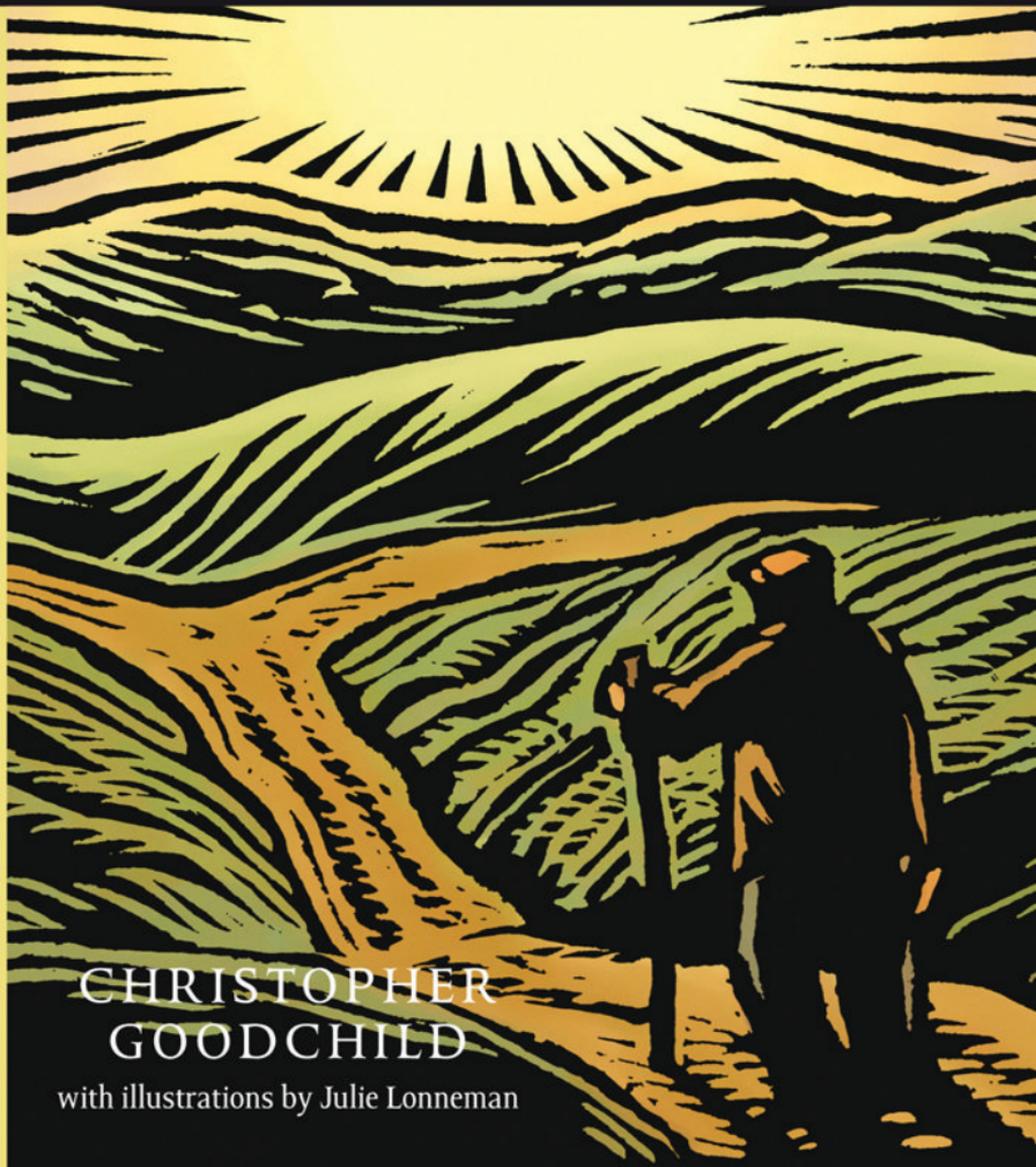


A Painful Gift

The Journey of a Soul with Autism



CHRISTOPHER
GOODCHILD

with illustrations by Julie Lonneman

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Christopher Goodchild

First published in 2009 by
Darton, Longman and Todd Ltd
1 Spencer Court
140 – 142 Wandsworth High Street
London SW18 4JJ

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A catalogue record for this book is available from the British Library.

Designed and produced by Sandie Boccacci.

