Better Living Through Cancer

Contents

Alien on my tongue

Friday, February 19, 2010

January 16, 2010

To use Ben's terminology (didn't think you'd mind), I have an alien growing on the back of my tongue. Some might all it a growth (isn't growth good?) or a nodule. I've had a sore throat for three of four weeks. After about two weeks, I saw Deb, our primary care physician. She couldn't see anything on my throat, but did a culture and everything seemed ok. After another week, I was scheduled with an ENT specialist.

Deb's referrals are top notch. In this case, the ENT is very capable, but lacks, shall we say, a warm personality. I imagine he needs to detach himself from his patients to be able to his job. He took a gander down my mouth and spotted the alien immediately. "Didn't you know it was there? You knew it was there." Well, my throat was sore and swallowing feels like I regrew a mini-tonsil, but my tongue? The ENT says it's "way" above my voice box which is "good". Anyway, his comment made it all real. The ENT feels that the alien is likely malignant, but we won't know for sure until a biopsy is performed. Luckily, the biopsy is scheduled for 6:45 am this Monday, so we'll have a better idea what I'm facing on Wednesday or Thursday. A cat scan and an MRI are on the agenda.

MY PARENTS DO NOT KNOW. Not that I expect all y'all to pick up your phones and call them, but we think it's best to wait and tell them once we have more information. They will want immediate answers to unanswerable questions. By mid-week, we'll have enough answers in place. I hope. When we know more, Ann or I will let you know. [Note: they know now, told them once we had a specific diagnosis. Not so surprisingly, they'd figured out something serious was going on.]

Today, we drove into Cambridge and told older son Dan. That was hard. Then, Ann Dan & I went out to eat at one of our favorite places, an Irish pub in a historic Inman Square building. Dan didn't touch a bite of his food. He's coming in (taking a personal day at work) on Monday to sit with Ann during the biopsy. I told him that wasn't necessary, that the biopsy is akin to having a tooth pulled under general. It's out patient at a surgical center not in the hospital (much better atmosphere.) Then again, I never miss one of my parents' tests. Younger son Adams is out in Colorado. We just told him by phone. You know, now I'm more worried about my sons than anything else. Now I know what was like for my Dad to give me similar news. Life is education.

I can bank on Dad's experience in facing the alien. And I can bank on Ben - thanks, Ben for sharing your thoughts step by step. We can compare scars in October. Appreciate any zooms, prayers, candles, karma, thoughts, jokes, etc. sent my way. Will let you know when I know. We'll take each step as it comes. Life is an adventure.

I probably won't be answering email. But I wanted you to know. I'm a little scared, but life has taught me that there are positive and negative aspects of every emotion. My body is telling me to rev up and get ready to fight. I plan on riding my bike every morning as usual until the meds suggest a break. Thanks for listening, for being part of my life, and being you...

Love,
Richard
Posted by greenpoet at 09:22AM (-05:00)

Alien on my tongue (big p.s.)

Friday, February 19, 2010

January 26, 2010

Thanks for the concern and support. I feel loved and not alone. It is a real challenge, waiting until we have enough information to decide on treatment options. I never like to wait. I never like uncertainty. Guess this disease will teach me valuable lessons!
We are looking at four options.
I saw a surgeon affiliated with Massachusetts General Hospital last week. Hoff, my friend since we wuz in diapers got me in to see him. The surgeon is gifted but somewhat unconventional. His patients include Julie Andrews and Ozzy Osburne. Good thing I don't have to sing for my surgery. He wants surgery first (9-12 hour procedure) then radiation and/or chemo. If we go with him, he'll take the tumor off the tongue transorally (through the throat), then make an incision from my ear to my Adam's Apple, a big curve, that he can peel up and through which remove lymph nodes and anything connected to them including the nerve that allows me to move my right arm above my shoulder. If he can't get the tumor off the tongue transorally, he'll continue the incision to the other ear and get it out through the neck. Sounds like fun, eh? Then radiation and/or chemo. The big challenge is to get the cancer cells that are in the lymph nodes not removed (because they are still too small to identify.) My lungs are clean. Ann is cooling towards the surgeon because he may not remove the tumor transorally. If we go through the throat for tumor removal, side effect possibilities include needing permanent feeding tubes and loss of speech. Hey, I can learn sign language. Talk with my hands. I won't mispronounce stuff.
My niece is a pediatric oncologist with Dana Farber/Childrens Hospital. She set up an appointment for me with the adult oncologist of her choice at Dana Farber Cancer Institute and his team for option #2 - that series of appointments are tomorrow.
Option #3 is a surgeon at Mass Eye & Ear who specializes in tongue & throat, recommended by our PCP and a friend who is an ENT.
Option #4 is a surgeon in Chicago who does surgery only on patients with my condition. He uses lasers transorally and micro-staging (as they remove tissue, they send it to the path lab until the sample is clean.) We have an appointment for February 1st and if I qualify, he can do surgery the next day (February 2nd, my birthday!)
Column A, B, C, or D? We'll see...
Love...
Richard
Posted by greenpoet at 09:24AM (-05:00)

Alien update (I)

Friday, February 19, 2010

January 26, 2010

Went to Dana Farber Cancer Institute today. My lovely niece, a pediatric oncologist at DFCI/Childrens Hospital, set up the appointment with her choice of throat cancer team. I saw a fellow, then - all at once - an oncologist, radiation specialist, and surgeon. When my throat got probed, it was probed four times. When they stuck the hose up my nose and down into my throat, there were four docs looking at the display and saying "a little more to the...". Then the four doctors went into a room with all the prior imaging I brought and worked out a treatment plan.

First, the oncologist believes the tumor was caused by the HPV virus. I don't smoke or drink, there is no collateral damage in my throat. HPV will be confirmed by examining the biopsy tissue.

I will not need the 9-14 hour surgery. I was geared and ready to go. Now I can take a breath and prepare for:

Imaging this week, then

6-8 weeks of chemo. I have lousy veins (take after my Dad), so they will put a port in on Monday, start chemo on Tuesday (Happy Birthday! truly.)

After chemo, new imaging, from which a plan for

7 weeks (35 sessions M-F) of radiation. Likely feeding tube as swallowing will become quite difficult and my mouth & throat will be a wreck, though I need to keep the swallow muscles working. Good news though - I won't need to shave my head.

We feel a lot lighter today. The first opinion from the surgeon was guarded with subtle warnings of a poor prognosis. If it's HPV based, the success rate is 80-90% and he said something about 92% with certain conditions at Dana Farber.

So I'm not out of the woods yet, but not caught in quicksand without a rope.

Thanks all for your love, support, and comfort... you are beyond words...

Love...

Richard

Posted by greenpoet at 09:26AM (-05:00)

Alien update (II)

Friday, February 19, 2010

January 26, 2010

I'm manic today. Well, maybe beyond manic. I remember when I was a DJ doing the 6:00-9:00 am (getting up at 4:20 or half after dark as BeJae coined it) drivetime show and having days when I had very little sleep. I used to think that I was quiet and subdued on the air those tired mornings. Then, I'd listen to the show tapes and find - damn, I was chatty! Jumped on a tangent and rode it off into the sunrise. Spin a song then spin a long(er) yarn. Today is like that. If I taped my conversations today, I'd probably hear them and think I was bouncing off the walls. Which I am. Without bruises.

Years ago, there was a comedy special on HBO and the comedian did a bit where he was calling his mama to tell her he didn't have AIDS (instead syphilis.) He said "I'm gonna go blind. I'm gonna go crazy. Hallelujah! Praise the Lord!" That's kind of a mental picture for me today. [So, YES, Eve - good news!]

I've always felt that God, my Higher Power always puts challenges in front of me when I'm ready for them, whether or not I think I'm ready. In this case, I met first with a surgeon whose plan was 9-14 hours of risky throat and neck surgery, 8 weeks of recovery, then radiation/chemo. His long term prognosis was veiled in murky, not reassuring comments. I readied myself for those challenges, worked on keeping myself positive about the future.

So as the Dana Farber team was presenting their treatment plan and prognosis, gently saying we know this is a lot to absorb and it can be shocking, trying to soothe, I wanted to stand up and yell "Hallelujah! Praise the Lord!" I told 'em bring it on! I'm good to go!

Manic... chatty... The reason for this note is to thank everyone for your emails. I appreciate them more than words could ever express.

Now I'll be quiet and all y'all can say "Hallelujah! Praise the Lord!" - I reached the bottom of this email!

Love...

Richard foxy
Posted by greenpoet at 09:28AM (-05:00)

Alien update 01/29/2010

Friday, February 19, 2010

January 29, 2010

Yesterday was hectic but satisfying. Went into Boston for a PET scan. Supposed to leave for home at 11:15 am or so. But... they worked in a meeting with the nurse who will supervise my care (Sheila is wonderful!) And a EKG. And prep with a PA and an NP regarding my port insertion surgery at Brigham & Womens Hospital. Then, a hearing test to confirm the chemo cocktail will not adversely affect my hearing. Now that's just hearing. They don't test my listening ability!
Slow day today. A little work. Doctor's appointment. Lovely lunch with my older brother Alan. Even less work. Home before curfew (set by Ann, someone has to set it and I'm no good at it!)
Today I saw Deb, our primary care doctor in Worcester. We love Deb; she is an excellent clinician and a caring, wonderful woman. I think the appointment was as much for her as for me - again, why we're so fond of her. We went over all the treatment protocol, appointments & doctor-ial perspectives in Boston, and then Deb wanted to look down my throat to see what she could see. Which was nothing. She told me she'd been having nightmares (literally) that she missed the tumor when I first went to her with the sore throat that wouldn't go away. She probed gently with a tongue depressor while I pointed and made unintelligible garbles trying to show her where to look. She kept pulling the tongue depressor out of my mouth, apologizing, afraid she was causing me discomfort. I told her not to worry. After the last two weeks of throat exams, she could cram a 2x4 down there and I'd hardly notice! So, Deb probed as deeply as her tools allowed and still could not see the alien. I felt grateful for her.
Here's the schedule as of now (subject to change): Monday, 6am/7:15am the port goes in. Tuesday, 9:45am-6:00 pm, I get hydrated and start chemo (three flavors at once: Taxotere, Cisplantin, 5FU) and get hydrated again. Wednesday, I get hydrated at 8am. Saturday, time TBD they pull the five-day 5FU belly pack off. Anti nausea drugs and antibiotics will be in the mix.
Had an easy fluid workout on my bike this morning - felt strong. Breakfast and the ration of two cups of coffee. I feel good. Dr. Deb says I look good. I'm raring to go.
Let's see how I talk my game after the chemo and steroids play with my head. Oh, yeah - stopped at the library for piles of books. Chemo means sitting around. Good thing I love music and books. Else, it'd be old magazines and daytime TV. Now that's really scary!
Love...
Richard
Posted by greenpoet at 09:29AM (-05:00)

Alien update Groundhogs Day Week 2010

Friday, February 19, 2010

February 3, 2010
From yesterday (02/02/2010 - my birthday): First perspective on chemotherapy:
They give me 4 plus liters of fluids plus chemo and THEN a diuretic to make sure I pee? and pee and pee and pee and pee and have dry mouth so I drink more so I...

On to today: Second perspective on chemotherapy

Well, me and the 5FU pump are getting along well. It purrs every time it gives me a dose. We sleep together, eat together, pee together, you get the picture. Me and the pump are hooked up until Saturday when Ann will disconnect it and clean the port. I am such a geek. Being connected to a piece of hardware is not an imposition. Instead of a beeper, phone, hearing aid, etc. - it's a cute little pump, a CADD-Legacy 1. I call it legs for short. Or cad if I'm mad. Of course, my other devices I could put down, say to dress, or shower, or... But it's all good.

I'm having another manic day, a combination of the steroids (there goes my baseball career) and hydration. Hydration is being hooked up to an IV machine and having 2 liters of fluid pushed down the vein. I'm on a host of medications to do this and that, so I don't know what's doing what. What I do know is that I'm feeling good. Oh, and that steroids are bad - Mark McGuire told me that. And Manny and David, but Mark is the expert. Jose I turn off, but maybe he's the honest one.

Dana Farber Cancer Institute (DFCI) is a wonderful place to receive care. The staff is friendly, gentle, and aware of the personal challenges each patient faces. The patients are warm and amicable, too. Most, like me, joke a lot. There's a lot of laughter in the chemo/hydration rooms. Not all laughter. But I see mostly smiles when I meet another patient's eyes. When I'm waiting around an elevator, someone will introduce themself, say why they are at DFCI and ask, "so what are you in for, kid?" This fellowship eases the tension and opens the mouths and hearts.

BeJae commented on the mortality issue in an email - here's a clip from my response: The mortality thing is an adventure. I think mortality and I have come to an understanding - course, it all had to be on my side. I focus on all I have to be grateful for in my life. That is a very long list (you're on it! - all of you are on it!) I see Dan & Ad grown men with good hearts, motivations, and focus. I used to have regrets. That was before I caught up with particular Clan Webster folks who knew me & my secrets from then - and before I went though the reflection and self-analysis (call it de-bullshitting and ridding of secrets) that I needed to do. I used to look at my college experience and think that I could have worked at it with more, full effort (it was easy to get by) and been able to do more. [Aside: what I really wanted was to share my life with Ann; think I knew that, just hadn't met her!] My Webby buds say Nay Nay - you were always up to something creative, artistically and/or academically - seeing a different way to look at things, be it a landscape, a verse, or Public Policy Analysis. The looking inside taught me to focus also on the good of my decisions - to understand that there is a range in all things, in all experience, in all emotions. If I feel something, it's not "good" or "bad" - it's my body saying "hello - there's something going on - pay attention!" I used to think anger was all bad. If I feel scared now, it's my body telling me to gear up to fight. And fight I will.

My current treatment schedule: First, three chemo series, each 21 days long (first week infusion, second week it hits me like a brick as the chemicals do their thing, third week recovery - I'll understand this truly in a couple of weeks or so), about 3.5 weeks. Second, imaging and development of radiation plan. I've been told that the chemo is a tool but that radiation is the cure. So my PET scans will help devise the plan. Also a big of preparation (feeding tube, etc. because swallowing will become difficult and I need to nourish.) Maybe 1-3 weeks. Third, 35 radiation treatments, five a week Monday-Friday for seven weeks. I'll take 'em a day or an hour or a minute at a time. It's what I've got to do to get better. And I plan to get better and have my life return to its normal mundane (ha!) pace. Again, it's all good. I grow from experience and astounding lessons await here.

Oh, one more. I was talking with Psychologist Doug about all this. He pointed out the steps in coming to grips with this experience. We started with acceptance and denial. I laughed and said that I got those two out of the way in the first five minutes. When the original ENT doctor examined me, he said "but you knew they (the tumor, the swollen lymph gland) were there" (I thought a throat boo-boo of some sort, but yeah, I did know they were there) and "we're scheduling you for a biopsy to see what kind of tumor you have. Here, hand these papers to my secretary and she'll set everything up." In the few steps from examining room to the secretary's desk, I got real light headed, managed to place the papers on her desk before fainting. Yeah, I do that. And without a tight corset. So those five minutes on the floor, I adjusted. No denial. Accept the battle that lays ahead.

Waiting for a treatment plan was hard on Ann & I. Now we go forward.

Thanks all for the cards and emails. They mean a lot. I appreciate all y'all have to say.

Love...

Richard

Posted by greenpoet at 09:30AM (-05:00)

February 5, 2010 – Hiccup & Activity Alert!

Friday, February 19, 2010

Yesterday was hiccup day. It started after I gargled. Took the anti-hiccup med and the ‘cups settled down. Ate my lunch. Took a long pull of Gatorade (part of my 2 liter per day requisite) and the hiccups came on strong. Waited an hour and took another med. An hour later (!), they settled down again.

Ann came home from work and I began to swig Orange Gatorade again (I-Man & Sandy must be proud, though if they ever talked politics, it’d be better than a UF-FlaState football game), which led to more hiccups, another med, and another hour of ‘cupping. A side effect of the ‘cup med is drowsiness. And that began to hit me. So I went off to bed and slept like a drunken baby.

My Mom and I have always had this tendency to hiccup when drinking carbonated beverages. You may remember going out to eat with me in the days when I cherished stout. I’d gulp two pints before the food arrived, because mixing food and carbonation led to instant, lasting hiccups. So, here they lie in wait again.

My mantra for today: small sips, tiny gulps, and wait…

At work, we’re repairing freezer floors. The jackhammers’ assault and the removal of large squares of material raise a fog of large particle concrete and insulation dust. Which I need to stay away from. So, I sit at home and I realize I’ve got to get up and move around. Originally, Ann and I decided to wait until the 5FU pump was disconnected on Saturday until I tried a bike ride. Once my head is clearer, I’m attempting a short ride. This afternoon, Rudy & Lacey Dog have vet appointments. I may come along for the ride. The worst thing I can do is sit on my rump or lie down and feel dazed. Geez, I may start feeling sorry for myself and that would even be more worser, might effect my ability to pound these keys. And reflect. Deflect. Object. And objectify. Maybe mentally fry…

Laura, you wondered how well DFCI’s clinicians have prepared me for the treatments. I think they’ve done a good job. Nothing has been sugar coated and nothing has been fearful. It’s what I’ve got to do. I feel trust and care. The hiccups were an unexpected side effect, but I have to expect the unexpected, too. And you said to keep writing if I can bear it. Given the dark source of much of my poetry, how could I not bear? It’s much easier to write from adversary. Happy is tough to express – at least, it feels that way to me. Oh, and the port is working well – thanks, Laura!

Well, off to de-daze de-glaze my brain. My bike awaits. Tomorrow, I can shower (finally) but I can sponge today.

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Ride was good. 12 minutes at normal resistance instead of my daily 36. Tomorrow,

without the 5FU pump, I'll go for 18, then see.
My head is still in a cloud. Chemistry was never my strong suit. Guess the chemo is kicking in. My sweet cousin Arlene warned me that reading might get challenging on chemo. I'm in the midst of a book I normally couldn't put down, Jennifer Egan's "The Invisible Circus", near the denouncement, and must take it, like the Gatorade, in sips. Hopefully, this update is coherent. I'll find out in a couple of weeks!
Love…
Richard
Posted by greenpoet at 09:32AM (-05:00)

February 6, 2010 – Unpump It Up!

Friday, February 19, 2010

Today finishes the first cycle of chemo intake, still have two weeks of chemical activity. Around noon, Ann disconnected my 5FU (yeah, getting lots of jokes that about name) pump. After five days, I'm untethered and can get up and walk without reaching to be certain my shoulder pack is in place. And the big news – a real shower! Shower power! All this activity has stimulated my appetite. Had two Boca Burgers and a can of corn for lunch followed by a nap followed by a bowl of mixed Soy Delicious, Mocha Fudge and Peanut Butter Zig Zag.
Having success with the hiccups. Per doctor's recommendation, I'm taking the anti-cup med preventively rather than in reaction to the start of a two hour bout. So far, so good. Tonight, Jesse & Susan will bring in real food (take-out take-in bring-away from Pho Dakao) for dinner. We'll see if the med is up for the test.
Reading is still tough. In lieu of a novel, I'm reading poetry, or rather the first poem in Karyna MacGlynn's *I Have to Go Back to 1994 and Kill a Girl* – there's a lot of substance in Karyna's couplets. Also reading *Jewish Spiritual Companion for Medical Treatments* brought to me by Rabbi Seth. Spirituality is essential for this recovery and the myriad of approaches in the companion offer perspective and comfort.

Wonderful dinner with Jesse & Susan. Pho Dakao has the best tofu in town (bet you're all salivating now!) After dinner, we watched the ugliest dog contest on Animal Planet. Pabst, a mutt, won, but he seemed pretty cute other than an underbite. Pabst had to face up last year's winner – Rascal (yes, Don) – to take the trophy home.
Only a single hiccup through dinner. But my head is back in the cottonball and it's time for a nap.
Thanks for the call today, Arlene!
Love…
Richard
Posted by greenpoet at 09:33AM (-05:00)

February 7, 2010 – Moderation!

Friday, February 19, 2010

Yesterday, I ate rather optimistically. Ok, I overate and am paying a bit of a price today. Ann went out and got me some hummus cups for lunch and that seems to hit the spot. Still being very careful about the hiccups, so I'm drinking slow and steady, Gatorade and water. Yum!
Dan is visiting. I'm not exactly a ball of energy, so we're watching "MythBusters." They just proved that a 44 cal bullet sized hole in a gas tank trailing fuel will not ignite the tank.

Now, they're trying to see if a car can be destroyed by its sound system. I sense a theme.

It's Super Bowl Sunday. We should have a pool on what time in during game I'll fall asleep. Or pass out.

The dogs are showing their innate intelligence, lying on the hardwood floor, basking in the sun. Maybe I'll join them!

I'm taking the reading down to a more basic level. Zoe sent me a copy of Terry Border's *Bent Objects*, amazing what the man can do with a little wire and assorted stuff: potato chips, toast, gum wrappers, an egg, etc. The constructions mostly accompanied by one line comments, but a few have a HOWTO to make your own, and some have a longer narrative. Haven't lost the plot line yet! (Thanks, Zoe! meets the moment!)

The Super Bowl "pre-game" is on. While I'm waiting for my Cream of Wheat to cool (mmmm supper) I'm taking my queue from Chris Chandler (via newsletter) who is contrasting Katrina to the Haiti earthquake. To be honest, I can't follow Chris and it sounds tack on, so I'll try to read it again next week. To be honest, I won't follow the TV "pre-game" because it's been said and said and said. Maybe if they upgraded the ads earlier in the day? (Nay nay nay.)

Having Dan visit is a lot of fun. For me, anyway. He and Ann can watch me nap between meds. I gotta remember to take my glasses off before sleeping – have a perfect mold of the sidebar behind my ear! Dan introduced us to a new show, "Man vs. Food" – this episode for the Super Bowl was surrounded by a Miami 16" x 4" Cuban sandwich, sliced pork, roasted pork, veggies, and some volcanic looking sauce. Truly big. A challenge for Rosey. Don't think they have the vegan version. Don't think I'd attempt it!

Colt picked to win. Saints the sentimental favorite. America awaits!

Love…

Richard

Posted by greenpoet at 09:34AM (-05:00)

February 8, 2010 – Super Bowl hung-under!

Friday, February 19, 2010

I watched most of the first half of the Super Bowl with Dan & Ann, dozed in bed for the second half but caught (luckily) the big plays. Woke up just in time to see Peyton release the ball on the big interception. Through my cottonball vision, it seems that the celebration for this game is special. We have the humane thread between New Orleans, Katrina, and The Saints. But The Colts, the second place finishers (won't say losers) are exhibiting a lot of class. It must have been such a trial for Peyton to present Drew with the SB MVP trophy, but he did it with commendable poise and sentiment.

I felt a little "bad" (yeah, ridiculous) drifting in and out of the game (sitting up, lying down, etc.) – like I was the lump on the log, the whisper in the room. In dealing with this disease, it's Dan and Adam and Ann who most concern me. It's harder on them in many ways. I remember the feeling of powerlessness during Dad's recent illnesses. Gives me motivation to emulate Dad's courage and grace, to move forward head high.

This morning, I'm being cautious about my food intake. I should be nearing the end of chemo based nausea. Part of the issue is that food tastes weird. *Coffee* – my sweet vice – tastes off. Trying to stay off the anti-hiccup med as long as possible. The med is a knockout drop. Before lunch, I'm going to ride my LifeCycle – Ann is right, I gotta keep pedaling to keep my conditioning level steady; will help the recovery.

Speaking of bikes, Ann & I & Rudy Dog should be down on Sanibel Island this week, February vacation. Instead of zipping my Catrike Trail over the bike paths, I dream of pedaling the island sooner, deeply breathing in the natural musk, watching the birds, bunnies, and creatures. When I lie down, I can close my eyes and find myself lying in the sun near the Gulf, relaxed and refreshed.

Successful 18 minute ride (let's see if I can ramp that up over the next two weeks!) on the LifeCycle followed by a delicious shower. Haven't taken the anti-hiccup med today. Lunch of hummus, bread, and lots of chocolate soy milk. Feeling almost human. Tired but clear. The sun pours into our living room and even though we're not on Sanibel, we can enjoy the sun's warmth and optimism.

We have "Modern Family" on DVR from last week. The show clicks with Ann & I (interesting…) so we'll watch the show and laugh.

Love…

Richard

Posted by greenpoet at 09:35AM (-05:00)

February 9, 2010 – Tuesday Noontime Blues in C

Friday, February 19, 2010

Some days, I'm going feel better than others. Yesterday was a good day. Today, the hiccups returned (but quickly squashed, though I must focus on drinking this afternoon, 'specially that luscious Gatorade.) The side effects of chemo are more apparent. The interior of my mouth is a war zone with the chemo trumping the quick growing tissue – which is the whole idea, right? Taste buds are all askew and even the texture of food is foreign. My stomach is pretty ok, but it does jump about a bit. "Oh the fun we shall have…"

I haven't talked about telling my parents about the cancer. Cancer is no stranger to our family. That said; I felt a need to protect Mom & Dad until I knew enough to answer most primary questions. When there is a health issue with my parents, I find out later, either after it's been dealt with or when long term treatment is necessary. My parents protect me, so I protect them?

While I was at Mass General being tested to determine a diagnosis, my cell phone kept ringing. Dad. I dropped the calls not wanting to start a conversation I couldn't finish. Dad kept calling – I don't randomly miss days at work and he knows that.

Late afternoon, we had a diagnosis and treatment option #1 in hand. Knowing my sister works nearby my parents, I called Renee and asked her if she could meet Ann & I at Mom & Dad's condo. I didn't call my folks, just drove the miles from Boston to Worcester, straight to their door. Renee arrived at the same time, and we all greeted Mom & Dad at once (no, that surprise is not suspicious!) Dad gently noted that he'd been trying to reach me all day. We presented the news and my parents were, as always, strong. Mom alluded to the Snider genes and miscellaneous tumors. Dad told me I'd be fine (and he has been through so much the past five years.) The overall theme was calm. The last thing *they* wanted was to upset me.

Whenever I need to discuss something "big" with Mom & Dad, the conversation teaches me that they've been there, done that. They've been on this earth 30 years longer than I and those years reflect a wealth of experience. And, whatever is going on, they've figured it out, maybe not the details, but the gist.

This morning, I was thinking of Nana Edith who died of cancer in 1965 when I was 12. In all my images, she is smiling, even when she came home from the hospital after massive surgery. I'll carry that smile today and forward. And I think of a trip to MGH with Mom & Dad for Dad's liver biopsy. It was like we were on a family outing. I got me some tough genes in here!

Love…

Richard

Posted by greenpoet at 09:35AM (-05:00)

February 10, 2010 – Magic in the mouthwash

Friday, February 19, 2010

Today marks one week and one day since I began chemo. I'm told that this will be my low energy week. Had intended to ride the LifeCycle for 24 minutes, but my body said "no, 12 minutes." I always have this debate between body and exercise, debate as in the former has no vote. I listen to my body today.

I'm on a second antibiotic because my port got a little puffy. So now my stomach is the staging ground between diverse packs of chemicals. I can tell the winner. Or rather, it tells me. I listen to my body.

Yesterday, I started using "Magic Mouthwash." It's a pretty pink color. I taste Maalox, a hint of lidocaine, and some other subtle delicacies. That is, I taste until I swish and swish and swish. Then my mouth is a heavenly numb, not frozen, rather there and quite usable (though my speech is a bit off if it wasn't off already before any of this started.) I use MM a half hour before meals. It's not taste; it's comfort at this point. I need that protein and those calories.

We have a dusting of snow falling today. Pretty view when I don't have to drive in it.

Ann started Steig Larsson's Millennium trilogy today (*Girl With The Dragon Tattoo* book one.) I'm betting that she'll read all three books by Sunday. It's the first series of books I couldn't put down to exercise – read while on the bike! Such a concept!

Ann saw our friend & dentist Jeff today. Jeff sent me some magic toothpaste and advice to "spit, spit, spit, and then spit some more." I think I can handle that. Note to self: use Magic Mouthwash after magic toothpaste. Spitting with a numb mouth is, well, an adventure! Val, thanks for the wonderful surprise!

Love…

Richard

Posted by greenpoet at 09:37AM (-05:00)

February 11, 2010 – Dr. Deb and the Dana Docs

Friday, February 19, 2010

Last night, I received a phone call from Dr. Deb, our PCP. Deb's first concern was how I was doing emotionally and how I am dealing with chemo and its side effects. We spent most of the call talking about me the person and then moved onto medical matters. We love Deb; she treats the whole person, and in our case, the whole family. I appreciated the phone call, its tone and purpose, the caring expressed, and knowing that Deb is there for Ann & I. People have diverse reasons for choosing a profession. Deb is a highly skilled doctor for all the right reasons.

Last night after a couple of hours sleep, for whatever reasons, I had my worst nausea. Deciding that sitting up would be most prudent; I went into the living room and played with my computer. I caught the night owls on line. I made Marshall laugh. In retrospect, that may have been the beginning of the low point for this chemo cycle. My energy level today is not great, but I'm hoping that tomorrow I'll start ramping up to "regular" activity.

Today, Ann drove me into Dana Farber for my mid-cycle checkup. I've lost a little weight (which they think will come back next week), but my vitals are strong. Saw Dr. A first and we went over my week and adjustments to living with chemo. Dr. H arrived and began to examine my lymph nodes. A smile crept on his face as he said that he could barely feel them! Ok, major boost! The chemo has started doing its job. We still have to finish this chemo cycle, then two more chemo cycles, followed by the seven weeks of radiation treatment. Still a long road ahead and no guarantees, but I can draw on today as we move forward.

As we move forward. Thanks everyone who is on this ride with me. The cards (Amy, your script is so beautiful I almost don't want to open the envelopes!), calls, and little surprises keep me feeling up and my thinking in the right hemisphere. I love and cherish all y'all.

Love…

Richard

Posted by greenpoet at 09:38AM (-05:00)

February 12, 2010 – Turn 'round day

Friday, February 19, 2010

Just a short update today. Feeling stronger, rode the LifeCycle for 18 fluid minutes and crept underneath my shower head for a sensational hot shower.

There is a battle going on and the battlefield is my mouth, tongue, and throat. (I'm spit spit spitting thanks, Jeff.) Which, since the primary tumor is at the base of the tongue, makes a lot of sense. I'm more observer than participant. The cancer has dug in and the chemo is attacking. Like any battle, there is "collateral damage" (oh, I love that phrase) and that damage is wrought on me. I'm not complaining rather stating the facts. The chemo is on my side but it has a distinct and harsh job to do. My doctors have given me a shelf full of potions to ease the pain. I'm learning the best way to use the meds. And you know what, they make me want to nap!

I understand now that during this middle week of the chemo cycle, I need to take a pain med as soon as I wake up. I need to use the big swatter instead of taking incremental steps that lead to the swatter after a couple hours of pain. With the pain, I can't eat or drink and that is bad. I need protein, calories, fluid. Those three are the priority rather than some notion I have that I should avoid the la la land. It's a battle in there and I've got to use the weapons at my disposal. This isn't a boo boo on my throat, it a real tumor.

The sun is shining again today. It's a toasty 29°F here in Worcester. We have a dusting of snow on the ground, just enough to bounce the sunlight up into the trees. No shadows on the pines. Today is peaceful in my backyard and living room.

But there is always a war going on.

Love…

Richard

Posted by greenpoet at 09:39AM (-05:00)

February 13, 2010 – Crock or crack?

Friday, February 19, 2010

It's like I'm a crockpot or something (hopefully, not the third one you got as a wedding/shower/housewarming gift and store next the spiders in the basement, though I'm a fan of spiders.) They set me to the proper temperature, added a couple liters fluid, then a liter Taxotere, a liter of Cisplantin, and then a diuretic before hooking up a 5FU pump for long term seasoning. Wait a day, add a couple more liters of fluid. Take off the pump after five days and move on to advanced seasonings to taste – anti-nausea, anti-hiccup, pain pill and pain wash. Now I simmer. Occasionally, I jump up and down to mix. Then the dogs will cannonball my gut just to be sure it's all bubbling. I've got a chemical stew to brew.

Humans process food in food out as a matter of survival turned pleasure (why else

Vietnamese spring rolls, portabella mushrooms, pizza my way, etc.)? It is a finally tuned miracle. Just now, Dana Farber has repurposed this fine tuned system. Another miracle. I've always believed that science is based on the observation of natural forces and then hopping on for the ride. I'm crockpot runnin' down the road. I'm a crackpot runnin' up that hill.

Lazy day. Larry & Lora are bringing in dinner (Pho Dakao – this is Worcester.) My white cell counts are still low, so we need to stay in and away from crowds. I'm about to take (another) power nap to be ready for the evening. I have wonderful friends. But you know that!

Hey Jonny Loomer – thanks for the new tunes! (Curious ? – hit MyStore) Picking my day up! I now have a strong playlist for my nest chemo session. Boogie with the bags and hoses. The "new" Hendrix will out by then. Who says there aren't many reasons to look forward to chemo?

