

Letter from Mumbai

THREE MEMBERS OF A FAMILY FROM MUMBAI

This *Letter* is devoted to Dr Mujtaba Tayabali, his wife Perveen and their daughter, Shaista.

Each of them is unusual in her/his own way. I have gained inspiration from them. I hope you will find this narrative of interest.

Mujtaba (Chhotu) Tayabali

When I first learnt of his nickname, I was amused for it is in keeping with Heraclitus' Law of Opposites. Chhotu is actually a Lambu! Chhotu has granted us the privilege of using this nickname so I take the liberty of referring to him thus from now onwards.

He was born in Zanzibar. His father, Tayabali Rajabali, was the aide-de-camp to the Sultan of Zanzibar and on one occasion, host to Mahatma Gandhi. Chhotu came to Bombay (present Mumbai) at the age of 2. After his father was appointed first Muslim Chief Justice of Udaipur, Chhotu lived in Udaipur with his parents until the age of 13, when he returned to Bombay to study at the Cathedral School. Chhotu's medical training was at St Andrew's in Scotland. He then studied radiology at Addenbrooke's Hospital in Cambridge.

On his return to Bombay, he was appointed Chief of Radiology at Breach Candy Hospital. Chhotu was always interested in art and painted in water colours while studying and working in Cambridge. He was influenced by his favourite painter J.M.W. Turner and tried to capture the play of light in his paintings. He started to paint seriously after he met the charming fellow artist to whom he has been happily married since. He chuckled as he recalled those early days. 'Looking back, it seems apparent that a major incentive to explore my artistic side clearly came from the drive to impress her!' (You can see some of his paintings at www.tayabali.com).

Our Department of Neurosurgery at the King Edward VII Memorial Hospital (KEM) in Parel, Mumbai had, from the start, its own radiology section. While training in neurosurgery at Atkinson Morley's Hospital, Dr Homi Dastur, the founder of the

department, had worked closely with Dr James Bull, chief of neuroradiology at the National Hospital for Nervous Diseases at Queen Square. The general radiology department at KEM already had its hands full with other work and Dr Dastur was more than willing to take over neuroradiology. As years passed, we felt the need to develop expertise in catheter angiography in our department. Only thus could we do selective and, later, super-selective intracranial and spinal angiography.

On learning of our need, Chhotu volunteered his help and guidance without any expectations. He came to our department once a week and spent time teaching us the technique of safe, efficient and accurate catheter angiography. Under his guidance, all three senior neurosurgeons gained confidence and our department was now self-sufficient in this area as well. In the process, he also became an admired friend.

Thanks to his help, Dr Anil Karapurkar, from our team, eventually developed into the first nationally reputed interventional neuroradiologist in our country.

A few years after his visits to our hospital in Parel, Chhotu suffered retinal detachments, which were corrected by cryosurgery. He continued to work and paint until he left the Breach Candy Hospital in 1993 and moved to Cambridge, England, where he and his family continue to reside. Ten years later he had cataract surgery performed at Addenbrooke's Hospital on both his eyes. Unfortunately, within six months of being operated on, he lost sight in both eyes. Although the surgery was successful, it had led to the fraying of his very fragile retina in both eyes.

Perveen and Chhotu held exhibitions of their paintings at the Taj Art Gallery, Cymroza and Jehangir Art Gallery while they were in Bombay. 'It was great fun,' he recalled. Perveen, he and, of course, Shaista, are also blessed with a deep love of literature.

He became adept in using Braille. Chhotu has always been a very active person and continued as many undertakings as possible, including his walks in the town in which they live. As vision dropped to nil, the walks outdoors had to stop, especially after he got lost during one of his walks in hitherto familiar territory and had to be helped home.

When we met him a few years ago in his home, to our astonishment, we learnt that his visual handicap notwithstanding, he had taken to astronomy and was reading extensively and listening to all he could on the subject. He remains a devotee of Indian cricket and listens to the commentary on each major match with gusto, exclaiming in joy or despair depending on how the Indian team is faring. He narrated vivid memories: 'I certainly recall all the KEM sessions in the neurosurgery department. Dr Homi Dastur had very powerful forearms in striking contrast to his gentle voice.'