Digital edition converted and published by Andrews UK Ltd 2010

Dedication

This book is dedicated to my son, whose love has helped me to find freedom – my love for you is as deep as the deepest ocean. And this book is also for those whose stories and cries for freedom will never be heard nor come to light in their lifetime.

Foreword

A painful gift
a book that wounds and reveals.

The story of a gentle man
who is constantly lost
yet found.

Lost,
because he never knew
he was sick with autism.
But found,
when it was diagnosed many years on.

It was no longer then a sickness
but part of his being.
A way of life
his way of life
and of relating or of fleeing relationships.

Found and lost through relationships
found by Jesus
and by Daniel, his beloved son.

A moving, deeply moving story
that can reveal our woundedness but also our hope
how quickly we judge through the prism of our fears and wounds.
Yet found by Jesus
who is always there – but so often silent.

Our hope.

Jean Vanier
November 2008

Quote

Love in action is a harsh and dreadful thing
compared with love in dreams.
(Fyodor Dostoyevsky)

Acknowledgements

In the National Gallery in London there hangs the famous Velázquez painting *Kitchen Scene in the House of Martha and Mary*. Although the techniques the artist used, as well as the message that he wished to convey, remained a mystery, what is obvious is that this seventeenth-century painting places Christ in the background, while the servant girl takes centre stage.

It is therefore fitting for me to refer to the imagery in this painting to acknowledge and thank my dear friend Katherine, who, like the servant girl in the picture, worked quietly behind the scenes of action, tirelessly helping me, and listening with such unfailing love that I trusted her to enter my world of autism. The love she has shown me remains as mysterious as the *Kitchen Scene in the House of Martha and Mary*. Not being a natural writer myself, it was only with her help that I have been able to give shape to my story. Because of the difficulties I have had all my life with writing, and because of the unusual and idiosyncratic ways in which I express myself, Katherine has taken great pains to understand and interpret my writing. Therefore virtually every line of the book has, in effect, been ‘translated’ by her to make it more accessible.

One of the ways I communicate is to remember and then replay as my own phrases that I have read or heard. I have tried to tell my story in my words but if any unwitting plagiarism remains I apologise.

I have changed some names, for reasons I think you will understand.

Thanks are also due to Brian, Katherine’s husband, who has shown me great kindness by helping to produce the early drafts of my book.

To my adoptive parents, and sister who cared for me as best they could and taught me more than they will ever know.

To the mother of my son, and his brother and sister and grandparents for letting me into your lives and loving my son in a way that I can never come close to either offering or experiencing.

To my godmother, my very first friend in life.

To Patrick, who taught me the art of listening with love.

To Marek and Maria, for their friendship and hospitality.

To Father Pat, who has shown me endless kindness and support over the years.

To Kate Frost fcJ, who offers me spiritual direction from the goodness of her heart.

To Linda my psychotherapist, thank you for illuminating my darkness.

To my brother Caspar, who designed my website and offered his technical skills.

To Annerie, a lovely and generous friend.

To Razz, who like my son brings me out into the light of the world.

To Brendan Walsh, for his vision, sensitivity and gifts as an editor, without which my story would never have reached publication. And also to all the team at Darton, Longman and Todd.

To all my friends in London, the Catholic Worker and fellow travellers everywhere.

Christopher Goodchild
19 August 2008

Introduction

Your joy is your sorrow unmasked.
(Kahlil Gibran)

As far back as I can remember, I recall a deep longing to enter into the unity of all things, and to connect deeply with the world around me. I ached not only to feel the sun on my face, the wind in my hair, and the smell of the garden in springtime – I longed to be one with them. It seemed mysterious to me then that the very things that brought me such joy would also bring me such pain. The sun and wind would bring blisters to my face, the may blossom would make my nose run and my eyes swell, and the kaleidoscope of colours would dazzle my eyes. It seemed I ached for what I could not bear.

When it came to the social world, I felt like a bewildered stranger, often drowning in a tidal wave of sensation. People, places and things would melt and blend like a surrealist painting. Words and sounds would scream at me and then like magic somehow melt away. Everything seemed transcendent and immanent all at once.

Welcome to my world. I have autism.

However, this book is not so much about my autism, but about the struggle to be truly myself in the world. To be fully human, to touch people and to be touched by people in return. As the Cistercian monk Thomas Merton once said, ‘To be a saint, is to be truly oneself.’

