

BOOK REVIEW

A lyrical account of living with Lupus

UPREET DHALIWAL

Shaista Tayabali, *Lupus, you odd unnatural thing - a tale of auto-immunity*, Independently published (December 2, 2021), 212 pages, INR 399 (Paperback), ISBN-13: 979-8777771766

The blurb claims that the author's aim is to promote "a deeper understanding of what it means to be a chronically ill human". The book begins to fulfil its promise as early as in the first few pages. This is not a book — it is a life told in prose and poetry.

Shaista Tayabali tells us a real-life story and through the telling reveals many facets of herself: she has the gift of language; a wry humour; brutal honesty; love of life, and of family; authenticity; wisdom, insight; great observational skills; and a unique voice. And alongside all of this, she has Lupus.

Shaista is uniquely qualified to write this book because she is living with Lupus, a life-altering diagnosis, and it helps that she has an MA in Creative Writing (never mind that she hates metaphors): *"I dislike the use of metaphor in illness. How can I describe lupus as a civil war in my body when actual civil wars have far more wide-reaching catastrophic consequences?"*

In the pages of this memoir, we are introduced to decades of a multi-systemic involvement that was formally diagnosed when she was eighteen years old. Her description of the autoimmunity that is Lupus is poignant:

"...something is being fought every day. Or most days. Something that provokes the encouragement of others to adjure me to, 'Fight, Shaista! Fight!'"

But people don't realise they are also saying, 'Fight Shaista'. Because the fight is taking place inside Shaista whether she is thinking fighting thoughts or not. Lupus is auto-immune...my body makes auto-antibodies. Self-attacking soldiers. The most

vital line of defence turns inwards and my body attacks itself."

Despite the seriousness of the malady, the memoir is not all doom and gloom:

"I want to die as much as I want to live. I don't want to live in quite this way, and I don't want to die any old way. We all think about dying in the midst of living but mental and physical wellness tip the scales in favour of living. It's so delightful to be alive and eating or walking or reading or even arguing for the sake of watching language form itself on your tongue in neat, clever arrangements."

We meet the people — family, other patients, "well-meaning" strangers, and healthcare professionals — who have journeyed with Shaista:

"A friend visited and did not like to see the tears in my eyes, my tiredness. 'I am a river of sadness,' I sighed. 'Well, you can't be,' he said, sternly. 'There's no such thing. Rivers move and change and take things away with them and pick things up, like flowers and happiness. Write me a happy poem!'"

"I remember a phone call from my grandfather when I was ten. Dada was discoursing on the power of the mind and its relationship to white and red blood cells. He was on speaker, and his deep, modulated British-Simla accent filled the room. He was teaching me about healing. He was teaching me how to live."

The author's experiences at the hands of members of the healthcare team are mixed, as can be expected. Many are compassionate, communicative, while some are anything but:

"Two days later, when I returned, Keith [Dr Meyer] was very surprised that his colleague had not used anaesthetic drops. He bathed my eye into numbness and within a minute had skillfully extracted five sutures. It felt peaceful having him attend to my eye while it rained and cool breezed outside. I acknowledged the difference in skill between the two doctors, but also in compassion."

"I look back at the girl lying face down on the bed with two junior doctors 'having a go' at my spine, not believing them when they said they would go away if I wanted them to, because I knew they would come back; they had to get the fluid; somebody always 'has to' do something to you in hospital because somebody else said so."

Then, there's this "menacing" explanation of her illness:

"Let me try explaining lupus to you the way I see it," said a GP,

Author: Upreet Dhaliwal (upreetdhaliwal@gmail.com), Former Director-Professor of Ophthalmology, University College of Medical Sciences (UCMS), University of Delhi; Founding Member, Health Humanities Group, UCMS.

