

@doctordoescancer

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Why am I so bone-crushingly tired? It must be residency. One-in-four call will do that to anyone.

I told myself this for four months. I woke every day feeling like I'd been hit by an 18-wheeler. I went to bed earlier each night and sustained myself with coffee to survive each day. After failing two courses of antibiotics for pneumonia, I suspected a more sinister cause for my fatigue.

October 12th was a blur. I was on my senior medical resident rotation. I ran two resuscitations that morning, then went to clinic for my own appointment. A nurse came in with an intravenous (IV) kit, and orders for laboratory investigations and computed tomography (CT).

I saw "LDH" (lactate dehydrogenase) written on the laboratory orders. I fell apart. I could have lymphoma, blood cancer. It had crossed my mind, but I wanted to be wrong.

Forty-five minutes later, I stared at images of the grapefruit-sized mass in my chest that was compressing my superior vena cava, the main vessel returning blood to the heart. I scrolled through my scan with morbid fascination, feeling detached. Many patients describe the sensation of being out of body when they receive bad news. Now I understood.

I returned to the interventional radiology department, where I had resuscitated a patient that morning. That afternoon, I was the patient, undergoing biopsies of a lymph node in my neck. One week later, I was diagnosed with stage IIBX primary mediastinal large B-cell lymphoma and started my first cycle of chemotherapy.

My diagnosis happened quickly, in part because of how severely my tumour was compressing my superior vena cava and the potential for airway compromise. I am thankful I had an expedited workup and diagnosis. I cannot imagine the agony of having to wait weeks for this kind of news.

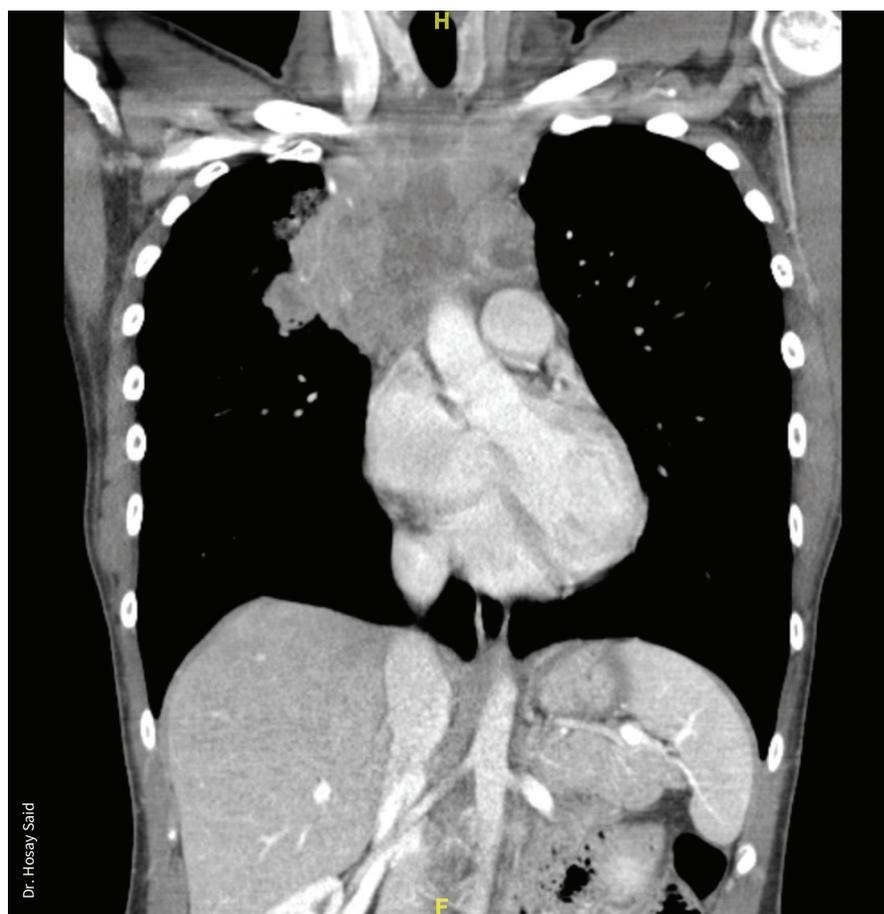
Over six months, I had six rounds of inpatient chemotherapy, five admissions for fever, an infected blood clot and one blood transfusion. I am profoundly grateful to say I am in complete remission. I created @doctordoescancer on Instagram to document my feelings during vulnerable moments and provide key "Patient Pearls" learned along the way. I do not want these lessons learned to end with me. My hope is these insights will improve the patient experience.

#1: Validate emotions

I distinctly recall losing control the day after I started chemotherapy. I returned

from my ultrasonography appointment and learned I had a line-associated deep vein thrombosis, a type of blood clot. Attempting to plug in my IV pump, I got tangled in the many sets of tubing from the infusions. I broke down. The emotions I had suppressed all week to keep myself sane and everyone else calm came rushing out. In that moment, all I could cry was, "This isn't fair!" I was a 28-year-old getting chemotherapy for a cancer I should not have.

My husband responded, "You're right. This isn't fair." No pep talk, no "keep your chin up." This statement was a breath of fresh air: it gave me permission to *feel*.