As a Christian I have always held a deep affinity with Jesus. When I first thought of writing my story, the Stations of the Cross offered me not only a useful structure for outlining my life with Asperger’s syndrome, but also powerful imagery to accompany people along the journey that led to my diagnosis in the summer of 2007. For those unfamiliar with the Stations of the Cross, they represent points along the way of Jesus’ last moments of his life, covering his trial, sentencing, crucifixion and resurrection and the people who came into contact with him at that time.

Asperger’s syndrome is a high-functioning form of autism and falls within the autistic spectrum. It was first identified over fifty

years ago by Hans Asperger, a Viennese paediatrician. I was in my early forties when I was formally diagnosed with it. The reason such an understanding of myself evaded me for so long will become clear as my story unfolds. In my story, I describe the life I led, unaware of my difference, and also my struggles with depression living in this 'cloud of unknowing' until my diagnosis, then I end with a reflection on how my outlook on life has subsequently changed so radically.

One way to describe a person with autism is someone who comes not from another planet, but rather from a different culture and who has a different way of perceiving our world.

Autism is a blessing, a gifted way of seeing the world. It is also deeply misunderstood. There is much talk today of finding a cure for autism, and even if that is remotely possible, I would have no interest in such cures, for the simple reason that there IS nothing wrong with me that needs curing. If anybody needs an immunising injection to shield against the crippling effects of their general predisposition, it is those who feel the need to fix individuals, societies, or whole cultures. For it is the inability to accept difference that cries out to be remedied.

However, although I regard autism as a gift, it can be a painful gift in many ways. Even producing this book has been painful, since writing has always been a distressing and uncomfortable experience for me because of my autism and dyslexia. It was an enormous strain physically, mentally and emotionally, so I regard the publication of this book as being a miracle in itself.

When I had nearly finished writing my story, and I realised that what I was writing might possibly find its way into the public domain, I became aware of the temptation to dampen down and sanitise the darker moments of my journey in order to make them more palatable to others. I resisted this temptation for the most part, because I felt called to share my woundedness in full, so that others might be strengthened in the process of bringing to light their woundedness too.

My deepest prayer is that all who read this book, including my son, if he so wishes when he comes of age, will be inspired to see that, as was the case in my story, it is often that which gives us the deepest sorrow in life that can bring us the greatest joy. It is for this

reason that my book is dedicated to my son, because, despite all the difficulties regarding managing myself when I was with him in the early years, the times I spent with him were, and will remain, the greatest and most joy-filled moments of my entire life.

Above all my son has taught me that great love and great suffering are part of the spiritual journey, and that it is only through great love and great suffering that human beings can be transformed, for it is, I believe, in my poverty and in my joy God resides. The fact that love and joy bring me such intense pain can only truly be understood by travelling deeply into my inner landscape.

... We are put on earth a little space
That we may learn to bear the beams of love.
(William Blake)

Station 1: Condemned

Jesus. How hard it is for me to be condemned, not by my difference, but by the world's indifference to my way of being that seems not of this world.

I was adopted at the age of six weeks from the Crusade of Rescue, which was a Catholic home for destitute mothers and their children. My adoptive parents came from working-class families and both grew up in North London during the Second World War. I had a sister, who was also adopted from the Crusade of Rescue; she was two years older than me. She was clearly different from me – she was talkative, I was quiet and learnt to talk later than the average child. In childhood photographs my sister is always beaming, but I have no trace of a smile. How to perform such a feat seemed totally beyond me.

When I was able to crawl I would struggle for dear life to be away from family members, only to be picked up and returned to them. Over and over again this painful ritual was re-enacted, painful because being held felt like what some people experience when they scrape their fingernails down a blackboard. The more I resisted my mother's attempts to cuddle me, the more she persisted. I soon realised the wisdom that comes with acceptance and in the end gave in to my mother's need to hold me, over my need to be away from her. It must have been hard for my mother to experience this rejection from me.

My earliest memories were of a world that felt totally overwhelming. Lights, sounds, movements and smells flooded into my senses, leaving me feeling distressed and anxious. For me it made perfect sense to remove myself from all social interaction. This way I felt safe from a world that was strange and alien to me, and the more I ventured out into the world the more I wanted to retreat from it. I soon learned that whenever I was able to shut my bedroom door behind me, all my problems just seemed to magically evaporate. How wonderful! What bliss!

One of my greatest difficulties was in understanding what

people were saying to me, as everything was so confusing. I recall working tirelessly from an early age, creating sophisticated ways of communicating in order to cope. I built entire systems in my imagination – my brain was like a library filled with images and words. However, in order to gain access to this ‘library’, I needed more time than the world allowed. Only in isolation could the conditions be created whereby my system of thinking would operate.

