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Book Review

Krishna Living with Alzheimer's

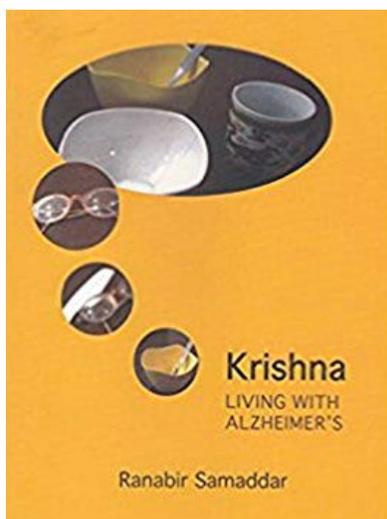
Ranabir Samaddar

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The book - 'Krishna Living with Alzheimer's'

Sritama Mandal

The blurb of the book introduces it as the story of Krishna Bhattacharya's fight against Alzheimer's, written by her husband Ranabir Samaddar, one of the leading social scientists of this time. I would rather like to look at the book as an attempt by someone who tried to come to terms with the ramification of the disease. And this he has done through his passionate care and understanding in view of the woeful inadequacy of medical knowledge. And in doing so he has raised some basic question about the quality of life, the ethics of care, the right of an ailing person to live with dignity etc. Last but not the least, he has shown how a meaningful relationship can be forged with an Alzheimer's patient, who is the denizen of a borderland with a 'new self'.



Alzheimer's or the commonest form of dementia is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of ageing. The disease progresses slowly in three general stages: early (mild), middle (moderate) and late (severe). In the early stage he or she may still drive, work and be part of social activities. But close friends or family members notice problems with remembering the right word or name, forgetting material that was just read and losing or misplacing valuable objects. Middle stage is typically the longest when one forgets about events or personal history, feels moody or withdrawn, faces trouble in controlling bladder & bowels and may become lost. In the final stage, individuals lose the ability to respond to their environment, carry on a conversation, and eventually control movement. They may still say words or phrases, but communication becomes difficult. The brains of individuals with Alzheimer's have an abundance of plaques and tangles. Plaques are deposits of a protein fragment called beta-amyloid that builds up in the spaces between nerve cells. Most experts believe that they disable or block communication among nerve cells and disrupt processes the cells need to survive. The destruction and death of nerve cells cause memory failure, degeneration of all motor abilities, personality changes, problems in carrying out daily activities etc. Closely related to Alzheimer's is what is called bradykinesia –an early sign of an illness or movement disorder somewhat like Parkinson's or Parkinsonism.

As to the treatment of Alzheimer's, it is said that the first step in following up on symptoms is finding a doctor with whom a person feels comfortable. There is no single type of doctor that specializes in diagnosing and treating symptoms of Alzheimer's. The disease is life-changing for both diagnosed individual and those close to him or her. Some medications, called psychotropic medications (anti-psychotics, anti-depressants, anti-convulsants and others), are associated with an increased risk of serious side-effects. As to new directions in treatment and prevention, one promising target is beta-amyloid. If it can be cleared or prevented from clumping together into plaques, it will be helpful. Emerging research also suggests that the steps people take to maintain heart health may also reduce the risk of cognitive decline. But medications can be helpful or effective only when combined with care and support. Since people with Alzheimer's gradually lose their ability to communicate, it is important to regularly monitor their comfort and anticipate their needs. It should target specific symptoms so that response to treatment can be monitored. Eating a diet low in saturated fats and rich in fruits and

vegetable, exercising regularly, and staying mentally and socially active may all help protect the brain. Research has shown that taking full advantage of available treatment, care and support options can improve quality of life.

Ranabir and Krishna got married in 1981 and Krishna died in 2013. They had a long conjugal life spanning over three decades. In any marital relationship, both the persons are different. They have their own choices, tastes and expectations. Ranabir was, according to Krishna, a 'public man' committed to demands in public sphere. Krishna was a professor, had done her Ph.D in Indology but suffered from the pain of childlessness in her daily life. Ranabir found in her the characteristics of kindness coupled with a readiness to help others and a persistent reticence. The insensitive comments of relatives on both sides for her childlessness used to hit her hard. She used to say her husband that she wanted a family with people around. In 1983, she had a major surgery in her eyes which impaired her eyesight greatly. From 1999 to 2003, Ranabir had to leave for Kathmandu. She was greatly shocked since she despaired loneliness and used to complain that there was no one to offer a cup of tea. He suspects that this loneliness gradually reduced her desire to cook, to eat, to lead a happy life. During her visit to Kathmandu, he found her somewhat less adept at chopping, cutting and cooking. Meanwhile, she began to forget some useful things and at some points of time it became difficult for her to walk alone. In her own place also, she was forgetting things, even the way to her home. In 2003, Ranabir came back permanently to Calcutta. Already, Krishna lost her ability to live independently. Four caregivers used to take care of her through a team work. The period from 2005 to 2008 has been described by the author as a 'period of confusion'. She had to wage an enormous battle with her failing memory and had to make daily adjustments to situational demands – how to bathe, how to eat, where to go, why were there so many books in the room. She forgot who Ranabir was. The caregivers called him 'dada' and Krishna also became used to it. Both of them had to make adjustments on a continuous basis to survive, till they reached an island of mutual recognition and understanding. According to the author, this was the cruelest and the most demanding period fraught with uncertainties, questions, dilemmas, the cruelty of human association and bondage. Still, their conjugal relationship of the past two decades was being redefined – from 'you' and 'me' they were becoming 'we'. In other words, they had recognized their destination, the shore they were looking for.