He remains as he was when we first met as regards *joie de vivre*, witty repartee and deep affection. May it always remain thus!

Perveen

Perveen's father, Mr Rustom Nadirshaw, retired from the railways as Deputy General Manager. Her maternal grandfather, Justice Mr Minocher Lalkaka, was the Chief Justice of The Court of Small Causes. Her paternal grandfather, Mr Dadabhoj Nadirshaw



FIG 1. The Tayabalis. From the left: Perveen, Shaista, Chhotu

was given the title of Khan Bahadur just like Chhotu's father, one of the many parallels between their lives.

A student of art, Perveen graduated from the Sir J.J. School of Art. She worked as a textile designer before embarking on her career as a full-time artist specializing in portraits. She is at home in soft chalk pastel, charcoal, pencil and oil studies. As she puts it, 'Portraiture fascinates me. The challenge lies in capturing that elusive presence of a particular personality and character.'

It is not surprising that a fellow-artist, who also happened to be a radiologist was smitten. As their courtship progressed, there was a dilemma well described by their daughter. '... unable to decide whether she, a Parsi, should marry a Muslim—a choice she had never anticipated having to make. Once she took her leap of faith, joy stepped into place.'

We are provided an intimate glimpse of Perveen's father by Shaista on pages 161–3 of her book (see below).

Perveen has her studio in the garden of their home. As requests for portraits pour in, this is where she spends hours in joyous concentration.

She has proved to be the rock supporting the family and has played this role with grace, humour and apparent effortlessness. Where she discusses *the milk of human kindness* in her book, Shaista tells us 'My mother offers me this kindness, this sweetness more often than I deserve it. It is because of her ability to offer me this solace that I am able to offer her the solace of my smile, teary but unclouded.'

Perveen is happiest when their lovely home in Cambridge is alive with the sounds of the entire family including her two sons, their wives and of course the grandchildren. Her cup of happiness overflows when Shaista borrows the neighbourhood dogs, as Perveen lost their own dog, Bruno, years ago. Shaista describes, with great sensitivity, Bruno's last moments on pages 162–3 of her book.

I would have liked to continue telling you more about her but will, instead, turn to someone she cares for deeply—Shaista.

Shaista

Shaista describes herself as a writer, teacher, artist and poet. She is also an ardent blogger.

Her *magnum opus*, entitled *Lupus, you odd unnatural thing*, is autobiographical. But with a difference. In describing her experiences with systemic lupus erythematosus frankly, she also gives us insights into her own intimate feelings on the consequences that flow from her disease; love, life and death. We also learn her silent responses in her mind during her interactions with doctors, nurses, ward attendants, other patients and members of society who advise and comment as they learn of her illness.

I am dealing with this book in some detail as I feel it needs to be read by every medical student, resident and physician. Here, they will learn the impact of their attitudes, statements and actions when dealing with patients—especially those with chronic illnesses. It is not likely that there will be many similar accounts, written by victims of such diseases which are as completely honest, sensitive and articulate as this one. As Shaista puts it, 'I don't write for catharsis. I write to tell the truth of my life.'

I have included below gleanings from her book, her blog and chapter in a medical text. I have provided references to each of them at the end of this *Letter*.

Let me start at the beginning. Where possible, I quote verbatim from Shaista's own writings.

I was born in Bombay when it was still called Bombay. We moved to England when I was fifteen... Life divides itself into Before and After the Move. I have been asked this question for 17 years: 'Do you miss India?' The question is asked easily, but there are no easy answers. How can you miss something that is a part of you?

I live with two artists who happen to be my parents. My father is a doctor, but also a poet, philosopher and watercolourist. My mother is an oil painter, a portraitist, a golden type – everything she touches becomes happier, thrives better, particularly plants, animals, father and myself...

I was nine when I had my first real flare of the disease—high fevers, swollen painful joints, mouth ulcers, but Systemic Lupus Erythematosus was not diagnosed until I was 18. Pain is pain. Entire universes exist inside of it...

Her understanding of the nature of her illness grew gradually.

