Cancer Health™

What to Say to a Cancer Patient

If you take nothing else away from this post, my best advice is this: “Let the silence do the heavy lifting.”

December 4, 2016 By Adam Hayden

Scooped by the NY Times

Dr. Stan Goldberg is a Professor Emeritus of Communicative Disorders at San Francisco State University and the author of the recently published book Loving, Supporting, and Caring for the Cancer Patient. Dr. Goldberg’s book is the basis for a recent NY Times Personal Health Column, “What Not to Say to a Cancer Patient” (November 28, 2016). This topic has been on my mind for some time—since my time in the hospital, anyway (May through June, 2016). During my few week stay I happily received many visitors—thank you to those who carved out time to spend with me in a sterile hospital room, seeing the world through double-paned windows.

Dr. Goldberg’s book, and the Times column based on it, is a helpful resource before visiting a friend or family member in the hospital or at home, and if your life is affected by a cancer diagnosis, for you or someone you care for, I encourage you to look into both. As we say on Twitter, a retweet is not an endorsement. Here I voice concerns with the Times column, and I reinforce points where my suggestions converge with Dr. Goldberg’s. Ultimately, I aim to support readers in their next conversation with a friend or loved one.

I hoped to write on this topic ahead of Thanksgiving, thinking I would frame the post as a pre-family-get-together primer for visiting the cancer patients in your life. Unfortunately, I was due up for my next Temodar (chemotherapy) cycle the week of November 21. The “5/23 TMZ cycle” as those of us with patchy hair and pending, possibly approved disability claims call it. The phrase, “5/23” represents the standard of care (SOC) monthly chemo cycle for brain cancer patients: 5 days on, 23 days off, Temozolomide (TMZ) a chemotherapeutic agent, administered orally, before bedtime, one hour following Zofran, with nothing else to eat or drink two hours before or after. The five days of TMZ cumulatively chip away at your energy level until you bottom out on days four and five. These would be good days to challenge me to a foot race.

The remaining 23 days of the month are spent recovering lost energy from the first 5. Usually labs are drawn in the couple weeks following the first 5 days to make sure blood counts are within range—Temodar (Merck’s brand name for temozolomide) targets rapidly dividing cells, including healthy cells, for example, the workhorse bone marrow, cranking out blood cells. Blood and platelet counts can precipitously drop while on Temodar. If all looks good, I am usually feeling pretty well in time to receive my next Temozolomide shipment, rinse and repeat for the next 5/23 cycle.

With Thanksgiving coming and going, the chemo cycle, not feeling great by the end of the holiday week, I didn’t push out my planned post: “What to Say to a Cancer Patient.” I thought, hey, no worries, I will write on the topic a couple of weeks into December with a similar theme. Maybe revised to include an addendum for making an appropriate greeting card selection!

Then…

I was scooped by the Times!

The Times ran their column Monday of the present week, and I saw my once-hot iron begin to cool. Did I miss the time to strike? I have decided to blog on this topic anyway, and I have decided to do so for three reasons: (1) I have a commentary I would like to lay beside the Times piece (who’s surprised?); (2) this topic is important to me. I started jotting notes in my journal two days following my craniotomy. Leveraging my experience to help others has been my goal from the beginning of this process. That goal continues to sustain me. Nothing is quite so uplifting as receiving a positive response to a genuine expression of the self. This is what my writing represents, and your feedback, likes, shares, and comments are powerful. Thank you for reading! In the theme of this blog, hopefully thoughts I share here carry you into your next difficult conversation with family or friends, furthering my goal of leveraging my experience to support others. And (3), let’s be honest, our loved ones need some help in this area!

It is difficult to visit our friends and family in the hospital or at home who are facing a scary medical diagnosis, and few diagnoses are scarier than cancer. The analogy I use is to compare the experience of visiting friends in the hospital to non-parents who visit their friends’ newborn infant. What do I say? “Hi, baby. Welcome to Trump’s America”?

“Can we hug?”

“Should I use hand sanitizer?”

“How are you sleeping?”

“We’ll keep your spot for Friday night Texas Hold ’em.”

Parenting is something that happens to at least half our population, yet, when it happens to us, we wish we had a manual for knowing what to say, how to act, how to help the friends it has happened to, and so on. I’m not saying having kids is like getting cancer—though, great fun could be had exploring that space, but many of us spend our 20s trying to avoid becoming parents, as we near our 30s the incidence of parenting become more common, yet some of us still think, “It couldn’t happen to me!”

Cancer is widespread, too: some 40% of men and women will be diagnosed with a form of cancer during their lifetimes, reports the National Cancer Institute. Nearly 1.7 million new cancer cases will be diagnosed in 2016. To make those stats hit closer to home, well, my home, anyway: glioblastoma (GBM) is the most commonly diagnosed malignant brain cancer, with 12,000 cases diagnosed annually. Only about 10,000 of those folks will live longer than one year. Yikes!