I remember, around the age of three or four, being given one of those objects which was filled with water and which, when shaken, would make snowflakes swirl around in some scene or other. I was fascinated by this object – it seemed so much like me with all that frantic swirling movement going on while the main character remained so visibly unaffected within the hermetically sealed container. I would love the fact that I had complete control over the movement of the snow, and I loved the way the soft white flakes fell so gently to the ground. I saw myself as a snowflake and my parents as hard rocks that I would fall against and then melt. I ached for them to be snow like me, so we could be held together, held together in a field of snow.

Beyond the place of right and wrong, there is a field – I’ll meet you there. (Rumi)

Station 2: Taking up the Cross

Jesus. How hard it is for me to accept at times, that I am the way I am. So broken, vulnerable and so susceptible to seeking love from others and not from that part of me that reaches out to you. I accept this as my cross. Help me. Help me to get out of the way of your loving grace.

‘Wake up, Chris. Is there anybody there?’

‘He is in a world of his own.’

‘Chris is not concentrating and appears not to be in the world at all.’

These were typical examples of my school reports as a child. I found school totally overwhelming. When the teachers spoke, their words echoed and repeated themselves in my mind, which was very confusing. Information had no meaning or significance. I couldn’t remember what the teacher said because I was too agitated. I couldn’t cope with written work at all. I had difficulty learning to write and my handwriting was very untidy – the letters often came out back to front and I couldn’t write on the lines. I often couldn’t read what I had written. I was never able to do any homework because I couldn’t remember what to do and I was too distressed. Having such serious learning difficulties was no fun. In fact it was soul-destroying being bottom of the class year after year, and being thought of as not caring. In fact I cared deeply, but was too fearful and bewildered to find a way of expressing myself to the world.

My earliest memory of school was in kindergarten and the teachers asking me to leave the class and do painting in a separate room. Such was the level of distress I felt at being completely overwhelmed by my inability to concentrate, that I became too agitated and fidgety to remain in the classroom.

Life at home was no easier. I felt terribly misunderstood by my mother who had started to drink heavily, and began telling me that I was behaving in an odd manner, and that I had to ‘act more normal’. I think she often overheard me having conversations with myself in my room, and

she would have also heard the various creative sounds I produced with my voice, in order to experience the pleasure that came from the vibrations in my head.

Social situations filled me with such intense anxiety, that I was totally unable to engage with an authentic sense of self, or participate most of the time without rigid control over my anxieties and behaviour. Often my way of managing myself in these situations was to hide or quietly wander off. This was my only way in which I could find the freedom to be myself. An unwritten rule seemed to emerge in my family, that 'Chris does not do social things'. I think I was often seen as selfish and inconsiderate, though I was always very polite.

To my parents, my preoccupation with objects and attachments to my toys, as well as my social exclusion, odd quirks, tics etc., not only seemed odd but also a threat to the family image, which everyone seemed to have a great interest in upholding. As a result, my difficulties were seen as something that needed to be 'got rid of' through harsh discipline because my very 'being me' was seen as an act of defiance against my parents' accepted standards of behaviour.

Even my appearance did not come up to their standards of middle-class respectability. A lot of the time I looked quite scruffy because the clothes I was expected to wear felt horribly uncomfortable, stiff and constricting, and the material they were made of, and the labels inside them, used to irritate my skin. This was especially true of my school uniform: I just couldn't bear my school tie tight round my neck. I could hardly wait to get out of formal clothes so I could wear something more comfortable and less restricting. I hated my clothes. I also hated having my hair cut. My father, who was very particular about how it looked, used to comb it for me, but I used to wriggle and wouldn't sit still long enough for him to tidy it up properly. The lotion he would put on it to smooth it down used to sting my scalp terribly.

My anxiety was unbearable at times, as my rigid routines and ways of managing myself in the world were condemned by my mother as mad, odd and disrespectful. When I was on my own I used to comfort myself by talking to myself, by making noises

and by going round my room stroking things, smelling things and touching myself, especially my head. These were things I had to conceal from my family, and conform as best I could in order to avoid being humiliated.

Most nights when my parents went to bed, and when they woke in the mornings, they argued. Their bedroom door was opposite mine. I would put my ear to their door, and listen to my mother talking incessantly, often screaming hysterically about how insane and affected I was.