Love…

Richard

Posted by greenpoet at 09:41AM (-05:00)

Comments

- fluffy February 20, 2010

It never occured to me, Richard, to share my writings when I went through what you are going through; but, I admire that you do. It was (and remains) my writing that helped(s) me to stay focused on the task at hand. (I even writing about a painting as it is forming). I completely understand the need to share this experience with your loved ones who now have intimate knowledge of what this time has been for you, coupled with a close-up look at what courage really is, and good attitude. It's always love that gets us through, that keeps us strong. Have you read Bruce Chatwin's "What am I Doing Here?' Love and Always Wishing You Well Again, Lorna Ritz

- greenpoet February 21, 2010

It didn't occur to me to write about this either and I call myself a poet. My mind was on the cancer and the treatment path. My friend Don White suggested I journal daily with a sense humor and humanity. Don thought it would be good for me and perhaps useful to others riding this roller coaster now and in the future. Don is a mensch. I listened to him. It's also been helpful as far as updating friends and family; far better than answering (or not) many emails. I will check out Chatwin's book.

Thanks for your words and concern. They truly help.

Love...

Richard

February 14, 2010 – Valentines Day Sunshine

Friday, February 19, 2010

Happy Valentines Day, All! Hope your teeth are thick with chocolate, your lips chapped from kisses, and no one in your class stiffed you (at Flagg Street School, we each decorated a paper bag, then counted our one piece and occasional folding valentines. Some of us got stiffed. The lessons learned in 4th grade are different than in

Kindergarten!)

Today is a real treat. Dan arrived around 11:00 am. We've been hanging out, watching The Olympics, eating a bit. I took a break and road the LifeCycle for 18 strong minutes. Dan took that time and visited my parents. Dan's turn to do software support for Papa!

Overall, I'm doing well today: more energy, less pain, longer periods of feeling "normal." My appetite is up, but I'm being careful to eat only small portions. The sun is shining and the dogs are fighting over the popular ball of the moment in the backyard.

Tomorrow is Monday. I hope to be able to go into work for part of Tuesday, Wednesday, and/or Thursday dependent on white blood cell count, energy, and clarity to drive (no meds.)

Thanks all for you notes today. Keep your eyes on the horizon, Bill – I believe in you! That goes for you too Prom Queen. Good luck Laura, got Tuesday on my calendar and in my heart. Talk to you soon!

And thanks for the Sorbet and Whole Soy Co. yummy yogurt!

Love…

Richard

Posted by greenpoet at 09:42AM (-05:00)

February 15, 2010 – Mouth/Throat Pain & Percocet

Friday, February 19, 2010

Back to the battle for Richard's throat, tongue, sinuses, and mouth. I watch The Military Channel on occasion – great planes/dogfights, great commanders, and general history. I imagine now a map of my mouth and throat, with perhaps the tongue playing the part of a pliable river. We see the enemy entrenched at the base of the tongue, forward units in the lymph nodes. The enemy is brilliant on the level of the cell, but its strategy is straightforward. And ongoing. My forces are chemo now with the radiation units saddled up and ready for the next stage. The three types of chemo show its' assault with a different color wave, maybe even a flag standing by each. All three do their job, all three pincer the growths. They have the bad guys in the lymph nodes on the run. The battle for the base of the tongue is in its planning; the radiation commanders drill their troops.

In every battle, there is collateral damage.

I'm dealing with at least three kinds of mouth pain: sores on the lips, cheeks, and other soft tissues; sores on the gums among my teeth; sores on and under my tongue. The sores have a few challenges. There is general pain. There is pain from trauma - even a direct hit by a blueberry skin is no fun. Then there is pain from muscular activity – as in swallowing, talking, and swallowing. The sores on the tongue seem to affect long tissue, the strings that make movement. When they hurt, it's no fun.

I eat a soft diet (scrambled eggs, cream of wheat, hummus, soy yogurt, etc.), but even soft is painful on the tongue. [Note: I now understand the difference in sensation from my throat and tongue. Who'd'a guessed it?] I drink gentle fluids but even a dime of saliva can hurt to swallow (let's not go into spitting - believe me, it's no fun!)

So the primary drug of treatment is Percodet. At its best, I can eat and drink comfortably. At its worst, I eat and pound my fist into my thigh (mature, huh? hey – all those hours on the bike are worth something!) I use Magic Mouthwash topically in between pills, do my rinses, etc. but Percocet makes the difference whether or nor I can eat. However,

When I'm blue, the Percocet makes me feel ok.

When I'm green, the Percocet makes me feel ok.

When my mouth stops hurting and I stop the Percocet, I still feel blue and green. Time to buck up and nap, ride, write, read my way through the blues and greens.

Sometimes good side effects are bad. No problems here. Awareness. Use the drug as it intended. It is a tool. I don't want my chemo soldiers running through the streets in a daze. Except for the victory lap several months from now.

One more lesson cancer has to teach.

I will need a feeding tube for radiation therapy (oh, joy!) Once the frontal assault on the primary tumor (or Mother Ship) begins, swallowing will become very difficult, though it will be important that I keep the muscles working. Chipped ice, I'm guessing. For now, I need to keep the swallowing apparatus functioning full tilt no boogie.

I haven't said this often enough or **LOUD** enough. Ann is a real rock through all this. I'm going to have my bad days and off moods. Ann knows what to say, when I need a buck-up, when I need to rest. She knows me better than I do. Isn't that love? She makes me scrambled eggbeaters whenever I ask. She reads me and fills in the gaps. I can't imagine going through this without her. I can't image going through anything with her. I love her. She's my best friend.

I live in now, day to day, hour to hour. I can't let myself go out farther, not even to next week; that may lead to Overwhelming Street, a neighborhood I must avoid.

Onward Cancer Soldiers!

Love…

Richard

Posted by greenpoet at 09:43AM (-05:00)

February 16, 2010 – Two weeks and to work

Friday, February 19, 2010

I took my chemo dose two weeks ago today, though the 5FU was hooked up for five days. Been though the active chemo, the immediate side effects, and the "working" side effects. Now, I'm experiencing the post side effects which is my favorite stage, at least so far. My appetite is back. I am hungry, eating larger small meals. I lost about 8-9 pounds that the doctors figure I'll put back on this week. Oh boy, you know what that means. Guilt free eating also know as (aka) free range eating. Aka by me. There are odd things. My stomach now speaks a new language. All these years, we've understood each other perfectly and now it speaks Japanese!

It says _“!@#$%^&”_ and I say “Huh? You hungry buddy?” _“)(*%^&*$”_ “Ok, no. Full?” _“)(*%^&*$”_ “Ok, no. Empty?” _“)(*%^&*$”_ “Need to poop?” _“)(*%^&*$”_ “Ok, let's try some more Tums. They have calcium. Calcium is good for bones.” _"#&$$%^&^ ^^$^$ #$%^&*!~”_ “Ok, we'll talk later. Huh? Oh, you'll talk later. I'll listen. Gotcha!”

My next two chemo series start February 25th and March 18th. Then, we're on to radiation prep.

Went into work for 2-3 hours today. Time flies when you're having fun and I was. Good to be back in my office in my chair. My office is the last down the hall, out of traffic, isolated in a sense. Don't worry, Mom & Dad, I stayed a distance from everyone and used lots of Purell. It was fun to hear the laughter, the voices talking, the machines rumbling over the freezer floors. Better to see everyone – Casie is engaged and very excited (well, we all are for her. Young love!) I hoped to complete the financial statement for January, but we made some logistical changes before I left and I spent a good portion of my time hooking up files. I ran all the reports I` need and tomorrow, I can get into the meat of the statement. If need be, I can finish on Thursday.

Cool news – Adam arrives in Boston on Wednesday night. Dan will pick him up at Logan around 10:00 pm. Ad will take a train to Worcester on Thursday. Will be wonderful to see him, wonderful to have the whole family together for a long weekend. Thanks, Ad!

Love…
Richard
Posted by greenpoet at 09:46AM (-05:00)

February 17, 2010 – Haiku Bridge Break

Friday, February 19, 2010

It was Haiku yesterday on the Webster70 listserve, so initiated by the big teddy bear, artful dancer (you want to be on his dance card), and SPAMku kahuna - Oyra.
Oyra sounds:
Alien subdued Fox returns to cold storage
Webster College sighs
I resound:
Round one nears the bell I regroup as alien reels Whose will is stronger?
Oyra responds:
Enjoying his food 1 800 eat veggies Fox is on the town
Sweet Paula, Prom Queen and Renaissance Woman, chimes:
Foxy outfoxes Alien allayed and down Cunning man eats, smiles.

Last night, I had an intense craving for Blue Jeans Pizza's ziti marinara with a nice vegetable salad, balsamic vinaigrette. We called and ordered in two. I ate half my usual portion, which means a regular human portion. (To be fair, while waiting for delivery, I gulped down a soy yogurt and a Boost.) I can't remember pasta tasting this divine. My stomach still confounded me. I think it was happy – for sure full. Maybe I should try alphabet soup.
My sleep cycle, post medications and chemo roller coaster, is still confused. In my prior life, I went to sleep at 9:15 pm and got up at 5:15 am. Last night, as the night before, I tossed and turned a bit, tried a relaxation technique, and though tired, would not sleep. I'm reading a dry memoir, so I tried a couple of chapters. At 11:15, my body finally said, ok, we'll sleep now. I did have a power nap after working yesterday, so today – no nap!
Today I was stronger at work, my focus sharper. I finished all the procedural work on the financial statement and everything looks like it ties. Tomorrow, I'll put the formal reports together, but my confidence level in the numbers is high.
Chemo is an amazing process. The immediate side effects crept up on me and then hit. Last Thursday, during the working side effects, I wondered if and when I'd be able to get back into the world. Today, I feel somewhat normal. My energy level is down, my brain is operating at reduced capacity, but I feel good. Even my stomach seems to be regaining its lingual acuity (shh, don't tell the tummy!) I will ride the bike in an hour or so. Keep moving forward.
Ann & I are planning a three-day getaway during the recovery week of my next chemo treatment. We'll head to Chatham on Cape Cod; ocean views, hopefully warm enough for beach walking. Ann lost her vacation to my treatments, so she'll get a little beach time this way.
Got get-well artwork from Brady and Dilan! Woo-yeah! Thanks, guys!
Thanks Don, for encouraging me to write this. It is good to write daily, no excuses!
Adam arrives tonight!
Love…

Richard
Posted by greenpoet at 09:52AM (-05:00)

February 18, 2010 – Good time for insomnia

Friday, February 19, 2010

First, one more haiku, from BeJae who taught me lyrics are verses that hang out in a bad neighborhood:
Fox to alien: Though grateful for your teachings I will not miss you

Overall, I feel good. I went into work and completed the financial statement for January. My brain seems to be kicking me on all cylinders. The current challenge is insomnia. Generally, I sleep from 9:15 pm to 5:15 am – like clockwork. For whatever reason – oh say all the drugs including the chemo that I've ingested this month and suddenly (happily) stopped – I'm tired at night but don't fall asleep easily. My conventional approaches to inducing sleep are not effective.

The conclusion I reach is that my body is not in a conventional state and I cannot expect conventional techniques to work. I have an uneasy truce with my stomach (until chemo starts next Thursday); likewise my brain and sleep rhythms and I have to get on the same page. I have a relaxation audio to try tonight. If I can't sleep tonight, I'll probably get up and read the memoir I'm crawling through. It is interesting but dry. Three chapters when exhausted leads to sleep. I'm hoping to find a better way.

Adam arrived last night around 11:30 pm. Originally, I thought I would be in deep sleep by then, but it was good time for insomnia. Both wide awake, we sat down and talked. Adam looks wonderful and happy. I'm really looking forward to this weekend with all four of us being together. Dan will drive in after work tomorrow.

My brother Alan brought lunch in for Ann, Ad, & I. It was wonderful to sit, talk, and relax. Lunchtime made the day special. Family and friends reaching out eases the process of the treatments. (Thanks again, Alan!)

For those of you wondering, Lacey now has her tinkle trousers and they are excellent! (http://tinkletrousers.com) They are the perfect solution for a sweet old dog with dementia (can be used on cats too, but good luck with the claws & teeth!)

Love…
Richard
Posted by greenpoet at 09:54AM (-05:00)

February 19, 2010 – Feeling back in the saddle

Friday, February 19, 2010

Managed a decent night's sleep and that feels good. Went to see Psychologist Doug yesterday and we talked about my insomnia. He gave me a relaxation recording, a technique we've used in the past, and it worked well even as my brain fought it.

Woke up hungry and have been eating ever since, lots of mini-meals! My stomach renewed our truce, which is very cool. I am learning to understand my stomach's new language, as it will not learn mine. Fair enough.

Between lunches #2 and #3, I rode the LifeCycle for 24 minutes at my pre-cancer intensity level. I felt good, back in the saddle, loose and easy. Considered (briefly) continuing to my pre-cancer daily time of 36 minutes but deferred for two reasons. One, I may regret it later and I have a sordid history of pushing my PT into extreme. Two, when I told Ann I rode 36 minutes, I would regret it immediately (both the riding & the telling, but the telling is honest.) I rely on her for many things, one of which is being the governor on my exercise engine, another for being smarter and possessing common sense.

With a 24 minute ride, I had adequate time to shave my head. My ideal LifeCycle ride includes: ESPN or NESN on the TV on mute, my iPod playing a mix of new and favorite tracks in random mode, and my razor in my hand shaving head and face (who needs a mirror?) Last week, I stopped shaving my head; when the chemo was in its active phase, the skin on the top of my head thinned out and became too sensitive (my face was fine.) Today's shave felt wonderful. The week's growth slid off smoothly. Hey, one thing about chemo, I get a great head shave! Feels smooth as a baby's bottom with minimal effort! Hooray!

I'm hopeful that the longer workout will trump my insomnia. Pre-cancer treatment, my day began with the LifeCycle at 5:30 am, followed by breakfast, and work. By 9:00 pm, my body was ready to sleep. So, between today and Thursday (next chemo infusion), maybe I can get that slice of life regular. It will make me stronger for the coming treatment, stronger and happier – maybe even my stomach!

Love…

Richard

Posted by greenpoet at 03:13PM (-05:00)

Comments

- Paula	February 19, 2010
Great idea, doing a blog, Foxy, and it looks good, too. So happy to hear you are feeling so energetic and enthusiastic. Thinking of you. Love.	

February 20, 2010 – Challenging time for insomnia

Saturday, February 20, 2010

I thought after a strong bike ride and full day that I would fall into a deep sleep last night. Not so. I guess insomnia will be a way of life until chemo starts up again. I've decided not to fight it. I'll sleep when I can and be sure not to tire myself out. My body is in an unconventional state and I can't expect conventional solutions to work. Like stomach, like sleep. I'm going to ask the doctors whether insomnia is common late in the chemo cycle. Then again, I'm one for the less common side effects.

Sent my friend Rozzy a reply to her email and decided to include it here. Sums up much of what I'm feeling. Rozzy is a spiritual woman, so she brings that piece of me out:

"Cancer is a test of faith. I believe that God put challenges in front of me when I am ready for them whether or not I think I am ready. My perspective has been altered by this disease in a positive way. I am so much more into the moment than ever, humbled by and grateful of all the wonders in my life, and able to face adversity with a grace and courage I never knew I had (but hoped I would.)

Please don't feel sorry for me. I don't feel sorry for me. Life is a package deal. We get our blessings and we get our challenges. That is a comforting balance. Cancer teaches and cancer gives while it takes. I firmly believe that I will be a better human being because of this experience. I will have something of value to share. My dear cousins Arlene and Betsy have fought and are fighting this disease. They are my heroes and my guides. I hope that when I come out the other side, I will serve others as well as they have helped me.

One thing about cancer, you feel the love and support of family and friends in a unique way. That is an indescribable blessing.
My faith tells me that in the end this whole experience will be a gift."

Busy day today – Dan & Adam are here for the weekend, my sister Renee plans to visit this afternoon.
Hey – I'm finally getting the benefit of chemo. I wrote about my smooth shave yesterday. Well, my head is still baby bottom soft! This morning, I discovered another bonus. My wild and wooly eyebrows don't need trimming and I can pluck them oh so easily with my fingers! Wonders never cease!

I had my first outing since the start of chemo. Ann, Dan, & I had lunch at El Basha on Park Avenue, fine Lebanese food. Usually, we just go there for dinner. Dan & I ordered falafel sandwiches ($5.00) and for another $5.00 they added an *El Morocco* salad (full size) and a bowl of lentil soup. Ok, easily two meals for me, so I saved the soup for supper. After lunch, we went to Big Y to pick up a few groceries. Yeah, big fun in the big city! Yeehah!
Love…
Richard

Posted by greenpoet at 02:19PM (-05:00)

Comments

- Stuart February 20, 2010

Everything about your response to your friend Rozzy is inspiring. Thank you for posting it, it's a gift to us. I'm glad that she brings out that piece of you.

- TaDa February 21, 2010

Richard.. I was cruising your blog... have you tried ambien cr... worked for me when I couldn't sleep during my cancer nightmare... (make sure to ask for the CR it is time release... That magic mouthwash was great for me..I am glad you have... towards then end they gave me liquid lortab... You are one of the best places in the United States... When I took ill my father wanted to fly me home to go to the Dana Faber... Time wasn't on my side my dr said... and I stuck with mine here in FL... I love him..

hang in there...

- greenpoet February 21, 2010

Thanks TaDa...

My docs gave me Ativan as a nighttime nausea suppressant and perhaps as a sleep aid. Thursday, I'm going to ask about a symptom specific sleep aid - appreciate the time release Ambien suggestion. Glad you are doing well, to hear your story. Thanks for reaching out. The people - staff and patients - at Dana Farber are wonderful. Feels like we're all members on an exclusive inclusive club!

Richard

February 21, 2010 – Sleep sweet Sleep

Sunday, February 21, 2010

Finally, a full night's sleep! Fell asleep at midnight and didn't get up until 9:39 am! For some reason, I feel different today. Rode the LifeCycle for a steady 24 minutes. Staying strong.

Yesterday, Renee & Marshall came to visit. Renee brought her Particle famous chocolate chip cake and a bunch of Middle Eastern goodies (real food). We had time for conversation and embarrassing stories from my childhood (great future fuel for Adam & Dan.) Not to worry, Eric is coming to visit next week and I'll find a few Renee stories to tell him!

The twenty-one day chemo cycle is a real roller coaster ride. All along, I've felt ready and willing for the next infusion. Today, I feel ready on a different level, Bring It On ready. The difference is that I was willing and able for the next treatment. Now, rested and with a "sweet" week behind me, I'm geared up and ready to roll. One chemo cycle down, two to go!

Radiation looms on the horizon, but it's beyond my vision. Thinking that far ahead is far from productive. I'm confident that I will be Bring It On up and good to go when the time is here.

Grandpa Bill (Ann's Dad) came to visit today and we ordered in from Blue Jeans Pizza, though none of us had pizza! Good to see Bill, first visit since my chemo treatments started. Then, I drove over to my parents' with Rudy Dog. Again, haven't visited with them since the start of my treatment. Daily phone calls keep us close, but being in the same room is incomparable.

Ok, busy day. Time for a nap. Thanks Arlene for the phone call. I always feel so energized after our conversations. You are my hero!

Love…
Richard
Posted by greenpoet at 03:45PM (-05:00)

Comments

- TaDa	February 21, 2010

Glad to see you got some sleep... Attitude is a huge roll in recovery (or at least it was with mine)

February 22, 2010 – Driving on empty

Monday, February 22, 2010

Had another fine night's sleep, especially fine because today was a busy day. A bit after noon, Adam & I left for Boston. Ad's flight back to Denver left from Logan at 2:45 pm and I had a hearing test at Brigham & Women's Hospital at 2:30 pm. Ad and I had time for insightful conversation and music as we navigated The Mass Pike (I-90 for you foreigners.) It's always hard to say goodbye, so we said "see you in March" instead.

I made the drive from Logan to Brigham & Women's with plenty of time to spare. My audiologist is seven months pregnant and very happy (expecting a girl, has a 2.5 year old boy – 3 years is a great gap, we agreed.) The purpose of today's hearing test was to determine whether one of the chemo agents – Cisplantin – has caused any hearing loss. Over the past ??? years, I've lost some of my high frequencies (remember those concerts in college after which our ears would ring for days? I can't forget them now.) After two years of Ann's suggestions (takes me a while to hear sometimes), I tried hearing aids (so I "carry" two more computers daily.) Ann (as usual) was right. I was stubborn. My loss.

Note aside to non-believers: hearing aids work and are worth every penny and every minute adapting to them. Not only can I hear conversations in a crowded room clearly, hear high frequency beeps such as electronic alarms, *I can hear music again*. I never realized what I was missing. One of the first CD's I spun with the hearing aids was Miles Davis' *In A Silent Way*. Tony Williams' drumming was a revelation. Instead of settling (unknown) for the muddy thumps, a full range of tone and pitch assaulted my senses. I could hear the intricacies of the top hat and cymbals. Return of the treble! Then Miles kicked in and took my breath away. Again.

Back to today. I was concerned during the hearing test. The drive into Boston had tired me more than I expected (which was not at all.) I had trouble focusing and concentrating (not to mention staying awake.) But the audiologist came back smiling and told me my hearing was unchanged. Good news. I mentioned the lack of focus, and she joshed "Gee, I can't imagine why." Yeah, Cisplantin and its friends Taxotere and 5FU affect more than just hearing.

As I got ready to drive home, I realized how beat I was. Brigham & Women's has an Au Bon Pain in its lobby, so I stopped for a "snack" – some might say a meal. I felt a bit better. It was still a long ride home and I was so glad to pull into our driveway.

Originally, my second chemo cycle was to start tomorrow, but Dana Farber gave me a two-day vacation by switching my start day for the next two cycles to Thursday. I'm good to go. Will spend the next two days eating and getting stronger. Thursday is Bring It On day.

Rozzy – thanks for the wonderful surprise. Forgot to tell you: Dana Farber has an amazing collection of Red Sox memorabilia spread throughout the facility. Near the 11th Floor phlebotomy room is a photo of Ted Williams taking his first at bat in Massachusetts as a professional ballplayer. It shows him swinging against the backdrop of Fitton Field and Holy Cross College, a mere five-minute walk from my office! It was an exhibition game against the Holy Cross nine. Serendipity.

Love…
Richard

Posted by greenpoet at 06:21PM (-05:00)

Comments

- TaDa February 22, 2010

You go... Your attitude is awesome... I call my hearing aided my "bionic ears".... LOL... I took those two same drugs... I luckyly got my hearing aides through a program here in my county...

February 23, 2010 – Documentation Day

Tuesday, February 23, 2010

If Dana Farber's infusion schedule hadn't changed, I'd be hooked up to the chemo infuser at this moment. They switched the day to Thursday, so I have a two-day vacation. I'm wondering what the cumulative effects of chemo will be. I feel good but not nearly as physically strong as I felt before treatment one. I'm not concerned, more curious. Whatever it will be, I'll take it a day at a time and work my way through it. My guess is that I'll sleep more. I understand how to use the meds and the flow of the twenty-one day cycle. In a couple of weeks, I'll be more than half way through chemotherapy.

Spent most of the morning and some of the afternoon documenting A&D's General Ledger Rollover procedures. My head is clear and I felt in full control of the task. I did the rollover as I documented it. My surprise is how much the concentration took out of me physically. The lunch break really helped get me revved up again. This is a lesson in managing my energy level. I am pleased how concentration trumped fatigue this morning. And I'm pleased how my mind and body bounced back after lunch. It feels wonderful to be productive. It also feels like a nap is in order.

Had another great night's sleep last night. The whole process of the treatments involves learning to make adjustments. I have a new body and the mind/body communication is a foreign language. Understanding that conventional reactions are no longer appropriate, I explore new ways. With the second chemo treatment, I'm sailing more familiar waters, but the weather is unpredictable! Bring It On!

Love…

Richard

Posted by greenpoet at 01:52PM (-05:00)

Comments

- TaDa February 23, 2010

I firmly believe it was my attitude that took me sailing through my chemo and radiation. Don't lose that! And most important ~ everyone's body reacts differently... don't listen to everyone's war stories! (including mine)....I am always available to chit chat.

Laura

- greenpoet February 23, 2010

Thanks, Laura. I have so much to be grateful for in my life. I have an excellent prognosis. So to chemo & radiation, I say Bring It On! I know it won't be easy, but there is balance in all things.

- BeJae February 24, 2010

Hey, cupcake. My money's on you in Round 2. I send you my love and my very best good, strong wishes. Knock 'em dead.

February 24, 2010 – Getting psyched for chemo

Wednesday, February 24, 2010

Had an odd night's sleep. Slept well but my legs and back were bothering me – aching almost like cramps. Woke up at 5:15 am (my pre-cancer treatment daily wakeup time), puttered around until 6:00 am when Ann woke up and then went and rode the LIfeCycle for 24 minutes. My guess was the lack of activity was causing the aching. The bike worked like a charm. Bike, breakfast, and it's time for nap. Good Morning!

Today we're packing up for a two-day trip to Boston's wonderful Longwood Medical Campus. Beth Israel Hospital is around the corner, but the Longwood campus features Dana Farber Cancer Institute, Boston Children's Hospital, and Brigham & Women's Hospital – all connected by bridges, all bright and welcoming. There's even a hotel and food court connected to the campus.

Tomorrow morning, I get some blood drawn (a trip to Dana Farber wouldn't be a trip to Dana Farber without a little blood), see the oncology team, and then head over to the infusion room to start Round Two of chemo. This time, after having near six liters of fluids pumped into me plus a diuretic, I don't need to endure a ride back to Worcester fraught with pit stops. Instead, we'll walk over to the hotel and stay there, which will be far more comfortable. The next morning at DFCI, they'll give me a couple of liters of fluid to flush my system and then we'll be on our way back to Worcester, well rested.

Maybe I'm naive or foolhardy, but I have no anxiety about Thursday's chemo treatment. I understand that I'll have a couple of rough weeks, but I've been there before and came back. I also realize that I started my first chemo treatment stronger physically than I am now and the therapeutic effects are cumulative. The bottom line is chemo is no stranger, rather a friend that has to hurt me to heal me. If I don't fight it and do my best to get along with it (go with the flow in hippie talk) my days will be lighter. A week from now, I may not be so cavalier, but this is how I feel today. Relaxed. Good to go. Bring It On!

Had a visit from nephew Eric today. He is in town on business. We talked music (including his new band and recording project) and film. Then I filled him in on the Sher family, specifically Yussel, an artist in oils and charcoal, and a mentor to me as a young poet. Yus was a beatnik, a denizen of Greenwich Village, and defied convention. Thought it would be good for Eric to be well versed in all the family history!

My back and legs are aching again. Will ask the docs tomorrow what they think. If this is a side effect, it is a late blooming one, though I did have lesser aches when the chemo was doing its most intense work. Then again, I was on painkillers for my mouth, so who knows?

We counted all the meds to determine what refills are needed. I start the steroids tonight. Time to finish the packing. Tomorrow morning, we head to Boston. Onward!

Love…

Richard

Posted by greenpoet at 05:03PM (-05:00)

February 25, 2010 – Dana Farber Kind Of Day

Thursday, February 25, 2010

Good nights sleep last night. Woke up around 6:00 am, wide-awake, and headed to the LifeCycle. Rode a strong 24 minutes – felt real good! Took a shower and chowed down breakfast and my preparatory meds and daily meds. Finished packing up my suitcase, loaded the car, and Ann & I got rolling to Boston. Had an easy ride in, just the usual delays around Newton and the I-95 interchange.

Got my blood work at 10:30 am and saw my doctors around 11:30 pm. My blood work numbers are all good. We discussed tweaking some of the side effect meds. I asked about the pain in my legs and back. They told me that the timing of the pain indicated that the source is likely my bone marrow firing up in overdrive to replace the white blood cells. A Percodet shuts down the pain, so we'll go with that.

Oh, the big news - the cause of the cancer is confirmed to be the HPV virus. The pathology confirmed what the doctors thought. HPV based cancer is slow and does not travel. Very excellent news!

We had lunch at the Dana Farber cafeteria, which has a diverse selection of excellent food. Ann had a chicken breast sandwich and I raided the salad bar: all kinds of beans, dried cranberries, and fresh cut vegetables. After I built my salad, I noticed all the other lunch choices and thought, "Gee, next time I'll look around first!"

Currently, I'm in the infusion room. I'm hooked up to two different liters of fluid and one bag of the first flavor of chemo, Taxotere. Drip, drip, drip. Pee, pee, pee. Well, the chair is incredibly comfortable and they gave me a hot blanket (my favorite part!) Ann is getting refills and a couple of new 'scripts at the Dana Farber pharmacy – then she's going to check us in at the campus' Best Western Hotel. Dan took the afternoon off from work and is here to watch the drip, drip, drip. Well, really to keep us company, which is greatly appreciated. I gave him my iPhone to take a couple of photos so you can all be part of the experience. Don't let the photos fool you (I'm at my least photogenic!), I feel really good. The chemo will start to hit me tomorrow, but right now I feel on top of my game! Hey, Rozzy – how's the cap look? I fit right it here at Dana Farber. You gotta take the walk by the cafeteria – they have an autographed baseball and jersey (including Ted and Yaz) collection beyond peer.

Time to sit and wait and sit. Cisplantin with all its side effects is next, then they'll hook me up to the 5FU pump, give me another liter of fluids and my favorite, the diuretic.

Love…

Richard

Posted by greenpoet at 02:42PM (-05:00)

Comments

- TaDa February 25, 2010

looks like you have a port.. I didn't have that so that is good.. make sure to ask the dr for some stuff for plumbing issues.. If my post bother you let me know and I will let up.... Autographed hat.... I love the red sox ~ Hang in there Richard.. your attitude is amazing !

- greenpoet February 25, 2010

Hi Laura. Yes, I have a port (thankfully, I have lousy veins). I'll go home with a 5FU pump (five day cycle) and Ann is qualified to unhook me, so we plenty of supplies. Dana Farber is Red Sox Nation. I love the Ted & Yaz jerseys! Thanks for writing and for the support.

- BeJae February 26, 2010

Oh, you're far too modest. I think you look quite handsome and distinguished when you're being infused … and it's hard to make a heated bankie look distinguished. You're always taking on the hard jobs.

Absolutely great HPV news! If you gotta have cancer, the slow, stay-in-one-place kind is the kind to have.

These updates are wonderful. Thank you.

- greenpoet February 26, 2010

I love my warm blanky. It makes the day special. The Red Sox cap is a gift from Rozzy who wears the BoSox on his sleeve while living in NJ. Rozzy can handle it. You'd like her, even more (off blog...)

February 26, 2010 – Return of the hiccups

Friday, February 26, 2010

Last evening before I got unhooked from the IV lines but had my 5FU pump attached, I had my first hiccip. So, immediately, it was Bacliphen to the rescue. One pill did the trick (which is good because two makes me punchy and three a zombie) and Dan & I went and had a dinner of pasta & vegetables over penne with a spicy pomodoro sauce preceded by a fresh crispy salad coated with balsamic vinaigrette. I'll be back to all soft food soon, so mealtime is exciting time now! Ann napped in the room while Dan & I ate though our leftovers made a good meal for her. I think these appointments and treatments are harder on Ann than me. The doctors talk to her in peer language, while I get the simplified version. She knows the implications of tests – e.g. my blood work – mere numbers for me (black is good – red is the normally abnormal to abnormal) but hard data to her. Often feels like I have the easy seat. I understand.

With my Dad, I went to his appointments and hospital sessions to support him in his trials. He, in turn, seemed more concerned about me, made the day a field trip, and laughed off all the probes going in here and out there.

Back to the hiccups. We had a wonderful nights' sleep. Separate Queen beds, one for me and my 5FU pump, one for Ann. The room was arranged such that the beds' headboards backed on to perpendicular walls. That helps with snoring, but also my pump's discharge gurgle.

Again, with the hiccups. After waking, stretching, and a good morning kiss, I went over to my dop kit, grabbed my toothbrush and hiccupped. Put down the toothbrush, grabbed a Bacliphen, picked up the toothbrush and hiccupped my way through brushing. Then through dressing and packing. Ann & I headed down for breakfast; we asked for a quiet table away from other diners. These industrial hiccups travel! We ended up in the same booth set back from the corner that Dan & I ate at last night. Kismet (well, maybe.) Half way through breakfast, the hiccups went away! Go Bacliphen, go quick response! It is was timely because breakfast was salty (I need salt – chemo sucks it out of my body) and I was mega-thirsty (I need fluids – chemo needs flushing.) Big breakfast in the tummies, we headed over to the infusion room. I have a corner chair again (oh lucky me!) lots of sunlight. I'm getting two liters this morning, a couple of hours' "work." Then we're off to Worcester where it is (not surprisingly) snowing. I'll pick this up later.

We're back in Worcester. Rudy Dog and Lacey Dog gave us a big greeting. So did Tweety the canary, but he doesn't run to the door. He sings and warbles.

We drove through snow from Boston to Westborough and then, atypically it wasn't snowing in Worcester! What has the weather wrought? No snow or just a dusting in Worcester. Ok, I won't argue. For other than the skiers, this is good news.

