



## Book Review: A Book of Light

### When a Loved One Has a Different Mind

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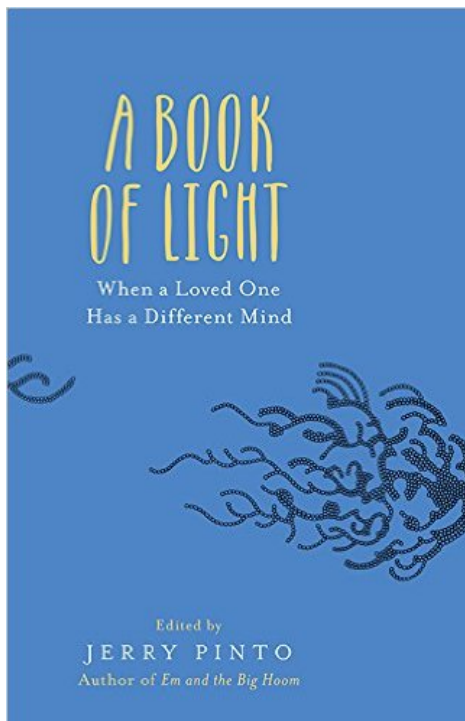
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Received: 02-FEB-2017

Accepted: 11-FEB-2017

Published Online: 14-FEB-2017



Editor: Jerry Pinto

Speaking Tiger Publishing Pvt. Ltd.

7 July 2016

Hardback, 216pp.

Price: Rs. 399

Mental illness is not just misunderstood, stigmatized and under-reported in our country, it also takes an immense toll of the care-giver and other members of the family. 'A Book of Light', a collection of thirteen stories, edited and with an

Introduction by Jerry Pinto, attempts to illuminate the secret, unspoken 'areas of darkness' in the middle-class Indian family.

The authors of the thirteen stories narrate

Cite this article as: Vaidya S. Book Review: A Book of Light. When a Loved One has a Different Mind. RHIME. 2017;4:12-15.

the experiences of parents, siblings, children and lovers of persons with mental illness or disability capturing both, the demands and the challenges of life with such a person, as well as the deep sense of love and duty that keeps them going against all odds. Pinto writes that the family that we read about in cinema and fiction is a sanctuary where people retreat when they are hurt by the outside world; where they can “lick their wounds in peace” and are healed by the love and warmth surrounding them. “But what if it is your mother who is wounding you and then soothing you by turns? What if it is your father who seems distant or desolate, living in a dark tower you cannot enter?” (p.10) The home, the epicentre of life’s most intense and intimate dramas, becomes a permanent battlefield, and life revolves around the highs and lows of the afflicted person. The judgmental, often voyeuristic gaze of ‘society’ compounds the isolation and misery.

Pinto is the author of ‘Em and the Big Hoom’ (2012), a novel based upon his experience of living with and caring for his mother with bipolar disorder. The response the novel elicited from readers who shared their own stories of silence and stigma with Pinto prompted him to compile this anthology. The book’s subtitle “When a loved one has a different mind” uses the term “different mind” not with an intent to sanitise or render politically correct the term “mentally ill”; rather, it conveys the idea of the personhood of the sufferer and attempts to understand and empathise with their alternate universes and realities.

The stories encapsulate the spectrum of emotions from love, pity, devotion and duty, to resentment, anger, grief, loathing, guilt and fear. These conflicting

emotions bring with them their own burden of unresolved dilemmas and internal conflicts. In his stark and deceptively simple account, Sukant Deepak writes with brutal honesty of the relief experienced by the family when his father, the acclaimed writer Swadesh Deepak, wandered away one day, never to return. Swadesh had bipolar disorder and his family had had enough.

Leela Chakravarti (pseudonym) tells us how intensely she loved her violent and erratic mother and how her mother “made our love unique”. ““Oh my God, you bitch, you whore, don’t you love your mother?” she asked me, again and again.” (p.26) Her love went hand in hand with fear, revulsion and a deep sense of being abandoned by the person whose care and protection she needed the most.

Patricia Mukhim lays bare her pain, guilt and sense of utter helplessness at the suicide of her bipolar daughter Daniella, and her own inability to understand what she went through in her short life. “How can a child born out of one’s womb be so estranged?” she asks. (p.87) The powerful, unanswerable question “Why?” reverberates in her narrative.

There is unconditional love and acceptance too, as in the piece by Madhusudan Srinivasan, writing about his autistic son, Abhimanyu; and Shashi Baliga’s loving tribute to her adventurous, playful, larger-than-life Anna (father).

