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BOOK EXCERPT

## How I discovered my wife was developing Alzheimer's disease

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Krishna, the author's wife, had forgotten who her husband was, mistaking him for her brother.



Image credit: youtube.com

I was her dada (elder brother). She had forgotten who I was, my name, everything. She was nearly blind; she probably could not see me even when I stood near her. But she knew my voice. She knew my touch, and – as I found out last evening – she still remembered that I am her dada, the name by which the caregivers have addressed me all these years.

Last evening at the hospital she had been seated in her room (308) on a chair beside her bed for one hour, and then the two caregivers tried to lift her onto the bed. They could not lay her down properly. Half her body was still off the bed, the upper half had barely been placed, and her head was hanging over the upper end of the hospital bed. She looked surprised as they struggled to place her on the bed.

I entered the room in the midst of this. I quickly went to her, held her lowered head, told the two girls not to hurry and put her on the bed gently. I lifted up her head, she was looking surprised and baffled at what the two women had been trying to do without asking her, and then finding me caressing and comforting her, saying nothing had happened, she cried out, "Dada, dada..."! Her last clearly spoken words, loud...

**Our marriage was based on a mutual understanding of our vastly different backgrounds, values, and attitudes.**

That understanding compelled us to persistently try and overcome the implications and fallout of these differences. Their traces have now dimmed in my memory. But this much I realised as time passed and her disease progressed, making her increasingly dependent on me, that it was these differences that had cemented our companionship.

I became tender; her grace became even more striking. Our long, eventful, wandering life of togetherness introduced in me the realisation that I had to cling to her even as she was dying, and she probably started clinging to me ever more lovingly, through indescribable gestures and ways, as the last pillar of memory in a life of togetherness.

As I recalled her long life of various illnesses – her degenerated retina, leading in the final years to near-blindness; two operations (eye and uterus); her occasional falls that some ascribed to epilepsy (of which she had no history); heart trouble; and now her failing memory – and what she had accomplished in her teaching and research career, her social work, and for the little ones in her family despite these adversities, as well as many more things of the past, my sense of what she required now deepened.

I started intuiting what she wanted, what would make her happy, what she should not be led into, what she should be protected from, and so on. How did this come about? I was not so much perplexed or worried about what she was remembering and forgetting, as I was by what I remembered of her, our moments of togetherness, our travels in various parts of the country, the initial days of hardship, our quarrels and making up, and all else. My memory was playing with me. Her fading memory was igniting many things I may otherwise have forgotten.

**I remember how, twelve years ago, I first realised that she appeared scared, that her sense of some of the routines of daily life – eating, changing her clothes, etc. – was slipping.**

During my occasional visits to Kolkata from Kathmandu I would find food rotting in the

refrigerator, the milk pouches untouched. She seemed anxious, repetitious and confused in her speech, but still suffused with the same tenderness and devotion that had marked her human relationships from the start. Almost mysteriously, she could be both anxious and boundlessly patient, scarcely ruffled by the troubles of the surrounding world.

I remember the first sign of her disease as it appeared to me in 2001. I was in Kathmandu directing the South Asian Peace Studies Programme and she was teaching in Kolkata. She had never reconciled herself to the fact that I had shifted base to Kathmandu after being driven out of a job at the Maulana Abul Kalam Azad Institute of Asian Studies by the BJP government at the Centre; no higher educational or research institution in Kolkata or Delhi in those days would touch me with a bargepole because of my “extremist past” (the Left Front government in West Bengal and the government at the Centre were the same in this respect).

Our economic need meant we had to live separately, she in Kolkata and I in Kathmandu, from early 1999 to late 2003. This was a great shock for her. I enjoyed my solitude in Kathmandu; she despaired and disliked loneliness deeply. Often she would say, “I come back home alone, switch on the lights, and sit in an empty home. There is no one; no one to even give me a glass of water or a cup of tea.”

I suspect this listlessness gradually reduced her desire to cook properly for herself, to eat, to lead a happy life. When she visited me in Kathmandu, she became sentimental, offering to do everything that would make me happy. As a result there was a sense of melancholia, more acute because our days together in Kathmandu or Kolkata would invariably be short in duration.

**In the summer of 2001, she visited me in Kathmandu and told me that the travel agent in Kolkata had not given her a return ticket.**

In those days tickets were non-electronic. No amount of reasoning could persuade her that the travel agent could not have done so, that the ticket must be somewhere in her luggage. We searched for it. I did not have the travel agent’s number. We went to the Indian Airlines office in town to get a duplicate, which luckily we got after forking out a penalty.

The travel agent later told me that she had already lost the ticket once, and the one she had travelled on was the replacement. During her visit on that occasion I found her somewhat less adept at chopping, cutting and cooking, though she managed to keep me company. The game with us was: she would cook for me in Kolkata, where I was the guest in her home, and I would cook for her when she was in Kathmandu as my guest.

Our companionship deepened as her vulnerability became increasingly evident. She managed to continue with teaching and later, administration, but I never asked how she was managing. I was afraid that her memory lapses would be causing confusion at work too, and inviting adverse reactions among her colleagues. I was scared to enquire about anything related to her work. Every evening, either Kathmandu or in Kolkata, I would listen quietly to her complaints, her incomprehension about whatever was happening at her college, who had told her what, or what work was being taken away from her. In this way I began to understand her mind, even while the contours and hues of that mind were changing daily. Her visits became a time of great expectation.

**By 2003 it became apparent that I was living in my memories of our companionship of the past, while her present was incomprehensible.**

I would have to get back to Kolkata. By the time I returned in late 2003 I knew I could not leave her alone for more than a month, at most, and in that event too, there must be someone present to take care of her. I now experienced the fear and anxiety of losing her. Yet even then she retained her dignity and pleasant demeanour.

This was the early stage. She would lose her purse, or think she had lost it. She was fidgety about her keys, uncertain about her office, and wanted me by her side at every moment, every hour. I realised that this disease was like a mask, covering a unique individual who was living, loving, and being loved. From now on I would encounter the disease on a daily basis, aware of the fact that Alzheimer's is a tragedy, not standardised, but unique to each individual afflicted with it. This was the moment when caregiving became my lifestyle.

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