What's bad news is the hiccupping started again on the ride home. I'm beginning to think that the Gatorade is exasperating the hiccup response. Gonna email one of the docs and see if water and magnesium & potassium supplements will do the trick. Hey, when I was in high school, they gave us Vitamin-C pills and Salt pills to keep us going. Oh, and Metrucal for lunch to keep us thinning.

Ann & I plan to relax the rest of the day. With the chemicals making their way through my body, I will likely nap (um, pass out) shortly. Hiccups have (for now) faded away. Feels real good!

Thanks everyone for you support and concern.

Love…

Richard

Posted by greenpoet at 01:59PM (-05:00)

February 27, 2010 – The Infusion Room

Saturday, February 27, 2010

Getting started early today. It's 5:14 am and I'm wide-awake. Once home yesterday, I took a couple of Bacliphen an hour apart. They worked, slapped down the hiccups (after an hour and a half), and kicked me into a three-hour nap. A sweet, deep three-hour nap, the kind from which I wake up gently and easily.

Emailed my doc about the hiccups and Gatorade. Gatorade seems to be the trigger. I wondered if I could switch to other liquids and take supplements. He replied very quickly that my magnesium and potassium blood work have been excellent and suggested trying other liquids for now. So far, so good. It's 5:22 am and I'm a thirsty boy.

I haven't been having nausea per se. Last chemo cycle, my stomach did all kinds of weird stuff, talked to me in a foreign language that gave me no clue what I supposed to do. So, I had a two-week tummy ache. Ann suggested that less might be better. So, other than Emend, I'm not taking the anti-nausea meds, which pull my stomach in opposite directions. So now, my stomach says very clearly "I'm hungry. Feed me Boy" and since I understand I can reply "Hang on there for a few more paragraphs, the mind has first spot in the body queue." Stomach says, "Ain't that always the way unless there's a chocolate pudding pie sitting in front of you?" And I say, "Chocolate pudding pie? Where? What you doing to me?" But the mind, ever smarter than the stomach, takes over and takes me back to the Infusion Room.

The chemo treatment is easy, especially with the port. I feel good as the fluids flow in (other than having to pee every 10 minutes) but know the next two weeks will have their challenging days (and hours.) At yesterday's infusion, there was a woman accompanied by her husband in the next chair (shades of the barber shop only with People Magazine instead of comics!) who had a painful time getting a good IV in. Again. Her nurse

suggested a port. Ann talked to her husband and I showed him my dual Power Port, explained how easy it went in (a visit to pre-op, a nice nap, minimal pain afterwards), and that it was in use the next day. Later, on one of my potty breaks, I showed it to the wife and answered her questions. She wasn't looking happy about her IV connection. And agreed that a little nap for a port might be a better solution. So maybe, I returned a favor others have given me as I go when they have been. That means you my fellow riders on this roller coaster, but also my patient partners I meet at the elevators, in infusion chairs next to mine, at the next table in the cafeteria. It is powerful how people endure and battle cancer with such positive and uplifting attitudes. I'm proud to be a member of this club. The secret handshake is a big smile and a warm welcome.
It’s 5:36 am and my stomach has been patient. Time to (quietly) hit the kitchen. Will pick this up later. Dan is coming to visit. Hooray!

Back up at 9:00 am. It’s snowing and all the trees and bushes are dusted. Pretty way to start the day a second time. Feeling up and strong, went and rode the LIfeCycle for 12 minutes. Found a better way to position the 5FU pump so my pedaling and the bag didn’t fight.
Dan is coming to visit this afternoon (repeating myself) as are Jesse & Susan. Afterwards, I’m betting on a nice midday nap. Naps are wonderful. Why did we fight them as kids? Is it a sign of wisdom that we now seek an afternoon sleep? Let’s go with wisdom!
Love…
Richard
Posted by greenpoet at 10:26AM (-05:00)

Comments

- TaDa February 27, 2010

Emend (the three day wonder and all the anti puke drips oh how I remember... Steriods steriods and more ... I was one of the few who gained weight throughout chemo rather than lose.... I can remember leaving the chemo room and beelining straight to DQ...

I am glad you are resting... and staying ontop...

peace

February 28, 2010 – Hey tomorrow is March!

Sunday, February 28, 2010

Yesterday was a fun day. Pam dropped by for a visit, followed by Jesse & Susan. Later Lora came by. Wonderful to have good friends in the house, though I’ve learned from my first ride on the chemo rollercoaster – keep visits short! As much as I’d like to gab all day, even as I’m falling asleep while sitting down, it’s not the best approach to healing. So, Ann has helped me set up reasonable time limits. I am so bad at setting limits on my time with friends and family.
Dan arrived early with a couple of bags of goodies from Whole Foods (Worcester doesn’t rate one) in Cambridge. He & Ann were going to do our regular household shopping, but Dan noticed Ann was tired and volunteered to do it alone. Dan is a rock. We hung around and watched the Olympics, mainly curling.

I’ve become a big curling fan. A couple of months ago, we Netflixed a film called “Men With Brooms”. It’s an independent movie made in (yes) Canada. The film is really fun, a romantic comedy / family drama built around curling. The first sporting event I watched on the chemo coaster was The Super Bowl and I had trouble keeping up with the pace. The Olympics arrive and with it, curling. I’m watching and thinking “hey this is a great sport, it’s like bowling mixed with billiards with chess-like strategy.” The flow of the game was exciting, stone after stone building the tension. Why was everyone else in the room yawning? Turned out that the pace of curling matched my attention span. Kismet!

We had dinner, talked some more, and watched the Men’s Curling Gold Metal Game (Suisse vs. Canada – you know who won, right?) Then Dan and I got caught up in the Four Men Bobsled Team runs – the Team USA “Night Train” sled. Ann went to bed but Dan and I decided I’d stay awake though the final bobsled runs. About this time, I began to feel a little nausea (must have been the end of Olympic curling) for the first time. I waited for it to pass, but after an hour or so, decided to take a couple of meds. The meds worked and I haven’t had nausea since. Less meds I take the better, so long as I take them when I need them! Dan left around 11:00 pm, and I read a bit as I waited for the nausea to pass. Last chemo cycle, I lost my ability to concentrate on the printed page. This time, I’m doing ok, probably a mix of less meds and better tolerance to chemo (we’ll see on this later as the chemo effects ramp up.)

Had a great nights sleep and woke with plenty of energy. While I was drinking a bottle of Boost, I read the ingredients and discovered that Boost has way more potassium and magnesium than Gatorade! Been drinking lots of Boost, especially when my mouth is sore. No wonder my potassium and magnesium levels have been so strong! No mo’ Gatorade - anyone want some?

This afternoon, Ann went to see the musical *Suessical*, starring Jesse & Susan’s daughter Julie. The show was too long for me to consider attending, also too many people while the chemo is pumping. In lieu of the show, I drove to my parents’ home and Rudy Dog & I visited for a (preset time of) half hour. Rudy is so excited when he realizes we’re at my folks’ place. He runs round and round the condo, through every room, greeting Mom & Dad with big doggie grins and a nuzzling head. We had a wonderful visit. Dad & I compared ports. Rudy & I returned home and I took a nap. My brother Alan stopped by with Uno Vegetable Soup, a nice and very welcome surprise (yum!) As soon as Alan headed to our parents’ home, Ann returned from *Suessical*. The musical and Julie were both wonderful, says Ann. It was especially fun for Ann, seeing the baby grown now into a beautiful young woman, putting her verve and personality into the challenging part.

Well, the hiccups are sneaking up on me, so I took a Bacliphen. It is really useful to know that the 5FU is the likely culprit (80.1 ml left on the pump.) The Gold Metal Hockey Game between USA and Canada has just started the third period. My book awaits.

Thanks everyone for your support and inspiration. Arlene, really enjoyed our conversation today. You are my hero!

Love…

Richard

Posted by greenpoet at 05:06PM (-05:00)

March 1, 2010 – Lion or lamb?

Monday, March 01, 2010

Happy March Everyone! It’s a gray day in Worcester, temperatures in the low 40F’s. Despite the gray, the house is bright and I’m feeling good. We learned a lot going through the first chemo cycle as far how to handle the immediate side effects, especially the

meds. But I also have a better handle on my day. Instead of sleeping in, I get up before 7:00 am, have my first breakfast and putter around a bit. The dogs are always anxious for me to have my second breakfast. They get a taste of my Cheerios with banana – but only in the kitchen at the food preparation spot. No food for doggies from the table! (That's why they don't beg, Mom & Dad!)

Mid-morning, I need a nap, and a half hour does the trick. Today, Lacey Dog already had the couch throw pillows spoken for, but let me snuggle in and share them. Dogs make naps sweeter.

I'm still able to read, to concentrate and fully drink in a book. I'm really grateful because I'll take reading over daytime TV (and most nighttime TV) any day. I'm finishing up the novel *Songs For The Butcher's Daughter*, by Peter Manseau, a gift from Burt & Charlotte. It is a magnificent read following lives from The Pale to The Lower East Side and beyond. Plot lines are cleverly intertwined. The characters are complex; their growth and development contribute to the richness of the story.

I'll pause for now. Around 4:00 pm, the 5FU pump will have done its thing and be beeping to be removed. Ann will free up the pump and pull out all the tubes, connectors, and copious sticky stuff that will remove what's left of my chest hair near the port. Chemo cycle #2 intake will be in the books. Onward!

Well, the pump kept a pumping until almost 5:00 pm. Ann just freed me from the tubing, etc. and I can get up and walk around without feeling for the pump. But I know the pump is my friend, so I'll appreciate it even if the 5FU brings me hiccups!

Finished *Songs For The Butcher's Daughter*, which has a poignant and powerful conclusion. The weaving of characters is subtle when it could be overdone. Manseau is a marvelous writer. Will check out his other works. (Thanks again, Burt & Charlotte!)

It's time for dinner #1. My mouth is starting to feel the effects of the chemo; my taste buds are starting to go feral and my tongue is readying itself as a prime battlefield. This is all good, the chemo is doing its work and my job is to be patient and take it a day or an hour at a time. The care at Dana Farber Cancer Institute is the best I've ever experienced. They are treating my disease while caring for me, the whole person. I feel at peace with this whole process.

Love…

Richard

Posted by greenpoet at 05:45PM (-05:00)

Comments

- TaDa March 01, 2010

Hi Richard.. I just cruised your site.. I didn't know you were typing me back...LOL I am new to this..sorry about that..I am glad I was not offending you.. I keep forgetting you are in MA .. I was born in Boston and raised in Weymouth.... The taste buds is a temporary thing while doing chemo ... it gets better quick once you are done..I once was so hungry.. I cooked a whole steak, mashed potatos and corn.. and all I could do was stare at it.. my stomach said yes but my tongue said NO .. and I don't care what anyone says >>> Attitude plays a huge role in treatment...I was the same way bring it on.. this is not beating me... (I had my share of melt downs) but I climbed right back out of them...

Hugs

Laura

- TaDa March 01, 2010

Oh also ment to tell you there is a site called carebridge.com where you can set up an account and it automatically updates your friends and family.... I know you got the blog but you may want to do that to...

Have a good night

- greenpoet March 01, 2010

Thanks, Laura. Appreciate your support and sharing of your experience. It's great to not go through the treatments alone.

March 2, 2010 – Chemo kick

Tuesday, March 02, 2010

Well, this chemo cycle has been pretty gentle until today. The primary side effects, the stuff that means the chemo is doing its task, are kicking in. My taste buds are shot. My stomach is doing turns. I'm tired and feeling yucky (poor baby!) But I have to take this in context. Chemo is no joyride and it has a big job to do. The immediate side effects were a breeze this time, so I'm a little spoiled as the primaries kick in. These not so fun days are part of getting well.

What I don't want to do is lie on the couch and pretend to nap. What I need to do is to keep busy. When I'm busy, my mind is focused away from the side effects. Today, I may go hour-to-hour. I just have to get into the flow of this stage of the treatment and move forward.

This afternoon, I have an appointment with a local oncologist. Dr. Deb feels it's important for me to have someone in town in addition to the doctors in Boston. We always listen to Deb.

A little later: Considered a LifeCycle ride, but my body said NO! so I settled for a 30 minute power nap. Woke up feeling better and had a snack (otherwise known as a mini-meal.) With the oncology appointment coming up, it was time for a shower. Today's shower provided more than the usual entertainment. My favorite part is usually inventorying my hair loss, seeing where the new Chihuahua effect is in place. (I'll leave today's inventory off the blog - ok? no! sorry.) I started soaping up my legs and discovered that I have tube feet. "What are tube feet?" you're probably asking. Well, before this week's infusion, I changed to a heavier weight sock. Apparently with all the hydration I received, the socks were tighter than my legs. From my feet to the top of the sock is a depression in my legs, much more fluid above. It's pretty funny looking. If I wasn't naked and hadn't been running tight on preparation time for the appointment, I might have taken photos of tube feet.

Went to the oncology appointment and arranged to have back up services in town. The doctor is very nice and knows the team who are treating me at Dana Farber. This provides some peace of mind, a ten minute ride instead of an hour plus.
Ok, I just checked my legs again. Still have tube feet! I have no shame. Here they are captured by the brilliance of my iPhone's camera:
Enough for today. I'm feeling much better now. I needed to adjust to the chemo up-ramping and doing its work. Thanks as always for your concern and support.
Love…
Richard
Posted by greenpoet at 05:16PM (-05:00)

Comments

- TaDa March 02, 2010

Hmmm I don't remember the fluid thing...My feet were always stone cold when the neuropathy hit.. There are additional meds they can give you to take whenever outside of Emend for the ick...Don't be afraid to ask. I also use to go in on off weeks to be pumped up via IV of just fluids..(that was only when I felt complete ick and it worked)..That is awesome the local Dr. (sike) ..Richard, remember your blood levels are in a whirl wind so don't be afraid to flop on that couch, it is your body telling you need it..

You are going to come through this with flying colors..

On a note of boredom... I was on a lot of meds through my treatment and found it hard to focus on like a book but puzzles occupied my mind and I would sit for hours and my kids would join in... just thought to share..

Night

- greenpoet March 02, 2010

My stomach is overall good - nausea is not a problem thankfully. Just the first day of the chemo primary effects hitting. This chemo cycle, I can read without a problem, for which I'm grateful. Thanks for the suggestions and concern.

'Night...

Richard

- BeJae March 03, 2010

Tube feet! They're so cute. Everybody's gonna want em. Okay, I gotta go drink some water and buy a pair of tight socks.

- greenpoet March 03, 2010

The recipe is 6-7 liters of IV fluid over 18 hours. You can press guitar chord shapes into the bulge that slowly fade away!

- BeJae March 04, 2010

I like the idea of being able to observe guitar chords on my legs. It's probably the only way I could learn some of those jazz chord shapes. If the students at Burklee find out about this ...

- greenpoet March 04, 2010

Berklee is on the other side of town. Dana Farber is short walking distance to Fenway Park. I dunno know what that means!

March 3, 2010 – Riding the chemo chimp

Wednesday, March 03, 2010

Had an excellent night's sleep and woke up somewhat energetic. Had breakfast #1 and after being followed and cajoled by the dogs, breakfast #2 (those doggies are focused on their morning Cheerio and banana slice and are not shy about it! I don't buy it when they say that they're concerned that I'm not eating enough.) I considered a LifeCycle ride but my body is still arguing against it and my job now is to listen carefully to my body. Though I feel good, I'm tired; find the occasional half hour power nap effective.

The chemo's primary effects are hitting my mouth. I can still eat without pain, though food has little taste, or even worse, an unpleasant non-taste. The mouth sores are on the rise plus the gum and cheek tissue are breaking down. I gargle with salt water at least four times a day. This past gargle woke me up! The salt found grooves and decided to oppose being rinsed. Nice burn! Be time to start with Magic Mouthwash soon. This is the week the chemo does its work and I wait patiently, the body being renovated.

I still have to shave my face, but less often, less area, and less growth (there has to be a bonus somewhere.) The top of my head continually feels like I shaved that morning, you know 5:00 shadow or maybe brush in this case (bonus cashed in.)

Tomorrow, Ann & I go into Dana Farber for my mid chemo treatment checkup. I'm curious as to whether they can determine any cumulative impact.

John & Wendy, thanks for the fine surprise in today's mail And thanks for the cards that came in the mail. Today was a mail haul.

Love…

Richard

Posted by greenpoet at 03:55PM (-05:00)

Comments

- BeJae March 04, 2010

So, when your taste buds are acting all funny like this, do you still want to eat or do you have to make yourself do it? Has this process changed how you think about food?

Glad you're otherwise feeling pretty good with this second round.

- greenpoet March 04, 2010

My stomach tells me I want to eat so I eat. If it were up to my taste buds, I'd skip meals. The odd thing is that some of my favorite foods gross me out (even the thought of them.) I drop ~10 pounds during the primary chemo week, but put it back during the sweet week (the next one) when I am constantly craving food and my body is rebuilding.

Vegan chocolate pudding works wonders!

- BeJae March 04, 2010

I'll bet vegan chocolate pudding works wonders for a whole lot of things.

- greenpoet March 04, 2010

Some I can't mention here.

March 4, 2010 – Dana Farber Rumba

Thursday, March 04, 2010

Ann & I went to Dana Farber Cancer Institute today for my mid-chemo cycle appointment. Ann drove and I had the ever so important job of napping both ways.

We met first with the Hematology/Oncology Fellow and then with the team leader, an Oncologist. We reviewed this treatment cycle, which is going easier than the first. I found out that my fatigue is cumulative as the cycles progress. I start each with less (but more than sufficient) strength than the one before. I keep urging myself to get on the LifeCycle, while my body says I need rest. I'll continue to listen to my body. Pre-cancer, I wouldn't accept any excuse for missing a daily ride. I think I finally have it into my head that this is different (silly boy!)

When the oncologist examined my lymph nodes, he raised a big smile. Before treatment began, I had five nodes affected with one especially prominent. Now, even knowing where they were, he can't feel the nodes. Good news! The chemo is doing its thing! I took my first Percocet of this cycle on the way home from Boston. Last cycle, I waited too long and it affected my eating ability (pounding my fist into my thigh is not a recommended form of pain management.) Came home and ate a sumptuous lunch of Whole Soy Peach-Mango soy yogurt, a Boca Burger on toast, a glass of Vanilla Silk, and a vegan chocolate pudding (I bet all your mouths are watering now!) After lunch, Rudy Dog curled up next to me and we took a long nap. Amazing how quickly his snuggles will send me into dreamland.

Side note: if you've never had Whole Soy products, find them! An absolutely superior soy yogurt product. They have frozen desserts, too, which I plan to check out asap.

So, today I feel strong, rested (you think?), and in a Bring It On attitude. Next Wednesday, we meet with the radiologist to map out those treatments. This whole process could feel long. My plan is to take it one day at a time. Days pile up and here I am halfway through the chemo. Life is good!

Love…

Richard

Posted by greenpoet at 04:03PM (-05:00)

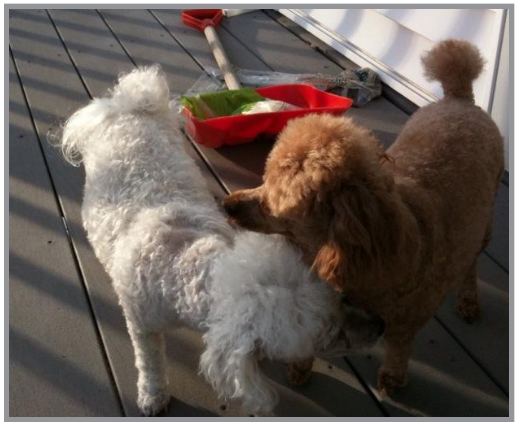
Comments

- TaDa March 04, 2010

Richard... A big "High Five" to you!

March 5, 2010 – Riding the chemo coaster

Friday, March 05, 2010



If this chemo cycle matches the last, today and tomorrow will be the nadir days. My mouth doesn't feel as beat up this time, but I'm also using the meds more prudently. Eating has become a challenge, but I have a wider variety of soft foods from which to choose. I am taking Percocet preventively, which works well for pain management, but also makes me sleepy. My plan is not to sleep the day away. Between lunches #1 and #2, I will try to get hooked up in my current book, *What Am I Doing Here* by Bruce Chatwin. The book is a diverse collection of off beat memoirs and essays. It's perfect, given my current short attention span and brain in a cottonball, that each missive stands alone. Ann is going to stop by our local library today and pick up a couple of books I have on reserve. I'm enjoying Chatwin, but am looking to getting my teeth into a good novel.

Today, it's just Tweety the canary and me at home. Rudy & Lacey Dogs are getting their new Spring 'dos. It snowed heavily on the day of their last appointment, so they are overdue for a bath and a cut. They left the house as big puffs. They'll return with slick stylish cuts. I'll try to get a photo or two. Tweety is good company. We have scintillating conversations such as "Good Morning!" "Tweet! (Repeat a half dozen times.) Then I walk away and he sets off on a long, complex warble. Tweety has a fluid sense of composition mixing harmonies (yes, dual voices), a bit of syncopation, and avian sensibilities.

Overall, I am having much less discomfort and pain on this cycle as compared to the first. The body is truly amazing and adaptive. The interior of my mouth is showing the collateral damage from the chemo – could be that's the same as before or maybe just not new and as noteworthy.

Finished Chatwin and will return to the world of fiction with Jess Walter's *Citizen Vince*.
It's a beautiful afternoon, sunny with temperatures in the high forties. Ann is back from her appointments; the doggies are still getting groomed. The sun bathing through the window, glistening off the wood floor makes the living room shine. It is very peaceful in the house just now.

Doggies are home and in constant motion. It's a lot of still life being groomed. Lacey is busy knocking every pillow off every couch and chair. Rudy is flipping his ball and chasing it. So getting them calm for a photo is not going to happen. I did take this quick snap of them on the deck.

It's been a great day given where I think I am in the chemo cycle. Tomorrow in theory should be the low point. I'm ready to keep moving forward. Thanks everyone.

Love…

Richard

Posted by greenpoet at 04:50PM (-05:00)

March 6, 2010 – Dreamscapes

Saturday, March 06, 2010

If the rhythm of this cycle matches the last cycle, today should be the nadir. Slept very well last night. Woke up around 8:00 am and grabbed a Boost as breakfast #1. Found swallowing a painful undertaking, so I took a Percocet and swigged with Magic Mouthwash. I waited a while and tried a soy yogurt and a pudding cup. Got them down, but not easily. Did a few chores (keep busy!) around the house, and checked my email. During the primary effects of the chemo, this start of my day, from waking up until my first nap, is most challenging. I feel the effects of the nighttime meds wearing down as a mix of dizziness and emptiness. The morning pain meds are in my system, but haven't kicked in. After a couple of hours of milling in place, I lie down and take a deep nap. When I wake up, I am refreshed and comfortable.

Today, the temperature is nearing 50F degrees and the sky is deep blue sunny. Ann & I hung out on the deck while the dogs ran around the yard. I love the way the air smells while Spring is in its early stages.

Just now, I'm typing away while trying to stay awake (though recording my real-time dreams could be interesting.) I have Adam Torres' *Nostra Nova* (thanks John & Wendy) playing on the stereo. The sun is pouring in over my left shoulder. My eyelids are too heavy. I think it's time for a nap.

Naps are delicious. They come in all flavors and don't hurt to swallow. If I'm lucky, I have a dog as a guide. Feel rested and refreshed.

Given the level of need for pain meds, I have to put my book away. It's a fine book. I'm enjoying the plot as it ramps up and the characters as their secrets and history unravel. It is not fair to the author if I fall asleep every few pages and forget crucial details. So, I'll let music and video take center stage.

The late afternoon sky is cloudy but friendly. I'm feeling very well for this stage of the chemo cycle. I'm curious to see if I start gaining strength tomorrow. Tomorrow is another day. I'm enjoying today.

Love…

Richard

Posted by greenpoet at 05:25PM (-05:00)

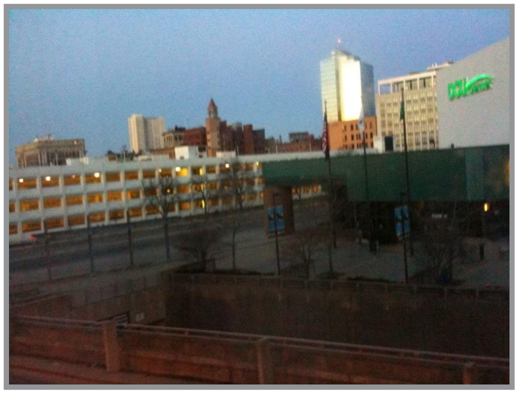
Comments

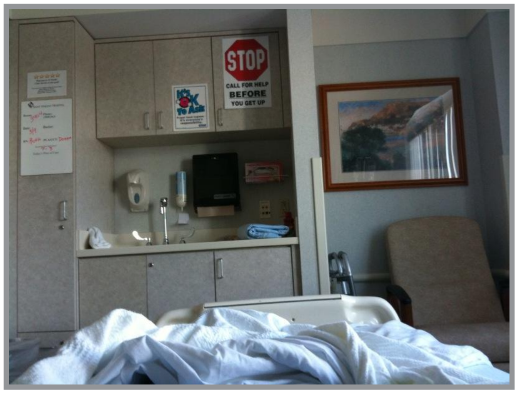
- TaDa March 06, 2010

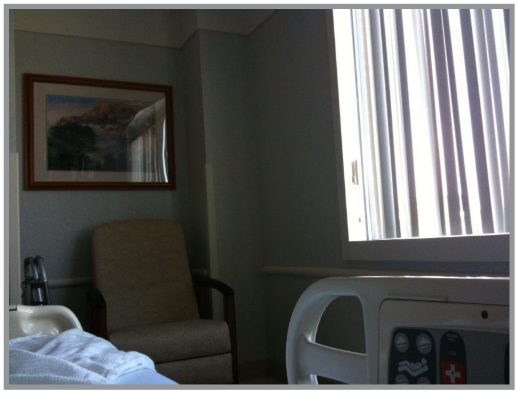
I hope you have a great Sunday!

March 7-9, 2010 – Would I disappear on you?

Tuesday, March 09, 2010







I haven't posted for a few days. Really, I had a good reason. Woke up Sunday morning, feeling weak with a temperature of 100.4F. (Note aside: don't get sick on a Sunday morning.) During this stretch of the chemo cycle, my white blood cell count goes down to nil and any infection is serious. The line in the sand is a body temperature of 100.5F. I didn't want to quibble over a tenth. We talked to the doctors in Boston and the doctors in Worcester, and it was decided that going to the ER at Worcester's St. Vincent's Hospital made the most sense.

We processed through to a room in the ER where they accessed my port and drew tube after tube of blood, had me pee in a cup, and took a chest x-ray. I saw the Emergency Medicine doc, he asked the standard questions, poked and prodded, got my white blood cell counts, and determined that I should be admitted. I was given a really nice single room, very sunny and bright. Looking out my window, I could see the DCU Center, Worcester's arena where Carrie Underwood, Michael Buble, and The Worcester Sharks (AHL) will all be playing this month.

A view of DCU Center from my window, Monday at 6:00 am: A parade of doctors saw me, from Internal Medicine to Infectious Diseases to Oncology. A regimen of IV antibiotics was prescribed, some once or twice a day, others on intervals – like every 8 hours. They also scheduled diagnostic tests.

What I didn't understand is that the hospital is a late night scene. It was a good thing I brought my iPhone and plenty of music! The 3:00 pm – 11:00 pm shift would race around getting the station buttoned down for the late night rockers of 11:00 pm – 07:00 am. I was ready for sleep at 10:00 pm, but why go to sleep when my vital signs would be taken at 11:15 pm, followed a late night cocktail at 11:30 pm – one of the antibiotic IV's? Then it was catnap time, stretches of yummy sleep punctuated with blood drawings, medications IV and oral, and more vital signs. The bed was comfortable, the staff friendly and in good humor. I had a light show from the DCU Center's multiple advertising boards. The late night nurse would also cruise the rooms, checking on her charges every hour. I discovered that IV's and iTunes go remarkably well together. A little Lee Rocker mixes well with IV's; hey they both are medicine!

I got to like my room, especially when the afternoon sun poured in.

What was the outcome of this three-day, two-night vacation? The antibiotics got the infection under control. The medicine injected into the skin of my stomach woke my bone marrow early and they produced white blood cells. And I have even more meds to take over the next 10 days. I may need a second shoebox to hold them all!

The cause of the infection is still "to be determined." All the tests were negative. It's not unlikely that we won't know the cause. When the white blood cell count hits nil, bacteria have an open court to play on. On Thursday, I have an appointment with Dr. S., the local oncologist Dr. Deb referred me to. I have a lesion (doc talk for boo-boo) on the fleshy part of my right hip. It's one of those skin things I take as commonplace as a 57 year male. Normally, my immune system would take care of it without me even noticing. But on chemo, my body is unconventional. With nil white blood cell count, the lesion doesn't even raise puss. By Thursday, there will enough to sample with a syringe. Dr. S. feels the lesion may be the cause of all this. Throughout this whole incident, Dr. S. was stellar, not only his medical talents, but also the way his calmness and understated competence made me feel in good hands. Thanks, Dr. S., for everything.

Tomorrow, Ann & I will head to Dana Farber to meet with the radiologist. I imagine we'll review the details of 35 treatments, and what we have to do get ready. In between, there is one more chemo treatment, but we're moving forward day by day.

Thanks everyone for your calls and emails. It will take me a while to answer. I'm tired from my "vacation." This cycle has shown the chemo is cumulative and my mouth, though better today, is still quite sore; my tongue is still a mess. I had my low point of the cycle in hospital (oh, fun getting bland food that I could eat without chewing – will spare you the food chronicles!) but each day going forward will be better. Soon, I'll be eating mass quantities in a guiltless fashion.

Ok, time for a power nap. Thanks, all y'all for your love and support.

Love…

Richard

Posted by greenpoet at 05:03PM (-05:00)

Comments

- TaDa March 09, 2010

well that sucks...! You need to get some gloves and masks to avoid the germs... especially in this weather and your white cells down.... take care... rest..

March 10, 2010 – A bit of advice…

Wednesday, March 10, 2010

Slept like a log last night. My hospital vacation took a lot out of me. Woke up still tired and in a blue mood. The oral antibiotics I started after leaving the hospital were doing a number on my stomach, already compromised from the chemo.

Ann & I headed to Boston and Dana Farber to meet with the radiologist. He gave us more details on the preparation for the treatments and walked us through the chronology of the seven weeks.

We returned to Worcester and had a quick late lunch. Then, we went to an appointment at Dr. S.'s office (the Worcester oncologist.) We met with his Physician's Assistant. They took blood to check my white blood cell levels (9.5 = excellent for today) and gave me a liter of fluids to hydrate me. I feel good after hydration. The PA consulted with Dr S. who was out of town. He eliminated the oral antibiotics and just the thought of not taking them (and enduring their side effects for the next six days) gave me a real boost. By tomorrow, my digestive system will be back to chemo normal. I'm a much happier camper. I really like the team at Dr. S.'s office. They are friendly, warm, and more than competent clinicians. It's wonderful to have them around the corner.

Ok, now for my advice. Without going into great detail, a member of the hospital's medical staff, a Hospitologist, was assigned as lead doctor for my care. She consulted an Infectious Diseases specialist, and we added Dr. S. as an oncologist consult. We could not get Dr. S. changed to the primary due to hospital policy. My body is not a conventional body while undergoing chemotherapy, especially my immune and digestive systems. So here are my words of advice: if you need to go to the hospital due to a fever, be certain your oncologist is assigned as your lead and primary doctor.

Tomorrow, we see Dr. S. He will take a sample of the lesion on my hip. He thinks the lesion in conjunction with my low white blood cell count caused the infection. It will be good to know.

I'm not returning email yet. My focus on the coming days is to get stronger. Next and final round of chemo starts March 18th. I'm waiting for that luscious feeling of hunger for every food in sight. My goal will be to get weight back on and ingest a lot of protein. Such fun!

Love…

Richard

Posted by greenpoet at 06:44PM (-05:00)

March 11, 2010 – Truce with morning blues

Thursday, March 11, 2010

Post hospital vacation, I've woken up with a serious case of the blues. Like everything else during chemo, it's an unconventional blues, one in a foreign language. If I were to sing it (now there's a really scary thought), it would be in the key of C# minor. I can't find this blues on any color map.

I just feel it, the combination of fatigue and emotional release, of the slow bounce from nadir point to hunger. I feel it. I can't let it control my day.

