

Chapter 9

The Need to Transform the Core Values of Medical Care and Health Organizations

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“IT’S YOUR LUPUS.” “IT IS NOT MY LUPUS!”

Patient Narrative by Shaista Tayabali

I am awaiting a telephone call. It was booked by my consultant, several weeks ago, as a follow up to a previous phone conversation, both in lieu of actual physical clinical consultations. And both a direct result of a distressing climax to a long year.

I am a woman, 32 years old, born to Indian parents. I was diagnosed with Systemic Lupus Erythematosus when I was 18 years old, following a lengthy stay in hospital on the Infectious Diseases ward. I had returned home to England, precipitously from a trip to India, with high fevers, which rose to 105 degrees; a terse ‘Take Paracetamol’ being the only instruction from the GPs at our local clinic. Days of fever later, my mother was finally advised by a friend to ring emergency services, and the doctor on call did not

hesitate to call an ambulance. The rest, as they say, unfortunately, is history; *my* history.

The year I was diagnosed was 1997. Lupus was not rare in and of itself, but in terms of awareness, both medical and public, I may as well have been the very first case. At the end of a month, buoyed up by penicillin, fluids, and daily blood tests, my diagnosis was confirmed by a cheery ID consultant. He was perfectly charming as an Infectious Diseases man, but his words confirming my future, still haunt me: “You have something called Lupus, but not to worry! You have a very mild form of it. You won’t even notice it. My advice is, go on holiday! Enjoy yourself! Live your life!”

Fourteen years later... he may even have been right. I shall never know, for the path from a diagnosis of SLE involves certain drugs, in particular, immunosuppressive agents and steroids. And each line of treatment has caused a further flare up of the disease, the most debilitating of which has been the impact of methylprednisone on my eyes. The five grams of methylprednisone first

DOI: 10.4018/978-1-4666-1876-3.ch009

injected into me as a direct response to peripheral vasculitis, resulted in steroid induced glaucoma. The immediate failure of my eyes to control ocular pressure led to trabeculectomies on both eyes within two months. I was blessed to come under the aegis of an eminent medical ophthalmologist. His appearance in my life was the result of my acute photophobia, which resembled minor epileptic seizures. He discovered retinal vasculitis in both my eyes, and has been my one constant link at my hospital in the UK. Since 2004, I have also been incredibly fortunate in my glaucoma surgeon, who after careful deliberation performed a rare Molteno tube implant following the failure of my left trabeculectomy bleb.

I take these blessings deeply into account now, when I stand at a crossroads; a crossroads created by the difficulty of having had no such constant link with the rheumatology team. Perhaps it is a measure of the well established faculty for glaucoma and other ocular diseases when compared to prevailing awareness, or lack thereof, for lupus. Perhaps the question is, how long is a patient of long-standing chronic and acute disease, expected to justify the distress caused by a department, based on this single premise: “Well, it’s just your lupus.” “It’s your lupus” has become a standard line of defence alongside the standard first and second line treatments for SLE. As though, once diagnosed, a patient is suddenly expected to contend with an auto-immune illness being normal for them; any new or old symptom that rears its head is proscribed to ‘your lupus’ and therefore nothing to worry about. Nothing for the doctors to worry about, that is; and is it just me, or do all lupus patients react as violently to the possessive pronoun? It. Is. Not. *My*. Lupus!

As I mentioned before, I am 32 years old. I say ‘old’ because that is precisely how it feels. I was very probably an SLE case from birth – my mother, strangely enough, was extremely allergic to the foetus when she was carrying me, but not with my two brothers. I had excruciating mouth ulcers from the age of nine onwards, a regular crunching

into my flesh every single month, most probably linked to the onset of my menstrual cycle. At ten, while still living in India, I was diagnosed with suspected rheumatic fever, presenting with very high fevers, swollen painful joints, and placed on penicillin, bed rest and confined to a wheelchair for three months. Since my disease manifests even today with high fevers and painful joints alongside the growing list of new symptoms, it was clearly SLE then. Since my eighteenth birthday I have watched this body undergo symptoms lifted off the pages of any basic book on lupus: the relevant immunological blood tests of ANA, anti-ds DNA, anti-DNA, high complement levels, high ESR and CRP, fatigue, mouth ulcers, joint pains, vasculitis, lymphedema, lymphadenopathy, pleurisy, pleural and pericardial effusions, photophobia, migraines, Sjögren’s, Raynaud’s, high sensitivity to almost all medication, frequent nosebleeds, infections, tachycardia, hair loss, brain fog and depression. Not to mention the most banal of all – pain. I say banal, because it is an almost humiliating experience to have to describe pain on a numbered level of 0-10. How is a person in pain, who has been part of endless layers of pain cycles, supposed to define their pain of the moment without a relativity scale playing in their mind? It is practically impossible.

So here is my predicament. I have been through Hydroxychloroquine, Methylprednisone, Azathioprine, Amitriptyline, Cyclosporin, Methotrexate, Mycophenolate, and Tacrolimus. Each drug has been used and then discontinued by the rheumatology team for reasons ranging from glaucoma, leucopenia and haemolysis to nightmares, hallucinations and an immediate and obvious deterioration. In 2008 I was admitted with enlarged lymph nodes and pleural effusions. I was told, by my new consultant, about something called Rituximab, which was proving useful in SLE and vasculitis, but it was also made very clear by said consultant, that I was not ill enough for such expensive treatment. I was sent home to trial a new drug. My condition deteriorated. I returned

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