And Ranabir does it by acknowledging the fact that the essential personhood of the patient does not disappear with memory loss. Memory may go, but one can still see in the way she was responding to the person around her. Her feelings used to convey the fact that she knew the author's importance in her life though she forgot who Ranabir was. And in this background Ranabir has delineated in details how care giving was done at home. He got the assistance of four caregivers who were mostly illiterate but kind at heart. They understood only the body. They noted when Krishna was smiling, what depressed her, the pattern in her recognition of people, voices, music etc. They helped to return Krishna back to her husband, palpably more closely. Surprisingly, no doctor had ever told how to take care. The author says that they learnt everything by trial, inquiry, error and close observation of the patient, e.g., the caregivers never gave Krishna anything without asking. They found this strategy very helpful. On eight out of ten occasions she would give a response that they could understand, and as time progressed, they understood more, even her inchoate sounds made sense. Hundreds of questions were put to her by the caregivers and her response, a glance of rebuke, of joy, pleasure, consent, annoyance, anger – marked the schedule of care. Thus a supportive ambience was created. The caregivers, through their words and actions assured the patient that she was enjoying life like a 'normal person'. Regular exercise, in case of Krishna, physiotherapy was very important to prevent the advance of the disease. Moreover, she forgot to swallow, therefore there was constant danger of aspiration. The author lamented that no doctor guided them in setting up an optimized regime of care. No text he could find to help him. He had to grope his way forward.

Moreover, the author repeatedly insists on the fact of making the life of an Alzheimer's patient not only bearable but happy to a considerable extent. He invited friends and kept Krishna in their midst. It was important to take her out at least once a fortnight to hear sounds, see trees and birds and experience life around her. He mentions an interesting event in this respect. Years back, he and Krishna used to go a roadside tea stall. And now when they were passing that corner she suddenly gestured towards the turning for the stall. One of the caregivers, Anjali asked whether she would go there. She kept on waving her hand. Ranabir recalls these small instances of her recognizing signs of life. He also feels surprised by the fact that she never forgot the fact that she could not stand independently after her femur bone got fractured in 2009 and she underwent a major operation. Rather, she became careful. One day she found herself alone in the staircase and asked crying 'Eije kothay jachcho?' (where are you going). Her caregivers and husband were surprised by her clarity of voice and power of recognition. It is this subjectivity with which they had to come to term and shape their responses accordingly. She knew that Ranabir and the four caregivers were clinging to her intensely. Otherwise, she could never respond to calls of 'Krishna' or 'didi' from them. Just two days before she was taken to the hospital for the last time, she asked Ranabir 'dada, eto der?' (brother, so late?). He could not recognize Krishna when she lay 'masked' on the bed of the hospital. The mask seemed to steal the essential personhood of Krishna.

Side by side with this human aspect of care, the author has shown how inhumanly the doctors treated the patient. He took the help of two super-specialty hospitals and specialist doctors in treating his wife. Surprisingly, no one even advised him about the trajectory of the disease. Instead, they administered heavy drugs and antibiotics to Krishna whenever she was admitted to the hospital. The author mentions that the hospital papers never did properly reflect medicines and doses administered. For example, an extremely toxic drug Colistin was given to her for 14 days, the use of which could cause renal disease and bronchospasm. Moreover, Krishna had respiratory trouble for which Colistin was not at all advisable. In 2012, she contracted a further infection from the catheter that had been inserted in her body in the hospital. She had klebsiella, which is seen in people with a weakened immune system. As a result, her total blood count jumped from 12,000 to 18,000 in 4 days. The use of antibiotics was also a risk-increasing factor in her case. Last but not the least, the doctors tried to treat her bedsores through debridement. They did not pay heed to Ranabir's plea that it could be taken care at home. But they forgot that anesthesia was undesirable for an Alzheimer's patient.

Throughout this book, Ranabir has brought home the fact that he and Krishna had commenced co-writing the most intimate chapter of their lives. He had to reckon with the fact that his lifelong companion was dying, that the end was approaching very fast. He mentions a book by one Harvard Professor of Psychiatry, Arthur Kleinman, who nursed his ailing wife who is an Alzheimer's patient. He wrote that only love and companionship (being with her) could help him to overcome this time. His experience reinforced Ranabir's own that the best caregiving derives from being with the patient – physically present, to talk to, to watch TV with, touching her affectionately, make her feel included. In this perilous journey, they remained steadfast. The half-closed, peeping eyes looking at him in the ICU in the last four days, validated that.

Ranabir is proud of the way Krishna fought back her illness. He mentions that there was always a smile on her lips. And her last photograph in the wheelchair shows the serene face of her where there was no sign of illness. He regrets that very few of the relatives were interested in knowing Krishna, loving her, meeting her tenderly or at least trying to understand the new relationship he was forging with her. Days after Krishna's death pouring visitors tried to console him by telling that Krishna had no quality of life since she could not speak, move or eat by herself. It was good that she passed away. Even the doctors never appreciated the resilience of Krishna. They were always surprised that she was still alive. Here, the author has raised a very serious question: whether an ailing person loses all his or her right to live with dignity or not. He himself shows that illness can in many cases produce care, sense of belongingness, a deeper love

between the ill and the rest. Those who think that an ill person has no right to live is really fascist in attitude. He has seen the seeds of fascism embedded in their mentality.

The pleasure and pain of a caregiver has been delineated in minute details in this book. This would be of immense help to the medical practitioners, who, unfortunately never consult the caregivers for their treatment. The act of companionship can give a new direction to the therapeutic acts. The society, the state should be more sensible to such patients. This book has done a lot to create this awareness.

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