So, I have devised a truce with the morning blues. I wake up and wash up, muddle into the kitchen to grab a vanilla Boost that I drink while checking my email and favorite sites. At this point, I want nothing more than to lie down and let the blues shake me back to sleep, sleep at this point I need less than activity. Instead, I keep busy. This morning I wrote for while, made a double portion of Cream of Wheat and let it cool while I emptied the dishwasher. I ate my Cream of Wheat and the blues faded. I leashed Rudy and Lacey Dog up and we took a walk. We were going at a nice pace until it started to rain on the loop back home. Lacey Dog, she loves the light rain and slowed to smell each clover (well, not clover, but let's say it was.) She and I had a conversation about our walking pace and she agreed to pick it back up. We returned home and I laid down for a power nap. I rested for twenty minutes or so, but even with the excellent help of Rudy Dog snuggled into the crook of my arm, I didn't sleep. I felt a little tired, but not fatigued. Ann arrived home from work; naptime was over.

After lunch, we headed over to Dr. S.'s office. First Dr. S. examined the lesion on my hip, which he now terms a "big pimple." I love medspeak. He decided to drain it and send the puss out to be cultured. As he thought, with white blood cell count up, the pimple had grown significantly. A little cut with small scalpel, a little gathering of liquid, a bit of expression, and it was done. It looked much better. Then, we went to the infusion room and I got a liter of fluid to perk me up a bit. Fluids are a big help in my recovery from the hospital vacation. And I especially want to feel good for tomorrow and the weekend.

Tomorrow, we're going to Chatham on Cape Cod for a three-day break. Cancer took away our February vacation; this will be a nice pause in midst of the treatments. On the way to the Inn, we'll meet up with Lynne & Alan for lunch. The weather is predicted as rainy and windy, but the weather on the Cape is volatile. Hopefully, we'll have clear skies for a couple of beach walks. At the very least, we can sit front of the roaring fireplace in the lounge. I'm really happy that Ann will get this change of pace.

Deb just dropped by with butternut squash soup with pureed organic vegetables, a real treat – thanks, Deb!

Congrats on your book being published, Rozzy! You go, woman!

I feel a good kind of tired tonight, tired not fatigued. Thanks everyone for your support and kind wishes.

Love…

Richard

Posted by greenpoet at 06:06PM (-05:00)

Comments

- TaDa

March 11, 2010

I love cream of wheat... have a great trip to the Cape... My family and I are planning a trip home to MA in May ... the Cape is on the agenda.. a friend works for the ferry to the Islands and is scoring us some passes for the Vineyard for free...

Enjoy!

- Libby

March 11, 2010

I'm so glad you'll have a break, stormy weather or not. Thanks for sharing that when the blues came to get you, you took it in stride. I'm impressed that you could step out of it far enough to ask "What do I need?" and do that.

You continue to be a warm, shining light in my world. Thanks for sharing yourself!

-Libby

- BeJae

March 11, 2010

C# minor is one of my favorite keys. It's the relative minor of E, one of the best keys for blues. Blues is music about hard times, but it's also music that gets you through those hard times. As usual, you're doing just the right thing in just the right way.

I had the blues so bad one time
It put my face in a permanent frown
But, I'm feelin' so much better
I could cakewalk into town.
(Taj Mahal)

March 12, 2010 – Time to call myself out!

Friday, March 12, 2010

Last night into this morning, I had what I hope was the final assault from the oral antibiotics prescribed by the Hospitalogist (don't you love the age of specialization?) My stomach is compromised as it is from chemo, adding in the oral antibiotics was just too much. So let's just say that Imodium was added to the mix, Imodium and lots of water.

We waited to see how the morning went, but at 10:00 am, we decided that the best course of action was to postpone the Cape Cod trip until next month. We were looking forward to seeing Lynne & Alan at lunch and having the weekend by the ocean. But my body is calling the shots.

I ended yesterday feeling very up – tired but feeling like I was headed into a sweet week of guiltless eating and feeling pretty normal. This morning I woke without the blues of the past two mornings, but with my stomach dominating my mood. I napped and drank water, got up and had some white toast, napped some more. So, ok, I was well rested and hydrated, but in a funk. And a funk is not good for someone undergoing chemotherapy. It's not good for anyone. I am the only one who is control of my mood. It is my responsibility to call myself out. I must keep stay positive and keep a tummy ache in perspective. Instead of worrying about how I will feel for next Thursday's chemo treatment, I have to keep my head into today, into this hour if necessary. You, my friends and family, help me stay positive, give me support I can draw on when I start to slip. But it is me who must stay strong and not let myself lose perspective.

I'll finish this later. It's a nice day. I'll take Lacey for a walk.

Lacey and I took our normal "short" route, a half hour loop through the neighborhoods. It's a brisk day and when the wind blows, chilly. I've been away from the freezers for too long.

I feel better. Instead of sitting on the couch thinking about my tummy ache, I have to be doing, keeping busy. The lesson from today is to call myself out when I start feeling sorry for myself. I have some challenges lying ahead over the next four months. But I have an excellent prognosis, world-class doctors at a world-class treatment facility (the radiation machine at DFCI is the only one of its kind), and superb local medical support.

Even more, I have the love, support, and inspiration from you – my friends and family. I have so much to be grateful for in my life. That is my focus.

Love…

Richard

Posted by greenpoet at 04:15PM (-05:00)

March 13, 2010 – Grey day Spring rain

Saturday, March 13, 2010

It's one of those New England March days, grey skies and rain, that makes it hard to get going. The whole day suggests a nap. It's the time when hibernation ends, so perhaps today is the precursor. Tomorrow, we are expecting the heaviest rains in six years or so, three to six inches predicted.

Having a good day overall. Seems my stomach is stabilizing, not quite there yet, but close. I'm ready for a big plate of penne pasta with pomodoro sauce. Not sure my body is, but maybe we'll find out tonight.

Woke up this morning feeling good. Had a Boost and checked email and my favorite sites. Did a bit of writing and puttered around the house. Made a double portion of Cream of Wheat for breakfast and drank a second bottle of water. Ann woke up from an early morning nap (dogs get up at 6:00 am so does Ann) and we watched a bit of television. We lounged in the grey light and rain, reading, watching, and talking. Then Rudy Dog curled up next to me on the sofa and I was fast into a deep power nap. Rudy is so good at that!

Woke up a little before noon, a few minutes before Dan arrived for a visit. We sat around and talked about our weeks past and coming. Dan is supposed to run in a race tomorrow and we wonder whether the rain will cancel the event. This is New England. Unless the course is over grass and soft ground (instead of road surface), my guess is that it will be on.

Rabbi Seth stopped by for a visit around 1:00 pm. It's always a pleasure to see him. Spirituality is important while facing cancer. Faith is intertwined with the challenges of chemo treatment. We talked about our families. Rabbi Seth has known Dan & Adam since they were toddlers, watched them grow through bar mitzvah years to college and into adulthood. Our conversation also touched the nature of illness and its effect on the person; how attitude, outlook, and perseverance affect the long road of healing. I talked about the infusion room and how it is a positive and inspiring place. We're all getting chemo pumped in but most everyone greets me with a smile and kind word. Visits from Rabbi Seth boost my mood.

I'm going to plunge back into my current book, Jess Walter's *Citizen Vince*. Ann is napping (told you, it is a nap day) but my body doesn't feel tired. Thought it was but it said "just fooling – go and get busy, boy."

Thanks Cousins Betsy and Arlene for your emails reminding me that I shouldn't expect to be in a good mood everyday. In regular (that would be pre-cancer treatment) times, I have up and down days. Am I expecting to have all up days as I go through chemo? Talk about unrealistic expectations! But I do need to be aware of what's going on emotionally, not feel sorry for myself, let myself feel sad and allow the emotions to work themselves out.

Ann's up and we're ordering in pasta pomodoro. It's a litmus test for my stomach. If all goes well (and it should), I can start eating with more variety and abandon. I need to put some weight on between now and Thursday.

Thanks all for your love and support. I draw on your strength.

Love…

Richard

Posted by greenpoet at 05:35PM (-05:00)

Comments

- BeJae March 14, 2010

What are your favorite internet sites, the ones you check when you wake up?

You say that you draw on our strength. I draw on yours. You inspire me every day.

- greenpoet March 14, 2010

ok, wake up stuff... slashdot.org, Boston Globe, New York Times, imdb.com, Sandbox (http://gocomics.typepad.com/the_sandbox), Facebook, espn.com, All About Jazz for today's sample (http://www.allaboutjazz.com/php/jazzdownloads.php), Worcester Public Library to check on my books. From there, whatever grabs my eyes...

Thanks for being here with me, BeJae!

March 14, 2010 – Visiting day (or is it visited?)

Sunday, March 14, 2010

It's been a quiet Sunday. The rain did come as predicted, but either I slept through the worst of it, or we had a lot less than anticipated. Dan did run in the race this morning. Though it was real wet in Boston, most of the five thousand runners who signed up showed and ran. Amazing!

We spent most of the day puttering around. Overall, I'm feeling much better. Imodium will be part of my life for the foreseeable future but that is under control. The day was punctuated by naps and visits.

Ann's Dad Bill and his friend Mary stopped by. This is the first time I've met Mary and the first time Ann & I have met them as a couple. They are very cute together. We're delighted that they have each other. Life is best lived with your best friend locked in step.

After an interim nap, my Mom & Dad came by to say hello. Mom's back has been bothering her, so the visit was all the more appreciated. Dad likes to watch the Celtics games, so we that be the backdrop.

Throughout both visits, we were serenaded by our canary Sweetie who is quite the singer. Rudy and Lacey Dogs were excited that everyone came to visit them.

I'm trying to push calories today. These are sort of interim days. The second chemo cycle winds down. Thursday the third starts up. Though each cycle has its own peculiar challenges, I know what to expect. Hopefully, what we've learned from the first two cycles will help us through the third.

Tomorrow afternoon, I head into Boston for a hearing test. One agent in my chemo cocktail, Cisplantin, can cause hearing loss. So far, my hearing has been unchanged. The team at Dana Farber wants one more test to be on the safe side.

So, a lazy day. Hope the rain was reasonable wherever you are. Thanks for being you, for your support, and comfort.

Love…

Richard

Posted by greenpoet at 05:41PM (-04:00)

Comments

- BeJae March 14, 2010

It was gray here today, too, and a little rainy … Not at all unusual for winter in Columbus. But, I've noticed new growth around the stems of last year's sleeping plants. It happened so suddenly.

Jackie and I played last night. We had an amazing guitar player sit in with us. His name is Jim Volk and he's worth looking for between slashdot.org and Facebook. (I turned Jackie on to Slashdot after you mentioned it … News for nerds is definitely right up her wake-up alley.) Today, Jackie and I have what's termed "gig hangover." Neither of us wanted to do much of anything. We lay around, blissful and lazy, ignoring all the projects that wanted attention. Ah.

Here's wishing you lots of delicious, guiltless calories. They're your job right now, after all.

Love to you, my friend.

- greenpoet March 15, 2010

Ah, bless you BeJae! Here I am tired but with insomnia (seems my typical night during week 3 of the chemo cycle) and I turn on the computer and find a note from you. Makes the insomnia worth every minute!

It's still raining here. For the past hour, I listened to the water rush the gutters and the sump pump in the basement below the bedroom purr into action every 20 seconds or so.

The rain's metronome.

Jim Volk - http://www.jimvolk.com/ - will check him out when I can make noise later today. Sounds like an energizing and enveloping gig. Glad you're finding music community in Ohio.

Well, I'll try the sleep thing again. Have to drive to Boston & back tomorrow afternoon.

Love to you...

- BeJae March 15, 2010

Ah, insomnia. I have that sometimes, too. We should be up Skyping in the middle of the night. "You sleepy yet?" "Nope … You?"

It takes me a long time to adjust to information like this. A dear friend has cancer? What? Now that you're just about to undergo chemo number 3, I'm getting my bearings enough to start wondering how it all works.

You mentioned that you have a chemo port so that they don't have to stick you every time. Is it in your chest? Does it bother you to have it there in between treatments? Does the chemo go into a vein? Does it circulate through your system? When you've described the side effects … well, I guess they aren't side effects … they're primary effects, intended effects … those effects seem so specific to your tongue and mouth. If the chemo circulates through your system, how does it end up at such a specific site? How does it, in ridiculously non-medical terms, know where to go? Other than some general fatigue, do you notice other parts of your body besides your mouth, tongue and throat that are involved in the chemo reaction? I know you say that you feel cotton-brained … but, do your knees ache? Your shoulders? Do you feel like you have the flu?

You realize, don't you, that by the time I figure this stuff out it'll all be over and you will have been pronounced all better. I'll write to you to ask, "Did your hands hurt when you had chemo for your tongue?" You'll write back and say, "B, that was two years ago, I don't remember if my hands hurt or not."

- greenpoet March 15, 2010

You do Skyping? I haven't ventured there yet!

March 15, 2010 – Rainy ride, Worcester snow

Monday, March 15, 2010

Last night was an insomnia night, typical for me in the third week of the 21-day chemo cycle. It was a weird insomnia because I was so tired. I got out of bed and fired up the computer. On the blog was posting from BeJae, what a midnight treat! BeJae asked some fine questions, so I decided to post the answers here. But first…

Had an easy drive into Boston for my hearing test, an amazingly easy ride in; light traffic, cloudy skies, misty rain. Arrived at the audiology office and went right in for my test. My audiologist told me that they had many cancellations due to the weather. Seems the eastern part of Massachusetts bore the brunt of the rainstorm. We did the three part hearing check and it turns out that my hearing has slightly improved. Well, truth is I had

less wax and fluid (isn't that just what you wanted to know?) than the earlier tests. So, we are good to go on Thursday with the chemo cocktail. Stopped for soup and a bagel at Au Bon Pain in the hospital lobby. The ride home was a bit taxing. The rain and wind picked up, traffic was moderate to heavy. In Worcester just now, the rain has changed to big heavy snowflakes. We are SnowCity!

Now to BeJae's questions. First: "You mentioned that you have a chemo port so that they don't have to stick you every time. Is it in your chest? Does it bother you to have it there in between treatments? Does the chemo go into a vein? Does it circulate through your system?"

I have a Bard Power Port. It's not expressively for chemo, but for anyone who needs constant access to the veins, especially when the veins are hard to access. Chemo does a number on one's veins, so I'm real grateful for the port. The Power Port has two channels. Special needles are poked through the skin into the port's dual membranes. Some magic happens within the port that funnels fluids in (IV fluids, chemo, medicines) and out (blood.) The other end of the port is connected to a large vein. In my case, the placement of the port was as close to the tumor as possible. If you feel my upper chest just below the collarbone but as close to the shoulder as to not interfere with muscular movement, you will feel a well-defined lump. The port is placed under the skin like a pacemaker. It's good for over 1,000 punctures. I'm not counting. How did it go in? I lay down in pre-op, took a nap, and woke up with a lump on my chest. Oh, and a really cool purple and gray bracelet! Port went in on February 1st, in service the next day. I notice it's there when I make extreme movements, no pain just awareness. My port rocks!

Second: "When you've described the side effects … well, I guess they aren't side effects … they're primary effects, intended effects … those effects seem so specific to your tongue and mouth. If the chemo circulates through your system, how does it end up at such a specific site? How does it, in ridiculously non-medical terms, know where to go?"

There are two flavors of side effects, the immediate impact of the chemo cocktail on the body which lasts for about six days, followed by the working side effects which last about eight days (maybe a little more, but when I'm on the way out of the effects, I feel lighter.) The immediate side effects are things like nausea, hiccups, and fatigue. The working side effects are due to the attack by the chemo on all fast growing cells in the body; they include pain (in my case concentrated in the mouth, throat, and on the tongue), major fatigue, lack of appetite (nothing – not even coffee – tastes palatable), loss of hair, tender skin, "short-circuited" joints (missed that one) and so on.

The chemo doesn't know specifically where to go. It attacks all fast growing cells. The tumors are the primary targets, but the chemo can't differentiate between cancerous cells and say, the fast growing cells in the wall of the mouth, on the tongue, in the sinuses, and in hair. The chemo cocktail prescribed for me at Dana Farber is particularly effective for treating my type of tumor.

Third: "Other than some general fatigue, do you notice other parts of your body besides your mouth, tongue and throat that are involved in the chemo reaction? I know you say that you feel cotton-brained … but, do your knees ache? Your shoulders? Do you feel like you have the flu?"

During the first cycle, my back and legs ached when my bone marrow kicked into high gear and pushed to replace the white blood cells. My body is weird; wherever there are fast growing cells, there is change. Head hair is generally the most noticed (and can be traumatic) but in my case, I went with the bald look pre-cancer. I certainly notice, though! My razor sits in the medicine cabinet looking forlornly at me every morning. My beard is gone except for a smattering of hardy white bristle hairs; I don't shave them. I figure they've earned it. But body hair is affected all over. All over. Every shower is an adventure. Use your imagination. I use a heavy hair filter over the drain.

I don't feel like I have the flu. Chemo is a unique feeling. Frankly, I feel like crap, especially when the chemo is doing its primary job. But the approach to how I feel, both in painful areas like the mouth and my general malaise (which is mind and body), is far different. Chemo does not make me sick in the sense that the flu does. Chemo is part of the cure. Chemo is the road to getting well and getting my life back. Chemo is my friend, but a friend that has to cause me pain to help me.

Thursday, they hook up the port and infuse me with the chemo cocktail and other fluids. I know it's the beginning of at least two hard weeks, but I say "Bring It On!" because the treatment is the way to regaining my health. The infusion room is an inspiring place because most everyone is in a good mood as this poison is pumped into their veins. Everyone knows what's coming. Everyone understands the price. But the smiles and humor express the hope in the room, the hope and faith that is so necessary for recovery.

Thanks everyone for your support and comfort. Happy Monday and stay dry!

Love…

Richard

Posted by greenpoet at 08:18PM (-04:00)

Comments

- BeJae March 15, 2010

I'm off tomorrow to Greensboro, NC, where I was born and grew up, to visit Jim Ritchey, my ex-husband, the man I toured and played music with for twelve years of my life. Doesn't everybody make sixteen-hour round trips for visits with their ex-spouse? They would if their ex was as kind and wonderful as Jim. Jim's wife, Marsha, one of the most active, vibrant people I've ever known, had a series of strokes a year or so ago and now lives in a care facility. Marsha, trained as a dancer and movement specialist in theater, can barely move. She is remarkable. She has turned her energy to healing and has turned a once hectic life into one of contemplation and mediation. She is cheerful and all the folks at the facility love her. Jim and Marsha's relationship has deepened through this experience. They are utterly devoted to each other. Marsha has made stillness her friend in much the way that you, Richard, have turned the infusion room into a place of smiles and anticipation, instead of fear and dread. This is magnificent, my friend. Every time I face something daunting these days (my taxes, an eight-hour drive alone tomorrow, loading gear for a gig in the rain) I think of you and the others in the infusion room. I think of Marsha. And you all keep me going. I'll smile tomorrow as I drive and listen to audio books and music and enjoy the sunshine that the forecast promises. I'll notice that spring is coming, that things change. I'll take pleasure in my very easy and privileged life and I will feel so grateful to you for helping me realize how good things are.

Thank you so much for your pictures, for your words, for your remarkable point of view.

- greenpoet March 16, 2010

Townes' "Greensboro Girl" !

I do love the recording of you & Jim playing in Dallas.

Wish I had the chance to do radio with Jim (while the board worked) - from all you've told me, his knowledge and perspective on music (and life) would have led to a singular conversation. And fine music!

Please give Marsha a hug from me. She is an inspiration. Grace and courage come from within, are earned qualities. She is a very special person.

Have a good road trip. Revel in the Spring. Sing to the sun.

You are special, too, BeJae. You touch the people in your life and enrich our lives with your warmth and wisdom. I'm very grateful you are my friend,

Love...

Richard

March 16, 2010 – Hi Ho L'Avodah Yavoh!

Tuesday, March 16, 2010

An extra two points to anyone who figures out today's title. Yavneh alumni from the 1960's are excluded.

Had a good night's sleep, didn't get up until after 9:00 am, though my body has had no reason to adjust to daylight savings time. Breakfast went down well. My taste buds are still askew but the Cheerios tasted all right today.

Went into work today for a few hours. It felt good to be in the office, to see all the folks. My brain definitely is not functioning at full tilt. While working on General Ledger with Jim, we encountered a few problems (standard for the course) and I felt the cottonball effect. I knew there was answer or a way to find the answer but I was still coping with the question. Part of this is cumulative fatigue and the effect of all the medications; I hope the rest is just rust. Last month, I did the financial statement and though it took more time and effort, I muddled through. To keep this in perspective, I need to look at my reading level. I'm back to reading novels, though much more slowly and carefully if I want to drink in the writing and nuance. I am not reading a book or more a week.

While at work, I munched on a Subway foot long veggie sandwich. I had the hankering and the hunger. It's time to chow down and add a few pounds until the chemo kicks in!

Tomorrow, we'll pack up and head to Boston. We're planning to stay overnight at the hotel in the Longwood Medical Campus for two nights. I start with chemo prep at 8:30 am Thursday, finish with post-chemo fluid infusion at 8:00 am Friday.

Alan just stopped by with some soup from Uno's and a batch of meeting cookies from Lynne and Charlotte. I have a real supper treat tonight! Thanks!

And thanks all for your good wishes and support. I feel loved and love you!

Love…

Richard

Posted by greenpoet at 05:55PM (-04:00)

Comments

- TaDa March 16, 2010

good luck in Boston Richard... will be thinking of you!

- greenpoet March 16, 2010

Thanks, Linda!

- BeJae March 17, 2010

Back in Iowa, I had two friends, Bo and Shari, who did a good deal of remodeling work on our very old house. Parts of the house had been neglected for a long time. The first part of every remodel was tearing down and hauling out the old, cruddy, icky stuff. Shari and Bo let me help with that, since it takes hardly any skill (which is exactly the amount of skill I have when it comes to remodeling). My favorite part was going to the dump. It felt so great to me to push nasty, moldy, gross stuff off the back of a pickup truck. It felt absolutely triumphant to me, the getting rid of what's not right and can never be right again. I especially liked pushing an old toilet off the back of the truck. Porcelain breaks with such a satisfying crash.

So, tomorrow, Thursday, you go in for another round of demolition, tearing out the icky stuff that isn't right so that your amazing body, the smartest remodeler ever, can build itself back healthy, vibrant, perfect.

It is a beautiful day here in Greensboro. I am thinking of you, Richard the Lionhearted, Peaceful Warrior, and the other remodelers who will meet in the infusion room tomorrow ready to swing the sledge hammer. It's hard, but satisfying work.

- greenpoet March 17, 2010

Oh, I love the analogy BeJae! You and Bo and Shari are welcome with your sledgehammers anytime! The infusion room is bright, has good acoustics, a dreadnaught would fill the room.

Thanks for thinking of me in Greensboro. The town must be a spiral of memories for you. Music and bricks & mortar bring pieces of our life back in focus.

Thanks for these lovely, thoughtful comments. They make me smile and feed my hungry brain. Onward!

Love...

foxy

March 17, 2010 – St. Patty's Day in Boston

Wednesday, March 17, 2010

Ann and I are comfortably ensconced in the Longwood Best Western on the periphery of the Longwood Medical Campus, which comprises Dana Farber, Boston Children's Hospital, and Brigham & Women's Hospital. Just for good measure, down the block and around the corner are Beth Israel Hospital and Joslin Diabetes Clinic. In this

neighborhood, scrubs are haute chic though today many people are wearing green. When we got to the hotel's check in desk, I thought for a moment that Irish attire was a requisite for the reservation! The room is nice. We're on the eighth floor and cannot hear the street noise. The room, as it did last time we stayed here, has two twin beds each with its headboard set against perpendicular walls. The two beds are important because tomorrow I'll be hooked up to the 5FU pump and it needs its own side of the bed.

The view is urban:

If you look to the left of the Longwood Food Court sign, you'll see a side entrance to Dana Farber. We are able to walk from the hotel lobby to any facility in the medical campus without going outside. Today through Friday are supposed to be sunny and in the 60F's, so we'll likely elect the outdoor route.

Dan will meet us for supper tonight. Dana Farber is reasonably close to his apartment. It will be nice for the three of us to have a relaxed dinner out.

I'm feeling good overall. Looks like I'll be on the Imodium express for the near future. These treatments are a match of chemical v. chemical with one of the playing fields my digestive track. This afternoon, I look at tomorrow and the start of my third of three 21-day chemo cycles as a marker reached. I still have the roller coaster ride of the cycle ahead, but I can mark progress.

It's Springtime and I've been sneezing a lot. I stopped Claritin when I began taking all the chemo drugs, but it may be time to start the allergy pill for the season.

We're going to take it easy and ready ourselves for tomorrow. Our first appointment is at 8:30 am and I'm scheduled to start infusion at 10:30 am. Onward!

Thanks everyone for your support and love. Arnold, it was wonderful to talk to you yesterday; you've been through the throat cancer treatments and can look back eleven years later at your path out of the box. Thanks for sharing your experience and wisdom. It really helps!

Love…

Richard

p.s. Ellen The Prom Queen earns two points and a star for correctly translating the title of yesterday's post: "Hi ho, hi ho, it's off to work we go!" You rock, Ms. Epstein!

Posted by greenpoet at 05:01PM (-04:00)

Comments

- BeJae	March 18, 2010

To the good fast-growing cells: I know, I know, it's not fair. You're beautiful and wonderful and doing everything right, silky hair, velvety insides of cheeks, pleasure-giving taste buds, secretive digestive entities. It's not fair that you good guys have to get knocked all whampy-jawed so that the bad fast-growing cells can get gotten. But, here's the thing … It's almost over. This is the last round. The next part of the treatment is area specific instead of type-of-cell specific, so it will be the good cells who just happen to be hanging out in the wrong neighborhood who will take the brunt of it. Try not to gloat when you’re feeling great and they are not. By then you’ll already be excitedly recovering your glory. You’re quick and smart and soon you will have forgotten that any of this ever happened. You’ll be busy growing unimpeded without the Alien sucking down all the good, delicious cell nutrition. It’s hard right now, I know it is. But, it’s almost over. This is the last round. And I’m pulling for you.

- greenpoet March 18, 2010

Oh, BeJae - that is priceless. I read it to my cells. I think the Alien's cells were set back by the very cool and very bad-ass comment. The good cells are dancing and readying themselves for this next ride.

You put a BIG smile on my face!

Love from sunny Boston...

Richard

- drjjcowgirl March 19, 2010

Richard - Even in your daily journal you are poetic. I appreciate being able to keep up; makes me think of Donald Hall's writing. I feel with you, want you to know, that even though I found out only days ago, I am now here, sending love, and healing light. Taught sonnets at the jaul today and one of the guys caught an extra beat in mine; it was a great day. We corrected my line. I went to a jewelry store after class and the guy was checking my license: "It's cool; I just got out of jail, maximum security floor, actually. So I'm fine." After a beat, I explained. Loving you, loving Ann. janie

- greenpoet March 19, 2010

Oh thanks, Janie. Means a lot coming from you. You are on fire - your poetry is stronger and stretches the envelope further every year! I look forward to seeing the Mrs. Noah poems collected. So much of Janie weaves through your disparate characters. You go! Cool what happened in the jail class today. I always feel like you're the toughest one in that room.

Last chemo cycle is pumping through my veins. Radiation starts around April 13th. Looking forward to giving you & Sondra big hugs in October!

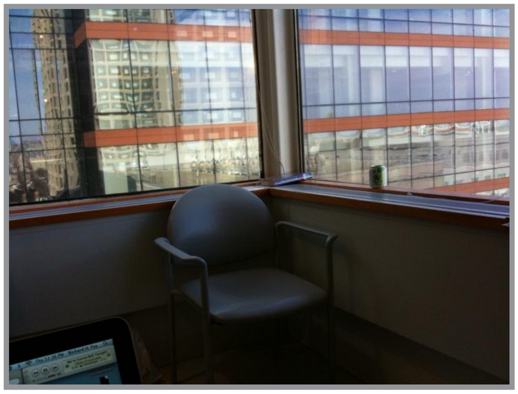
Love from Ann & I. Thanks for being here!

March 18, 2010 – NY Times Opinion & Infusion 3.1

Thursday, March 18, 2010

We’re at Dana Farber for the day. Got my port set up with both lines active and have some blood drawn. Saw the oncology team; found out that my white blood count is back up to 11.5. Dr. H. poked and prodded my neck but couldn’t feel my lymph nodes. This delighted him, Ann & I even more.

So now, I’m in the infusion room, a corner chair. Sun is pouring through the windows (so



nice!) and my fellow patients have sunny smiles. I've very comfortable here.

This is the start of my last chemo cycle. I will have chemo weekly while receiving my radiation treatments, but it will be a less profound cocktail, one designed to work with the radiation.

There was an opinion piece in the New York Times titled "With Cancer Let's Face It: Words Are Inadequate" this week. (The link is: http://well.blogs.nytimes.com/2010/03/15/with-cancer-lets-face-it-words-are-inadequate/?scp=1&sq=With%20Cancer,%20Let's%20Face%20It:%20Words%20Are%20Inadequate&st=cse .)

A few people have sent it to me and asked what I think. I agree some with the article but disagree more. First of all, ask a writer, when are words ever inadequate?

To the NY Times piece:

I see myself in a clear battle with cancer. A friend, Stu (an ENT), described it as a fight with a micro cellular enemy. When I was first diagnosed, I called my primary tumor the alien. I borrowed the term from Ben who gave the term to his brain tumor. Alien seems appropriate, an alien invasion. I think of my mouth, tongue, and throat as a battlefield with a lot of collateral damage.

The author also says the body is a battlefield, but here I disagree strongly with the author's assertion that the cancer patient is on "a quest out of Tolkien, or a dark waltz." This battle is mine against this invader and on my turf. The author continues writing that cancer is "a long and difficult journey." I prefer to look at this journey on a day to day (or even hour to hour) basis. It affords me no comfort to consider seven weeks of radiation treatment when I'm in the midst of chemo cycles. When I get there, I'll deal with it day by day. I do believe that I will learn valuable lessons from this experience and I do believe the experience will make me a better human. The most profound lessons in my life have always had a cost associated with them, be it pain, hard work, or sacrifice. This is no different. There is balance in living.

I've always felt angry when hearing coaches (especially youth sports coaches) rallying their teams by comparing a sporting event to a "battle" or a "war." Such a comparison is not only disingenuous to combat veterans and their families, but also a poor lesson for the kids/athletes. Coaches are teachers, have influence over their players, and should speak with discretion. As well, the coaches' actions during practice and matches serve as a model to the team and I've seen kids poisoned by their coaches. (Ok, I'm getting off topic.) But I do not feel that the term "battle" with cancer is inappropriate. I am battling for my life and facing pain and hardship. But I realize that I am so fortunate to face pain and hardship surrounded by the comfort of home, friends, family. I fight my battle engulfed by close and immediate love.

Two more quick points or I'll end up writing a full rebuttal to the New York Times. First, I don't see myself as a victim; it's nothing personal, just a virus. We take the good and bad with health. Secondly, I will see myself as a survivor. The author is limiting the scope of the word to combat experience. I find that a narrow interpretation. Perhaps, what's most important is what one does with the gift of survival. To me, there is a responsibility that accompanies survival's grace.

Well, I'm on chemo bag #2 and my brain is easing into that cottonball effect. It's gradual. By tonight, profound. Maybe I'll watch NCAA basketball. I know, I know, curling is more my pace but at least they show the score and time remaining. If I can't read my book, I

bet I can still grasp the stats!
Thanks all for your love, support, and comfort.
Love…
Richard
Posted by greenpoet at 01:35PM (-04:00)

March 19, 2010 – Infusion 3.2 – pure joy!

Friday, March 19, 2010

I'm exhausted now, otherwise feeling ok. Before, during, and after chemo infusion, I need to take a lot of steroids. Steroids are wonderful to counter Cisplatin's side effects, but come with their own set including insomnia. With today's dose, I'm tired but not sleepy. Ah well, insomnia ends with a good sleep. I'll get Rudy Dog to cuddle with me. He is the nap inducer king!

We had a wonderful surprise in the infusion room this morning. I was in for hydration and reading a Jess Walter novel. In walks a young couple who settle into the next chair, our cousins Darlene & Alan! Alan is the son of my first cousin Anita, Arlene's sister. There are certainly far preferable places to run into family, but we had a lovely visit. Alan is sweet and sincere and devoted to Darlene. I've enjoyed conversations he and I have had in the past, conversations in the midst of family gatherings. This morning we could focus on one another. Ann & I haven't had the opportunity to talk with Darlene before today. She is a delight (she says "blankie", too!), sparkling with her words, and strong in her fight with cancer. She and I agree that Arlene is our hero as we ride the roller coaster of cancer treatments. We both marked the end of intensive chemotherapy infusion (though we have the three week cycle ahead of us), she a longer course than I. The treatments are a lengthy road and marking steps on the way shows progress and helps the spirit.

Ok, I'm going to stop and try that nap now. The combination of insomnia fatigue and cottonball chemo brain make writing a bit of a challenge.

Back from the nap. Rudy took in a sunbeam and then joined me on the couch. He's back in the sunbeam now. If I didn't have the 5FU pump, I might join him on the floor. He looks comfy!

I wish I could be more effusive about the serendipity in the infusion room this morning, but my words are coming harder today. The next couple of weeks I'll be thinking, "this is the last dose of intensive chemo." I can really live in the day this cycle.

