

ENCOUNTERS

Reading one's symptoms

My point is that illness is not a metaphor, and that the most truthful way of regarding illness — and the healthiest way of being ill — is one most purified of, most resistant to, metaphoric thinking. — Susan Sontag, *Illness as Metaphor* (Penguin Modern Classics eBook), p. 9.

An invisible monster that surprised me with stealth attacks, my asthma was a metaphor. I was a victim of this monster until I was a teenager and learned to use an inhaler. From then on I understood that the monster was only my body, and my body was in my care. Thus, I sought, and complied with, medical treatment. In 1991, a new corticosteroid inhaler gave me some stability. Despite seasons of bronchitis, I believed myself in control of my asthma and my body.

So confident was I that, 20 years later, when my rest was disturbed by new symptoms (queasiness and post-menopause night sweats), I ignored them at first. There were good reasons to do so. We had just moved from Canada to England, one of many international moves. Although I had handled previous moves calmly — phlegmatically even — I was familiar with the transitory ailments that plagued expats: anxiety-induced palpitations, stress-related weight loss, stomach distress during the adjustment to unfamiliar food and water. Therefore, when I switched from the summer clothes of our move to winter clothes and found them sagging, I was surprised (I hadn't felt stressed) but not concerned. It would pass.

Pass it did not. I worsened gradually, almost imperceptibly. Despite eating through the nausea — as much as my teenage daughter ate — weight loss continued. I befriended the bathroom floor, crouched with nausea that twice ended in vomiting. By the time I took my symptoms seriously, they were joined by cloudy urine, quick bruising, and incidents of sudden drops in blood pressure, causing blackouts. Although bewildered, I didn't relapse into meta-



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phorical demonology: I simply wanted to know what was making me queasy and tired. My quest to solve my medical mystery took three years.

Given the possible adverse effects of my asthma medication and the bouts of heartburn that had followed a treatment of the antifungal itraconazole for allergic bronchopulmonary aspergillosis, I reported my symptoms to my GP. He listened kindly and sent me off for blood and urine tests, which showed no infection and normal levels for iron and vitamins.

But why did blood tests leave me limp? Why did the flu shot send me to bed?

When early tests showed nothing wrong with me, I blamed myself. If I was tired, I needed more exercise and more sleep. If I was too thin, I needed more food. If I was constipated, I needed more water and fibre. If I couldn't write creatively, I must sit at my desk longer.

In one year I lost 10 kg, a vanishing act aided by a restrictive diet during food allergy testing. When my weight dropped towards 40 kg, which was below my recommended body mass index, my GP suggested that I see a dietician. Insulted, I replied I had a healthy diet. But weeks later I changed my mind. Was it the mirror showing the knobs of my spine, and my feet so skinny I couldn't walk without padded socks? Or was it the episode of palpitations and nausea that landed me overnight in the emergency department?

And so, I mounted a medical merry-go-round: seeing specialists and filling enough vials of blood to keep a vampire fit. The cardiologist proved that my heart was not damaged and was innocent of any charges against it. A dietician told me what to eat (protein), and the food allergist told me what not to eat (foods high in histamines). I gagged down a gastroenterologist's hose to

guarantee that I was neither sharing my food with undesirables nor wasting from malabsorption. A neurologist showed me my bug-eyed magnetic resonance image and concluded that I was suffering from food-induced migraines. “But,” he said, “in a case like yours, nothing is certain.” Like fairground music, their all-clears were uplifting. Relief that it was nothing sinister was followed by the question: If not this, then what? Down I went into the dragging unhappiness of a sugar-sated child on the way home from the fair in the dark.

Meanwhile, I grew worse. At my lowest point in the winter of 2014, I lingered in bed some mornings, listening to my husband and daughter prepare for their day, wondering if I was dying and no one had thought to tell me — succumbing to the morbid thoughts of the ill. And up I got to prepare a breakfast that would tempt any gourmand.

Then a scan confirmed a worsening of my ongoing bone loss. I found an endocrinologist specializing in osteoporosis and requested a referral.

The endocrinologist said, “Let’s talk about why you’re not gaining weight.”

She said, “And how do you feel this afternoon, right now?”

“Queasy,” I said. “Tired,” I said.

The results of the blood tests and the short tetracosactide test revealed that my adrenal glands were “lazy” or suppressed. She explained the blackouts as the body shutting down because the adrenal glands were not reacting to the stress of an infection. In fact, two of my blackouts had been swiftly followed by pneumonia, and the other two black-

outs had preceded respiratory infections. Her diagnosis: Adrenal insufficiency, likely to be secondary to long-standing use of inhaled corticosteroids. She’d made this diagnosis for other female patients with asthma.

Again I experienced the carousel up and down: relief that it was not the more serious Addison disease, but reluctance to take on a new disease. Frustration at how long I’d been circling for a cure, at time wasted on medical visits and tests, but acceptance when the endocrinologist assured me that neither my GP nor the specialists could have known.

Fatigue had numbed emotion. I discussed test results in a flat voice. Watched my family express excitement that I did not share. Within days of taking the adjusted hydrocortisone dose, however, not only did my skin rehydrate and my flesh plump, but I laughed. Rushing around doing things, I was happy and optimistic. As the fog in my head cleared, I was able to write again. Suddenly a merry-go-round seemed sedate; I wanted the roller coaster.

I also felt anger. My voice squawked against the unfairness of having taken my inhalers as prescribed and now I suffer the consequences. With anger came doubt that I was ever in control of my health or ever would be again. What would be the unforeseen consequences of my new treatment?

During three years, as my adrenal function declined, I changed from an energetic woman to one I hardly recognized: two dress sizes smaller, tired, reluctant, joyless and grimly determined to find out what was wrong with me. Humbled that such a small gland could so adversely affect my personality and my life, I can confirm Susan Sontag’s statement that illness is not a metaphor: I am my body and my illness is me.

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This is the author’s story.

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“Imagination is more important than knowledge. For knowledge is limited, whereas imagination embraces the entire world, stimulating progress, giving birth to evolution.”
— Albert Einstein

Encounters articles give patients and health care practitioners room to reflect on their experience of illness or medicine. Encounters are memoirs that become narratives through a turn of the poetic possibility and a nod to literature, as well as imagination, storytelling and a creative exploration of metaphoric spaces. Together, these allow a sliver of understanding about life. Patient and colleague confidentiality must be respected, therefore, signed releases are required from anyone who may self-identify. Narratives should be limited to 750 words; all submissions are peer-reviewed. Contact Barbara Sibbald, Editor, News and Humanities (barbara.sibbald@cmaj.ca), to discuss ideas.