Cancer is big! Cancer is Scary! Cancer is confrontational, in your face, imposing! Many of the treatments include side effects worse than the disease. Patients are conditioned to accept hair loss, nausea, and fatigue with the same dispassionate concessionary stance as insurance copays and terrible hospital cafeteria food. Yet, like automobile accidents and house fires, we rarely prepare for a cancer diagnosis personally, and we are never quite sure what to say when a diagnosis is given to a close friend or family member; though, it is statistically inevitable that nearly half of us will be on the receiving or delivering end, sharing bad medical news with loved ones, at some point during our lifetime.

So here I am. I write with the goal of helping caregivers, friends, and family feel more confident engaging their loved ones facing a cancer diagnosis and helping my sisters and brothers battling cancer that our visitors may not be quite so uncomfortable.

If you take nothing else away form this post, my best advice is this, borrowed from the coaching and consulting resource, Fierce Conversations, “let the silence do the heavy lifting.”

“How Are You?”

The Times column emphasizes two key messages: (1) avoid stock questions and platitudes, and (2) offer specific, actionable assistance to patient-friends to provide meaningful support during a difficult time. The reasons for (1), on the surface, anyway, are fairly obvious. It is difficult for a patient to meaningfully respond to the prompt, “How are you?” The question strikes us as too shallow to address someone who is hospitalized, facing a difficult diagnosis, or recovering from surgery. This is easy to see in the abstract, for you right now, reading this post, it is obvious, nearly cringe-worthy, to imagine walking into our friend’s hospital room and almost-cheerfully ask, “How are you?”

The scene is too extraordinary for such an ordinary question; this juxtaposition gets at the audacity of the situation.

This is an obvious point maybe, but do not judge too hastily. What presents as obvious on paper, is often more complicated in real-time. This is the differential diagnosis of interpersonal communication: what can I possibly say to my friend who quite well may be dying?

“How are you?”

How do you begin the conversation? What will you say, standing in the door frame, your friend, in bed, gowned, electrodes adhered to his chest, nested in coarse, black chest hair, wires twirling, twisting, stretching to beeping, whirling, buzzing, printing, machines. Two or more IV bags drip through a line, into his exposed arm, bruised in the creases of his elbow from blown lines and stubborn sticks. Train tracks of shiny staples flash in the fluorescent lights like a zipper across his shaved head. Standing there, in the door frame, you take in the scene. You almost catch your breath.

Eyebrows lift, attention drifts, if only for a moment. Then. Unexpectedly.

“How are you?” you ask. The words spring free of your lips.

“Shit.”

“I mean.”

“How are you feeling, man?”

Beep. Buzz. Print, print. Nurse walks in. The conversation gasps to a halt like a child, choking on a hard candy.

“Go on, sweetie, I’m just here to get vitals,” says the nurse, uninterested, busy, overworked.

You glance at your friend in bed, he’s pulling back the sleeves of his gown to allow for blood pressure, maybe draw a vile of blood from the IV. He softly smiles at you, nods, encouragingly, inviting you to continue.

“How are you?” you repeat, with the hesitation of someone who has been impromptu asked to deliver the grace before a meal at your in-laws’.

“Other than the brain cancer, I’m in great health!” I often joke with friends, but like each joke that is, “funny because it’s true,” my response is designed to make you squirm, if even only a little, because, “How are you?” and “cancer” are not compatible in the way that “What’s the weather?” and “sunny” happen to be.

“How’s the weather?”

“F5 Tornado, and cows are literally flying through the air.”

Lesson: identify and eliminate stark contrast and juxtaposition.

“A Heightened Sense of Vulnerability”

The Times article cites another reason for avoiding the question, “How are you?” This “rattled my heightened sense of vulnerability,” related Dr. Wendy Schlessel Harpham, recurring cancer survivor and author. Dr. Harpham recalls feeling the need to fight the fear and grief that fills the room, following a rather mindless inquiry, “How are you?” Often the patient is put in the position to console the visitor.

Dr. Harpham suggests visitors sit as a calm and quiet presence.

In other words, let the silence do the heavy lifting.

Dr. Harpham is right, or at least, her experience is consistent with my own. I often take a deep breath after saying goodbye to visitors and wonder to myself, “was that visit for me or for them?” My hypothesis is something like this: there is a correlation holding between a patient’s vulnerability and a visitor’s comfort level. Dr. Harpham writes as though she is uncomfortable confronting her heightened sense of vulnerability. This is her truth and story to share, and it is not mine to critique. I will say in my experience, I gave myself over to the process very early on, and I think a balance of surrender and control lay at the heart of vulnerability.