Ann told me I missed Dr. H's comment yesterday after he poked and prodded looking for the lymph nodes in my neck. He said his inability to find anything is a "complete response." I guess that's good! Ann & I are curious to see what the pre-radiation CT/PET scan will show. We wonder what the current size of the alien mother ship (my primary tumor on the base of my tongue) is.

Thanks everyone for your support and love. It's an immeasurable comfort to know I have the embraces of friends & family on this journey.
Love…
Richard
Posted by greenpoet at 04:53PM (-04:00)

Comments

- TaDa March 19, 2010

You sound good Richard.. Cisplatin (uuggg I know that drug to well)... don't be afraid to ask for a non adictive sleep meds... lunesta and ambien CR are great .. I used the ambien cr (the cr means it is time released through out the night)...have a great weekend.. I hear the weather is gorgeous up there..

hugs

TaDa

- greenpoet March 19, 2010

Weather is beautiful, sweet New England Spring! I'm going to use Diazepam for a sleep aide. Has worked well in the past. But the steroids in bulk are hard to counteract - but they do their job!

Thanks, Linda for your comments and concern!

March 20, 2010 – Busy day in Wormtown

Saturday, March 20, 2010

Insomnia feeds on itself. Last night, I had a delicious uninterrupted eight hours of sleep. Could have slept longer, but I'd like my sleep cycle to be as normal as possible. Got up around 8:00 am, had my first handful of pills followed by a Vanilla Boost for breakfast #1. Checked my email and favorite sites while I waited for the meds to settle, then poured a bowl of Cheerios with Silk Vanilla Soy Milk for breakfast #2. After the bowl, had my second handful of pills. Back in the chemo saddle again!

I puttered around, feeling energetic and real fine. It's Dad's birthday today and for some reason, I hadn't been able to shop for a gift for him. He's tough to shop for, but I know he's been having a problem with the wireless mouse on his iMac. It's just not smooth, even a bit of a pain for me at times and I get along well with devices. So a new mouse was just the ticket, but one I'd have to try before buying. Not only does it need to fit my hand, but be easy for an 87-year-old man to operate. Ann offered to drive me to Best Buy and then CVS, but I felt up for driving – plus I had the feeling that this was going to be a slow shopping trip, a pace I enjoy but one that can drive other people bonkers. Put a geek among aisles of devices; you know I gotta try all the cool ones and even some of the semi-cool ones.

Had a nice sunny drive over to The Greendale Mall, once a bustling place, now basically Best Buy and a bunch of hanger-on stores. I played with a bunch of mice, but kept coming back to the new Apple Magic Mouse (and yes, Stuart – I *was* channeling you!) The generic mice designed for PC and Mac platforms had too many potential pitfalls, i.e. too many buttons, wheels, and combinations that could get Dad in trouble. The Magic Mouse is slick and after enough play, I decided that it would fit Dad's hand and that enough of the esoteric geek-beloved features could be turned off to make it fool proof. Headed over to CVS Pharmacy to pick up a prescription and some miscellaneous supplies. I got the Rx first, paid for it separately and my CVS Card gave me a $5 off $25 purchase coupon. So of course, I had to meet that $25 threshold; destiny isn't it? Well, it certainly is to a chemo-addled brain! I muddled and puttered the aisles figuring out what stuff I'd need over the next month, threw in a magazine for Ann, and ended up spending over $35. Those CVS people know what they are doing. Fortunately, I did get stuff we need. Between my compromised arithmetic and the attraction of all the shiny packages on the shelf, I spent quite a while at CVS, but it was fun!

Got home and began unpacking my shopping trip. Dan arrived to visit Ann & I and to see Dad/Papa on his birthday. We ate a quick lunch and called over to Dad's. When I talked to Mom/Mema last night, she there was absolutely no way that she was leaving the house today. She generally plays cards on Saturday afternoon but the combination of a lingering back injury and a very busy Friday shopping with Renee convinced her to cancel the card game. However, my family is a card playing family, especially The Greatest Generation. Therefore, at noon Mom relented and took her seat at a friend's table and kept the game at full tilt. So, Ann & I & Dan & Rudy Dog visited Dad without Mom there. We gave Dad a couple of cards and the wrapped Magic Mouse. He opened the package (Apple's new minimal environmental friendly packaging without labeling) and had no idea what he was holding. Dad thanked us and we told him what his gift is. Dan set the mouse up to its simplest configuration and showed Dad how it works. It is much easier for Dad to manipulate, both the optical tracking and the single button that is the top of the mouse (no confusing scroll wheel.) The top button can be programmed to do all kinds of slick geeky things dependent of where you press, how many fingers you use, and many dragging strategies. But for Dad, this mouse can slow dance with terrific response. Rudy Dog kept checking the house for Mom, but gave Dad a lot of attention. He loves to visit them!

We returned home and Ann took Lacey Dog on a walk as consolation for being left at home alone. Lacey is a sweet old dog but does not like car rides and also (see the prior TinkleTrousers.com discussion) has a bit of dementia that affects her once spotless housetraining, not a good combination for today's birthday trip. Ann and Lacey arrived home just in time for a visit from Larry & Lora, just back in town from a visit to Florida (including lovely Sanibel Island.) We watched basketball and talked about their trip. Rudy Dog was real excited. Not only was Dan home, but his friend Larry was here!

After Larry & Lora headed home, I lay down on the couch with Rudy snuggled in the nap position, but I wasn't tired. So I rested and talked with Dan & Ann. Last night's sleep was carrying me through this day. This is my third chemo cycle and we've learned from the first two cycles. The 5FU pump continues to push its nasty self into my vein, so maybe I feel a bit cavalier. I start to think, "hey, this cycle will be a comparative breeze." Let's see what I'm saying (and feeling) in a few days! Monday, the 5FU gets disconnected and the chemo cocktail begins to peak. Today, that peak is far away. I live in the day. It's a good day. I'm having fun.

Around 6:00 pm, Jesse & Susan just back from a trip to (yes) Florida, stopped in with take-out from Pho Dakao, a local sumptuous Vietnamese restaurant. Rudy was excited – now his friend Jesse was visiting! The five humans sat down and gorged ourselves with Asian delights, and found room for dessert (one must have priorities!) Then, we moved to the living room and continued the conversations until it was time for Jesse & Susan to meet up with daughter Julie.

My original plan was to take periodic rest breaks in the bedroom during today's visits. But I didn't (and still don't) feel tired, drained, or mega cottonball brained. I believe I'll sleep real well again tonight. So again, I'm going to ride this day for all its worth – but with the understanding that I have to take care of myself and be smart. So, to bed early despite all these exciting Men's and Women's Tournament game going on into the wee hours.

We'll see what tomorrow brings, how I feel after this busy and fun day. I may regret my level of activity. Then again, I may be reading my body correctly. Life is about learning. Thanks all for your comfort and support. Knowing that I'm not going through this alone raises my spirits immeasurably.

Love…

Richard

Posted by greenpoet at 09:59PM (-04:00)

Comments

- Stuart

March 21, 2010

Sounds as though you had a great, busy and productive day. And yes, the mouse -- which I actually think is now called the Magic Mouse -- is exactly the one to buy. Please wish your father a (belated) Happy Birthday for me. I'm glad that all seems to be going so well, Richard.

- greenpoet

March 21, 2010

Feeling good today. No errands to run, but maybe that's best. I have a tendency to overdo it. Passed on your birthday greetings to my Dad. He & Mom always love getting updates on your news, so I told them about some of Christian's latest adventures. Hey - and when I'm healthy, we definitely got to do Average Joe's or a house visit asap - ok?

Thanks for the Magic v. Mighty correction. I guess I still must have a thing for that cartoon!

Love to you, James, & Christian!

March 21, 2010 – Lazy day in Wormtown

Sunday, March 21, 2010

First of all, you may ask “What is Wormtown?” To those involved in the Worcester Arts & Music Scene (yes, there really is a vibrant one) Wormtown is the alternative name for the city as designated by Brian Goslow, our Minister of Culture, music and arts reporter extraordinaire. In my radio DJ days and as a poet, I got to know Brian well and appreciate his contributions to drawing a spotlight to the largely underground heartbeat in the city. So, often I defer to our old mill town’s nickname. Without worms, we have no agriculture. Without Wormtown, we have no culture.

I got to bed around 11:30 pm last night and slept through until 9:30 am! Well, slept through does include a pee trip every 60-90 minutes, but I fell right back into deep sleep every time. Ah, hydration, so important as the chemo seeps through my body, wakes me but assures me that my fluid intake is more than adequate.

Today has been a lazy day. Did my usual morning and breakfast routine, then Ann & I watched “Sports Reporters” and some home renovation/staging shows on TV. Ann & Pam took Lacey Dog and Pam’s pups, Sam & Lily, for a long walk through Moore State Park in Paxton, just north of town. Rudy doesn’t enjoy the walk through the woods, so he hung out with me.

Most of the day, I’ve been listening to The Grateful Dead’s *Dick’s Picks Volume 14: Boston Music Hall, 11/30/73 and 12/02/73* while watching the Women’s & Men’s NCAA Basketball Tourneys on mute. In many cases, TV is best enjoyed on mute, especially with fine music to fill the audio track. The 1973 lineup isn’t my favorite Dead period. I much prefer the 1966-1970 years when Pig Pen’s blues chops shaped much of the band’s direction. Jerry’s guitar playing was fiery in that era, less restrained but not undisciplined. I do love how over the decades he and the band constantly experimented with style, took artistic plunges, and grew their sound. But I will always have a soft spot the band’s early days when the boys were focused on raw energy, playing on young legs.

I’m feeling pretty chipper today. My big plans for the rest of the day are to catch a little nap, trim my fingernails, and finish the Jess Walter novel. I only have about 40 pages left in (and I'm loving the book), so I'm saving them for a moment of literary hunger. The next books I have queued to read are waiting in the Auburn MA (town just south) library but the libraries are all closed today.

I'm feeling pretty chipper, but the 5FU pump will complete its program tomorrow afternoon and soon after the primary chemo side effects, the working side effects, will kick in. I think that they may seem gentler than the first two times. First of all it will be the last intensive chemo cycle; staying in the day or even the hour will be easier. Plus, the knowledge of how to deal with the side effects picked up over the first two cycles will help. Lastly on Tuesday, Dr. H. has scheduled me for an injection that should prevent my white blood cell count from falling to zero as it has during the first two cycles. 12% of Cisplatin patients have the low white blood cell side effect and the injection, into the stomach roll, has proven to be effective. So maybe I'm being cavalier, but I expect an easier cycle. Check in next week!

Thanks for the cards and emails of support. I have the cards stacked up triple deep on the broad windowsill. It's a joyous and colorful view that reminds me of all of you. I walk along the windowsill and see friends and family, makes me smile and feel loved. Thanks also to the 7th and 3rd Grade classes at Temple Sinai who dropped off a Passover Basket for us today. More sunshine in my day!

Love…

Richard

Posted by greenpoet at 05:55PM (-04:00)

Comments

- BeJae March 22, 2010

I dreamed about you last night. I was with you at your house for a big chemo party. The house was full of family and friends who were all having a rollicking good time at this party that went on non-stop through all three intense cycles. Partiers would come and go, but you were the constant. You'd nap every once in a while on the couch as the party rolled along around you full of festive laughter and music. (I, too, napped every once in a while in this dream during the chemo party. I often dream that I'm sleeping. That probably says something weird about me, something that Ann could probably diagnose, but please ask her not to, because I don't really want to know just how weird I am.) The best part about the dream was that I got to see you and spend time with you. It was one of those vivid dreams that seems real and lingers during the day like a recent memory instead of vaporizing as dreams often do.

While not quite as festive as in my dream, I'm so happy to hear that this cycle is riding more easily than the others, at least at the start. You're really getting the hang of this intense chemo thing now that it's nearly over.

Have you seen Festival Express? It's a documentary of a rock festival that traveled from town to town by train through Canada in 1970. There were lots of notable acts, Buddy Guy, Janis Joplin, The Band and a bunch of others including the Grateful Dead. There's footage of performers casually jamming on the train and in that footage it is so apparent what a great player Jerry Garcia was. You can also very clearly hear his folk and bluegrass roots in those casual jams. I was never much of a Dead fan, but it was so obvious in this film who could really play and who couldn't. And Garcia could really play.

I love knowing what music you're listening to as you ride the chemo cycle. And thanks so much for inviting me to the party.

March 22, 2010 – Tired boy…

Monday, March 22, 2010

Busy day today and I am officially a tired boy. Today is the day that the 5FU pump ran its course (and I got to lose my 24 hour a day shoulder pack.) Fatigue was expected as the primary side effects of the chemo started to kick in. After the mild weekend, I expected to ease in. So what was my day?

This morning, Ann & I headed over to Dr. S.'s office (my Worcester oncologist) in separate cars. Ann had patients today and my appointment was going to be long. Dr. S. wanted to examine me as I enter this third cycle. We don't want a repeat of the infection and hospitalization of last cycle. My blood levels all tested as excellent. My vital signs were fine. Dr. S. took a gander at the lesion on my hip that likely caused the infection last cycle. There was still liquid below the scar and the size of the lesion was a concern. So, he decided to lance it again while my blood counts are normal, before the low white cell counts that invite infection. We needed to wait for the appropriate room to open up.

The wait was fine; it was time for hydration. During chemotherapy, hydration aids the process. It also helps the patient (me) feel better. As I lay back into the recliner and had my port hooked up to the IV line, I discovered that my earphones were not with me. This was a particularly bad omission because I was out of books. Instead of bemoaning my lack of entertainment, I made phone calls. Then I tapped through my iPhone. Good thing, it has Solitaire; I was able to play many games without a winner (but I kept trying!) I laid back in the recliner and tried to nap. The folks in the infusion room were in good moods; the laughter and conversation were too musical a background for sleep.

Luckily, Dr. S. came by and said he was ready for a little lancing. My IV bag still had fluid, so we rolled the post and my pump down to the exam room. Dr. S. decided to make a longer incision to insure that the lesion would be completely drained. A little slice and all he found was dried blood, which was good.

Back to the infusion room where my IV fluid bag finally emptied. We checked the 5FU pump and figured that I had at least an hour before it would be done. I decided to run errands while the pump ran. I drove to Auburn, picked up my library books (a Dennis Lehane and another Jess Walter), and went to Papa Gino's for a quick lunch. I ordered penne with pomodoro sauce, a dish I've had many times before pre-cancer treatment. I was hungry and scoffed it down, but slowly realized that the sauce tasted well, odd, and not in a good way. Was it spicier? More garlic? No, it was the chemo reprogramming my taste buds. Back in the saddle again.

Drove back to Dr. S.'s office and settled into a chair in the infusion room. I opened Lehane's *The Given Day* and prepared to dive in when the 5FU pump alarm beeped – running on empty! One of the infusion room staff came over and disconnected the 5FU pump and the IV line from my port. It was a boost to lose the pump bag! Side note: Dr. S. and his staff are wonderful and caring. I feel comfortable in his facility.

Got into the car and drove home. Let the dogs out and in then collapsed on the couch. Rudy Dog, ever observant, jumped up into nap position and to sleep we went. I didn't realize how drained I was. Such a change in a day, but that's the way of chemotherapy.

Woke up when Ann arrived home. Had a little supper, doing a little writing. Tomorrow, we head into Boston. I'll have the stomach injection that should keep my white blood cell up and then go for radiation prep.

Tomorrow, Adam arrives for a week's visit. He has work to do while he's here which will coincide nicely with my naptimes. I'm looking forward to having the time together. Over the weekend, we'll have the whole family home, sheer bliss.

Thanks everyone for your love and support. You carry me through these days.

Love…

Richard
Posted by greenpoet at 08:46PM (-04:00)

Comments

- BeJae March 22, 2010

Listened to The Given Day as an audio book a while back. Loved it! I think you will, too.

Sounds like a bit of an uphill ride today ... But, remember: guiltless eating enjoyment on the downhill side. Pace yourself, my friend, take it easy, keep on going. My money's on you.

- greenpoet March 22, 2010

Thanks, BeJae. Loved the stream you left yesterday. Will answer tomorrow. Time for bed, pumpless! You brighten my days!

- TaDa March 22, 2010

On Ward! Keep the awesome attitude up... Do they not have Wfy in the chemo room ??

- greenpoet March 23, 2010

Infusion room has WiFi - read a little of the NY Times and Boston Globe. But I yearned for music! Music to be infused by! Thanks, Linda!

March 23, 2010 – Wiped out boy

Tuesday, March 23, 2010

Note to self: stay home and rest during the days after the 5FU pump is disconnected.

Second note to self: go appointments when scheduled (today, we had an injection followed by radiation prep on the board.)

The two notes have an essential contradiction. The appointments trump rest. That doesn't mean my body isn't without a trick or two. I took my shower this morning and was lightheaded and tired. We had breakfast, got into the car, and headed off in the heavy rain to Boston. On the way, I felt very fatigued and even more lightheaded. I put the passenger seat down flat and Ann helped me into patterned belly breathing. I fell asleep as she navigated the morning traffic and wet weather.

On the way to Boston, we got a series of phone calls from a concerned (and very nice) Dana Farber nurse informing us that my injection (to boost my white blood cell count) scheduled for 9:45 am had to be postponed until the afternoon. The drug, without a special order written by a physician, cannot be administered within twenty-four hours of the 5FU pump being disconnected (2:00 yesterday.) I explained that originally the injection was scheduled for yesterday. She said the injection would not be released by the pharmacy without the special order and that she would keep calling to facilitate the order.

Despite the weather and my meltdown, we arrived at Dana Farber on time. Ann parked the car while I raced up the 11th floor. When I checked in, I was told that my injection was now scheduled for 1:00 pm. I recounted my conversation with the nurse and they paged her. She told me that she still didn't have the order and the injection was still at the pharmacy. She called for the order again, without success, while Ann joined me. We decided to postpone the injection until the afternoon.

We walked from Dana Farber to the radiation prep suite at Brigham & Women's Hospital. The prep was fun – well, this is me talking! I stripped to the waist and lay down on a table with a special head support. The two techs explained in great detail what was going to happen. Apparently, this process is worrisome for folks with claustrophobia. In my case, I go into science fiction land. So, as they carefully laid out each step, I rested and took in all the devices in the room. I restrained myself from asking about each. I figured they wanted to finish today.

The main goal of the prep is to construct my radiation mask. They prepared my face (a facial like solution, warm and relaxing) and then pulled a large piece of tight plastic netting over my head, neck, shoulders, and upper chest. The netting was hot but not too hot. The techs carefully shaped the material to the contour of my face and upper body and snapped down each region of the mask until it was taut. After the mold was dry, they slid it off me and showed me the result. These masks – post-radiation treatment – are popular for Halloween.

The last step was a trip for my new doppelganger and I to a special MRI machine. We were assembled on the tube's table and locked in place. Time for a mini-space flight (again the tech was relieved that small spaces are not a problem for me – hey, I used to go spelunking!) In and out, in and out, to Ben's favorite click clack magnetic percussion and we were done.

We met briefly with Dr. T., my radiologist, and went over procedural details. He sent us back to Dana Farber to meet with his nurse for radiation orientation. We spent an hour going over treatment protocol, dental care, side effects (oh, this is going to be lovely!), and dealing with side effects. We have pages of instructions. The details will slip out onto this blog as I experience them. During the orientation, I leaned against the wall and tried to stay alert, or even awake. Ann took in the nurse's dialogue.

We finished and took the elevator up thirteen floors to where my injection waited. The same nurse (I felt bad for her – she felt bad for me – the morning's delay was out of our control) brought me into the blood room and dashed the needle into my arm. I thought the shot was to be administered in the "loose folds" of my stomach. Stomach, shoulder, whatever; we were done.

We left Dana Farber and walked into rainless skies. A very tired Ann drove home. I fell asleep as soon as we hit Storrow Drive and didn't wake up until we were home. Ann had patients, so she went off to work. I fell on the couch and Rudy Dog immediately assumed the napping position. Good pup, he knew how I felt! I slept deeply enough that Lacey Dog's howls didn't wake for doggie dinnertime. Finally, I rolled off the couch, fed the dogs, and shook myself awake.

I am very grateful that I have NO appointments tomorrow! We have one on Thursday at Dana Farber. Adam arrives tonight, so we'll have another driver.

I'm feeling better now, less fatigued. The naps certainly helped, but having all y'all on this ride with me helps me move forward, especially through the tough moments. I cherish you!

Love…

Richard

Posted by greenpoet at 06:52PM (-04:00)

Comments

- TaDa March 23, 2010

Wow.. I didn't give any thought that your mold would be on your facial area.. mine was my chest..(did you get fancy tattoos too)?

Rest.. hang in there..

Laura (not sure where you get Linda from)

- greenpoet March 23, 2010

Sorry, Laura. I'm like my Mom - I mix names up. When I was young, I used to tease her when she did. Now, she just stares at me when I make a name faux - much more effective!

No tattoos - the marks go on the mask. My face and upper body will be immobile and not real visible during treatment.

Sounds like a rough ride - the pace will be gradual and progressive. One day at a time, one hour even...

- BeJae March 23, 2010

I guess we'll have to draw straws for the Halloween mask. I hope I win. I can't imagine a higher honor than to masquerade as you even just for a day.

I'm so glad that the radiation room has the sci-fi lure for you. Sometimes we have to take our fun where we find it.

Stay with this curious trip, my friend. Know that I'm riding with you over here in the O state.

- greenpoet March 24, 2010

Re: the mask. I have a big head (don't worry Ann reminds me!) and wear large hat sizes. So maybe we can have a party and take portraits. The key is, what kinds of food & beverages go with masking?

I've always wanted to go into space, ride a rocket to orbit and beyond. The machines I'm surrounded by look like something from a sci-fi movie, only they're real and they get to play with me. Sign of geek = technology cheers me up and brings out the little boy wonder.

Thanks for being on this ride with me. It means more than I can say. You brighten my day.

- TaDa March 24, 2010

I was in a body cast from the wait to my neck back side only... I laid in it to line me up and stay still... I got the tattoos on my chest one in the middle, left and right... just blue ink dots... I did well with the radiation... It sucked my energy up and made me really tired but no burns... my throat suffered but liquid pain meds worked... and to date i just double the nexium and I am good....

You are a trooper I sure you will fly through it...(like I did) .. I don't care what anyone says Attitude plays a huge part in the process...

praying and thinking of you

Laura...

- greenpoet March 24, 2010

Thanks, Laura. I agree - attitude is huge. I will have red areas on my neck, but they have a special cream to minimize the effects. I won't worry about the radiation. The time will come and I'll deal with it day-by-day. I'll have a calendar where I can "X" off each treatment. Don't know why, but that sounds like fun!

Thanks for your support, Laura. Much appreciated...

March 24, 2010 – Nap day

Wednesday, March 24, 2010

Fatigue is cumulative with chemo. Each cycle, I’ve been more tired than the one before. This third cycle, even given the busy schedules of Monday and Tuesday, the fatigue is deeper.

Adam arrived last night and has had the entertainment of watching me nap most of the day. I’ve briefly answered a few emails and spent a little while surfing the web, trying to keep busy instead of sleep. I’d like to read, but lack the concentration. The couch ends up having too much of an allure. I lie down and Rudy Dog assumes the nap position.

My mouth is being impacted by the chemo. The pitting and sores have established growing beachheads and my taste buds are shot. I’ve been drinking Boost and eating soft food, but it finally occurred to me to take the pain med this afternoon. I’m not too smart about the pain meds. I wait too long to start and then have catch up with the pain control. Gee, maybe I’ll be able to eat scrambled eggbeaters, toast, and a veggie burger once the meds kick in.

This is a day of rest. Tomorrow morning, Ann & Adam & I will drive to Dana Farber for my mid-chemo checkup. I’ll have a break after that. My next appointments (well, as of today) are not until April.

Radiation sounds like a tough road. I understand they have to cover every conceivable side effect, but the list is a long one. Thankfully, the list of meds available to counter the side effects is even longer.

The radiation will be delicate because of the contents of the mouth, throat, and neck (saliva glands, voice box, taste buds, swallow muscles, and a bunch more that the nurse listed as I tried to stay awake. Don't worry - Ann took notes!) I know the radiation will present many challenges. My task is to meet them one at a time as they arrive, not to think about what's next. It may all be easier than I think. I'm not planning for the worst, or the best, just planning on keeping my focus on the day, on now. Thirty-five radiation sessions; I’ll mark them off on a calendar, my countdown to freedom.

Thanks all for the surprises in the mail, for your love and support. Especially on a week like this, you elevate my spirits and keep looking forward.

Love…

Richard

Posted by greenpoet at 04:34PM (-04:00)

Comments

- BeJae March 24, 2010

Ah, but remember: The couch is your friend … For now, anyway. You'll have so much time to be busy and productive after all your treatments are over. You may never again have long days of sleeping on the couch with a snuggly, sweet dog. I say go with it … Of course, I'm pretty much of a slacker myself and feel compelled to recommend lying around to all you energetic, over-achiever types. I know you're afraid that, if you allow yourself to give in to the lying around and sleeping all day, it will claim you for good. It won't. I promise, it won't. I've been working on Jackie (another over-achiever) for twenty years now. Every once in a while I can talk her into lazing around … but, it doesn't claim her … and it won't claim you. Go with it. Just for now. It may be your only chance to experience true laziness … which I find completely blissful. Think of it as a creative activity. You'll be in and out of sleep, which means you will remember more dreams. (Have you noticed if the chemo affects your dreams?) So, pursue laziness as a goal during these high fatigue days. Think of lying on the couch keeping Rudy good company as your job. Get busy, Fox.

Love you, cupcake. Are you asleep yet?

- greenpoet March 25, 2010

Oh yes, the couch is my friend. And Rudy Dog understands that I'm ill. Soon as I lie down, he settles into the crook of my arm and we drift off into dreamland. Don't know If I remember my dreams more vividly than usual. When I was working long hours & days, I yearned for a break in the action, a break highlighted by a daily nap. Little did I know! Not worried about getting back in the flow of work. This experience is making me tougher, more able to face tough challenges. Looking forward to getting my life back.

There is a surreal quality about my naps this cycle. They are so deep and when I wake it's gradual like I'm slowly stretching from a fetal ball into a standing position, disc by disc.

I'm staying busy. Naps are an excellent chore. No appointments until April 8th - a vacation!

Love you, too! You are the icing on many lives!

March 25, 2010 – Nap day, take two

Thursday, March 25, 2010

I could almost write "ditto" for today. Could but that wouldn't tell the full story. My body is demanding sleep and I am happy to oblige.

Slept really well last night and woke around 6:15 am. Took pain meds and my before breakfast meds, checked email and favorite sites, and then downed a Vanilla Boost. Hopped into the shower – man, does it feel good to be able to get wet without worrying about the pump or lines – and took a long steamy one. Got dressed and noticed that the pain meds had kicked in, so I made breakfast and ate quickly.

While I was going through my morning routine, Ann and Adam were also getting ready for the day. Rudy and Lacey Dog followed us around the house, identified our activities, and knew we were heading out.

At 8:00 am, we climbed in the car and set off for Dana Farber. It was a sunny, crisp morning, an ideal day for a road trip. Overall, it was a smooth ride into Boston – smooth for Boston that is. We only hit two major backups, around the I-90 / I-495 and I-90 / I-95 interchanges. We negotiated our way through the Cambridge/Allston exit to reach Storrow Drive. From there, Dana Farber is just down the road.

Ann parked the car while Adam & I went up to the 11th floor for my blood work. On the way up, I showed Ad a bit of Dana Farber's vast Red Sox memorabilia. Blood work was easy (oh port, I sing your praises!) Ann joined us, and we walked over to the Thoracic Cancer suite for the vital signs check and my appointments with Dr. H. and Dr. H.. My vitals were spot on. I was especially pleased to find that I gained a few pounds.

Drs. H. kicked my tires and checked my fluid levels. They peered down my throat, probed my neck in search of my lymph nodes (they felt nothing once again- yay!), and interpreted my blood levels. Then we discussed the post-intensive chemotherapy steps that pave the way for radiation and the likely pattern of companion treatments I'll have during radiation.

We left the 11th floor and made a side stop at Lower Level 1 which houses the cafeteria and one of the major Red Sox memorabilia collections. I showed Adam prime autographed Carl Yaztremski and Ted Williams game jerseys coated with Fenway dirt and a massive autographed baseball collection.

From there, it was on to patient parking and a sunny ride home to Worcester, which I naturally slept through (oh, but the sun on my face was a joy.) How did I spend the afternoon? On the couch curled up with Rudy Dog napping. There was vacuuming going on inches from my head that didn't stir me.

Around 4:00 pm, I woke and decided it was blog time. To be honest, I fell asleep several times while trying to write, so I sought inspiration in music: Erin McKeown's *Small Deviant Things, vol.1* and The Benjy Davis Project's *Dust*.

On this sunny evening, I thank you all for your love and support. You make my days lighter.

Love…

Richard

Posted by greenpoet at 06:51PM (-04:00)

Comments

- BeJae March 26, 2010

Limbo, one of our cats, and I fell asleep on the couch last night as a tribute to you and Rudy. I had the green throw blankie and Limbo covering me, and an old repeat of Seinfeld on TV as the temperature outside dropped and the rain turned to snow. I thought of you and hoped that your naps are that delicious.

Some of the snow has lingered into today and the wind whistles through the alleys behind and beside our house. But, the sun is out. And it's toasty inside. And I'm imagining you and Rudy all warm and comfy.

I'm so glad the report from your appointment yesterday was so good. Keep that good news coming … between naps, of course.

March 26, 2010 - Back at St. Vincent's Hospital

Friday, March 26, 2010

I SPIKED A FEVER, SO I'M BACK IN THE E/R.

ADMITTED FOR A FUN VACATION.
Posted by greenpoet at 09:14PM (-04:00)

Comments

- TaDa March 26, 2010

get better.. it is normal to do that crap through chemo.

- BeJae March 26, 2010

Thanks so much for letting us know. I'm glad they're keeping a close watch on you. We're thinking of you over here in Ohio, wishing you well. Keep going. The hill is steep right now, but soon you'll be coasting and everything will taste good again. I'm glad you have your sweet family for company.

- Nancy March 27, 2010

Hope you are feeling better today!

- greenpoet March 28, 2010

Thanks for the thoughts and words of support. I'm back home - tired, but doing well. Gonna try to post later today...

Love...

Richard

March 28, 2010 – Hospital adventures, take two

Sunday, March 28, 2010

I really thought I was feeling fine on Friday; yes fatigued, but I was entering the peak impact of the chemotherapy side effects. Woke up from another nap around 4:30 pm, and felt ok but a bit flushed. Ann used her time-trusted thermometer – her forehead to mine – then grabbed the digital one – 100.7, above the 100.5 cutoff to head to the E/R. I put together a hospital kit while Ann called doctors. Adam took care of the dogs and called Dan who was driving in from Cambridge for a weekend visit.

Ann, Ad, & I piled into the car and made the short ride to Saint Vincent's Hospital. Our experience last month proved invaluable. We knew how to present my symptoms in the way that highlighted both chemo and a very low white blood cell count. I was triaged and then isolated in the triage area. A nurse took vitals, blood, gave me some meds and then moved me into an isolated room in the E/R. A chest x-ray, urine sample, and port activation later, they were moving me up to a private room with a "gloves and masks" restriction. Dr. Deb was not on call this weekend, but we were happy with Dr. J., the doctor assigned to me. The first consult was to the oncologist on call. We were headed in the right direction.

I was very happy with my care at St.V’s this time around. The nurses were wonderful and caring. The doctors prescribed a course of action that made sense for a patient undergoing chemotherapy. Dr. J. listened well and explained the purpose behind the treatments clearly. He has a trait I admire in all professionals; when encountering a problem that is outside of his field of specialization, he says so and consults an expert. Basically, the plan was to check the usual list of suspects for infection while starting IV fluids and antibiotics. In the end, the conclusion was that the infection was caused by an unidentified source, exasperated by the low white cell blood count from chemotherapy.

During the three days and two nights I was in the hospital, I was constantly hydrated. The fluids made me stronger. Dr. S.’s partner Dr. D. came in daily as the oncology consult. Like everyone in her and Dr. S.’s, practice, she made me feel cared for and in good hands.

I returned home today a little after noon and collapsed with Rudy Dog on the couch. The rest of the family watched me sleep while reading, computing, and watching TV. This evening, Dan drove back to Cambridge to be ready for tomorrow, a workday. Ann, Ad, & I are sitting around, taking it easy.

This was not the family weekend we hoped for, but we certainly spent a lot of time together! Adam & Dan were both here to help in any way needed. That took pressure off of Ann.

Passover starts tomorrow night. Don’t think I’ll be eating much Matzo with my mouth sores!

Thanks everyone for your support and notes of concern. With your help, I move forward.

For now, I nap again!

Love...

Richard

Posted by greenpoet at 07:06PM (-04:00)

Comments

- BeJae March 29, 2010

So gald you're back home again! You just can't go off for too long and leave Rudy to nap alone. A dog's gotta have some company, doncha know.