At the time I did not know how seriously unwell my mother was, so her talking about me in this way deeply unsettled and unhinged me and gave me a fear of being mad which has haunted me ever since. My father had great difficulty supporting me, choosing instead to just listen my mother out. This pained me, for I ached for my father to stop her hurting me. It was in these moments with my ear to my parents' door, I could feel myself entering into the world Thomas Hardy offers us when he said

Childlike, I danced in a dream,
Blessings emblazoned that day;
Everything glowed with a gleam;
Yet we were looking away.

I was splitting in two. Feeling totally defeated, I retreated ever more deeply into my secret world.

I remember kissing my favourite toys and then tying them up with strong cotton or string, and throwing them out of the window. However, I did have every intention of salvaging them after the great sacrifice, that is, if they survived. Some never did and they got lost for ever. I remember once, one of my favourite toys got stuck on the roof below my bedroom window. I panicked, and jumped out of the window crashing straight through the asbestos roof and landing on the floor below. I don't remember feeling any pain whatsoever as my body crashed to the floor, and my head and shoulders took the full force of the landing.

When I picked myself up and walked back indoors, my mother

was washing up. She looked at me, saying ‘Why are you looking so disgracefully filthy?’ To which I replied in a monotone and with a rather affected manner, something like, ‘I appear to have fallen through the roof, and it seems I have done some considerable damage, mother.’ In response to this I was told to go to my room until my father returned from work and tidy up my room because it was a disgrace. My mother must have thought I was just fooling around and I was unable to convey to her how I felt; it was impossible to get her to believe me.

My mother seemed so sad to me, I so wished she could accept me for being so sensitive, and yet my quiet and aloof ways, my very being me, seemed to pose a great threat to her. ‘Why do you have to be so abnormal?’, ‘Why do you take such great delight in acting odd all the time?’ and, worst of all, ‘You are destroying my life – wait till your father gets home!’ That one hurt me the most, because I hated the thought that it was I who was making my mother’s life so miserable. All this seemed in such stark contrast to the mother who was at times able to be gentle and attentive, when we would say prayers together at night-time. Although my mother was brought up in an Irish Catholic home, she had little desire for the faith any more, yet I recall times of great tenderness saying the Hail Mary together on occasions at bedtime.

Living in a family that was so driven to be normal at all costs was a great strain on everyone, not only myself. This resulted in my adapting and creating many skills to face the world with a convincing façade of normality. I learnt to master the art of simulating normality to such an extent that I learnt to conceal almost all visible traits of affectedness such as tics, blinking quickly or slowly, touching, odd quirky sounds etc. However, I just did these things when no one was around, and had the ability to conceal my many quirks and unusual habits for the best part of the day, that is, until I got home and entered my room. And then, as soon as I gently shut the door behind me, my little body would melt, and I would become one again.

I must have been so hard for my parents, for my actions seemed to imply I did not want to be with them. The truth was, I just did not know how to be with them.

Station 3: Falling down

Jesus. Be in my thoughts and actions today. But if my thinking escapes you and I fall, lead me back to you, as gently as a feather falls unto a feather, gently lead me unto you.

The weight on my shoulders was fast proving too great for me to bear. By the age of seven I remember feeling gloomy, unhappy and alone. This was the first time I remember thinking, ‘What’s the point in trying if I never get anywhere?’ My school reports continued to show I was deeply withdrawn and fast becoming unreachable and unteachable. An educational psychologist assessed me with a view to evaluating my suitability for education in a public school. As his report said my IQ was above average, the message was to pull my weight and knuckle down.

My mother’s depressive condition got worse, and the daily humiliation at home continued unabated. I started counting obsessively and realigning my toys in symmetry over and over again. Also I would often hide in my room and create new personas and characters from listening to the radio or from watching films. This equipped me with certain skills in order to avoid being seen as odd at home and in school. I was teaching myself social graces, like an actor preparing myself for a play.

At this time, I recall an incident where my mother was aggressively cleaning the family dog, the steel comb digging into his skin. I remember hearing his muffled whimpers (all the family’s dogs learned to dampen down their cries as my mother would beat her fist in the dog’s face if it showed any defiance), and seeing his pathetic eyes so beaten, and watching my mother’s face all contorted, as the sharp teeth cut into his scrotum. Just hearing his cries broke me. These awful displays of such insensitivity would be carried out quite openly. No one really challenged my mother, not even me. I was mute. But deep inside me I cried and felt absolute outrage for her callous insensitivity, and guilt for my complicity.

I formed close relationships with all the family dogs, simply