My neurosurgeon called the day before my craniotomy to inform me that after review of my functional MRI images and discussions with his colleagues, he decided to perform the surgical resection of my brain tumor while I was kept awake with conscious sedation. This approach to the procedure would allow me to respond to questions and commands to protect the maximum degree of motor and sensory function while aggressively resecting the maximum amount of tumor. I received two more telephone calls: one from the anesthesiologist and a second from the head OR nurse. Each of these three calls invited me to surrender more and more of the control over the process I naturally sought to cling to, yet, where I would have control, these opportunities were emphasized by my medical team. Namely, I would be asked at some point during the surgery how aggressive I would like my neurosurgeon to be, resecting tumor, at the cost of permanent function and sensory loss to my left side.

My medical team made clear where I would be in control, so I felt more comfortable abandoning the areas where I would exercise very little control. I am vulnerable because I am willing to surrender control. I surrender because my medical team helps me understand the choices that are mine to make. My vulnerability helps my visitors feel less doom and more comfort, and so the visits are shared experiences.

Lesson: identify and surrender some control in exchange for embracing the autonomy you have.

What to Say to a Cancer Patient

The Times article concludes with a number of “dont’s” to avoid saying to your friend or loved one. The topics to avoid includes light-hearted remarks, discussions of why the diagnosis or cancer type is “better” than another, estimates for prognosis, or suggestions for treatment. This is a good list, and this is a bad list and both for the same reason: these are the topics we all really want to talk about!

The Times column is titled, “What Not to Say to a Cancer Patient,” but defining something by what it is not is notoriously difficult and abstract. Better to say what it is, and own it. This is why I call my post “What to Say to A Cancer Patient.” It is good for the patient to discuss cancer type, treatment strategies, prognosis, clinical trials, side effects, end-of-life planning, and so forth. Visitors, friends and family members, loved ones, provide a safe space to explore these topics! So do not avoid these topics, do not think “what not to say,” but instead, consider, “what do I want to say, and how will I frame that discussion appropriately?”

I do not mean to sound inconsistent—on the one hand criticizing, on the other, lifting up, but a good starting place is with the “dont’s” list near the end of the Times article. There, topics are reframed more appropriately for discussion with a friend facing a difficult diagnosis. Here are the most common things said to me by visitors that I wish would go unspoken.

- Statistics, statistics, statistics. Avoid them, unless either (a) I share them first and you are responding to my comments, or (b) you are aware specifically of clinical data relating to patient outcomes for a chosen treatment options I have discussed with you. I diverge some from my sisters and brothers in the patient/survivor community because many of us rally this battle cry, “I am not a statistic!” Sure, sure, but, honey, the stats are made of people like you and me; hence, to turn a blind eye towards stats is foolish if we seek to be well informed patients. I want to know the stats. Regardless, if X percent of diagnosed patients made it X months or years, even if you wish to encourage me, don’t mention these numbers to me. When patients say, “I am not a statistic,” what they mean is something like what I have said, before, I follow a strict, calorie restricted diet, I maintain my activity level, I take my medications at the directed dose and time, I avoid known carcinogens, I supplement with vitamins, herbal supplements, and essential oils. Even if said with encouragement, “Adam, I know you’ll be in such and such percent,” is to ignore the discipline, restriction, and intention I apply toward almost every aspect of my daily life.

- Not to mention… Statistics, statistics, statistics, picking me out to be in the “good” statistics is to ignore the loss for folks who comprise the “bad” statistics, regardless of their anonymity for you and me.

- “You look great!” “I am so happy you’re doing so well!” “It’s great you’re feeling well enough to get out of the house.” “Your color looks so good!” I hear this frequently. I understand these compliments are paid to me because, well, dammit if I don’t look pretty good most days of the week! I do get myself up, dressed, and ready for the day 9 days out of 10. My color is good. My cognition is pretty unaffected (most days), but the gap between good coloring and terminal diagnosis is a broad one. Just because I’m up out of bed, and I look good, and I’m not a frail bag of bones, your seeming surprise is not helpful. In fact, it conjures feelings of guilt that I am somehow not as sick as you thought me to be. Similar to my remarks about the statistics. To emphasize how good I look, and to do so with near-surprise, is to take away from the deliberate effort it took me that morning brush my teeth, put in my contacts, get some clothes on, and face the day.

Lesson: Ensure comments reflect your knowledge of your friend or loved one and not only the patient population he represents.

The Next Difficult Conversation.

Here are the lessons I hope you carry into your next visit with friend or family member facing a difficult diagnosis.

- Avoid stark contrast between the circumstance and your spoken words. “Hey, how are you?” is good for the locker room, not a hospital room. Take a few moments to rehearse your opening words before stepping through the doorframe.

- Be vulnerable: surrender what you do not control, and embrace your autonomy. When visiting a loved one surrender your (mistaken) control over their mood, their diagnosis, the hospital setting, and take under your control your attitude, how you frame the dialogue, and how you engage with medical staff.

- Frame your comments about the individual, not the disease or diagnosis your family or friend represents.

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