

Soon Will Come The Light

Book Written by Thomas A. McKean

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Few books have been written by individuals with autism. Thomas McKean has added another. He successfully provides the reader with a new wealth of insight into areas known only to those individuals with autism. Parents, hungry for greater understanding of their children with autism, will ravenously devour this wonderful autobiography. He cautions parents to "be careful in the way you raise your children. You never know when one of them may grow up to write a book about you." McKean challenges professionals to learn what makes him tick so they may begin to strive to separate the autism from the person and see only a person of value, worthy of respect, dignity, acceptance and friendship.

McKean's book is divided into two sections. Section One consists of six chapters about life with autism. Original poetry is sprinkled throughout, beginning with "Soon Will Come The Light," which introduces the dominant book themes of fear, loneliness, love, and escape. Section Two contains, "Poetry, Writings, Ideas & The Future." The Preface is written by Gwendolyn Jebb, whose long term friendship McKean credits with bringing "me out of the shell... And keeping (me) alive." She describes McKean as "talented not only in music in writing... a gadgetry wizard... Brave, tender, compassionate... a work of art in progress." Mira Rothenberg, author of "Children With Emerald Eyes," in her introduction, notes the remarkable changes in McKean during their friendship and evolving trilogy of letters to her which formed the basis for this book. McKean's foreword describes his awe at how he went from crying alone in the darkness with his bear to being an overnight international role model with ever mounting friendships, speaking invitations, and opportunities to make a difference for others with autism. His reason for writing the book, "I am tired of denying who I am. Before I can know, love, and accept who I am, and who I am growing into, I must find that person inside of me."

McKean leads the reader through a maze of autism with sparse childhood memories. McKean recalls his fifth birthday and a feeling of overwhelming terror when friends gathered too closely. Terror at the presence of other people

continued for several years. He acknowledges that, "I was making my parents life a living hell... doing exactly what a young autistic child was supposed to be doing, and being quite good at it, perhaps even going above and beyond the call of duty in the name of dedication to my job." The obvious resentment at being yelled at and punished is mixed with pleasant memories of his mother's calming Irish songs and stories and father's condoning of his strong need to know how the world worked. (Dismantling everything from toys to appliances and often putting them back together with more features than before.) Moving from school to school resulted in no chance to make friends.

At age 14, McKean left home for a three week stint in a psychiatric institution. Three weeks became three years. Descriptions of rigid institution routine and aversives made this parent reviewer recoil. Fond memories were few; writing letters to pod-mates and articles for the campus newspaper, taking guitar lessons, performing in the band called, "Us," combining his savant music ability and writing talent to create many songs.

Numerous adverse memories included: unisex living arrangements, staff supervision of bathroom use, solitary confinement, threats of being strapped down and forced to take medication, female patients subjected to "close" inspection by male staff, and his own suicide attempt. He credits another patient, Lisa, for beginning to help him out of his shell. Description of frivolous antics with his Madeline Machine is overshadowed by McKean's comment of seeing "enough depression, suicide, and other things that no one should be forced to witness" during his time in the institution.

McKean comes down hard on the professionals who ignored the obvious ultimate therapy - a direct and unpatronizing acknowledgement of his intelligence and his autism. "Thomas, this is what the problem is. This is what it is called. This is what it means, this is why your ears hurt, this is why you need to be held, this is why you see things differently than the rest of us, this is why you can't do the schoolwork, this is why you don't understand the math, this is why you can write and play music better than the rest of us, this is why you retreat into your own world, this is why people frighten you, and this is what we can do to help you with it."

McKean chronicles his pursuit of a college degree, work force attempt, and relationships. His dream for quiet and security becomes a reality when he moves alone into his condominium. The demise of McKean's brief engagement leads to his search for answers. In his medical records, he finds AUTISM. "For once there was a name attached to the problem and there had to be a weapon to fight it - that weapon was knowledge." He writes, "I was being bathed by the light, yet I was still walking in darkness." Just as a parent of a newly diagnosed child with autism, McKean began reading everything on autism that he could find. He began attending autism support group meetings where he became a sought after commodity - a person with autism who could describe it. Suddenly, what he had

been punished for was the same thing he began to be praised for. The old Thomas was gone. A new Thomas had taken his place.

The new Thomas helps us understand autism with a conglomeration of miscellaneous comments on various topics: speech - requires great effort and energy; fear - his most dominant emotion; change - needs feelings of sameness and security; sleep - aided by bear, heated waterbed, crying self to sleep, talking alarm clock to refocus as waking; libido - has no sex drive; eating - lacks appetite and has limited food preferences; computers - uses to communicate without sensory overload; nerves - are never calm; social interactions - "Humanity is one big enigma to me" and needs constant interpretation; aversives - adamantly opposed to use of aversives and punitive measures; pressure cravings - constant low-intensity pain is relieved by his pressure suit, pressure wrist bands, brushing; sensory - hands and feet are super sensitive, human touch is soothing and necessary, haircuts are painful, hairbrush better than comb; drugs - should be avoided or use "lowest possible dosage"; facilitated communication - controversial, but "far too precious to dismiss" because children with autism have "thoughts and feelings and intelligence that are screaming to be free."

McKean shares a fascinating description of what he experiences when he "tunes out." He enters a world of alternate reality created within the boundary of his imagination. A scary darkness leads to majestic mountains, a castle, a dragon field, a domed city, ocean, sunken ship, red fluorescent caverns, forest, and abandoned mansion. He expresses a fear of exploring too far and being unable to find his way back. How many of us wonder what our children with autism see when they have that far away look in their eyes?

The reader must not skip over the 31 poems by McKean illustrating that "Poetry is just way. How we see ourselves." McKean's poetry reflects his yearning for the gentle embrace of a friend to escape fear and pain into a world of comfort and calm. Here is a gentle man. Here is a person with a great sense of humor. Here is just a guy writing a poem for his newborn niece. Here is life from the eyes of Thomas McKean - my friend.