I hope that the mouth sores settle down and that, after Passover, you'll feel like diving into the guiltless eating.

Welcome home!

March 29, 2010 – Post hospital Passover blues

Monday, March 29, 2010

I felt good, fatigued but good, when I went to sleep last night. Felt good while sleeping and during my pee breaks. Woke up around 8:00 am, got out of bed, and felt punky (this does not mean ready to go a Clash concert in 1979; that is good punky.) I was lightheaded, weak, and able to eat only part of a bowl of Cream of Wheat and drink a Boost. I hit the couch and moved in and out of naps.

I was concerned that my blood numbers might not be bouncing back. I felt flushed and wondered if I was running a fever. Made a phone call to Dr.S.'s office and made an appointment to see a NP, have blood drawn, and get hydration at 2:00 pm.

Adam and I watched TV and talked until Ann returned home from seeing patients. Ad went to workout at a local gym while Ann took a look at me. She noticed my flush, but the thermometer did not show a fever. Ann asked me how much I was drinking, which was not a lot, and sat bottles of water in front of me and encouraged me to drink. Adam returned home. We each had our own version of lunch, for me a Boost. After lunch, Adam worked on his laundry and began packing for his trip back to Boulder.

I'm still in the midst of the peak working side effects of the chemo cocktail. My mouth has more sores and my cheeks have increased pitting. My gums are very sensitive. I know one day I will wake up and the process will reverse. Until then, I hunker down and deal with it an hour at a time. The stay in the hospital has impeded the healing process.

Ann & I went to Dr. S.'s office and met with the NP. I had my port accessed, blood was drawn, and hydration hooked up. Adam joined us; the three of us sat around and talked. This wasn't too fun a Spring Break for Adam. He knew he was coming during the hard week of the chemo cycle. The hospital stay and its aftermath got in the way of a family weekend. We did get to spend a lot of the days together. It was nice that he & Dan had some time with each other.

The NP came back with my blood numbers, which showed significant improvement over yesterday. The hydration ran its course and gave me a boost. A nurse deactivated my port and we headed home.

The first Passover Seder is tonight. Ann decided that she didn't want to leave me here alone (a good idea.) Adam drove my parents to Lynn & Alan's home for the Seder in their car. After the Seder, Adam will drive into Boston with Dan, and catch his flight to Colorado in the morning. Someone will drive my parents and the car home after the Seder. It will all work out. I'm sad to miss the Family Seder and this is the first one in several years that my parents have been healthy enough to attend. Every Seder, I look around the table and think about the faces there and not there. Seders mark the years. This year, it's my turn to be a face not around the table. My job is to get healthy. Tonight, I'll be grateful for all gifts in my life and know that the Family Seder awaits me next year.

I haven't been up for returning emails. In a few days, typing will get easier and I'll get back in the swing. Thanks all for your support, love, and good wishes. They really help on days like today.

Love…

Richard

Posted by greenpoet at 08:14PM (-04:00)

Comments

- TaDa March 29, 2010

Good wishes.... Always....

- Nancy March 29, 2010

hope you rest and recover.hope the worst is over,and that tomorrow is a better day.

- BeJae March 29, 2010

I don't know very much about Seder, but I read that it symbolizes sacrifice and hardship. (Of course, it's much more complicated than that.) Even though it is a remembrance of historical hardship, it seems like it might also remind us of our own hardships, things like mouth sores and nausea and being separated from our loved ones during important rituals. So many of us have ease through most of our years. But, none of us is exempt from pain and sacrifice.

I want you to know how much I appreciate your devotion to all of us symbolized by the sharing of this experience through your writing. The more we can understand about other people's struggles, the more enlightened we are about our own. And we will all have them. We will all have our years of being missing from the table.

I'm sure that being with you is exactly the spring break that Dan and Adam wanted and needed. It's no vacation this year (I'm sorry, but hospital vacations just do not count, they don't, no), but it is one of the most valuable learning experiences they will ever have. To see someone meet hardship with patience, humor and grace is a very meaningful experience for all of us. To taste the salt water and the bitter herbs and to still smile in gratitude for the goodness of life is the most important lesson of all. Your sons are fine, good men. They will be even better for this. We all will.

I hope that you will nap and heal and bask in the love of your family and friends. We bask in yours.

- greenpoet March 30, 2010

Thanks Laura, Nancy, and BeJae - feels so good to have you hear with me!

- greenpoet March 30, 2010

BeJae - when I feel stronger, I gotta riff off your words. We'll have to do a spokenword venue sometime. Your lyrics must be on fire! Love you!

March 30, 2010 – Keeping busy…

Tuesday, March 30, 2010

I went to sleep last night with the thought in my head that each day is going to be better. Yesterday was the crash day after coming home from the hospital. Today with a day of rest on the books, I would be stronger.

I woke up working to shake the cobwebs out of my head. Had a Boost and my first meds, sat down and checked email and favorite sites. Wasn't feeling great. Morning is the most challenging time of the day. Instead of making Cream of Wheat right away, I decided to wait until my stomach said "feed me." Over the past few weeks, I have accumulated a list of home office chores. Started at the top of the list and took each task on. Nice feeling to check each one off. As I kept busy, I felt better. I took the focus off of chemo and put it on accomplishing small chores. My small list spanned over two hours. I was hungry and made Cream of Wheat while finishing the last two items on my list. Ate my cereal and decided I'd earned a nap.

One of my chores was to try to fix Ann's laptop. It's off its three-year warranty. Trying to repair the most visible issue, I discovered a couple of larger issues. Decided that the potential cost of fixing the computer versus its value once repaired didn't justify the repairs. A new item was added to the list (a fun one), get Ann a new laptop.

As Rudy & I tried to nap (I was tired but less fatigued – keeping busy did the trick), Ann phoned me from her office and we decided to do a Best Buy and library run. Best Buy is a fun store. It's prudent to have a firm list in hand when entering those doors. There were two models of MacBooks that fit Ann's criteria of a 13.3" screen. After playing with the two, she picked the MacBook. We'll set it up tonight and move all her user data over from the old machine.

The last week or so, a gradually louder howling has been emitting from behind the television. I traced the source to the fancy surge protector all the components are plugged into. While at Best Buy, I picked a simpler model. It's all gray, instead of a rainbow of colors. I think it will still work fine.

We made the drive through unusually slow traffic to the library. Ann dropped off a couple of books and picked up one we had on hold. The drive home in heavy rain and heavy traffic was not a lot of fun. Worcester is great at starting road projects but not so good at finishing them. A friend from St. Louis once thought the city's name is really "Under Construction." I had to explain a loose consortium of Boston songwriters had already claimed the name (great CD, by the way, echoes a seminal time in the MA music scene.)

We arrived home. I opened the new surge protector box and edged behind the television. The fancy old one seeing the plain new one began to howl. I powered the old one off and was rewarded with delicious silence. Moved seven plugs & power blocks to the new one, powered it on, and we were good to go!

Now, I was good tired. I lay down on the couch with Rudy, put baseball on the TV, and eased into sweet sleep. Note on the baseball games: when I was a child, Zady would put me on his couch with blankie and pillow, turn on the baseball game. Instant sleep. The technique still works.

After the nap, I made a few phone calls from my phone call list (tomorrow morning's keep busy list.)

My mouth is still a wreck, a little worse than yesterday. I know one morning I will wake up and it will be a little better than the day before. Then, it will improve daily and at a rate that will amaze me. In the meantime, I need to keep busy and be productive. It's easier to live in the day or the hour when I'm active. My thought tonight as I go to bed will be on my early morning tasks for tomorrow. Keep busy, boy!

Thanks all for your support, notes, and comments. I never feel alone on this journey. You are wonderful beyond words.

Love…

Richard

Posted by greenpoet at 05:54PM (-04:00)

Comments

- TaDa March 31, 2010

You are so strong...!

March 31, 2010 – In like a lion, out like a lamb

Wednesday, March 31, 2010

I had another fine night's sleep. Woke up around 8:30 am in my current morning punk funk. I feel great in the afternoon and evenings. I know I'll feel better as the day progresses. Just got to get there, to figure out the route. Slogans work for me. So I kept telling myself "Keep Busy" and "Push on Through." I had a Boost with my first handful of meds then did my email and web sites check. There was miscellaneous household picking up and putting away to do. I found the cables that I'll need to transfer the data from Ann's old computer to her new one. Checked my list of phone calls and made the first two on the list.

My body felt different today, so I spent a little while listening to it. My stomach was crying for food, but more of a snack. Instead of making a double portion of Cream of Wheat, I toasted a piece of white bread and covered it with blackberry jam. It hurt to eat the toast; had to find the less damaged areas of the mouth to chew and swallow. Took a long time to get that slice down. My reward was a swig of Magic Mouthwash, a totally numb mouth. Today, my body said "take a morning nap." Rudy & I hunkered down on the couch and fell into deep sleep. An hour or so later, the phone rang. I woke feeling pretty good. I've only felt better as the day has moved on.

Keeping busy! Ann was ready to set up her new computer. One of my favorite computer acronyms is NASAIS – not as simple as it seems. Generally setting a new Mac and transferring data from the old machine is a breeze. Today had a big curveball, which really was good for me. Computers don't frustrate me. They give me high level puzzles to solve. I had to call Apple on this one. Ann's MacBook does not have a firewire port (transferring the data is the only time she'd ever need it), so we had use Ethernet. There is a glitch with the automatic transfer, so had to set up the machine, download and install the OS updates, and then manually transfer the data. It's still chugging. I'm like a cook, smelling the broth now and again. It will feel good when the new machine is up and churning. The new MacBook is an elegant little box.

Mouth sores have fuzzy logic. Each round of chemo, I've had one that is perfectly placed for pain. This cycle, the sore sits a little below my lower lip where my front teeth normally rest. It's in a can't miss zone. This too shall pass!

Tonight, I'll again go to sleep with positive thoughts about the morning. In the morning, I'll see where I am. If it's bumpy, I keep busy. I do know that one of these mornings, I will wake up and feel up, ready for the day. Until then, I work the moment. Cancer has many lessons to teach me.

Thanks for your support and for here being with me.

Love…

Richard

Posted by greenpoet at 04:02PM (-04:00)

Comments

- BeJae March 31, 2010

It's sort of like a particularly hard Iowa winter: You know it will pass, you just don't know when. I have several friends with acreages. There's always stuff to do in the winter, it's always outside and it always hurts, because it's too cold to be outside. Sometimes it seems to drag, the winter does, but the chores, the animals and the incredibly scary drive to the faraway grocery store keep your mind focused and, somehow the winter passes and there are a few warm days in a row. There's the melt and the mud. Then it snows again. More melt, more mud. It gets a little bet. Then one day it's a lot better. Then it's spring; time to plant, lots to do, lots to keep you busy. It's a good life. You think back over that awful winter, look at the photos of the snow piled up six feet on either side of the driveway. You remember it was bad, really bad, but you don't remember exactly how it felt. And you begin to tell yourself that it was bad, sure it was … but, not all that bad … not really.

I can read the melting in your words. You're getting better. One day, you'll be a lot better. On that day, we will celebrate the fact that we can get through pretty much anything, even a particularly hard Iowa winter. And even this.

- greenpoet March 31, 2010

Iowa Winter - what a charming and apt metaphor. I'll read these words in the blue morning. BeJae, these messages are incredible gifts. They get me through the hard hours.

I'll dream of celebrating tonight!

April 1, 2010 – No pranks thanks.

Thursday, April 01, 2010

I had another marvelous night's sleep last night. Even better, I woke in a good mood and stayed in a good mood. Had a Boost and tried a piece of white bread with jam, but even with pain meds in gear, I couldn't chew and swallow the soft bread. So, I had another Boost.

Chemo is cumulative and each cycle has its own rhythm and meter. During chemo orientation, I came away with the impression that the first cycle would be a blueprint for the next two cycles, i.e. how many days out would mark my low point, when the "sweet week" would begin. All three cycles have had significant variations in both timing of stages and physical effects.

Today (well, all week), I am aware of my mouth. Though the pitting and number of sores feel less (in quantity) than in the first cycle, what I have is more severe and more painful. My daily dental care is a real challenge. If the toothbrush is off by a millimeter, I jump through the ceiling! I use Magic Mouthwash before brushing, but even MM has its limits.

Chemo is a mind and body experience. Though it's tougher physically each cycle, I have developed tools to deal with the pain and fatigue. It's most important to listen to my body. I need to understand what I need physically. I need to listen to the cues my mind is sending me via my body. Everyday is different as the chemicals find new ways to twist my anatomy.

After my usual morning routine, I stayed with the "Keep Busy" theme and knocked off the rest of my phone call list. I read a bit of Jess Walter's *The Zero* until my eyes got heavy. At 10:30 am, Rudy & I stretched out on the couch and fell into a deep nap. We woke an hour later and I was hungry. Made a double portion of Cream of Wheat and blended in brown sugar. After lunch, the doggies and I sat out on the back porch. It was a beautiful day, warm and sunny, the pinnacle of New England Spring. My original intention was to take the dogs on the medium walk today, but fatigue set back in. I read while they ran around the yard. The book is really engaging but try as I might, I kept drifting off. We headed back into the house, Rudy & I to the couch to nap all afternoon.

Ann & I are spending a laid back evening. We sat on the porch and talked, enjoyed the sweet breezes. After supper, I tweaked a couple of things on her new computer. She's enjoying it.

Today was a long nap with a few interruptions. I'll sleep well tonight despite my hours on the couch. Over the past decade, I've focused on listening to my body. Like everything else with chemo, this listening has become unconventional. I've had to learn new strategies and a new vocabulary. My body is trying to express a wholly new experience while my mind is busy rearranging its templates for understanding. Emotions, my link between mind and body, are oddly more stable. I know to let myself feel them, to let them play out, and to follow them to the source. My emotions are using the same language and mode of communication as before cancer treatment. What I once thought to be the most volatile part of my being has turned into the stabilizing element.

Thanks everyone for your support. You are a well from which I draw strength and energy. I can't imagine going through this without you.

Love…
Richard
Posted by greenpoet at 08:34PM (-04:00)

Comments

- BeJae April 02, 2010

Unconventional listening: See, I think you've always been adept at it. It's why your musical taste is so broad. It's how you so easily get both Don White and me, even though we're very different in our approaches to songwriting and performing. (I think Don is great, by the way … and my musical taste is far narrower than yours. I realize that pretty much everybody thinks Don is great. He's irresistible, as far as I can tell.) You listen to each of us differently and you hear and sense what's behind what we do. Your skill as an unconventional listener is the reason you and I know each other.

Unconventional listening, it seems to me, requires noticing information from different sources in different ways; hearing the strings of the guitar, but also feeling the twitch of the muscles and the coursing of the blood and the sting of the chemicals, tasting what was delicious yesterday and noticing that it's odd today, seeing and smelling the day-by-day change of winter into spring. Some of it is sudden and obvious, but much of it is subtle and slow. And it's not just noticing the information. It's taking it in, being moved by it and acting on it. These are all part of unconventional listening. This is a skill we all need to learn. It takes great flexibility and patience. You model it so beautifully.

As volatility turns to stability, know that everything is on your side … Even what you least expected to work for you is pulling you through.

Here's to you, my friend. Thank you for writing. I am listening.

April 2, 2010 – Cumulative and cumulous

Friday, April 02, 2010

The physical effects of chemo are cumulative. They are easy to quantify, classify, and identify. The physiological effects are also cumulative, but subtle. I began this journey upbeat with the resolve to stay upbeat. Overall, I think I've been successful. I have my easy days and my challenging days. I keep the focus on now and don't get lost in the unpleasant details of my future treatments. Throughout this process, I've kept a camera running on myself, watching for any signs of self-pity or negativity. What goes on in my head is my responsibility and I have the tools and motivation to stay level and positive.

That said fatigue is physical and mental. I'm really ready to be finished with this period of active chemo symptoms. My mouth and tongue are still pitted and covered with sores. I would love to eat something other than Cream of Wheat or scrambled eggs. Mostly, I'd like to feel quasi-normal for a couple of weeks.

In my daily routine, I focus on dealing with the physical aspects of fatigue. Today, I realized that I need to extend that focus to my mind. It's a pretty obvious concept but one I haven't addressed. Mind and body are intertwined and, when I listen, clue me in on what the other is experiencing. Keeping the fatigue focus on body only doesn't cut it. Mind and body support one another. I'll start by using self-hypnosis and relaxation tools. Today was a gorgeous Spring day. Ann & I and the doggies sat out on the deck. We talked and read, but mostly soaked in the sun. I love Springtime in New England. The air is sweet and musky. A wide variety of birds visit our backyard. We live about quarter mile from the headwaters of the mighty Blackstone River. On a quiet day, I can hear the water flow from the pond into the river. I have a Blackstone Valley vanity plate on my Prius. It feels like (and is) home.

I figure by Monday, I'll be out the other side of the working side effects of the chemo. That will give me a couple of weeks to put weight on before the radiation treatment starts.

Thanks for your support and good wishes. You carry me through these days and I am ever grateful to have you in my life.

Love…

Richard

Posted by greenpoet at 08:12PM (-04:00)

Comments

- BeJae April 03, 2010

You have been so amazingly positive through these chemo cycles. I know someone else who went through treatment for throat cancer this winter, so I've heard how difficult these treatments are. Your attitude and your stamina are matchless. Though you tell us of the challenges of your treatment cycles, and I appreciate that so much, you never complain. I never detect even a hint of self-pity in your words. Your mind and all of your senses are always on the goal of reclaiming your good health. You keep on going, relentlessly, tenaciously.

Reading your blog has been a remarkable experience for me. It has touched every aspect of my life. It says to me, "Come on, come on, you can do it." It reminds me that, if you can get through this extraordinary challenge in your life, I can get through whatever seems difficult in mine. Thank you for that. It is invaluable.

Okay, what you really need during this phase of treatment is grits … yummy, soft grits. But, here's the problem: Grits aren't so good without buttermilk and cheese, neither of which you eat. There's always a catch with southern cooking, have you noticed that? Could be worse. I could be suggesting redeye gravy. Even I can't go quite that far into the swamp.

Greens would be good, and you can make them real tasty without meat, and you can cook them long enough that they turn into soft mush, but they must have vinegar … And vinegar, right now, would send your poor mouth into agony. Always a catch with southern cooking.

I am thinking of your poem, Roux, and wishing that I could hear you read it out loud right now. I wish you heat and spice and a savory blend of experiences, my friend. I wish you the soft sounds of your beloved river, which must surely flow from where you are to where I am.

April 3, 2010 – Perspective

Saturday, April 03, 2010

I judge a good vacation by how well I don't know what day of the week it is. If I have no clue, the vacation is smoking!

Since I've been in cancer treatment, I'm real foggy as far as what day it is, most notably during the weeks I'm dealing with chemo side effects. My phone and computer beep at me to remind me of doctors' appointments (someone has to be in charge) otherwise one day is like another. So here it is, a beautiful sunny Saturday, once the reward for a good week's work, now a day in the down period of a chemo cycle. The sun and blue sky helps my spirit. How could I ever feel down on a day like today?

My perspectives have been altered in more than a temporal sense since I started cancer treatment.

The boy who was me before cancer would tense up before having blood drawn. Now, I have perspective. Blood drawn? Can't use the port for this one? Ok – but my left arm is shot, try the right one. No, not there, that vein collapsed yesterday. How about here? Too deep for you. Top of the hand? Sounds grand.

Pre-cancer, the thought of having a lesion lanced would have led to a sleepless night. Now: Where do you want me? Using a scalpel instead of a needle? Cool. This is going to sting a little? Ok. On three, all right, 1 – 2 – hey that was on two! Naw, didn't sting at all. Ok, maybe a little, but it was nothing. Great job, Doc!

Being in the hospital negated my sense of modesty. When I was in my Worcester oncologist's office getting hydration just after a hospital stay, he wanted to look at my lesion. There in the infusion room, I started taking my jeans off, and Dr. S. said "we can wait until the examining room."

Being in the hospital changed my outlook on my body. I need a shot in my stomach, ok. Do I mind if the student nurse administers it? Have you done this before? Once? Ok, go for it! (And she did, assertively, but that was cool.)

The port surgery was a snap, a nap and when I awoke I had a device implanted. The feeding tube surgery will be the same deal. I didn't and won't lose any sleep over a simple procedure.

Maybe I was just being a baby about all this stuff before. A needle, a scalpel, they hurt for an instant (sting / burn / pinch) – it's really nothing. I think of all the time I wasted worrying about these "procedures" and laugh at myself.

Cancer has many lessons to teach me. These are useful ones. Perspective comes with a price but also with humor.

Thanks everyone for your thoughts and prayers. I am so grateful to have you with me on this journey.

Love…

Richard

Posted by greenpoet at 04:52PM (-04:00)

Comments

- BeJae April 04, 2010

Welcome to my world of the flexible schedule and often being vague about what day it is … Only I don't have to have lesions lanced and shots in my stomach, so I guess it isn't quite the same. And I still have my non-hospital modesty … You're way ahead of me, as usual.

Jackie and I were talking yesterday about a trip to Florida I have planned for May. I'll be visiting my friend, Kathy, who I've known since I was six years old. We played together as children, were best friends in high school and took different paths in our wild years, but always managed to keep in touch and to bridge the gaps in time between visits, in view points and in temperaments. She and I plan to drive the panhandle of Florida listening to Tom Petty CDs. We'll explore fishing villages and small towns that have been overlooked by developers. Florida is so exotic and spooky. You see it even in Orlando where there's been a lot of development. You go outside in the morning to find your car and there are wild turkeys wandering around the parking lot. There's no telling what we might find wandering around the parking lots of small towns in the panhandle.

Jackie, knowing of Kathy's and my long relationship and our rambunctious natures, asked that we not pull a Thelma and Louise on her, since it doesn't really end all that well.

No. In the first place, that sort of thing only looks good in a convertible and we don't have one. In the second place, I'm just not an adrenaline junkie. When I go, I want to go fast, but I don't want to go scared. I'd have to drive off a cliff every day for two weeks before it would start to feel exciting instead of horrible to me. I'm pretty sure you aren't allowed to drive off a cliff every day for two weeks to get used to it before you do it for real.

I think it's amazing what we can get used to. I have no memory of my first six months of being a fulltime performer. I was so numb with terror every time I was on stage that I can't remember it. But, I got use to it and now I pretty much remember most of my shows. I often can't remember where I put the money I got paid for doing the shows, but I remember the shows. (I've put Jackie in charge of the money for obvious reasons.)

It's amazing that you've gotten use to needles and scalpels and taking your pants off in public … But, since you have to put up with those things, I'm very glad that they don't bother you much anymore.

I hope the vacation gets better all the time. But, next time, I think you should do a curse or something instead of chemo … You know, if somebody gives you the choice …

April 4, 2010 – Crawling out of the hole

Sunday, April 04, 2010

I slept heavily last night. Got up around 9:30 am, had breakfast and only some meds. My mouth was feeling better, so I cut out the pain meds and Magic Mouthwash. I did my usual computer check, then settled back on the couch and fell fast asleep.

Dan arrived a bit after noon and brought lunch from Pho Dakao. I had my first "real food" in maybe ten days – Tofu Summer Rolls – tofu and minced vegetables rolled in rice paper with peanut sauce on the side. After lunch, we (with Rudy Dog) drove to my parents' home for a visit. We stayed for about an hour, until I started feeling fatigued.

We returned home and Dan & Ann & I sat outside. Today was another gorgeous Spring day. Dan threw the ball until the dogs wore themselves out playing fetch. After a while, I was too warm, and soon found myself sleeping on the couch again. This was beginning to be one of these visits where Dan watches me sleep. Not too much fun for him. Woke up mid-afternoon and we decided to watch a bit of TV. We had episodes of "Modern Family" and "The Big Bang Theory" on the DVR. Laughter is good; it pulled me fully awake.

We cobbled together a bit of supper. I was able to eat a Boca Burger without too much discomfort. I'm hopeful that tomorrow, I'll be able to resume a near regular diet.
I'm not certain why I'm so tired today. It could be the change in all my meds as I finish the difficult period of the chemo cycle. Perhaps, it's the aggregate fatigue of the chemo process. I do know that I have to snap out of it. Tomorrow, I need to get busy and stay busy. There is a long road ahead and I must be ready to move forward shoulder down into the wind.
Thanks everyone for your support, hopes, and good thoughts. Thanks for being on this ride with me.
Love…
Richard
Posted by greenpoet at 07:26PM (-04:00)

Comments

- TaDa April 04, 2010

that magic mouthwash pulled me through at times... Sorry I haven't been around.... went to the beach yesterday and despite my husband covering me with shade, I got nailed with sunburn on my face (compliments of my meds)... oh well... glad you are feeling up to Par.... keep up the great attitude...

Laura

- BeJae April 04, 2010

I remember you predicted a few days ago that you'd probably feel better by Monday. Of course, I have my fingers crossed and my expectations up. Those expectations can be dangerous fun, I know that. You can never tell for sure what the chemo cycle will bring … or when …

There's this great drummer in Des Moines named John Kizilarmut. He sat in with us for one show when our regular drummer couldn't make it. He told me about playing in a show band for a while that required him to enter and exit the stage on a unicycle. Kiz said he didn't know how to ride a unicycle when he started with the band and that he neither got very good at it nor learned to like it. But, he could ride just well enough to wobble to his drum kit, play the show and wobble back off again … night after night after night. Kiz plays at such a high level that it's hard to believe a human being can do the things he does on drums. But, he just wasn't much on a unicycle.

I think of this every time we talk about the chemo cycle.

I hope that the ride is good tomorrow and, even if it isn't quite fun, I hope that the rocks are out of the road at least.

- drjj April 05, 2010

Foxy - Glad spring has come to you as well. Spent the day on the filthy back porch and cleaned enough just to sit out and enjoy the day. Off to the AWP Writers Conference in Denver on Tues. and am overwhelmed; lots of academics. Will try to watch and learn. Two new wild Mrs. Noah's and when I get back I should send them along to you. Both are very silly and funny and surprising to me as I struggle with my own demons. The newest on is Mrs. Noah Chats with Simba, a sestina. When in doubt I return to the sestina as it takes me places that surprise me and they seem to write themselves, I just

don't get it. Again, I hope you are saving what you're writing as there is great beauty in it. I get to touch you through your words, I get to be with you. Thanks for letting me go through this with you. I love you, Richard. My love to Ann.
janie

April 5, 2010 – Earn those naps

Monday, April 05, 2010

If I'm not careful, I could start these postings the same everyday. Here's how I started yesterday "I slept heavily last night. Got up around 9:30 am, had breakfast and only some meds. My mouth was feeling better, so I cut out the pain meds and Magic Mouthwash. I did my usual computer check, then settled back on the couch and fell fast asleep." I can say basically ditto for today (got up at 8:30 am), which is a bad pattern.

I am in some kind of funk; think a lot of it is anxiety. It could be from this whole process wearing me down, it could be the pending radiation treatments which are starting earlier than originally planned. Instead of a couple to three-week break, it's really less than a week. Whatever the cause, I need to root it out and deal with it.

When I began treatment for cancer, I was bound and determined (and continue to be) not to feel sorry for myself, no pity pot. My goal was and is a positive attitude with which to fight this disease. I have to balance that goal with an understanding of how I work emotionally. When I set the bar, I usually set it too high and too rigid. Nothing is absolute. These treatments are difficult challenges and I may not be allowing myself enough space to feel those difficulties. I can't pretend the pain and anxiety away. I can't work it away. I have to find a way to let myself feel what my mind and body are telling me, embrace the emotions, and then let them go. I think the anxiety may be breeding there.

When I'm home alone, I'm left with my mind for my companion. My mind can be a dangerous neighborhood. Sometimes, I trick it (really myself) into being a surreal but happy place that has no roots in reality. Other times, it plays games with me and sends me into dark moods. What's important for me to constantly acknowledge is that I am responsible for what goes on my mind. Instead of accepting a view that is too soft or too harsh, I must challenge what's going up and inject a bit of reality.

I've decided that I need augment my KEEP BUSY slogan with another: EARN YOUR NAPS. I still need more rest than usual, but I also need activity just as much. If I want a nap, I can pay for it with chores, a walk, or a bike ride. If I let myself be a couch potato, my body will atrophy and with it, my mind. Got to keep those two in tune.

At lunch today, Ann & I took the doggies for a short walk around the neighborhood. My legs felt fine after the walk, but my body a bit dazed. Without the meds, I should be clear. I need to get active.

My stomach is playing games again. At the point in the chemo cycle when I drop the pain meds, I go from stool softener mode to Imodium mode. All I ingested this morning and noon was a Boost and white toast with jam. At about 3:00 pm, I downed a double portion of Cream of Wheat and that has settled well. I'm considering a short bike ride followed by an earned nap.

Thanks everyone for comments, emails, and support. On the easy days, you make me glow. On the hard days, you pick me up and get me moving in the right direction. I can't imagine being on this fight without all of you standing with me.

Love…
Richard
Posted by greenpoet at 03:20PM (-04:00)

Comments

- BeJae

April 05, 2010

Well, I just have to say that I love the dangerous neighborhood of your mind. Oh, I know, I know, you gotta keep it wrangled, I'm with you on that. It's easy for an inventive, imaginative mind like yours to create run-amuck anxiety just like it creates poetry. It's kind of like a husky: It really needs a job and, if you don't give it one, it's gonna tear up the couch. I'm so glad you've given your mind the task of writing about your days and how you feel. It would be just fine with me if you wrote the same thing every day … but, you won't … because you're not going to feel the same every day. I know it gets frustrating sometimes when you're waiting for a major change for the better and all you get is a subtle one, or no change at all, or even something that feels like a backslide. It starts to feel like it's always going to be this way. But, your amazing body won't be full of chemo forever. It's gonna get rid of it and the Alien with it. You're gonna feel great again. You're gonna get used to feeling great. You're gonna get so used to feeling great that you'll start worrying about dumb stuff that doesn't really matter like the rest of us do.

I still think that the naps are part of your job right now. The body does miraculous stuff during sleep. It's fixing itself while you nap. It never stops.

I send you my love, my friend, and I wish you something better than Boost and white bread tomorrow.

April 6, 2010 – My bike is my friend

Tuesday, April 06, 2010

Yesterday, I did take that ride on my LifeCycle. Road 12 minutes at half my normal intensity. Turned on my iPod, and in random mode it kicked out the following two songs to start: The Allman Brothers Band "Midnight Rider" from *Live At The Fillmore East (Deluxe Edition)* and The Rolling Stones "Happy" from *Exile On Main St"*. These two songs immediately reminded of my Webster buddies Papa Ray and I-Man; the two albums tie to adventures, musical and otherwise, I shared with the two JAX boys. I was on that bike pedaling and Duane's guitar cut right through me. And I got mad. Mad for the first time in a long while. Mad at cancer. I can't be nice in a fight for my life. I had a rush of energy along with the anger and started yelling (in my head, expletives omitted) at the tumor. Anger is not something I do well or often. I used to see all emotions as "good" or "bad". As I've gained wisdom and less hair (pre-cancer), I've grown to realize that each emotion has a full range of good to bad. What I do with the emotion is the key. So, here I am pedaling and seeping anger and it felt so good! When my bike ride was finished, I was in the best mood I've been in a long time. And I carried some of that being pissed off with me. My task now is how to harness it when I need it.

I'd certainly earned a nap, but didn't fall asleep immediately. I lay on the couch patting Rudy Dog and having him snuggle closer. At some point, I went deep into nap land. When Ann came home, it took me a while to wake up and sit up.

My stomach is still playing the Imodium game, so I ate a careful supper. My digestive system has to straighten itself out; I need to eat mass quantities and put some pounds on before the radiation treatment starts.

I stayed up late watching the Butler v. Duke NCAA Men's Basketball Championship. It was like a book I couldn't put down. I was rooting for Butler, who lost by a bucket, but it was an exceptional game to watch. Tonight my Connecticut Huskies take on The Stanford Cardinal in the NCAA Women's Championship. I've got my bottles of water lined up! Side note: did you see President Obama play Clark Kellogg in horse (renamed POTUS for the occasion)? The President has game! He was consistently hitting long three pointers. Clark let Obama win the game I think (amid some gentle trash talk), but the President's left hand jump shot is impressive.

I woke this morning feeling better. My stomach is still unsettled, but I'm hoping it will straighten itself out soon. Chemo attacks cells from the esophagus down to the lower GI tract. It's such a pleasant side effect.

I started the day with a Boost and a bowl of Cheerios with a banana and soymilk. It's odd, I I normally love Cheerios, my choice for breakfast for years. But now they taste, uh, not so good. I ate them, need them, ignored the taste. Being a vegan toughens up your taste buds. I did the dishes and cleaned up the kitchen, then poked around on my computer before taking my morning nap.

