

FIRST PERSON //

The Health Within Illness

■ BY HAVI CAREL

Stairs used to lead somewhere; now, stairs go nowhere. Meeting rooms on the fourth floor no longer exist for me. Slight inclines have become hills; hills, mountains. I think twice before going downstairs to collect the mail or buy milk. The geography of my world separates me from the healthy people I walk among.

This chasm opened up one year ago when I was diagnosed with lymphangioleiomyomatosis, or LAM, in which the lungs are invaded by abnormal cells, progressively destroying lung tissue. All LAM patients—with few exceptions—decline. Ten years is the official average survival figure, and a lung transplant is a last resort. But there is a great shortage of lungs for transplantation, and the risks and complications of this procedure make it far from a cure. Ten years. That would make me 45. My life will end in 10 years.

At what exact moment did a single cell mutate, lose its TSC2 gene and become the first LAM cell in my body? What was I doing when that cell slowly migrated to my lungs and began to divide? That question, about origin, time and consciousness, is one I have returned to repeatedly since my diagnosis. How could I not feel this momentous event taking place? Are my body and I so out of touch?

Illness changes everything. It is a relational concept in that it changes not only the state of my internal organs but also my relation to my body, my relation to others, their relation to me. The world of the sick belongs to a different universe than that of the healthy, and the movement and interaction between them is clunky, difficult, abrasive.

Some writers have tried to associate health with authenticity and illness with inauthenticity. Health and authenticity are both transparent, where the ease and the taking for granted of doing things is the rule, and the exception is, say, a toothache or the flu. Losing this immediate and natural unity

with one's body is inauthentic, they say. Being ill is inauthentic because it makes one out of synch with one's body.

I agree with the diagnosis—illness does obscure the transparency of our bodily existence—but I disagree with the labels. My illness gave me authenticity, a kind of ability to be, which is demanding but also opens up avenues of authentic understanding. Illness has allowed me to see my life and the lives of others for what they are: brief, full of emotion and agony, activity and joy, sadness and pettiness. I see people arguing over nothing, fretting about wrinkles and careers. Illness makes you immune to that.

From the great distance and loneliness into which you are forced, you see the world anew. Your horizons, expectations and perspectives shift, and you become aware of the incredible luck you've had so far. You pace yourself and rejoice in small pleasures. You become generous toward yourself and others. You learn not to think about the future. You learn, in short, to be a little less controlling and a little more accepting of your inability to be. And within this inability, if you search well enough, you find an ability to face yourself as unable and to embrace this unable self. ■

→ post-op originates at the other end of the stethoscope, presenting essays and commentary from patients, consumers and other medical outsiders. proto invites your contributions; please send ideas to protoeditor@mg.harvard.edu.

