Cancer Health™

Learning Lessons Wearing Cancer

We, each of us, carry pain, heartbreak, embarrassment, fears, and injury, just below the surface.

November 30, 2016 By Adam Hayden

Cancer.

The “Big C.”

“C-A-N-C-E-R” my wife often spells the word when our kids are around. The idea maybe is that to name something is to give it power.

Beetlejuice. Beetlejuice. Beetlejuice.

Or maybe she hopes to avoid the inevitable question, “What’s cancer, mommy?” Worse yet, Isaac may tell friends, “Daddy has cancer,” and no telling where that conversation leads in a school classroom full of five-year-olds.

Lessons for Kids and the Rest of Us, Too

Whitney and I do our best to communicate with the kids openly, honestly, and with integrity. Whitney and I have been up front with our kids that “daddy has a boo boo on his brain that the doctors are trying to fix.” Isaac and the younger boys visited me in the hospital and later in the acute inpatient rehab facility following my surgery. Cancer aside, the double-digit number of staples in my head was frightening enough—especially for toddlers who aren’t conceptualizing the silent killer of malignant cell proliferation. In a flash of parental clarity, I reminded Isaac of his many scrapes and bruises suffered to his knees and elbows following rambunctious play or tripping on the sidewalk.

I asked Issac, “Did it bleed?”

“Are the scrapes there now?”

“Did the scabs heal?”

“The boo boo on daddy’s head is healing, too.”

Isaac visited me again a week or so later and he showed me his knee, bruise-, scratch-, scrape-, and scab-free. Lightbulb. The kid gets it. I showed him my staples.

What lessons does a parent take away from this brief interaction with his son? What lessons are available for the rest of us? I think it is the following: I managed to normalize a scary and intimidating situation for Isaac. Isaac understood, in that moment, anyway, that pain, injury, and healing are familiar experiences, something he can recall, and those experiences are shared by others, too. Dad looks scary, he is in a strange place, he has a visible injury, but even if the place is unfamiliar, the experience in broad view is normal: scrapes, cuts, bruises, bangs, dings, bumps, and band aids. Let the healing occur.

“Look at my knee, daddy! It’s all better.”

Empathy and Normalization

Our empathy is hard-wired from our great ape ancestors: in a very real sense we feel the pain of others, and our ability to contextualize, to see ourselves in the situation of another, represents an evolutionary advantage in so far as cooperation, problem solving, and social development rest on a foundation of finding threads that connect our experiences to the experiences of another, even if we have not faced their specific challenges. We think of ourselves as good spouses, good friends, good legislators, good faith leaders, good mentors, Big Sisters and Big Brothers, Rabbis, and Imams, Doctors and Nurses, because we imagine ourselves into the circumstances of our community, our cities, our classrooms, congregations, and hospital beds. Patient-centered doctors facilitate a role-reversal: they empower patients to take an active role in their treatment and recovery by answering the big question when prescribing medicine or writing orders: why? When patients view themselves as members of their medical team, these empowered patients contextualize their experience in following a treatment regimen to the doctor’s experience in prescribing one. The doctor and the patient are both sharing in the message of why a therapy is important. I call on doctors to explain to patients why a treatment strategy or plan of care is important in such a way that the patient is empowered to explain the same information to her family or friends. A doctor’s one-on-one communication with a patient is equipping the patient to have the same conversation with her loved ones. It is not one-on-one, but doctor-to-patient communication is one-to-many. How might a doctor’s communication with a patient change if she realizes the conversation is not only to inform the patient but equip the patient to inform others?

Good doctors and empowered patients walk (or roll, scoot, transfer, gait belt, etc.) together. It is a partnership.

Normalizing Novocure

My scalp itches and burns. It’s my electric cancer hat.

To maximize therapeutic efficacy, patients are instructed to meet a ‘compliance’ threshold for wearing the device. Compliance is a recommended 18 hours of daily use, but my oncologist (and clinical data) suggests that longer duration of daily use translates to increased therapeutic efficacy. The system includes an adapter for wall-outlet power and a 2 1/2 pound backpack (when loaded with the device and a battery) for getting around or out of the house.