I had a few emails about yesterday's posting. My dear Webster friend and ace nurse Laura advised "I REALLY THINK YOU ARE EXPECTING TOO MUCH AT THIS TIME.!!!!!!!!!!!!" and then elaborated in great graphic detail about each paragraph in my posting. She wasn't sure whether to send the message, but I wrote back, yes, please hit me upside the head when you think it's called for. Laura's a peach; she never minces words. Cousin Betsy wrote "I understand your anxiety; you wouldn't be human if you didn't have some. You're dealing with the unknown. And if you're asleep, you don't have to think about what's next on the agenda." and "I'm in disagreement about earning your naps. You're undergoing treatment for cancer.....those naps are well-deserved and greatly needed. I feel like I earned every single nap.... Your body needs to regroup. I never fought it. I think naps are as important as medication, maybe even more so." Betsy just finished her cancer treatment and has been wonderful in holding my hand as I go through the process. Cousin Arlene added, "Please don't be so hard on yourself... All your feelings are normal. You still have a long road ahead but you will take it 'one day at a time', one moment at a time. One thing that can't be controlled is the passage of time and it will pass, along with your treatments." Arlene is the sweetest and toughest woman I know. She's fought cancer three times and is an inspiration to the rest of her family currently fighting the fight.

This whole anxiety and attitude thing is my current challenge. Am I being reasonable with myself? If someone else were dealing with this same issue the way I am, would I think they were being too hard or too soft on themselves? My mind is a dangerous neighborhood. The monsters and the angels are me or mine.

I rode the LifeCycle again today, same time and resistance. It was a fluid ride and felt good, but I didn't have an epiphany like yesterday. Hey, how often should I expect an epiphany? I'm off to see psychologist D and see if he can help me clarify what I'm feeling and thinking.

Thanks everyone for your support and good wishes. I never feel alone in this fight.

Love…

Richard

Posted by greenpoet at 03:14PM (-04:00)

Comments

- TaDa	April 06, 2010

Nobody should ever feel Alone... You are strong and your attitude is everything... I am sure your drs have told you the same....

bicyle .. you are brave...!

- BeJae April 06, 2010

If someone else were dealing with this same issue the way you are, you would think that you were reading the words of one of the strongest and bravest people you'd even known. You'd worry that he was being too hard on himself, that he was not resting enough, that he was not being gentle enough on himself. You'd worry that he was being too soft on himself and not shepherding all of his forces all of the time so that he could get through this very difficult treatment. You'd worry. But, you would realize that he is smart and wise beyond measure and you would know that he would find a balance between the two. You'd call on all of your experience, personal experience if you had it, professional experience if you had that, to try to help minimize the burden knowing that, ultimately, he would have to find his own way. You'd wish that you could do something, take a round of chemo or radiation for him so that he could at least have a break. You'd feel a little helpless. You'd feel deeply grateful reading his posts every day, deeply thankful to know that he was still there, still fighting, still mad, still connecting (and still listening to the Rolling Stones). You'd feel honored to be included as a friend in his life when it was hard and when it's glorious. You'd feel blessed, even though you don't like that word very much (oh, wait, that's me, not you), to be a part of it all. That's what you'd think if someone else were dealing with this same issue the way you are.

Just so you know, I'm with Cousin Betsy on the sleeping thing. If it were me, I'd want to sleep through not only what's next on the agenda, but the whole series of treatments. I'd asked to be knocked out for the whole thing. (That's not advice, by the way, I'm just expressing my own anxiety. I went to the hospital and got knocked all the way out to have my wisdom teeth extracted. I'm not brave when it comes to medical/dental procedures. I just want to sleep through it, thanks.)

I made eggplant curry with peas and tofu on rice and quinoa for supper. I cooked it down to mush, all but the tofu, which isn't really any chewier than white bread. It was yummy and soft and you could have eaten it. You should have come over. It's only eleven and a half hours, if all goes well. It's a long drive for something that might have tasted like today's Cheerios to you. But, you would have made me think it was the most delicious thing you'd ever tasted regardless. You're just like that.

April 7, 2010 – Dancing with Drs. D

Wednesday, April 07, 2010

Had a good session with psychologist D. Got to examine what's been going on in my mind, as far as emotions and attitude. One concept I carry from our discourse is how to approach what I'm thinking and feeling. When I interpret what my body is telling me (physically) about my digestive system, I do so with the understanding that my body is no longer conventional. I am dealing with a body that has endured three cycles of powerful chemotherapy. When trying to come to grips with my feelings and attitudes, I treat myself no differently than my pre-cancer treatment self. It's important that I understand that my mind is no longer conventional, too. Between the chemo agents and all the medications I've ingested, my emotions and attitudes are reeling and still seeking equilibrium. Once radiation starts, my body and mind will be facing new challenges. Again, I will have to learn the new language(s) that they are speaking. Being gentle and patient with myself will be important. It will be all new, though the adjustments to chemo will serve as a foundation to dealing with my radiated self.

Last night, I had my first insomnia night of this third chemo cycle, which technically ends today. Whoopee! I had really strange dreams during my intermittent sleep periods. Should have written them down. I can remember two: being in an institutional building (medical, business?) with odd corridors and elevators that had a food court like area that included shops and an open theater. A weird play about Jewish doctors was scheduled to open and I discovered that BeJae was one of the co-writers. I kept looking around for a placard with her name on it so I could snap a photo and email it to her. But, as happens in dreams, the placards kept shifting and moving as I pulled out my iPhone. I was thinking what a surprise and I found it first! The second dream, recurring, was that I was late for my dental appointment today. Each occurrence, the time, the reason I was delayed, and the cast of characters were different. I guess I was worried that my insomnia would keep me in bed too long. Ha! I have a 57-year-old prostate that guarantees I will not oversleep!

So, I did get up on time, 8:00 am for a 10:00 am appointment. Had a bowl of Cream of Wheat and a Boost for breakfast and did my usual morning things. I left the house in plenty of time and drove over to Jeffrey's office (my dentist and a family friend who is family.)

When I first talked with the medical team at Dana Farber, they went under the assumption that I didn't know my dentist's name. Apparently, a lot of people don't enjoy going to the dentist. I'm not one of them. Ann laughed at the Dana Farber team and said that not only did we know our dentist's name; we knew his grandchildren's names. After my examination, the team complimented Dr. Jeffrey's fine work on my teeth and gums. It wasn't what they were expecting.

Jeff wanted to look at my mouth post-chemo and pre-radiation. There are options for dental self-care during radiation treatments and he wanted to confirm his earlier plan. My mouth looks good considering the three cycles of chemo. Jeff finalized a few details on my daily care and gave me some supplies to get me started.

As I said, I enjoy my visits to the dentist. The music is always good and the conversation mighty fine. Jeff and I often swap albums; looking for tunes that other might like and may not have heard. Today was no exception. Jeff's lovely wife Nancy arrived just as my dental exam was finished, bringing a copy of Angus & Julia Stone's *Down The Way* (I have more commute to Boston music!) and a sweet card. The card is our windowsill along with the all the cards sent by friends and family. It's a way you're all here in the room with me.

I returned home and had a few chores (for work and home) to do. Then I settled down for a power nap. Ann came home and said hello, but I didn't wake for another hour. Guess I needed the sleep! Spent the afternoon outside with doggies in the 80F degree sunshine and inside catching up on email.

Tomorrow morning, I go to Dana Farber for a CT/PET scan. That data will be used in planning my radiation treatment. It will also define the impact of my chemotherapy (especially curious about the primary tumor.) I need to drink two bottles of water, but cannot eat or drink anything else. Have to be there by 9:30 am, but given Boston traffic (and a fire in Boston today), I'm leaving the house at 7:30 am. I'll bring a book and hope I'm early.

Thanks everyone for your emails and messages. I'm grateful all y'all are in my life and are here supporting and comforting me on this journey.

Love…
Richard
Posted by greenpoet at 05:45PM (-04:00)

Comments

- TaDa April 07, 2010

Wishing you well with your Pet Scan tomorrow.... Postive thinking coming your way!

- BeJae April 07, 2010

I'm so thrilled to have turned up in one of your dreams … as a writer, no less. I'm familiar with the shifting placard phenomenon in dreams. I used to have frequent dreams about trying to get to gigs at shifting locations through shifting streets. I'd finally get to the location hours late, set up and begin to play only to discover that I didn't actually know any of the songs on the set list. I'd try to fake them, which never turned out very well. In one of the dreams, the set list was written in symbols instead of words. I'd made up the symbols and then forgotten what they meant. (That doesn't actually sound all that far-fetched.) These are the anxiety dreams.

I've always had very good relationships with dentists, even moving around and having to find new ones. I always seem to luck out. I've never known their family members' names though. I've got an appointment with my new Columbus guy in June. I'm gonna ask him personal questions about himself. He'll say, "You need another crown." I'll say, "Do you have kids? What are their names?"

I'm so eager to hear the results of the scans you're having tomorrow. I've got a feeling that the Alien is on the run and will be finished off in the sci-fi radiation room. (Remember, you kind of liked it with all of its odd gadgets.) Thank you so much for keeping us up to date on all the developments. It means more to me than I can tell you. I look forward to your posts every day. I think that all of your unconventionals are amazing, your physical self, your mind, your attitudes, your feelings … You speak all the new languages beautifully.

Good luck with that Boston traffic.

April 8, 2010 – Rockin' to Boston and back

Thursday, April 08, 2010

The best way to view a morning commute into Boston is as a sterling opportunity to listen to music. Since I was driving alone, I had full control over the playlist and VOLUME. Yeah, it's a pleasure to drown out all the road noise. I left the house at 7:30 am with an empty stomach (clear liquids only before the scan) figuring I had built in an extra half hour for my appointment time of 9:30 am. Forty-five miles, two hours, no problem, right? Ah, Boston, sweet city of art and culture, perceived liberal base of the USA, most noted for its virulent drivers and random cow path roads. On the way in, I listened to Dan Bern's new live release *Live In Los Angeles* which our son Dan alerted me to yesterday. It's a ninety-minute show, similar to the show Dan & I saw him play at Club Passim on the same tour (except the Passim show was on the anniversary of John Lennon's death and Dan Bern did a fitting tribute – anyone tape that?), but not long enough for my ride. So I segued into JJ Grey & Mofro's *Orange Blossoms*, a release highly recommended by Papa Ray. Over the past forty years, I have never been disappointed by Papa Ray's recommendations and today was no different. As I locked into the teeth of Boston's urban mayhem, JJ Grey's hard driving vocals cut my way through cursing criss-crossing drivers. Papa Ray says Grey is the best white rock vocalist from the South since Greg Allman. I wasn't disappointed.

I made it to the Dana Farber garage at 9:20 am, parked and hustled to L2 and the nuclear medicine department. Made it just in time. Got registered and the CT/PET Scan tech called me in. We went to a “quiet room” and I was given an IV injection of nuclear material and rested for forty minutes. I was able to finish my Jess Walter book and start Christopher Moore’s new one *Bite Me: A Love Story* (if you haven’t discovered Moore, grab a copy of *A Dirty Job*, *Fluke*, or *Lamb* – he’s twisted in all the best ways.) Then we moved to the scan room. The CT/PET Scan is similar to an MRI only much quieter. Down the tube, in and out as it adjusts, and then it takes a series of digital images from just above the nose to the top of the thighs. I lightly napped for the half hour. The tech came in and said all done.

It was about 11:45 am. I called my sister-in-law Lynne who was with our family friend Fran at Brigham & Women’s Hospital. Fran was in for some diagnostic tests for a likely malignant growth. We agreed to meet up after I had a quick lunch (well, breakfast.) After a trip to the Dana Farber cafeteria, which confirmed that my taste buds are still out to lunch, I walked over to Brigham & Women’s. Fran & Lynne were in the same wing where I had my mask built. We sat and caught up on family news and talked about cancer. Fran dealt with the disease seven years ago and has been in remission. We shared war stories and talked about our positive experiences at the Longwood Medical Campus. A conversation between two people who have been in or are in cancer treatment is a special sharing. It’s not possible to understand the experience unless you live it. It goes beyond the physical and mental effects. The impact on family is paramount in the patient’s thoughts. Chemo, radiation, and surgery are difficult and painful as is the understanding that permanent changes are part of the cure. But it is more difficult to watch the effect on family members. As a caretaker or observer, one is powerless; there are many things that one can do – drive to and keep company during treatments, keep the refrigerator full, be there with love and support – but there is a boundary that only the cancer patient can cross. As I go through treatment, I am still powerless, but I am actively doing something. There is pain and discomfort involved, but there is a plan and I can mark off benchmarks. Today, I can say I have finished my three intensive chemo cycles and anticipate radiation as the next step. It’s no fun experiencing the treatment, but at least there is the feeling of actively seeking the cure.

After her tests, Fran got good news. She has a node that is contained. It will be removed by surgery and followed up with radiation and maybe light chemo. To the non-patient, this treatment sounds harsh; to the patient it is a relief. I went through a range of emotions during my diagnosis. The first surgeon I saw offered a poor prognosis and said that the cause of the tumor was unknown. The team at Dana Farber identified the cause as a virus, offered an excellent prognosis, and a treatment plan that may have once sounded horrific, but put in perspective seemed like a gift.

My ride home was much easier, under an hour’s drive. I finished the JJ Grey album, and moved into the Angus & Julia Stone CD Jeff & Nancy gave me. I fed the dogs early, then collapsed on the couch and slept for a couple of hours.

Tomorrow Ann & I are headed to Chatham on Cape Cod for a mini-vacation through Sunday. We need a break but Ann I think even more than I. See above. Our friend Charlene is coming to dog sit. Lacey Dog is very excited because she & Charlene share a love of long walks. Rudy will nap. I will likely check in via the blog during our break, but briefly. I will stay off email. It is vacation!

Thanks everyone for your support and comfort. You make my days brighter. Knowing you are here with your love makes each treatment gentler. You are wonderful and appreciated!

Love…

Richard

Posted by greenpoet at 09:13PM (-04:00)

Comments

- BeJae April 08, 2010

Listening to music and actively seeking the cure: It seems like this is what I do every day with stings and electricity. Your cure and your malady are specific. Mine are vague. But, you inspire me to keep on listening and actively seeking.

I hope you have a wonderful vacation, a real vacation this time, not a hospital vacation. I imagine Ann, barefooted, the wind lifting her hair just a little. I imagine her carefree in moments, defying gravity. And I imagine you there with her listening with all of your senses. You are both so lucky to have each other.

You are a marvel.

April 9, 2010 – Day One In Chatham

Friday, April 09, 2010

Ann & I got up this morning, packed our bags, and drove leisurely to Chatham on the elbow of Cape Cod. On the way, we stopped at Uno’s in Bellingham MA. Ann had the Asian Salad. I had the endless soup and salad which amounted to one salad and one bowl of Uno’s delicious vegetable soup. We arrived at the Inn around 3:00 pm and have been relaxing ever since. I tried for a nap, but my sleep cycle is shot. Eventually, I’ll fall asleep.

It’s raining today, but Saturday and Sunday are supposed to be sunny. We’re looking forward to walking the beach tomorrow!

During our three-day Cape Cod vacation, my postings will be brief. I’m also staying off email. This is a break!

I shared this information with some of you last night as insomnia kicked in, but it’s really happy news. At 11:00 pm, I received an email from one of my Dana Farber team about yesterday's CT/PET scan. It was sent by the hematology/oncology fellow who never seems to sleep and always seems to be at Dana Farber:

"Your scans confirm a response to the chemotherapy - which we already suspected based on the clear decrease in the lymph nodes in your neck that we could feel. It's not completely gone yet, but we've definitely made progress."

Now we're gonna kick that cancer's butt out with radiation. Course the radiation will kick my butt, but I'll recover in two months.

Thanks everyone for your support and for being on this roller coaster ride with me. I never feel alone. I am so grateful that you are all in my life.

Love…
Richard
Posted by greenpoet at 05:39PM (-04:00)

Comments

- TaDa April 09, 2010

that is awesome Richard.... have a great weekend

April 10, 2010 – Day Two In Chatham

Saturday, April 10, 2010

Ann & I are having a great time. We're relaxing, taking the day slow and easy. I finished Christopher Moore's new book and will move on to Lori Lansens' *The Girls*, the first time I'll read a novel on a Kindle. Oh, I do love tech toys and even more the folks who gifted me this one!

The weather is sunny but breezy. We spent the morning wandering around outside the Inn exploring places to sit in the sun. The view of the Atlantic Ocean with the Chatham sandbar prominent is magnificent. We hiked down to the beach and listened to the ocean. Ann took a walk while I sat and read. After lunch, we leaned into soft easy chairs in front of the fireplace and picked up our books. We returned to our room where I lay down on the couch to relax and fell into a deep power nap.

Speaking of lunch, I've been eating up a storm (what does that mean anyway? I love metaphors, but a storm? How do I digest that?) Let's just say, that I keep finding add-ons on the menu to augment my meal.

This is a really fine break. I go long stretches without thinking about cancer or cancer treatment. We are both recharging. Having time just for us with no distractions and no schedule is delicious.

Thanks everyone for your support and kind thoughts. A special thank you to the Kindle crew. I am truly blessed.

Love…

Richard

Posted by greenpoet at 05:02PM (-04:00)

April 11, 2010 – Home, thinking radiation

Sunday, April 11, 2010

Ann & I had a big, lovely breakfast at the Inn in Chatham, and then left for home around 10:30 am. We arrived a couple of hours later and were greeted by two tail-wagging doggies and our friend Charlene. The doggies, as always, were good for her. Lacey & Charlene got in long walks.

I unpacked my bag and took inventory of my body. My calves are still sore from the walk down to the beach and back up to the Inn. That's a bit disappointing; the walk would have been easy and not taxing before chemotherapy. Our weekend was a bit more active than normal. I feel fatigued even after a nap on the ride home.

Ann & I & the doggies spent most of the afternoon sitting out on our deck. We talked, read, and soaked in a gentle Spring breeze. I'm finding the Kindle easy to use and view. Lori Lansens' *The Girls* is fascinating and when I finish, I'll just move the cursor to choose from six other books on the device.

I've been trying to get at the source of my down days. Part of it is physical with the fatigue and other changes in my body, but I was stuffing my feelings, which is never productive. After my session with psychologist D, I've been focusing on my mind-set. When I feel blue, I sit and let the emotions settle and concentrate on what and why they are telling me.

When I started cancer treatment, I saw the intensive chemotherapy as the great challenge and radiation as the lesser. My energy level and degree of fight were both at their maximum. The chemo ate away at energy and fight, but in a normal course. Once horns are locked, all reserves are used as needed. The chemo cycles became a known entity and I worked through them.

I have to admit that I am a bit intimidated heading into the radiation therapy. The unknown has sharper teeth. When Ann & I met with the radiation team, I was at the nadir of chemo cycle #3, probably not the best day for me to hear all the details. There are many potential side effects to radiation and it's the responsibility of the team to alert and prepare me for all of them. Though there are remedies for each side effect, there will still be discomfort (duh!)

The mouth and neck area contain the saliva glands, taste buds, gums and teeth, voice box, and swallow muscles (among other delicate items.) All of these will be impacted by the radiation. I will have a speech therapist and a nutritionist working with me as my treatment progresses.

A major goal is to keep my weight stable, vital for healing. I'll have a feeding tube put into my stomach on April 30th. I'm not worried about that procedure, it's similar to having my port put in: go to Brigham & Women's Hospital day surgery, check in, take a nap, and wake with a new device implanted. Once such a procedure would have been intimidating. At this point, it is a minor event (and I sleep really well the day after anesthesia!) Cancer treatment has gifted me perspective and taught me to relax when I need a bit of bodywork.

The weekend away was a chance to recharge in a beautiful setting. I helped my body by eating mass quantities (still about 8-10 pounds below my weight before chemo), getting some exercise, and resting. My mind was off cancer most of the time, though the emotions about radiation treatment surfaced from time to time. I let them sit prominently with me and felt the fear and the intimidation lurking. Once acknowledged, the fear lost its teeth. The intimidation fell into perspective. Radiation will not be a lot fun. It will be a significant challenge but I will work diligently on whatever therapies/remedies are prescribed by the medical team.

The key is that I feel ready to face the challenges of radiation therapy. I have come to grips with my fear. Today, I read through Dana Farber's mouth and throat radiation therapy guide. It lays out how we will manage pain and counter side effects such as dry mouth (most of the saliva glands will be out of service), nutrition, and speech issues. They know what they are doing. They care for me as a patient and a whole human being. I will be fine. On Tuesday, my Bring It On mantra will lead me into radiation treatment. I will fight my way through the treatment day-by-day and know the finish line is ever closer.

Thanks all for your comfort and support. I never feel alone.

Love…

Richard

Posted by greenpoet at 06:32PM (-04:00)

Comments

- TaDa April 11, 2010

your in my thoughts.... Onward! You can do it!

April 12, 2010 – Burning the candle

Monday, April 12, 2010

Today is my vacation day before radiation starts. Tomorrow afternoon is the "dry run" when they hook me into the mask, fire off lasers in all directions, and align my penetration points. Wednesday, we go live. Watch for my glow on the horizon.

For today, I have no cares. I woke up hungry and with plenty of energy. After breakfast and puttering around on my computer, I set off for The Worcester Public Library and Worcester City Hall. I found an unbelievable parking place in the library lot and its meter showed an hour and eleven minutes' time remaining. Hot stuff! Then I looked over at the library and its big sandwich sign "CLOSED ON MONDAYS!" and looked back at the parking space. Oh well! City Hall is a short hike from the library, so I set off on a walk across The Worcester Common, the oldest public common in the United States. People used to graze their farm animals there. Now, the common features a controversial skating rink. It was a big issue last election; should the city have spent the money? The sun was shining and there was a brisk but not unpleasant breeze. I greeted street people and babies in strollers. Once at City Hall, I took the elevator up to the Tax Collector floor and paid the real estate taxes for our home and my parents' condo. I love traversing the corridors of City Hall; there are many languages in the air.

On the hike back to the library parking lot, my legs began to complain. I began to complain to myself about my level of conditioning. The first two weeks of radiation treatment are supposed to be easy, so I hope to ride my LifeCycle every other day starting tomorrow. When I reach a point where my body tells me I need to rest, I'll back down the exercise. The information packet from the Dana Farber radiation team suggests the patient maintain as much activity as is possible. The more activity, the easier the recovery and healing go.

With the Worcester library closed, I decided to head one town south to Auburn. The Auburn Public Library is open on Monday. All the Central Massachusetts libraries are part of the CMARS system and a card in the system is valid at all the member libraries. I was starting to feel tired, but I figured that Ann is going to be sitting in waiting rooms a lot over the next month (radiation is daily.) She finished her last book yesterday and it would be cruel for her to be stuck reading old magazines while I was being radiated. The ride to Auburn was easy and I found nine mysteries that I *think* Ann has yet to read.

In the library parking lot (no meters in Auburn), my stomach started the "I'm hungry for lunch" dance. I phoned Corner Grille and ordered a Thai Veggie Wrap, a tangy combination of assorted grilled vegetables, Thai black rice salad (with beans), topped off with tamarind sauce. It's a two-hand sandwich. I met Ann at home during her lunch break and we spent the early afternoon together.

Dad called with a computer problem. My niece sent him some photos of his great-grandchildren via the Kodak website. A login is required and Dad was confused about the password, thinking it was the computer's operating system making the request, not the website. When Ann left for work, Rudy Dog & I drove over to my parents' condo to visit and "fix" Dad's computer (success.)

Rudy gets really excited when visiting my folks. Mom was home resting her back and Rudy jumped up on her bed and rolled around on her comforter, snuggle greeting her. Dad wasn't home yet, so we hung out on Mom's bed. I showed her my Kindle and Mom was fascinated. She isn't device friendly, but yet she was amazed at the screen's clarity and the number of books the Kindle already contained. I showed her how books are downloaded and she kept saying "what a wonderful idea and what a wonderful gift!" Dad arrived home from his exercise program. Rudy gave a quiet greeting bark then ran to the door and jumped up and down around Dad. Mom asked me to show Dad the Kindle and I did. He agreed that it was amazing and wanted to see all the things it could do. Dad has a habit of pressing buttons unintentionally (makes computer and cable/DVR phone support challenging) and the Kindle has many buttons Before I could run it though its paces, I had to undo the journey Dad had embarked on within the device. The three of us sat around playing with Rudy and talking. When it was close to doggie suppertime, Rudy & I left for home.

After feeding the doggies and letting them run a while, I thought I was ready for a power

nap, but my body said "No! You go blog, boy!" So here I am.
You may notice that this posting has little mention of cancer or treatments (don't worry, starting tomorrow I'll go all medical on you again.) I'm having that kind of day. The weekend was renewing and today my body feels good. My mind is clear and my only thoughts about radiation are Bring It On! I was hoping for a longer break between chemo and radiation, but this day has been sterling. It reminds how I will feel after my treatments. The sooner I start radiation, the sooner my treatment is complete. Onward!
Thanks everyone for your kind greetings, support, and love. I go forward with vigor because you are along for the ride, bumpy or not!
Love…
Richard
Posted by greenpoet at 05:49PM (-04:00)

Comments

- BeJae April 12, 2010

I have had a big weekend of gigging, socializing and yard work, while you and Ann had your real, non-hospital vacation (finally). I thought of you all weekend and imagined the two of you walking in the sand and hearing the wind and the water.

I thought of you, too, while in the throes of yard work. I'm a yard work duffus, just so you know. My friend, Shari, from Iowa, who knows all things flora and fauna, told me to cut back the grapevines in the alley outside our fence, if I didn't want them to knock the fence down. She said that the vines will grow back from the main stump, but that they have to be wrangled. She suggested a folding razor saw for the project, but cautioned me to be very careful, more careful than I'd think I needed to be, and to wear long pants. I bought a folding razor saw (I already had the long pants) back in the early winter just before the weather got bad. It's been lying there in the garage all these months. I was all eager to open 'er up. The folding razor saw worked well on the thick vines and on a few small volunteer trees that were threatening the fence. I cut right through those vines … and then pulled. I realized, too late, that the vines were all entwined and would have to be cut apart with hedge trimmers to short enough lengths to fit into yard waste bags for a Monday pickup. It was one of those moments when I felt that sinking, "what have I done" feeling. I thought that the job of cutting up that whole mass of vines was too much for me and that I shouldn't have started all of this in the first place, that I should have left well enough alone. But, the vines were already cut down and they were a big mass blocking the alley. There was nothing to do but to work on them a little at a time until everything was wrangled into bags. I couldn't leave the alley blocked with grape vines. I just had to keep going, even though I thought it was too much for me.

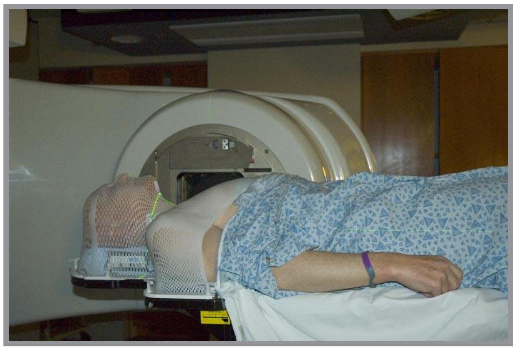
You are not a quitter by nature or nurture, I know that. I also know that there must be moments when this all seems like too much. But, there's nothing to do but to keep going … Once you've started a big snarly project, you gotta just finish it up a little at a time. At some point, it's done … and it seems like utter magic. It does to me, anyway.

Grapevines are easier and quicker than radiation and chemo, that's for sure. But, the amazing thing is that you're so far through this chore already. You're through the bad-ass, hard, intensive chemo. And you felt good today. Oh, sure, you don't have the endurance you had before chemo … But, you felt good. Think how you'll feel when this is all over, when you've wrangled those tangled vines into manageable pieces that have been hauled away … gone.

I love you, my friend. You inspire me every day.

April 13, 2010 – Radiation dry run and THE MASK

Tuesday, April 13, 2010



Today was an interesting day. Got up this morning and found myself back on the Imodium train. I would say that eventually the chemo would wash out of my system and my stomach would recover except I'll be having a low intensity chemo dose every Monday during radiation treatments. Oh well. Overall, I feel good. Rode the LifeCycle for twelve minutes at half my usual intensity before lunch. Took a shower and found that my back was having spasms. I hit it with a lot of hot water. Of course, this happens on a day when I need to lie prone on a hard table! After a quick lunch, we packed up and drove to Boston.

The Nuclear Radiation Department has a greeter. He gave me my radiation treatment card and showed me the workflow system. The card has a bar code on it. Once scanned, the monitor briefly displays my information and then shows a list of the radiation machines and their status (e.g. On Time or Delayed At Originating Airport.) If the doctor needs to see me, his name will appear next to my machine. Slick technology, when I scan my card, my data goes to the radiation machine team and the nursing staff.

One of the radiation techs came over and sent me into a changing room where I stripped off my clothes from the waist up and put on a johnny (why is called a johnny?) Once I was ready, he took Ann & I on a walk down a corridor to the radiation control center for my machine. The center features multiple monitors including one with my photo (just so they know they have the correct patient.) As far as I can figure, each component of the radiation machine is hooked into a separate monitor. The tech explained that the staff would monitor me via video cameras and that the room had microphones so they would hear anything I said. Then we went around the corner to the radiation room and entered the world of sci-fi turned to reality.

I didn't have a lot of time to examine the machine. I was laid down on a table (similar to a scan table) and my head was centered on a support. When my mask was constructed, my head was on a twin of the support. They aligned me left to right and then brought out MY MASK. They slid it on and locked it down. My head, neck, and chest were immobilized. Wearing THE MASK is cool, especially with this massive device with multiple arms and lasers spewing green and red beams. Ann took a photo of me on the table fully masked. Note the laser beam on my neck and another across the johnny.

Once I was locked in, everyone else evacuated the radiation room. Soon, the multiple arms of the machine began moving. Each stopped over my head, flashed lights and lasers across me and hummed. Once each arm was done, it blinked and moved on. I felt like I should be replying to these arms or at least be saying hello or thank you or something polite. The whole process took about fifteen minutes. It was similar to a live run, only instead of radiating me, they took x-rays and measurements for review by my radiologist, a physicist, and one other specialist. Oh, they play music over the loudspeakers while the treatment is going on. They picked out Elton John for me (must be my age and lack of 'do - all the hits: "Goodbye Yellow Brick Road", "Benny And The Jets", etc. – at least they could have given me *Tumbleweed Connection*) but invited me to bring my iPod, iPhone, or a CD with music of my choice. That's going to be interesting.

Not only will the music be for me, I also get to educate the ears of the radiation room staff as every sound in the room is piped to them. I'll avoid the impulse to bring Coltrane's *Ascension*. But I will have fun with musical selections. I'll keep you posted.

After my dry run, we saw one of my radiologist's nurses who went through miscellaneous details about the treatments. Then we were free to drive home through Boston traffic, a packed Mass Pike (until the I-495 interchange), and rush hour Worcester mayhem.

I feel good. I feel Bring It On good, ready for the radiation treatments to begin. I've halfway there. Let's go!

Thanks as always for your comfort, support, and communications. You are all unbelievable and I appreciate every thing you do for me!

Love…

Richard

Posted by greenpoet at 05:52PM (-04:00)

Comments

- TaDa April 13, 2010

Richard is the part that goes over your face mesh? I see strap over your head...?? Geez and I thought I had it bad with my boobs on display..

Well you are taking it standing up which is the only way to do it.. I truly believe it was the radiation part that disolved my tennis size tumor.. my only complaint from the radiation was fatigue (spelling)... worse than when I was pregnant.. mini naps needed all the time.. but every body is differnt so you can't go by what everyone says...

When you use to intercome in "laura you ready" I would yell back "beam me up Scotty"... LOL

Hugs my friend..

warm wishes and strong prayers from FL

- greenpoet April 13, 2010

It is mesh, but a new kind of mesh. Runs from below the pecs to the top of the head.
My oncologist said "Chemo is the preparation; radiation is the cure."

It is a surreal sci-fi setting! Hugs back...

- TaDa April 13, 2010

Oh good you can breath..I have to agree with your oncologist... I think it was the radiation was the main factor that took it out of me...

- BeJae April 13, 2010

Oh, see, the sci-fi aspect has fascinated you once again. I wonder how many patients think they should make a polite response to the lasers, "Thanks so much, good to see you." You are ready. You look good. (Thank you, Ann, for the picture.) You feel good. You're good to go. You're good. You're just very, very good. So, go, my friend. Just keep boldly going. (Jackie is an uber Star Trek fan. Some of that is bound to rub off.)

April 14, 2010 – Radiation treatment 1 [34 to go]

Wednesday, April 14, 2010

Today, we went live. Ann & drove into Boston. We left plenty of extra (read: unexpected traffic) time and arrived early. Once down on L2 in Dana Farber (where the nuclear medicine department is – below ground), I took my new check-in card and placed it under the scanner at the greeter's desk. On one monitor, my personal information flashed on the screen for about fifteen seconds and then cleared. On the second monitor, it showed that "my" machine, Novalis Tx, was on time. The greeter Roy made sure I had a bottle of water (dry mouth is a major side effect of radiation; the saliva glands get fried) and offered me a second.

Next, we went to the Novalis Tx waiting area and I went into the changing room to strip to the waist and don a johnny (Loomers pun.) Ann & I sat and read until my name was called.