To cite: Dhaliwal U. A lyrical account of living with Lupus. *Indian J Med Ethics*. Published online first on May 3, 2023. DOI: 10.20529/IJME.2023.030

Manuscript Editor: Sanjay A Pai

Copyright and license

© Indian Journal of Medical Ethics 2023: Open Access and Distributed under the Creative Commons license (CC BY-NC-ND 4.0), which permits only non-commercial and non-modified sharing in any medium, provided the original author(s) and source are credited.

intending camaraderie. 'You are rotting, and fast. The only thing in some measure controlling the speed of rotting are the drugs you are on. Stop them, or try to tinker with them, and...'

A menacing pause."

The anecdotes in this book highlight the right and the wrong way to establish rapport and trust in the unequal relationship between a doctor and a patient. This book, therefore, would be of use to healthcare learners and practitioners who want to know more and want to do better. Perhaps in an attempt to make sense of the gulf between doctor and patient, Shaista writes:

"Doctors can be described as non-patients. But they can be patients too. There is a potential to connect in fellowship, but doctors rarely reveal their personal vulnerabilities. Is it because they are professionally bound not to? Why? Because it would blur boundaries? Who designs the boundaries? Would a doctor lose power if she shared her own experience with illness? I believe she would gain connection."

Some of her perspectives took me by surprise, if surprise is the correct term to call the disquietude I felt on learning that I might have put my patients — inadvertently — through some of what she describes:

"A patient must always be on guard, prepared to answer questions, when often all we want to do is curl into ourselves, shut down unnecessary avenues of energy expenditure and be quiet enough to heal. But we are not in a place conducive to self-healing. We are here to be healed."

and:

"Hospitals require us to talk on command. Be examined, questioned and then re-questioned. And then again, and again."

The author describes the clinical encounter and the onerous burden it places on the patient who is interviewed by a dozen different people, sometimes on the same day:

"A chronic illness patient must provide a memorised narrative of their history every single time they encounter a new doctor in or out of the emergency room. 'Tell me your story, in your own words,' the doctor will encourage you. If your diagnosis was made a year ago, or if you don't have a multi-system, auto-immune disease with fourteen co-morbidities, perhaps you stand a chance of providing this narrative without wanting to gnaw your knuckles off first."

And when it is a condition that tends to remit and relapse — is "repetitive" — like Lupus:

"The thought of regurgitating this for the twentieth year in the ER while I am wracked with the chills that accompany fever, is enough to make me want to drop to the floor and roll under the emergency room stretcher, face palming all the while."

Through it all, there are moments of wry humour which makes this book such an engaging read:

"I never tell it the exact same way. I try to keep things interesting, for myself, at least. As a writer, I am perennially afraid of striking boredom into my audience."

She shares instances of a presumed, precarious autonomy:

"Do you mind if I...?' the doctor asks. The patient's acquiescence is a mere formality. The patient knows that any hedging is useless, maybe even dangerous, because you will be considered to be obstructing procedure. Non-compliant. Emotional. 'Patient would not permit...'"

The writing is easy to relate to, and not dry and academic as one might expect a book about an autoimmune disorder to be. Having learned that the author is a published poet, I found myself looking for poems in every chapter, but found only a handful. However, I did not feel too bad since I found the prose to be almost lyrical in places:

"I wait for someone who loves me, to come be my transport, and carry me home."

"And eventually, when I had my first walk in too many weeks to count, I did write that happy poem. Arm in arm with my big brother, down to a field of gold I never knew had existed all along, outside the ward. There were bees and butterflies. I wiggled my toes in the cool fresh grass, and unfurled my wings, a little, at last."

This book allows us a candid look into what life looks like for a person living with a chronic illness. Unless a physician/nurse/technician/researcher/health professions learner knows what living with illness truly entails — beyond symptoms and signs and labs and quality of life metrics — how can they design protocols to heal? Not just treat, but heal in a way that is meaningful to the most important stakeholder — the patient.

This book holds up a mirror to healthcare practitioners across the board. Read this book if you enjoy lyrical non-fiction; read it if you work with chronic illnesses; or if you want to learn more about the daily struggle of living with Lupus; but, most of all, read it to figure out all the ways in which you can support someone with a life-altering illness.