# A Walk in My Shoes

It is easy to neglect the symptoms of chronic illness when we do not “see” them.

April 3, 2017 By Adam Hayden

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This is a first-person experience story of living with three young children, a dedicated, hard-working wife, and, yes, brain cancer. My objective is to remind us to not discount patients’ chronic illness on the grounds that you cannot “see” the symptoms.

A parenting instinct activated upon the first steps taken by your first child heightens a sixth-sense ability to recognize sharp corners, protruding from dining tables, low counters, wooden chairs with arms, open cabinets, and playground equipment, to name a few of such hazards. With little thought, no break in conversation, with the finesse of a no-look pass into the paint, a parent will reach down to place a hand around the bottom of a protruding corner as her child stumbles by and ricochets off the safeguarding hand—rather than, say, ricocheting off the sharp corner. My family recently moved to a new home and our kitchen counter appears custom-built to the median height of 36-to-48-month-old children. My corner-sense was tingling! Contusions avoided.

These days I recognize myself doing something else to safeguard these corners: no longer do I protect the bottom of the sharp edge to keep little skulls safe, I cup the entire corner to keep big skulls safe, too. See, I am prone to seizures, and I have before struck a kitchen table while experiencing a seizure.

My seizures are well-controlled with Keppra and Vimpat, the peanut butter and jelly of the epileptic neuropharmacology space. Though as I discovered on the morning of March 6, after delivering a public lecture to 250+ attendees on March 5, followed by dinner with close friends, my fatigue and anxiety is pretty well correlated to seizure incidence. On the meds my unconscious convulsions are a distant memory from inpatient post-surgery recovery (and that one time at my folks’ with the table), but light-headedness, dizzy spells, and left-leg weakness are the trademark signs that I stretched myself too thin. I am experiencing them near daily this week.

The following is why. March 5 I delivered that public talk, March 13 I sat for a 90-minute interview, rehearsing my story and discussing end-of-life planning for a palliative care website (IKS.com; here is my blog post about that experience), March 29 I delivered two back-to-back lectures at Marian University. In April our family moved homes, during the rest of the month I delivered a lecture with an IU School of Medicine narrative medicine course, and I delivered a lecture sponsored by the IUPUI Religious Studies department. I prepared a proposal for an interdisciplinary conference (Communication Medicine and Ethics) that was accepted; I will present in June. This weekend I am scheduled to visit Washington to conduct meetings with Indiana's elected representatives and senators to advocate for cancer research funding.

This is all to say, I am busy. And I love it. Writing and speaking are therapeutic, I teach medical professionals to consider more deeply patient interactions, and I advocate on behalf of fellow patients and survivors. Advocates like me are preparing a better road for you if you face chronic illness. Please reach out and invite me to address your patients, faculty, medical professionals, clinicians, nurses, chaplains, and so forth. It is my passion, and I am good at it.

Back to the topic: I am pretty worn out these days. How am I feeling? Not great. I'm safeguarding the top and bottom of each corner I pass for fear a mild (or major) seizure incident will send me, head first, into the sharp edge. I require a cane for balance, and I "furniture surf" through my home to keep from losing balance.

The following are symptoms I experience; in some cases, I offer actions you can try at home to emulate my symptoms—clear the area of sharp corners!

- Headaches, local: these are localized to primarily the area of my surgery (craniotomy). There is a divet and line tracing the incision and partial skull removal where the bone is fusing. Consider a broken arm and dull aches even after cast removal. Examine scars on your body with your fingertips—broken bones, surgical scars, places where a laceration required stitches, and so on. Let your sensitive finger tips distinguish these areas from unblemished tissue. Now imagine these vulnerable areas are on your head. My "head divet" aches.

- Headaches, global: I experience near-daily general headaches. These daily headaches are often tension or compression headaches. After resection of a 71mm mass and edema my healthy brain tissue is reclaiming available space in my skull. My parietal lobe healthy tissue is moving back toward the occipital lobe. Squeeze a few inches of muscle tissue in your arms or legs and consider how moving tissue feels with respect to connective tissue and your skeletal system. Tissue is shifting inside my head.

- Motor deficits: fatigue exaggerates my motor deficits, and chemo makes me very fatigued. Think about your last leg day at the gym. Jello legs? My left leg feels like this nearly all the time, and my right leg bears the compensatory burden. My left hand is slow, and anything held for long periods of time in my left hand is almost always tilted, spilled, or dropped. (“Oh, Lefty,” my wife and I will say to ward off frustration with humor.) My left-hand fingers and thumb are lazy while I type out texts, tweets, and emails.

- Sensory deficits: communication between nerves and my sensory cortex is damaged. I often feel sensations on my left leg, but I am unable to locate where or what these sensations are without visual input. My leg and foot tingles and feels numb.

- Proprioceptive difficulties: related to sensory deficits, I struggle to locate my left side in space. I often bump into people and things given a spatial and sensory left side “blind spot.” Try this, find a step, stand on the step and let your left leg suspended above the floor. Close your eyes and move your foot and leg in a big circle, hovering over the ground, then stop and try to tap the ground, no looking, this is how each step with my left foot feels. Or close your left eye, keep your right eye open, and make an obstacle course in your home around tables and chairs.

- Light-headedness: during my most fatigued days I feel like someone has taped a helium balloon to each side of my head, and the feeling—though not the visual experience, is wayward and wobbly, swaying back and forth.

It is easy to neglect the symptoms of chronic illness when we do not “see” them. It is easy to think of me doing well, and think, Adam is so active, he is in great shape. Do not think that in the absence of oxygen tanks and chemo infusions that I must be doing OK. Do not think that because I am able to speak publicly, to accompany my family on errands, or because I have a date night with my wife every few weeks that others are granted license to state how I am feeling. It is almost always better to ask me. “How are you?” Doesn’t feel quite right, but, “how are you feeling today,” is good.

My talks and other activities are not done in the absence of symptoms, but despite them.

Please don’t mistake this honest (and at times assertive) post as a call for acknowledgment or recognition, but as a reminder that few of us are granted access into the inner lives of our friends, family, and acquaintances, but inaccessibility does not warrant assumptions.

Let us seek to walk in each other’s shoes before critiquing their fashion sense.

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http://beta.docker.cancerhealth.com/blog/walk-shoes