

ENCOUNTERS

The other side

It happened over the course of a few months while I was a medical student — bundles of hair left on my pillow, large tufts going down the shower drain, burdening my brush, and the shiny new bald spots that kept appearing and growing steadily, the smooth skin feeling foreign to my touch. The diagnosis was alopecia areata, an autoimmune condition that causes patchy hair loss on the scalp.

When my hair was almost all gone, I decided to buy a wig and went to a specialized store. When I got there, I was brought to the back of the shop, hidden away, as if I had to be ashamed of what was happening to me. I tried on different wigs in various shades of brown; they all felt scratchy and heavy and didn't come close to what my hair used to look like. I finally picked one and paid an exorbitant sum.

It wasn't long before I had to wear the wig. Alopecia areata had quickly developed into alopecia totalis — no hair on the scalp. My curly healthy brown locks were gone, and my bald scalp remained. Soon my eyelashes and eyebrows were getting sparse, and my body hair was falling out. Finally, I had no hair at all — alopecia universalis. Every time I caught a glimpse of myself in the mirror was shock. I looked ghostly. I tried to cover it up as best I could, thinking that if I looked normal on the outside perhaps I would feel normal on the inside, too.

In addition to wearing the wig, I used eyeliner and eyebrow pencils daily, struggling with getting the lines straight and symmetrical. I didn't have much time to dwell on it. I was in my second year of clerkship and was busy with a heavy workload, on call, new rotations every month and studying for never-ending exams. Part of me wondered whether the stress of medical school and applying for residency were to blame. But there had also been the sudden unexpected end of a friendship. I couldn't understand why it had happened, where it had come from or the lack of control I had over the situation. As my hair fell out, part of me blamed my friend and the pain she had



15_ImageSource/stock

caused me. I was suffering and yet she looked unscathed.

Through it all, the doctor-in-training in me tried to reason with the part of me that was mourning the loss of my hair. It wasn't that big of a deal: I didn't have a deadly disease, I wasn't dying of cancer, I wasn't sick. My problem was superficial, only hair.

Still, tears flowed freely and without warning, such as when I asked my fiancé to shave off the last few strands of hair because I couldn't bear do it myself, or when I thought about my upcoming wedding and how I wouldn't be able to grow out my hair. When I got home at the end of a busy day, I would throw my itchy, annoying, expensive wig across the room in a fit of fury. I couldn't look at old pictures of my previous self looking healthy and happy. Emotions bubbled beneath the surface, and it didn't take much to set me off.

My entire life changed. My close friends were supportive, but I worried about sounding depressed. After a

while, I stopped talking about my situation. My parents and my sister were supportive, but they lived in a different city, and there was little they could do. My fiancé was the only person who truly understood and was there at every step. But I worried about the impact it was having on our relationship. Was it too much, too soon? He hadn't signed up for this. I wondered what my life would look like in the coming months and years. I felt lost and hopeless.

I read about the latest research on alopecia universalis, hoping I would find something positive, something to give me hope. The statistics were grim: the chances of my hair growing back were slim to none. I thought about taking time off, but I didn't know if it would help, and I worried that I would never go back. I wanted to graduate in the spring with my class. While at work, I tried to put my concerns aside and focus on helping others feel better; that was my job.

I saw about half a dozen health professionals over the course of a year, hop-

ing someone would be able to help. Then, in a waiting room one day, I was given a questionnaire to fill out about how my condition affected my life. Finally, I thought with relief, I am in the right place; here, I can be a patient and be listened to; I can receive hope and empathy. But that initial relief quickly dissipated when I met the physician, who spoke to me like I was a medical student on a clinical rotation. She told me about my “fascinating and mysterious” condition, how we do not really understand how it happens or what triggers it, and that the probability of my hair growing back was almost nonexistent. She never looked at me, her eyes off in the distance as she recited statistics. I was offered a treatment with little long-term safety data and a very low success rate for alopecia universalis. Not once did she ask me how I was feeling or coping. Not once did she see the pain in my eyes or the despair that overwhelmed me during the 15-minute appointment. I left in tears. I felt betrayed by the medical system that I aspired to join. I was certain that no one could help me, but worst of all, I felt that no one wanted to listen. Later, my analytical type-A self looked over the information on treatment options and decided that the risks outweighed the potential benefits, and so I did nothing. At least there were no adverse effects from wearing a wig and makeup.

Somehow I made it through the next few months. I graduated from medical school. I got married. My relationship with Sean got stronger and better. I moved back to my hometown for residency.

While doing an internal medicine rotation one day, I was called to see a patient that the emergency doctor thought needed to be admitted. I read

through the patient’s chart before going to see him and saw that he was an older man with many medical conditions and “failure to cope.” I also read about a skin cancer being removed from his face. He had undergone multiple surgeries for this and had been cleared of the cancer. As I approached his curtained-off hospital bed, I announced my presence and slowly pulled the curtain open when I had the okay from him. What I saw took me by surprise. He was missing part of his face and was completely disfigured.

I sat with him and listened as he spoke. He talked about what he had gone through, how the surgery for the skin cancer had been “a success” (no more cancer) and how he did not have enough money for reconstructive surgery. He did not go out much now, mostly because of his appearance, and he did not look forward to anything anymore. During the course of his admission, we found out that he likely had a different advanced cancer, but he did not want any further investigations. He was transferred to a palliative care facility soon after.

The patient’s disfigurement after the removal of his skin cancer was never a priority for the doctors he had seen. It

was not deemed “serious” or “life threatening,” but it was definitely life altering. The effect was enormous, and he was never the same.

I might not have been able to do much as a doctor to fix his problem, but I hoped that listening and trying to understand the effect it had on his life helped in some way, even if the ultimate outcome was unchanged.

Somehow, this experience allowed me to come to terms with the fact that I am also forever changed by my “cosmetic” condition. What happened to me might not be life-threatening, but it has been a shattering personal experience. I hope that this understanding might be helpful as I move forward in my career, focusing on the overall well-being of my patients and being present when they need more than a medical opinion.

Valerie Hertzog MD
Ottawa, Ont.

This is a true story; details have been changed to protect the identity of Dr. Hertzog’s patient and the physician.

This article has been peer reviewed.

CMAJ 2016. DOI:10.1503/cmaj.151093

“Humanities are the hormones of medicine.” — William Osler

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.