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Reflections on Illness, the Body and the Mind

By: Poornima Kumar

A 23-year-old reminisces about her 16-year-old self that was afflicted by a lifelong autoimmune illness, prompting recollections of the questions she asked herself then to make sense of life. There are new questions now and her search for answers continues.

The memory is clear, quite vivid even. It was June 2010. I was 16, simply enjoying the extended exhilaration of finishing my board exams for the 10th standard. It all started fairly insignificantly, a slight shooting pain in the left arm when I stretched it.

“Nothing to worry about,” he said. “Some Neurobion and a couple of Ibuprofen will fix it.”

Little did I know that 10 months down the line I’d be down by 18 kilograms and would be slowly losing the sensory functions of my left arm. And three years down the line I’d be diagnosed with a lifelong degenerative autoimmune disease.

What does a 16-year-old make of this? How does a 16-year-old then make sense of life? What becomes the nature of that 16-year-old’s relationship with the self (her own body and mind) and the people around her? I write this not as a student of palliative care or someone exploring palliative care, but as a 23-year-old reminiscing on that 16-year-old self; the questions I had asked then and the questions that I ask myself now.

Spirituality is subjective, in meaning, interpretation, and experience. The ways in which I experience connection to the moment, the self, and the people around me is my spirituality. I do not seek spiritual expression in organised religion, but in the everyday. Of course, as a 16-year-old I wouldn’t have thought about it that way, but I do remember asking myself if this was it. Was my experience of life going to be sealed by a permanently dysfunctional arm, a weak body and constant fatigue, and a digestive system that restricted almost everything that I liked to eat? Wouldn’t I be able to play the guitar again, wouldn’t I be able to travel, would I have to be dependent on my parents forever for care?

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I remember being overcome by a sense of restlessness and fear, partly because the medical ambiguity meant these questions could become permanent facts of my life and partly because if that did happen, what would be the meaning of this life?

Accompanying this was a deeper question—who am I? Am I this illness or is this illness me? Am I nothing else but this illness? The questions were often triggered by the ways in which people around me perceived my presence, my existence. Suddenly everything became about me and my health, whether at school, college or home. There is no denying that the people involved came from a position of genuine concern, but it only worsened my identity crisis. I didn’t want to be this autoimmune disease, this liability to those around me. I wanted the same opportunity that other “normal” teenagers had to figure out who they were. But my body and the numerous restrictions it brought with it were a constant reminder that this illness had spread to my sense of self. That this was going to be a part of me took a while to accept.

Then, of course, there was the question of God. I come from a family whose members are quite scattered on the religion spectrum. Not in terms of the number of religions but in the intensity of their religiosity. While one side didn’t care much for it, the other, a product of Sanskritisation, made up for it. So I grew up being a witness to rituals as elaborate as big pujas and as simple as my mother’s daily prayers, with my grandfather’s incessant chanting of the rosary in between. Yet I had been quite agnostic, even critical of temples and idol worship, constantly questioning the oft-repeated religious interpretation of my illness.

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But what always posed a bigger mystery to me was and is the power of prayer. It has been eight years since all of this began and there has not been a single day when my mother doesn't pray for my health. It is perhaps from this constant prayer that she drew strength on during my worst days. What was the source of this immutable faith? A question I still struggle with.

And yet today I am relatively healthier. My left arm has regained 80% of its functionality and more than half of the weight I lost is coming back. I spent two years living in a city on my own, a task that I thought was impossible five years ago. The medical ambiguity around my initial deterioration and subsequent improvement was just another thing that strengthened my mother's faith in the power of prayer, only making me only more confused and at times envious even.

When dealing with issues around the spiritual needs of people grappling with chronic illness or those nearing the end of their lives, it is easy to assume that religion would be the channel that fulfils that need. But the possibilities are many, and how individuals carve out that journey for themselves is what matters, and this needs to be acknowledged by all palliative care teams. To all the questions I asked then, I found answers to some, others I am still looking for. While religion might not have helped, there were other things I took to.

Reading about the social constructions of illness helped me come to terms with my illness and accept it as something that might always be a part of me. I had control over how I perceived it. That illness is not merely a bio-physiological state but a social construction that is endowed with meaning from comparisons to the notion of a "normal" or a "perfect" body completely changed the way I perceived my own body.

Michel Foucault became my guardian angel. The medical discourse (power) imposes its construction of a normal body (knowledge) and my constant self-comparison to this normal body had led to an erosion of my sense of self. Moreover, it was not the disease itself but the social interactions and the physical and social restrictions that came with it that altered my sense of self. I realised that control over how and what meaning was endowed on my illness could be entirely in my hands if I wanted it to be. All I had to do was reconstruct my identity and vociferously assert that this was my normal.

This assertion of my new normal in many ways also reduced my sense of being a liability, a burden on those around me. But what really changed this was my encounter with feminism. I had grossly misinterpreted the meaning of feminism in my life. For me, being feminist had meant being fiercely independent, not needing to depend on anyone for anything. I aspired for this and my inability to be this made me push my body all the more (I still do at times; old habits die hard). A more nuanced exploration of feminism revealed that this whole notion of being a "sole rider" was in itself quite patriarchal.

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And how could I forget the epiphanous moment when I was introduced to queer theory. My queerness was not limited just to my gender and sexual identity, but had expanded to reimagining my entire world, breaking down structures of traditional family and commitments, transforming them to become relationships of mutual care. It became increasingly impossible for me to imagine my family bound in and emerging from a heterosexual marriage. My efforts to build relationships outside these structures were now based on collective and mutual support and care. It was okay to offer help and it was completely okay to ask for help (something I'm still learning to do).

And so I found meaning in life by forming human connections (not an easy task considering I'm highly socially awkward). We're all in the same boat, constantly negotiating with structures around us, living or subverting identities. This common thread in the people I met and the friendships I built in some ways strengthened my faith in the spirituality of everyday. I also found solace in that my relationship with myself had become central to my spirituality, to how I understood myself, my body, and the various identities associated with it. My every action and every thought were set to an auto reflective mode. Through this process, I emerged more confident about navigating the complex relationship with my body.

And yet my mind still fears the uncertainty of the future. I may have figured out the answers to some of the questions, but practising it has been very hard. It is difficult to vociferously assert your normal when you are constantly reminded that you don't look too well. One does not move on to relationships of mutual care overnight, especially when one is socialised to believe that asking for help reflects vulnerability. Having a vulnerable body pushes you to pretend to be "un-vulnerable" in other ways, only making it more difficult to form relationships of mutual care.

My illness gave me a lot to reflect on and I have learnt a lot, but the struggle to negotiate and renegotiate your position in the world is never a one-time affair. It is an ever-evolving process that is intrinsically linked to the quest for spiritual relief. With every negotiation, the questions you ask keep changing, and the source of the answers keep changing as well. All it takes is a seeker and the choice to seek. Doesn't matter how you do it; only matters that you do.

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(The writer had put this article down five years ago; she is publishing it in 2022 as she now feels confident of sharing it with readers)