

CREATIVE SPACE

The warrior poet waits for spring

SHAISTA TAYABALI

About me

I live a meditative life in a green village in England. I was diagnosed with Lupus when I was 18 and some of my poetry writes itself in response to living with such a peculiar, demanding and life-altering illness. And some of it is about love longing hope birdsong waiting for spring... I write about freedom. And heroes. I am often and very easily inspired!

On the first day of January 2009, I started a blog (www.lupusinflight.com) with the intention of recording my poetry online — a reference point for myself as much as the (as yet unknown) reader. When I fell critically ill in February 2009, and remained an inpatient until the summer of that year, this blog became my lifeline. I pulled through and kept writing. Here exists an archive of my poetry just as I had hoped, but it is also the place I gather all the disparate threads of the uneasy life of living with chronic illness. This blog taught me how to be heard, how to become my own advocate. It teaches me how to be imaginative whilst living a solitary life.

Advice: Poem for a Ninja

Never ask why. Read nothing Never give up. from silence. Never stop. Imagine no one Smiling laughing pleasing teasing. from darkness. Never cry. Never spin tales. Never weave dreams. Listen to the birds and the wind. Still you must hope. Light candles Always believe. to bring truth in. Try everything. Never win. Now forget and start again.

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L'Esprit

(Am heading into hospital again this morning for the second round of Rituximab. The sun is shining shyly, with no hint of what the day may bring. I am scoffing porridge and posting this poem, which I read aloud on radio... my fellow guest responded very hearteningly to it — by shedding tears!)

The hours are greater now, and the Rheumatols,

they reach past four and five and six. the Oncols

The loss is greater now and the On Calls

I've tasted each sweet kiss

of faith, of peace, and just for larks, the Dentists,

of truth, of bliss, the Pharmacists, the Specialists,

and seen through all the dreary mists

of teams of all the 'ologists. and still I insist

upon the breaking of the dawn,

Radio and Cardio, this Warrior, this poet,

Neuro and Nephro, this Shaista must exist.

the Opthalmols

- July 20, 2011

A Bruising Waltz

"Put me into one of your books," orders Laura.

We have been neighbours since Tuesday, the 18th of April. I know her first, middle and last names and she has never once asked for mine. I'm usually "You. In the corner." Or "S'cuse me." It only takes her a turn of her head and a command and I obey. Mostly. I did not obey her demand to be taken down to the concourse for a walkabout. She hasn't left her bed for weeks. The responsibility! She is keen to be discharged to get back to her little flat and herb garden, so yesterday she perked herself up and got out of bed with a jam doughnut in hand and slid round my curtain to prove her improvement. I jumped up and pretended to waltz with her. "Not strong enough for that," she chided. Then she disappeared. Next thing, there was a commotion outside by the nurses' quarters. Laura had keeled over and bruised her elbow and head. I felt instantly guilty. I ought to have accompanied her. But how could I know she'd attempt a sudden jaunt outside?

She knows she is good material. The other night the new patient and I were told off for chit chatting with our lights on. "You're both young," scolded the nurse. "She's old. And needs her sleep." Referring to Laura. I, submissive, obedient, flicked off my light and plunged myself into a darkness I was not ready for. I was scribbling an email to my beloved friend Mary in the dark, when pungent clouds of cigarette smoke wafted across. A smoker! At half past 11! I mentally accused Maria, my new 18-year-old rebellious friend... sorry, Maria! Didn't it turn out to be Laura?! Maria and I texted across the ward, keeping tabs on proceedings. The nurses seemed only mildly shocked. There's oxygen in hospital, they remonstrated. It's dangerous. But Laura was unfazed. The nurses had taken long enough for her to drag half a ciggie's worth of much craved tobacco into her lungs and she was satisfied.

Laura often refers to the other nurses as my 'coloured and Oriental friends' because they are from Kerala, the Philippines, Nigeria. I try to explain they are not 'my' friends, but 'our' nurses. Finally, I take a piece of paper across to her to show her my name and helpfully pronounce it Shy Star. "Oh, I don't like that," she says. "Sounds too much like a shyster." Anyone who says this to me is instantly someone I never want to speak to again.

"My name," I say, with as little heat as possible, "is Persian. I am not a shyster. You can call me Shy if you prefer."

I return to my bed. A bit defeated. Eighteen years of casual racism in this very hospital has toughened me up. But I am not invulnerable.



Silence.

"Persian, did you say?"

"Yes. Persian."

"I think I'll call you 'Little Lotus Flower'."

"Sounds a bit of a mouthful," I return. "But if you like."

"Well. I'm just trying to think of something pretty to call you. Something soft and gentle."

Then...

"I like my name," I say into the silence. "Very much."

"I like mine too," she replies.

And we leave it at that.

- April 25, 2017

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