The device is wired to a medical-grade adhesive holding multiple series of ‘transducer arrays’ that emit alternating electric fields, targeting a solid mass tumor. The electric fields disrupt the process of cellular division (mitosis). Maintenance requires patients change the arrays every two to three days, depending on a number of variables. Optune is FDA-approved for glioblastoma, so I presuppose this application in the remainder of this post, but TTFields are currently in clinical trial for brain metastasis (#bcmets) and mesothelioma. I change my arrays more often because, no secret to many of you, my super power is growing hair. The arrays must be in contact with a shaved scalp, and hair growth can interfere with array-to-scalp contact, causing hot spots, and disrupting therapy. When I stretch the arrays out to three days without a change, my rapidly growing hair causes the arrays to lose contact with a freshly-shaved scalp, and the device 'alarms' (*beep beep beep*)—not great for uninterrupted sleep. So it's every other day for me that I remove the adhesive and arrays, treat my irritated scalp with shea butter, hang out, feeling liberated for a couple of hours, then shower, scrub my scalp, shave, and Whitney applies a new set of arrays. This is our routine. It has been more difficult for me to adjust to than I imagined it would be. It may not be too hard to understand why.

Mitch Hedberg tells a joke about how uncomfortable it is to wear a turtleneck with a backpack. I describe wearing Optune in similar terms: it's like wearing a snug beanie and carrying a large bag, 20 hours a day. The bag restricts your movement and the beanie makes you hot. You're hot and restricted! It is hard not to become irritable.

I nearly abandoned the Optune effort, but what I have failed to recognize until just a day or so ago is that I have not answered for myself why it is important I follow through with this therapy. There are at least three reasons, the first of which is obvious, and the latter two are consistent with the themes of this blog.

- First, clinical trial suggests newly diagnosed glioblastoma patients experience an increase in overall survival with Optune compared to standard of care (SOC) alone.

- Second, I am a pioneer in a new treatment modality. Yes, Optune is FDA approved and is frequently becoming another SOC protocol in the treatment of GBM (resection + radiotherapy + chemo + Optune), but we are early in discovering the wide ranging applicability of TTFields in the treatment of solid mass tumors. It is exciting to consider myself a partner in this new frontier for treatment.

- Third, as a novel therapy, it is patient responsibility to help push cultural norms to improve the experience for future patients. Normalizing the wearing of Optune allows me to confront uncomfortable or strange interactions in public so that the next GBM patient may walk through

> the restaurant, car dealership, kids’ preschool, or grocery store without feeling the weight of quite so many eyes.

Wearing Cancer

Like Isaac’s skinned knee, the staples that were in my head, and now Optune, I am wearing my cancer. It is easy to hide behind the visuals that project our pain to the world, yet we all realize, don’t we, that these are superficial and cosmetic; the tips of the icebergs. We, each of us, carry pain, heartbreak, embarrassment, fears, and injury, just below the surface, not in the light of day, exposed for the wandering eyes and strange looks from others. I think ultimately I wear Optune because I am coming to understand the act of wearing the device expresses solidarity with all of us facing hot heads, heavy bags, and restricted movements: our jobs, our relationships, our budgets, our health. It’s tough out there, friends.

I become irritable, itchy, hot-tempered, and worn out. I get short with the kids. But I also get this strange pass, right? Because of the Big C. Because of C-A-N-C-E-R. Because of Optune, and my affected gait, and my cane.

Many of you have thanked me for writing this blog, and you have said wonderful things about me and my experience: that I am inspiring, uplifting, strong, positive, and courageous. Friends, you are these things. I have been branded with the global identifier of cancer. I get head tilts and sad eyes. People are soft on me by default. The model I am living up to is the one set by all of you, who face an often mean world, and you do it with enough grace and kindness that at the end of your long days you have enough energy left to send my family a card.

We imagine ourselves into each other’s context, and we find empathy, strength, and partnership in that shared space. The analogies I draw from my experience and the lessons I galvanize show up in meaningful ways: this blog, like my description of doctor-patient communication, is not one-on-one, but one-to-many. I seek opportunities to tell my story, and I could not be more thankful for your support. More to come!

Cheers —AH

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