I had never heard of the disease Lupus when I was diagnosed with it at 18. The doctor who delivered the news to my parents and myself, did so cheerily. He told me I had a mild form of the disease and I would probably never even notice it. He prescribed hydroxychloroquine, told me to go away on holiday, and with another cheery wave, stepped neatly out of my life...

Lupus, which is Latin for wolf, is only part of the disease's name. It is actually called Systemic Lupus Erythematosus. Systemic because the disease affects a patient anywhere, everywhere. And erythematosus, derived from Greek for 'red' referring to the vascular effects: the butterfly rash across the cheeks, which can scar... the metaphorical wolf first arrives in 850 AD with a man named Eraclius, the twenty-fifth Bishop of Liège, who was very ill with *la loupe*, so called *because it eats the flesh*... In the 1840s, the Viennese physician, Ferdinand von Hebra, made notes on a distinctive rash *mainly on the face, on the cheeks and nose in a distribution not dissimilar to a butterfly*... From wolf to butterfly in a few hundred years...

Quinine, which was prescribed so enthusiastically by my very first doctor, was *discovered for Lupus* in 1894. Since then, there has been another new *discovery* in the 1960s in the form of corticosteroids. Since then, nothing. Nada. Just the horrors of drugs poached from other conditions like cancer (methotrexate) and transplant therapy (cyclosporine). Fifty years, and this illness, so romantically symbolised by the wildness of a wolf and the tenderness of a butterfly, eats away at women all over the world. It is never mild. It is never forgotten.

She has, since, experienced galloping myopia, glaucoma (from high doses of corticosteroids), vitreous detachment, optic nerve damage, vasculitis, necrotizing lymphadenitis, pleurisy, migraines, hypothyroidism, muscle cramps and has undergone several operations including the insertion of a Molteno implant and a Baerveldt shunt in her eyes. Heavy

menstrual periods led to the diagnosis of multiple uterine fibroids.

Despite her handicaps, she obtained a First in both her Bachelor and Master of Arts degrees in English literature and Creative Writing at Cambridge.

When doctors make thoughtless statements or act in a demeaning manner, they undo self-acceptance gained gradually over weeks and months. She has voiced her feelings to those close to her. This has resulted in her being offered advice such as 'Be thick-skinned when you enter a hospital or a consulting room.' Shaista points out that when she goes to a doctor or the hospital, she is at her most thin-skinned, literally naked when undergoing physical examination. 'I have always struggled with knowing when to don and when to remove skins.'

She has often pondered life, disease and death. Here is her own summing up of her thoughts:

Let me try telling it this way.

Draw a horizontal line. On one side write, 'life,' and on the other, 'death.' If you perceive life moving toward death in a chronological fashion, then you'll probably write 'life' on the left and 'death' on the right. Or you'll put 'death' on the left and 'life' on the right. Death as a beginning. Darkness as a beginning. Moving toward light, toward life.

Now collapse the center point of your line into a sunken bowl.

This is chronic illness. Chronic illness is the in-between place of stuck. Life shouts out to you, 'Grab hold of me! Come on, I'll pull you across with my words and these movies and this travel brochure.' Death says nothing. But life looks at you knowingly: 'Is that what you want? To just give up and die? Fight! This is the good side!' Life is the place where everything happens, from the expected

to the unexpected. The learning to walk, run, drive, feel, study, make money, lose property and possessions, create more of yourself, grow. Death, they tell us, is the place where it ends. All the money, the property, the human bodies you loved but cannot pull across to the other side with you.

In between, in the place of stuck, we (victims of lupus) share the human terror of a life with no possible change. So deeply uncomfortable are we with the place where nothing seems to happen that we plague each other by asking the question 'What do you do?' What do you do with your life...?

There is much, much more in her book that I would like to dwell on but must call a halt and leave you to explore.

Yeats is one of her favourite poets. In *He wishes for the cloths of heaven*, Yeats spread

...the heavens' embroidered cloths,
Enwrought with golden and silver light,
The blue and the dim and the dark cloths
Of night and light and the half light,
under your feet.

Shaista has spread her innermost thoughts and her dreams under our feet. As we read her book, we, too, must pay heed to Yeats' request: '*Tread softly because you tread on my dreams.*'

REFERENCES

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SUNIL PANDYA