calculated to be as high as 1% of the UK child population. It is a brain disorder varying in severity and the spectrum includes the severely autistic on one end and the more able diagnosed with Asperger's syndrome on the other. Autism is characterised by a triad of impairments - difficulty with social relationships, with verbal and non-verbal communication, and the development of play and imagination. My son struggles in all three categories, his most obvious trait being prolonged speech delay. Some of the everyday behaviours are mood swings,

lack of or echolalic<sup>2</sup> speech, hyperactivity, lack of eye contact and sleeplessness.

My son is no savant like the autistic genius Stephen Wiltshire who can sketch buildings and landscapes in amazing detail from memory<sup>3</sup>. Neither is he a mental wizard with numbers like the character portrayed by Dustin Hoffman in the film, *Rain Man*.<sup>4</sup> No doubt, he does have some above-average abilities, but it has taken me a long time to accept the fact that he is not amongst the rare but specially gifted group of autists. For the most part, the skills he develops will require the patience and perseverance of others to harness them, as has been the case so far.

By now I thought my son would be cured. It has been a bitter pill to swallow that autism still has him in its vice-like grip with his eighteenth birthday on the horizon. He has had many hands laid on him for prayer and prophecies galore spoken over him. He has ingested countless vitamin and herbal supplements. His diet has been constantly tweaked and much money spent on getting him the highest quality gluten-free and casein-free food and vitamins. I have researched *ad nauseum*, read innumerable books and attended workshops, yet his progress seems miniscule.

By now I should have been mentally exhausted, my

2 Echolalia refers to the habit of repeating or echoing what another person has said.

3 June Southworth, "Stephen's Magic Eye," Daily Mail, February 11, 2000.

4 *Rain Man*. DVD. Directed by Barry Levinson. 1988; New York City, New York: MGM, 2000.

hopes should have been irretrievably dashed, I should have been admitted to the psychiatric hospital, I should have resorted to the bottle or prescription anti-depressants. Having a child with a 'life-long, incurable' disability is supposed to be amongst the top three most challenging life events which people dread the most. I once read a Daily Mail article whose headline left me dumbstruck - 'Having an autistic child wrecks your life'.<sup>5</sup> According to the writer, my life should be ruined, my hair should be covered in grey, I should be prematurely wrinkled by permanent disappointment.

But for me giving up is not an option. There is too much at stake. As I learned early on in the journey from the book 'To love is to be happy with'<sup>6</sup> there is no such thing as false hope, for hope is what equips you to wake up and fight each day. I have also discovered that the adversities we face in life can either make us 'better or bitter'. Thank God, I am not bitter, having been exposed soon after my son's diagnosis to the life-changing message of the Options Institute<sup>7</sup> philosophy. I was able to view my motherhood as a special blessing – a gift from God. Rather than ruin my life, autism has improved it beyond my imagination in terms of the person I have become and my perspective of

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5 Sarler, Carol. 2009. "Why can't we face the truth? Having an autistic child wrecks your life." [dailymail.co.uk](http://www.dailymail.co.uk/femail/article-1116602/-why-face-truth-Having-autistic-child-wrecks-life-.html), January 15. <http://www.dailymail.co.uk/femail/article-1116602/-why-face-truth-Having-autistic-child-wrecks-life-.html> [accessed April 19, 2012].

6 Kaufman, Barry Neil. *To Love is to be Happy With*. New York: Ballantine Books, 1983.

7 [www.option.org](http://www.option.org)

what truly matters. The matters which tend to floor people, tend not to even make me bat an eyelid. I often jokingly say to my son - "If Fela is okay, Mama's okay." And I reassuringly say to my concerned husband after I have thrown a major wobbly (a tantrum) and he asks me how I am - "I'm always alright." I now have a permanent measuring stick of what constitutes being okay.

If you're reading this book, autism has likely touched your life in some way. You may be a parent, a person on the more able end of the spectrum, a family member, a medical practitioner, a carer/ support worker, a friend, a researcher. This book is as much for you as it is for me. There were times when I did not want to write it as I had initially envisaged that it would be my farewell to autism, my tome of triumph. Instead it has become my way of processing the journey of my son's last eighteen years, the challenges and what I have learned along the way. This book has been many years in the making. I often could not harness my emotions and order my thoughts sufficiently to write until some time after events. There were times when I felt too sad, confused or frustrated. It is a homage to endurance and hope against all odds.

It is no longer strictly accurate to say that autism is incurable. I am not one to argue over semantics and so I refuse to get 'hung up' over the words which people like to use - 'cure', 'treatment', 'recovery', 'improvement', 'healing'. What is indisputable, however,

is that there are a subset of autistic people who have lost their diagnosis. I am currently reading a book by the mother of one.<sup>8</sup>The daughter of my son's former biomedic nutritionist is also numbered amongst them; It took her 8 years to recover. Raun, the adult son of Mr and Mrs Barry Neil Kaufman (founders of the Options Institute), was told he would never develop beyond the mental age of a two-year old, yet today he shows no sign of autism. It has constantly amazed me that the press and the scientific community never made a song and dance of such breakthroughs. Instead, the media prefer to spin the outdated view that autism is incurable. Recently I read an article, the first line of which declared the following – "autism is not necessarily an incurable condition. According to doctors who specialize in biomedical treatments..."<sup>9</sup> Surely, if only one case transpired where a person lost his or her diagnosis, then it can no longer be tenable to assert that autism is incurable. So why have documentaries and biopic films not been produced, or Nobel prizes been awarded? The only answer I can proffer is that a pharmaceutical cure has not been concocted, no patent has been registered, so there are not huge profits to be made. But there are much weightier issues at stake – there is much human potential to be salvaged before it is too late.

Indeed, the medical establishment have placed a

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<sup>8</sup> McCarthy, Jenny, and Jerry Kartzinel, M.D. 2009. *Healing and Preventing autism: a complete guide*. New york: Dutton.

<sup>9</sup> Lisa King, "Message of Hope for the autistic," *Daily Nation* (Barbados), October 18, 2011.

label “incurable” on a syndrome that has defied their understanding since it was reported by Leo Kanner in 1943. Though many theories abound as to what causes autism[birth difficulties, viral infections (possibly through immunisations), genetic defects and even a leaky gut wall], the lack of certainty as to its causes leaves parents with one of two options – either total despair or the hit-or-miss approach of trial and error when it comes to treatment. One thing is certain – the time, dedication and money needed to treat these children is immense. They require one-to-one therapy involving constant repetition of words, sing-a-long rhymes, pointing games, visual cues and makaton (a basic form of sign language.) Progress can be slow and patchy, but every iota of achievement is worth the time, effort and money as it serves to fuel hope for a brighter tomorrow.

Traditional medicine offers parents of autistic children little or no hope so it is only to be expected that those prepared and able to do their own research, will turn to the alternative health field for insight and answers. Perhaps the biggest lesson of autism is that those who carry the diagnosis cannot be neatly assigned to one box or another, and that what works for one person doesn’t necessarily work for another. I sometimes grow weary of trying different things with apparently no significant gains, but it’s highly probable that Fela’s gains have come cumulatively and gradually and will continue to do so. Perhaps one day the light bulb will finally come on in his head, and he will begin to share

all his myriad experiences as if he had been in a dream all along.

My son loves jigsaws which is ironic because he is oblivious to the fact that he is the greatest puzzle of all. Autism is far more daunting than a jigsaw of a million pieces. You could work on it bit by bit, a little each day, and pray you live long enough to complete it. I started out in hot pursuit of a cure or a miraculous healing. Now, I pray for survival and the preservation of sanity. Yet beneath it all still lingers the longing for the land of normal.