A disturbing and deeply unsettling theme that runs through the book is the sense of unpredictability and instability; “days of panic and terror and heart-thumping worry” (Baliga, p.152) that families of mentally ill persons live with. In Parvana Boga Noorani’s story titled ‘You didn’t

know her when she was normal', the author takes us through the extreme highs and lows of her brilliant, scholarly mother's illness and the minute changes that signal a future flare-up. The family is dispersed and tries hard to cope. The daughter asks, "So who was my mother? The caring woman who taught several generations of women mathematics? Or was she the woman who cornered me one day when I came out of my bath, a wet and skinny ten-year-old, saying, 'Your sister's not here to protect you now, what are you going to do?'" (p.158) In another incident, the mother holds a sharp knife to her daughter's throat and threatens to kill her. Noorani recalls: "I also remember my heart threatening to burst out of my body while trying to look and sound calm. Putting this down on paper right now my heart is hammering - and she's been dead over twenty years." (p.159)

Shashi Baliga describes her father's moods; the transformation from an exuberant, talkative vivacious man to a quiet, withdrawn one, who "sat in a protective bubble of silence inside which you sensed a great turmoil. A man trying very hard to hold all the quivering pieces together." (p.144) Leela Chakravarti's story is particularly harrowing to read, as she takes us through her mother's extreme behaviour and violent outbursts; her sexually explicit displays and her refusal to protect her daughter from sexual abuse.

The theme of care and care-giving also resonates in the stories. Amandeep Sandhu's poignant account of his mentally ill mother's cancer, brings out in minute detail the decline and decay of her body while giving us glimpses into the life-long torment of her afflicted mind. Administering food and medicine, bathing and toileting, cleaning her wastes and soiled clothing, dissolves the barriers

of age, gender and ego. "We dressed Mamman, helped Mamman to the potty, bathed her. I carried a naked Mamman to and from the bathroom and Maasi gave her baths." (p.44) Just how debilitating care-giving can be comes through in Sukant Deepak's account of his father's hospitalization and his mother's service: "My mother bore quietly the torture of travelling forty kilometres to Chandigarh from Ambala every day. She did not explode. Not even once. [ ] But one day he said that his tooth hurt and she couldn't hold back. 'Look what you have reduced me to, you bastard. I was such a beautiful woman once; I look like a beggar now. Why don't you die?'" (p.21)

Violence, both physical and psychological, is a recurrent theme. Sharmila Joshi's deeply moving account of 'the man under the staircase', her gentle uncle Vinay, also tells the story of a family destroyed by violence and abuse. Vinay, the alcoholic wastrel, who simply did not fit into a ruthlessly competitive world and chose to drop out of it, is considered a blot on the family of the respected Judge, and is the recipient of his harsh brother's beatings and verbal violence. Ultimately, he is evicted from his 'home', a small alcove under the staircase, and left to die on the streets. "Vinay died within a year of losing his home. He had just turned thirty. His liver could not handle the alcohol. And his heart, I believe, had a hole which got bigger with time as he struggled with the sorrow of dealing with a world that he could no longer fit into." (pp.95-96).

Nirupama Dutt's story of a cognitively disabled girl addresses structural violence that a girl child, "tatti" or shit, as the patriarch of the family calls her, is exposed to. Snatched from her mother's breast and thrown out of a moving train, Prerna survives, and is raised by her adoptive mother. The story ends with her

becoming the mother of a baby girl, resolving to protect her from the violence which she herself was subjected to. The stories also reflect upon the impact of the loved one's affliction on the future lives of family members; failure in adult relationships, substance abuse, withdrawal from the world and an inability to find closure. Baliga writes: "Are we 'normal' ourselves? And the question that cuts closest to the bone for people like me; 'Am I going to get it?'" (p.152)

And that brings us to the fundamental question of 'normalcy'; the fine dividing line between the normal and abnormal. Is 'normality' an absolute category or a shifting, contextual one? Anna Furtado, reflecting upon her family's experience of mental illness observes: "No one is merely crazy. We just don't know how to describe the illness. The lines between normal and abnormal are often so personal. What may seem normal to one may be abnormal to another." (p 135) Is 'normality' sought to be imposed on our loved ones for their sake or our own? Srinivasan, writing of his autistic son, makes the point that children like his Abhimanyu actually demand nothing at all from anyone. However it is we who place impossible demands on them, in

our endeavour to meet society's norms.

At the same time, the veil of ignorance, secrecy, and shame that makes mental illness a 'family taint' needs to be blown away. Many of the authors found it hard to come to terms with the fact that they were left exposed and vulnerable, deprived of counselling and care, forced to deal with their feelings of fear, guilt and shame on their own. The need for non-judgmental companionship, of friends who offer support rather than unsolicited advice, is acutely felt. It is in this sense that this collection truly becomes a "book of light" for those struggling in the darkness; by sharing these deeply personal and painful stories, the authors have opened a crack in the door to let in a welcome ray. I recommend this book both for its literary merits as well as for it being an important source for those dealing with the issues of mental health and family therapy. The discourse around mental health is incomplete without bringing in the family as a critical partner and stake-holder.

I will let Jerry Pinto have the last word: "This is how life is. Open-ended. Challenging. Terrifying. Demanding of us all that we have, and then some." (p.13)