The author's diagnosis was revealed by computed tomography of the chest, showing a 10 cm × 7 cm × 10 cm mediastinal mass with severe compression of the superior vena cava.



Dr. Hosay Said

This photo was taken part way through treatment. The author's husband, Karim, shaved his head in solidarity to make the physical and emotional changes of cancer more bearable.

These were my emotions, my experience, my pain. I felt like I was allowed to grieve how drastically my life had changed in such a short period of time.

Negative emotions do not always require morale-boosting positivity. Nowadays, I do not reflexively offer solutions when patients express anger or fear about their illness. Sometimes patients need a supportive space where they can just *be*.

#2: Please, take a seat!

Despite being taught the importance of sitting down in medical school, I had no idea how much I would dislike the sensation of someone towering over me in my hospital bed. I felt like they were in a hurry to leave,

even if I knew this was not their intention. Evidence suggests that patients perceive that providers who sit instead of stand spend more time at the bedside.¹ I felt my shoulders relax when doctors sat down or crouched by my bedside. Kudos to my oncologist who crouched for an entire 30-minute conversation! I now spend a lot of my day crouching to ensure patients feel like an equal during every encounter. Take this step to mitigate the power dynamic between doctor and patient.

#3: Think before you prescribe

Shortly after diagnosis, I was on two subcutaneous injections, two mouthwashes and four pills. Each of these medications had

specific timings, strict guidelines and uniquely unpleasant adverse effects. Prednisone tasted like bitter, rotten eggs. Dalteparin caused bruising and nosebleeds. Filgrastim made my bones ache. I assumed I would have no trouble being compliant, but it was hard! Even on good days, I struggled to keep up. I was also fortunate enough to have private drug coverage but was aghast to learn how expensive these medications were. Seven days of filgrastim was about \$1000.

It is easy to blame patients or make assumptions about their motivation; however, there are many factors that contribute to adherence. I have noticed a distinct shift in how I approach this with patients now. Whenever possible, I simplify medication regimens to once or twice daily dosing. Discussion around financial barriers or cognitive impairment happen before I prescribe, not after. We, as physicians, are responsible for making patient-centred treatment recommendations to facilitate their success.

#4: Help patients feel human

Having cancer triggers an identity crisis. Everything that defined me was suddenly gone. I did not recognize the bald, moon-faced alien staring back at me in the mirror. "Chemo fog" made simple tasks feel impossible. My life revolved around appointments and neutrophil counts. Cancer robbed me of normalcy.

However, there were moments I felt like myself: when providers saw beyond my diagnosis and asked about my favorite television shows, restaurants or travel destinations. I understand the pressure to get through the day. However, seemingly innocuous conversations about patients' lives leave lasting impressions. They can build a level of trust and respect that will not be forgotten. I make a concerted effort to learn something new about my patients every day. Take the time to help your patients feel human.

#5: Empower patients during times of uncertainty

As a patient, I struggled with the sensation of losing control and the fear of the unknown. In a 48-hour period, I went from managing patients' conditions to becoming a patient, forced to hand over the physician role to my health care team. As the end of treatment neared, my anxiety worsened: end of



Dr. Hosay Said

This photo was taken immediately after the author completed her last cycle of chemotherapy. In the absence of a traditional bell to ring on the oncology ward, she ordered this T-shirt to celebrate this moment in her cancer journey.

treatment meant evaluation of treatment response. Each round of imaging triggered “scanxiety,” a tumble down the dark hole of possible negative outcomes: residual disease, stem cell transplantation and, should all else fail, salvage therapies. Although I am in remission now, this does not preclude the possibility of relapse. Life after cancer is like walking on unsteady ground that may fall out from under your feet at any time.

I grew tired of feeling crippled by anxiety about relapse and decided to focus on something I could control: regaining my physical strength. I set specific, daily goals with quantifiable markers of progress, like increasing duration and intensity of physical activity. This kept me anchored in the present. I now do this with patients. We discuss what their goal is for the day, including things like sitting in a chair for 30 minutes or walking to the end of the

hall. These specific, achievable goals give power and control back to patients during a time when nothing feels certain.

#6: Healing is not over after cancer

During treatment, my singular focus was survival. After my last cycle of chemotherapy, I felt lost. The following months of adaptation to the new, postcancer “normal” were tough. Grocery shopping was more tiring than 26-hour call shifts had been. Facing potential infertility at 28 was overwhelming. Survivor’s guilt is real. Why did I live when another person my age did not? I am not and will never be the same person I was before cancer.

To suggest that patients are healed once cancer is gone or that life picks up where they left off undermines the struggles they face *after* surviving critical illness and denies the enormity of the impact of the illness. I discuss this concept with patients and their families to try to break the pattern of guilt and isolation patients face during recovery. Recognize that being well goes far beyond being cured.

This experience has given me perspective, insight and patience. The journey was — and still is — hard. But it has made me a better care provider and for that, I am grateful.

Hosay Said MD

Department of Internal Medicine
McMaster University, Hamilton, Ont.;
Waterloo Regional Campus, McMaster
University, Kitchener, Ont.

Reference

1. Swayden KJ, Anderson KK, Connelly LM, et al. Effect of sitting vs. standing on perception of provider time at bedside: a pilot study. *Patient Educ Couns* 2012;86:166-71.

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This is a true story.