I followed the tech down the corridor past the control room with my photo on one of the monitors and into the radiation therapy room. The machine treating me is a Novalis Tx linear accelerator. If you're curious, general info on linear accelerators can be found here. The first thing I did was pull out my iPhone with my music and a tech hooked it into the room's stereo system. Immediately, BeJae Fleming came blasting through the speakers (selections from *Navigating Limbo* and *Red Cross Woman* – BeJae's been with me all the way on this journey, so it seemed fitting to start radiation with her songs, voice, and guitar.) Then I popped out my hearing aids, took off my glasses, and assumed the position on the table with my head & neck on the aligning support. Unlike yesterday, when everything happened slowly, as soon as I was settled on the table, my mask was put on me and locked down. A tech told me they would first take a couple of x-rays. The arms hummed and flat panels covered with lights (not LED's, something much cooler) inspected me. A couple of red flashes went off. The tech returned and moved my shoulders slightly to the left. She left and I heard the door shut. Immediately, the arms hummed and began a series of movements. They would align the position of a third arm with horizontal laser like lights in patterns crossing the entire panel. I figured out that green light is the lasers' aligning and red light is the linear accelerator shooting radiation. As BeJae's songs filled the room, the three arms danced and flashed lights. I didn't feel a thing; the side effects will come gradually. The radiation will cumulatively affect parts of my mouth (saliva glands, taste buds, swallow muscles, speech box, etc.) while destroying the tumor and cancer cells. The linear accelerator suddenly got quiet and immediately a tech was unsnapping my mask. I was up and off the table and techs were "See you tomorrow." Time for the next patient.

Today was fascinating from a geek viewpoint. I know the fatigue and other side effects will hit me soon. For now, I'll enjoy the ride and live out sci-fi fantasies. Any anxiety I had about radiation therapy is gone. The treatment is a known entity. In a couple of weeks, the effects of the radiation will present challenges, but it will be a gradual ride to the top of the roller coaster and a fast (though longer) ride down.

Thanks everyone for your support and comfort. I feel you walking with me. Cancer treatment is difficult physically and psychologically. You all soften the blows and I appreciate that beyond words.

Love…

Richard

Posted by greenpoet at 05:48PM (-04:00)

Comments

- TaDa April 14, 2010

You have to drive to Boston everyday for the radiation??? Oh man ~ is there somewhere local you can crash during the week?

- greenpoet April 14, 2010

It's an hour ride with normal traffic; 2+ hours during rush hour, which is what we'll be driving through for the next 9 sessions, and I'm there less than an hour. But it's worth it. The machines at Dana Farber are state of the art, on the cutting edge. Rather be home than away all week. Most of my sessions (late April on) will be at 10:40 am - means a real easy comment.

Thanks!

- greenpoet April 14, 2010

Oops, commute not comment. Or both, I guess!

- BeJae April 14, 2010

I am honored beyond words to have been with you, in recorded form, during your first radiation treatment. That is just so lovely. I spent my morning imagining what your experience might be like. I so appreciated seeing the picture of you in your mask. I was comforted just by knowing what the mask looks like. But, reading your description of the experience made me realize what a low-level imagination I have where sci-fi medicine is concerned. I need to ratchet it up a whole lot of notches for your machine.

I couldn’t find a picture of your Novalis Tx linear accelerator, so I went to another site and looked at pictures of the six million dollar particle accelerator used to attempt to smash protons together to recreate the Big Bang. (The site says that no one knows exactly what will happen if they succeed in smashing the protons together. Hmmm. Is this really a good idea, I wonder?) I figure all those accelerator thingies are probably pretty much the same. They are, aren’t they? I have to say, your linear accelerator sounds amazing. And, even better, it sounds very, very precise. Precision seems like a good thing in a radiation machine.

I am very proud to be with you as your Big Bang accelerator machine smashes the Alien into oblivion. Science rocks!

- drjj April 15, 2010

Hey Foxy,
I'm back from Denver and AWP - lots of arrogance - I like us better - I thought of you a lot and this writing/memoir of yours, plus your poetry. Have you written/ are you writing any poetry? And are you checking your email? And is it the greenpoet account? I want to send you poems, but I'm untogether and it may have to wait. I'm having shoulder surgery Monday and my arm will be in a sling a couple weeks. I'll figure it out. Your "challenge" gives me perspective. I will go into my ordeal open, looking at the machines as science fiction, take my ipod, and visualize healing. I'm just going to be very loose about this. I'm in so much pain that daily gets worse - calcified tendonitis, so I'm hoping removing the calcium will stop the pain. Visualizing a lot, coloring an anatomy coloring book for fun and relaxation with Sharpies, a really messed up sentence, but you get the

idea. I highly encourage coloring. I have my adults in Monday night, and my prisoners, color mandalas before writing. They're beautiful. I want to cut them out and mount them on something. I'm thinking of you and sending love and healing energy your way, and of course, zooms. Much love and support to Ann.
janie

- greenpoet April 15, 2010

BeJae: who else to start me musically on this new tour? Yes, precision is a good thing in the Novalis Tx. I'm waiting for the little bang when the Alien is routed and gone.

Janie: haven't been writing poetry lately. I guess prose has grabbed my hands. Maybe a prose poem will be the bridge? Yup, the greenpoet email address works fine and I am checking email. Sorry to hear about your shoulder - that is very painful and one of those injuries where a comfortable position cannot be found. Still planning to see you & Sondra in St.L in September for Reunion 2010. We'll do a day trip this year for sure!

BeJae and Janie - gonna have to introduce you one of these days. Jamming and riffing. You're both on fire artistically!

April 15, 2010 – Radiation treatment 2 [33 to go]

Thursday, April 15, 2010

I won’t start off by saying that today is a taxing day, but my iPhone calendar does make note of it. Forgive me, I woke from a very heavy power nap and have been trying to clear my head ever since. Just had a scrumptious lunch (PBJ, soy yogurt, chocolate silk soy milk) and my body is staying in a seated position without the extreme urge to lie prone on the couch. Rudy Dog keeps an eye on me. We napped together earlier and I think he thinks another nap would be a fine idea. Why so tired?

My back is still bothering me though it’s better than yesterday. Last night, I took a Diazepam and a pain pill before bedtime. The combination is effective for my spasms. Also, it knocks me right out. When I woke this morning at 5:30 am, I was stiff and sore but the spasms were gone. Why were we up so early?

My initial radiation treatment yesterday was at the fine time of 2:20 pm. The next nine, including today, are at 8:40 am, smack on the nose of Boston rush hour. So we needed to leave Worcester at 6:30 am. The remaining treatments will be at the ideal time for avoiding traffic of 10:40 am.

The ride in today took a little less than two hours (arrived at Dana Farber parking garage at about 8:20 am) but I don’t remember much of it. The meds from the night before were still doing their thing and I snored my way down I-90. The rest of the day went exactly like yesterday. I checked in at nuclear medicine, donned a johnny, and we sat until my name was called. A tech brought me to the radiation room, hooked up my iPhone to their stereo, and helped me onto the table. Another tech quickly put my mask on and locked me in place. Then the techs left and alignment x-rays were taken. Today, I needed to be shifted to the right a bit. Then the linear accelerator did its thing. It occurred to me that it’s a good thing I’m a nose breather. As tight as the mask’s mesh is, I’m not certain that I could breathe through my mouth.

I decided that a drowsy morning called for ethereal jazz. So, today’s music was from Miles Davis – “Right Off (Take 12)” from *The Complete Jack Johnson Sessions* followed by “All Blues” from *Kind Of Blue*. A few folks asked which of BeJae’s songs played yesterday. They were “You Married Louise”, “Navigating Limbo”, and “Out Of The

Heartland" from *Navigating Limbo* and "Let's Drive On (Jackie Says)", "Iowa", and "Those Summer Nights" from *Red Cross Woman*. I'll list songs going forward.

After my treatment, I changed back to street clothes (a Webster Alumni sweatshirt for good luck) and Ann & I set off for Worcester. The ride home was easy, light traffic and fair skies. When we arrived home, I lay down on the couch, Rudy assumed the position, and the rest you know.

I feel well and stronger, still no side effects from the radiation. I would have ridden the LifeCycle today, but my back is sore in a spot that tells me a ride would be counterproductive. I have a bad habit of exercising through pain and making an injury much worse.

Thanks everyone for the words of comfort and support. We're over halfway through the full treatment cycle. You've made this a gentler, warmer, and easier ride.

Love…

Richard

Posted by greenpoet at 02:34PM (-04:00)

Comments

- BeJae April 15, 2010

Ah, so happy you're making friends with Little Big Bang. She's so friendly now, even though she sometimes gets up too early. I know that she'll probably give you the blues before it's all over, but, in the end, she'll come through for you … And coming through for you is coming through for us … Because you are a fine man and we all love you. You shine like rain on a blacktop road.

Tell Little Big Bang I said, "Hey."

Tell her I said, "Thanks."

Tell her I said, "Come on now, be gentle, act right. You've got important work to do. Do it well. Do it easy. Yeah."

April 16, 2010 – Radiation treatment 3 [32 to go]

Friday, April 16, 2010

Three treatments down, thirty-two to go. I'm 1/12th of the way through radiation!

Ann & I had an easy commute to Dana Farber this morning. You can never tell how a drive into Boston will go during rush hour. We arrived about forty-five minutes early for our 8:40 am appointment. We're starting to recognize the patients who have treatments around the same time as mine. Everyone is upbeat and positive. Everyone looks good. Today, we met a couple whose slot is normally at 10:00 am. The husband is also being treated for throat cancer and also has Dr. H as his oncologist and team leader. His treatment path is similar to mine with the same three 21 day chemo cycles before radiation. The reason he was in early is that he was having his stomach tube put in today. He started radiation on April 1st, so he is about a half month ahead of me. He looks good and is pain free. While he was being radiated, his wife & Ann talked about watching husbands go through cancer treatment. The couple is much younger than us, he's 40, and they have two young children. It was helpful for me to see someone two plus weeks ahead of me in treatment looking well and still eating normally. My stomach tube goes in on April 30th. Guess Friday is tube day!

My treatment was similar to the first two, except I needed two adjustments by the tech before I was lined up to their satisfaction. One of the techs was especially interested in today's musical choice, selections from Jenny Lewis with The Watson Twins' *Rabbit Fun Coat*. With the adjustments, I was on the table longer and heard the following songs: "Run Devil Run", "Rise Up With Fists", "Handle With Care", "The Charging Sky", "Melt Your Heart", "Rabbit Fur Coat", "You Are What You Love", and a bit of "Big Guns."

I keep forgetting to mention Mesh Face. When I change back into street clothes, in the mirror is my face, marked by the mesh. You could use my mug for graph paper or a crossword puzzle. It's pretty funny. I think with Sam's (costuming) help and a bit of stage makeup, I could be ready for Star Trek!

When we returned home, Ann went grocery shopping and I rode the LifeCycle for twelve minutes at half intensity. I was debating whether to wait another day, but my back wasn't stiff from the car rides, so I went for it. Also, Monday we have multiple appointments at Dana Farber, so now I can ride Sunday and be on the desired every other day ride schedule. My back feels good but I still need to be gentle with it.

Tonight, we're going out for supper to El Basha with Jesse & Susan for a little Middle Eastern food. My appetite is good and I'm up to indulge. This is the time that my goal is to pack on the pounds. There is balance in all experiences!

Thanks for all the cards, calls, posts, and emails. I feel so lucky to be surrounded by love and comfort. I always know I have friends and family with me, holding me as I walk this path.

Love…

Richard

Posted by greenpoet at 02:51PM (-04:00)

Comments

- BeJae April 16, 2010

I'm so happy to hear that you had another good day with Little Big Bang! I love it that you feel good enough to ride your cycle and to have a food indulgence. I can't tell you what great comfort I feel knowing that others who are a little further down the treatment road still feel well. Radiation has come a long way and Dana Farber is obviously up to the minute with it.

We need a picture of meshface, you know that, right? I think you should do the makeup and ride the train back to Worcester at rush hour. We could come up with some really good stories for the commuters.

I wonder how many of us will sell CDs to radiation techs during your treatments. You have always been a wonderful musical ambassador treating all of us to new discoveries and deeper understanding.

I hope the treatments keep going this well. Jackie and I play tonight in a little place in German Village. We'll play some songs especially for you.

Ride on, my friend.

April 17, 2010 – Taking it to the limit

Saturday, April 17, 2010

Last night, I took my taste buds out for a test ride. Chemotherapy affects the quick growing cells in the buds. At its worst, all I could tolerate was bland food. How bland? Applesauce burned. Pudding burned. Soy yogurt burned. My diet consisted of eggbeaters, Cream of Wheat, and Boost/Ensure. Since I finished my third and last intensive chemo cycle, I've gradually been branching out into pasta, salad (how I missed salads and balsamic vinaigrette), and sandwiches with a little bite. Last night, I challenged my taste buds without thinking about it.

Ann & I had dinner at El Basha (Middle Eastern food) with Jesse & Susan. We ordered a hummus and babaganoush appetizer which tasted just yummy. For my main course, I chose an El Salad with a side of meatless stuffed grape leaves. My taste buds rejoiced and the tart flavor of the grape leaves stayed with me until I fell asleep.

The El Salad is named for the famous El Morocco Restaurant that graced Worcester for ~five decades. It started in the basement of a three-decker where it had a Beat Generation feel. Jazz musicians would gather after gigs and jam into the wee hours while munching on Middle Eastern treats. Theater and major entertainment stars would drive to Worcester and the El from Boston for after performance dining (their photos covered the walls.) In the 1970's (I think), the El moved into a glamorous new building across the street. It was set on a hilltop with a panoramic view of Worcester County. The New El had a lavish dining room and function rooms that often were used for jazz concerts. In the late 1990's, this landmark restaurant closed leaving a hole still unfilled in the city, musically and gastronomically. El Basha has revived the revered El Morocco Salad (now if they could only get the recipe for the Mud Pie!)

After dinner, Jesse & Susan suggested we stop at The Bean Counter to pick up dessert. The Bean Counter is noted for its coffee and home made treats. They even do vegan! My big vice in life pre-cancer was coffee (Café Americano with an extra shot, cold soy, Splenda) but during chemo, coffee first tasted bland and then sour in a very bad way. Now, it is suggested that I avoid coffee and caffeine. But I loved walking into The Bean Counter and inhaling deep lung fills of coffee and espresso. I chose a couple of vegan cookies: chocolate chunk and oatmeal raisin. It's been a long while since I've had a rich cookie!

We four came back to our home, sat around and talked. Talk led to a lot of laughter. I've known Jesse since childhood and Ann & I met Susan early in our marriage. Our kids grew up together and still make time to see one another. These life long friendships are special and priceless. It's more than the history; the understanding exceeds mere words.

Today will be another cool day. Cousins Alan & Arlene are coming by to visit this afternoon. Then tonight, another life long friendship couple, Larry & Lora, are taking us to Bertucci's in The Solomon Pond Mall where we will meet up with Cousin Betsy. I get to see the two women who are my rocks in the same day! They have guided me through cancer and treatment, sharing their experience fighting the disease. I don't know where I would be without their counsel and wisdom.

Thanks everyone for your comfort and support. I'm beyond lucky to have friends and family like you.

Love…

Richard

Posted by greenpoet at 01:32PM (-04:00)

Comments

- BeJae April 17, 2010

Ah, so happy to hear about the feasting and, more importantly, the enjoyment.

So, do you have weekends off from Little Big Bang? Do you visit her five days a week? I'll bet those techs are eagerly awaiting the next round of unfamiliar music.

- greenpoet April 17, 2010

Another feast tonight! Yes, have weekends and Memorial Day off from Little Bang. She needs a break, too!

Eventually, I will bow to peer pressure and bring in Coltrane's "Ascension" (Edition II - prefer it to the first take which has wider distribution - as did Coltrane, only two takes) and I wonder what the techs will think. When my mentor (I was in 9th grade and he was a college student at Clark U) turned me on to "Ascension" (take 1, the only one available in 1967), I was a captive. Listened to the entire piece (over 40 minutes) twice a day for nearly two months. Mom took me to Radio Shack and let me pick out fancy headphones, so she wouldn't have to hear it. Listening to "Ascension" then was like galloping on a horse, bareback, in rain driving so hard that all I could see was wet blurs. Sometime during the second month, I got "Ascension" well enough to be able to feel it, understand its structure, and listen lockstep. On the first listen, it's a foreign world, one where pain and pleasure are not distinct.

Hope the radiation techs will let me back in! Or do I save it for treatment #36?

April 18, 2010 – Pushing the limits

Sunday, April 18, 2010

Friday was the test drive for the taste buds. Last night, I pressed the accelerator to the floor hard enough to feel the skin on my cheeks peel back. Ok, that’s an exaggeration. That’s how I used to feel driving my 1972 Mustang Fastback with a 302-2V featuring twin Holley carburetors. I guess the reason that analogy popped into my head was a conversation about our kids driving to and from college/work in distant cities and how it seemed too long a haul. When I was living in St. Louis in the early 1970’s, I made the drive to Worcester in about 21 hours, timing my arrival at The Boulevard Diner for around 3:00 am. After a salad, veal parm with penne, a piece of Table Talk Boston Crème Pie, and a few cups of coffee, I’d wander home to collapse and sleep into the next afternoon. No, I was not a vegan then. Though a part of me yearned to be a vegetarian, but didn’t have a clue how to get there. Besides, St. Louis had too many (or not enough) Steak ‘n Shake drive-ins.

Yesterday was a special day. Ann & I took it easy most of the morning and early afternoon, doing a few chores, taking a couple of naps, watching a little TV (home improvement shows on HGTV), playing on the computer, and reading. I finished Lori Lansens’ *The Girls* (highly recommended) and started Karl Mariantes’ *Matterhorn*, both on the Kindle (loving the Kindle!)

Around 3:00 pm, Cousins Alan & Arlene arrived for a visit. I can’t write this too often, so here goes. Arlene has been a rock and inspiration to me during the cancer experience, from diagnosis to treatment. She’s fought the beast three times over three decades. Arlene is one of the sweetest people I know, but also one of the toughest. I lean on her experience and try my best to emulate her positive attitude towards life's challenges. We email daily and talk on the phone weekly. She is still recovering from her last bout with cancer, but always puts the focus on me.

We traded treatment stories and caught up on health details. Then, we reached into the rich trove of family stories. Arlene & I are the children of two of three brothers. The three were each other's best friends. Many of my happiest childhood memories revolve around the interaction of the brothers. Their patter during card games was dicey and priceless. I grew up with my cousins; we spent lots of days as one family and the ties run deep and true. Near the end of the visit, we listed our favorite movies and found almost an absolute overlap. We go for the off-kilter comedies. It was a funny and fitting conclusion.

Ann & I caught our breathe for an hour and then Larry & Lora arrived to pick us up for our evening dinner plans. As I wrote yesterday, lifelong friends are special and to be cherished. Larry & I grew up together. Our parents were close friends before they were married. The memories go back as far as memories go. Like our parents, we've raised our children together from infants to adults.

We headed out to Bertucci's in The Solomon Pond Mall in nearby Berlin and met up with Cousin Betsy who drove in from the other direction. Truth be told, Betsy & I are not exactly related but we've decided that we are cousins, so that's all that matters. Betsy just finished treatment for cancer, her second bout with the microcellular beast. Betsy started treatment well before me, but we've overlapped the joys of chemo, tests, and being poked and prodded. She's been with me all the way, emailing suggestions and perspectives on dealing with cancer. We traded stories about our treatments and how we leave modesty far behind once in the milieu of hospitals. As we went through chemo and lost our "normal" taste buds, we wrote about meeting for dinner one day and being able to enjoy our meals. It once seemed so far away, but here were today munching on Bertucci's outstanding rolls. Betsy has been a real friend & cousin, a fellow traveler on this difficult path. We could blow off steam and laugh about the disease. I often expect too much of myself in dealing with the side effects of chemo and Betsy has been really helpful in telling me to rein that in, to be more gentle with myself. There were times I really needed to hear that.

Dinner, wasn't that the starting point of today's post? I had a salad with balsamic vinaigrette, three rolls, and three quarters of a pizza with no cheese topped with spinach, portabella mushrooms, and caramelized onions. I was ready to stop at half a pizza, but my body urged me on. In the pre-cancer days, I would have downed the whole pizza, but a guy's gotta work himself back into shape, right? But I could feel that skin on my cheeks peeling back or maybe it was just the garlic.

If I'd been able to see Laura today, I would have been in the company of all three fellow travelers on this road of cancer treatment. Laura, a friend from college days, lives outside of St. Louis, so that would have been a bit of a trick. Laura does a real good job of hitting me upside the head when I really need it. That's what friends are for.

Dan arrived around noon today (just after my 12 minute LifeCycle ride.) We've been sitting around, taking it easy, playing with the pups, and watching a few episodes of "Big Bang Theory" and "Modern Family." I really appreciate his weekly visits. He's been wonderful and helpful all through my treatment. When we really need a hand, Dan's always here.

Tomorrow is a busy day. We have five appointments at Dana Farber (radiation, radiologist, blood drawing, oncologist, chemo infusion) starting at 8:40 am. The drives in and back will be interesting. Tomorrow is Patriots' Day, a Massachusetts holiday, and the day of The Boston Marathon. Our normal route will be blocked by the marathon, so we'll try to sneak into Boston via Route 9. Some people have Patriots' Day as a holiday (I never have), so the traffic might be lighter. Then again, there will be thousands of people going into Boston to watch the event. We'll leave a little earlier and hope our alternate

route works.
Thanks everyone for your support and wishes. I feel connected to you all and never alone.
Love…
Richard
Posted by greenpoet at 05:38PM (-04:00)

Comments

- BeJae April 18, 2010

Fabulous food and beloved friends and family: Wow, what a day! I am so thankful that you can enjoy all of this during these difficult treatments for this very unsettling illness. Your blogs remind me not to take these lovely things for granted.

I hope that your alternate route takes you right where you want to be just when you need to be there.

- fluffy April 25, 2010

Hi Richard,
Happy to know you are hanging in there, are so loved by so many, are so easy to be happy, (in spite of all you presently must endure). You 'will' get through. Here's yet one more person 'out there' sending you best wishes, who knows from the inside through what you are going. I hope to see you soon. Glad you liked, 'What am I Doing Here?"
Love, Lorna

April 19, 2010 – Radiation 4 [31 to go] & big news!

Monday, April 19, 2010

Today, in deference to The Boston Marathon and the need to find a new route without streets closed down due to the race, Ann & I left twenty minutes early for Dana Farber. We took I-90 (The Mass Pike – give it a name and you can charge a toll) to Natick where we picked up Route 9 for the remainder of the ride into Boston. Traffic was light and the sun was bright. Naturally, we made it in early to Dana Farber, before 7:15 am! The early arrival turned fortuitous, as there was some shuffling of the five appointments I had for today.
My radiation, scheduled for 8:40 am, was completed before 8:00 am. Today, the techs hit the ball on the nose when they arranged me on the table and no adjustments were necessary. Music for radiation 4 was from Sara Hickman's *Necessary Angels*, the following tracks: "Pursuit Of Happiness", "The Best Of Times", "The Place Where The Garage Used To Stand" and "Sister And Sam". As soon as I was out of radiation, we had our appointment with Dr. T., my radiologist. There's not a whole lot to evaluate after four treatments, but he talked about the full cycle of radiation. One question I had was whether my saliva glands that need a heavy dose would grow back. Dr. T. said it's likely that the glands will be gone permanently on the tumor's side, but I will have at the very least the large gland on the other side of my mouth. There will a new normal as far as my mouth is concerned. But hey, I'm getting real used to dry mouth anyway! And it's a small price to pay.

We went upstairs to have my port hooked up (both channels, they needed flushing) and blood drawn. That appointment was for 9:00 am, but the process was complete well before that.

Our next stop was to see my oncologist and team leader Dr. H.. He reviewed the results of my post-intensive chemo CT/PET scan. The news is exciting! I still have one lymph node that is large but has declined in size from SUVmax 5.2 to 2.8. It could be malignant or it could be scar tissue. The primary tumor on my tongue has decreased in size from SUVmax 11.1 to 3.1, a significant change! Dr. H. said the remainder could also be just scar tissue or a small patch of tumor. Next, he stuck the hose up my nose. Ok, the hose has a camera on it and outputs to a monitor allowing the doctor a clear view of the tumor site. He liked what he saw, but could not determine whether the remainder was scar tissue or tumor. So, he decided to stick his finger way down my throat and see if he could tell tactilely. I've gotten real good about having stuff stuck down my throat without the gag reflex kicking in (or out.) The tactile approach was also inconclusive. My radiation with chemo booster protocol would be the same either way. Dr. H. has said all along that intensive chemo is the preparation and radiation is the cure. The goal is to be certain that 100% of the tumors/cancer cells are eradicated. The technical medspeak for the results of my intensive chemo is a partial response. That means they got a lot of The Alien rousted with a little more to go. Yes!

Dr. H. looked at my blood profile and is concerned about my red blood cell count and protein level. The former may still be recovering from the intensive chemo; my calves ache the way they have before when my bone marrow is working overtime. For both, I need to analyze my diet carefully and push iron and protein. If my red cell count stays low, the response would be a blood transfusion and I'd prefer to avoid that. If necessary, I may augment my diet with fish. We'll figure it out. Once I have the feeding tube in (scheduled for April 30th), they can fill my tummy directly with anything I need.

Dr. H. started me on a weekly low-level dose of Carboplatin (chemo with platinum in it!) Its purpose is to enhance the effectiveness of the radiation. Dr. H. has researched the interaction of chemotherapy and radiation (including the order of the treatments) at Dana Farber. I am so fortunate to have him as my oncologist (thanks again, Rachael!) and Dana Farber as my hospital.

We went down a floor to the infusion room and they hooked me up to a fresh blend of Carboplatin. Half an hour later, it was done. The nurse flushed my ports and we were good to go.

After a quick lunch, Ann & I headed back to Worcester. Because of the marathon, we took the same route we used on the ride in. Our travel time was less than an hour. We're going to try the route again tomorrow to see if the traffic level is always as fluid as today when some folks had the day off. We took Route 9 to I-95 to I-90. As we drove on I-95, we looked up to an overpass bridge and saw the marathoners running. That was very cool.

Going to take the rest of the day easy. I may nap if my body tells me to. A trip to the market is a possibility if we decide that I need to augment my diet. I am fully entrenched into Mariantes' *Matterhorn*, so I may read all afternoon. I am fatigued and chemo-brained, but so very up after today's news. Maybe I'll put on music and dance! Dancing is good for the soul.

Thanks everyone for the emails, cards, calls, and surprises. Every day, I am grateful for your comfort and support. Thanks for taking this walk with me.

Love…
Richard
Posted by greenpoet at 03:37PM (-04:00)

Comments

- TaDa April 19, 2010

Hey richard... maybe by the time April 30th rolls around you will be holding your own and wont' need the feeding tube.... One can, hope, pray and wish...

glad you progressing good..

- greenpoet April 19, 2010

The feeding tube is a must. Because my radiation is concentrated on the throat, mouth, and tongue, I will reach a point where I cannot ingest enough calories by swallowing. I will have PT exercises to do for my tongue and other swallow muscles. It is vital that my calorie intake is maximized and my weight is stable. I need that for my recovery to be optimized.

Thanks for the kind words, thoughts, and support.

- BeJae April 19, 2010

It's so great when the route is well chosen, the path is clear and the destination is within sight. I hope you'll tell us more about the PT for tongue and swallow muscles when you get to that. I'll also be interested to hear how the radiation chemo differs from the intense chemo in terms of side effects.

I'm gald you had such a lovely weekend. Now it's time to entertain Little Bang and her techs with another week of music they may not have heard before.

I am so very happy and grateful for all the good news today. The Alien is on the run.

- JohnWeiss April 24, 2010

Richard, I have not contacted you, since news of your health issue (cancer) became a subject of conversation. I have however, been thinking about you, and sending good vibes. I am very happy to hear that your treatment is progressing. I know you have been reading a lot, and I reserved a copy of a favorite book of mine for you, but I need an address to send it to.

April 20, 2010 – Radiation 5 [30 to go] & swallowing PT

Tuesday, April 20, 2010

My plans for yesterday changed the moment I laid down on the sofa and Rudy Dog snuggled up on my arm. I was out until after 5:30 pm! The busy day topped by chemo won out, well sort of. Before I was hooked up to the IV, the infusion nurse handed me a cup full of pills including a few mega-steroid greenies. I was worn out in the afternoon, but wide-awake most of the night. I took a couple Diazepam, but they were no match for the greenies. I've been up and active all of today, no nap, and still have that wide-awake feeling even with fatigue creeping in. I wonder how sleeping will go (or not) tonight. Stay tuned!

Ann drove into Boston this morning and chose our usual route. Renee advised us that

Route 9, on a normal day with schools open and everyone working, is gridlock. Traffic on the Mass Pike was heavy but steady. We left Worcester at 6:35 am and arrived at Dana Farber around 7:40 am. I was the first patient to arrive at nuclear medicine (which technically opens at 8:00 am), and the Novalis Tx staff took me right away. Today, I needed no adjustments to my position on the table, and Little Bang was done before 8:00 am. Today's playlist was the opening two tracks from The Grateful Dead's *Road Trips Vol. 3 No.2 – Municipal Auditorium, Austin TX, 11/15/1971*: "Truckin'" and "Bertha". I was hoping to take a meshface photo today, but the mirrors in the changing rooms were removed and replaced by exquisite artwork. (Dana Farber feels like an art museum. Diverse framed media donated by grateful families covers every corridor, except for the spots reserved for Red Sox memorabilia.) So, I'll have to figure another angle on catching the mesh in action. Tomorrow, I'm bringing my D70 rig in to shoot some quick photos of the Novalis Tx. The online photos just don't it justice.

We were done early and took the elevator to the 11th floor to the Head & Neck Oncology Department. An appointment with the Speech & Swallow Therapist was scheduled for 10:30 am. Dana Farber is not your conventional hospital. Perhaps the difference lies in its major research focus. The appointment desk at Head & Neck texted the therapist and she responded that she could see us at 9:00 am. Amazing.

The Speech & Swallow Therapist, as have other staff specialists, outlined the treatment plan for the duration of my radiation and the period of recovery that follows. She urged us to focus on today and not get ahead of ourselves worrying about what will happen and how we will respond in the weeks ahead. That's our approach, so we are in sync. I have a series of mouth and tongue exercises to do three times a day. They are pretty simple and can be done in the shower, the car, or while sitting around (but not at dinner – lots of open mouth work!) We'll be meeting with the Speech & Swallow Therapist most weeks.

After our appointment while crossing the Head & Neck waiting room, we bumped into the couple from Sterling we met down in radiation last week. The husband is going through the same treatment protocol as I am for throat cancer. He's a couple weeks ahead of me, so he can clue me in what to expect next. His advice was to eat up over the next week; my taste buds will soon be heading south. Again. Oh, the couple's names are Jeff & Nancy. Some of you will find significance and coincidence in that! Starting next Tuesday, Jeff & I will have consecutive radiation slots. Like me, he doesn't smoke or drink and is a gym rat. We've already commiserated about having our workout routines disrupted by cancer treatment and look forward to the day when our energy levels return to normal.

Ann & I needed a little break before driving home, so we stopped at The Longwood Food Court. Ann went to Dairy Queen for a chocolate sundae. Remembering Jeff's counsel, I went to the Red Barn coffee shop for a Café Americano with cold soy and Splenda – my first coffee in over a month. During intensive chemo, coffee tasted sour, so sour that I gave up my favorite vice. But now, for this short window, I can indulge! And dream of the days, soon to come, when I can wakeup with a bike ride and a wicked strong cup of Café Americano!

I was feeling wide-awake and very up, so I drove home. It was an easy ride. When we arrived home, Ann decided she needed a nap. I paid some bills, made a few phone calls, and had a light lunch. Then I decided to do the grocery shopping. Grabbed the list and drove to Shaw's. I started in the produce department and spent twenty minutes selecting lettuce, tomatoes, bananas, and blueberries. It began to dawn on me that chemo brain was fully engaged. Over the next hour and half, I managed to get almost every item on the half page list (and a few impulse buys, I was still hungry!) If someone diagrammed my path through the market, likely you would get to see the most inefficient shopping trip of all time. While I was in the checkout line, Ann called to see where I was. Still shopping!

When I returned home, Ann & I put away the groceries. I've committed to riding the LifeCycle every other day, so I changed into my exercise clothes and road. The ride was

fluid. I hope I can keep up the riding through radiation. The more activity I put into my day, the quicker and easier my recovery will be. That's motivation enough. So no nap today and lots of keeping busy. Getting back to where I started, let's see if I sleep tonight! If not, I have plenty to read and eventually the greenies will wash out of my system.
My brother Alan is driving me into Dana Farber the next two mornings. It's a really big help for Ann (& I.) I'm not alert enough to drive to Boston early in the morning. Having the two mornings free opens up a lot of time for Ann to see patients. We really appreciate the help.
Thanks everyone for your support, comfort, and messages. This is one of the most (if not the most) challenging times in my life and knowing how so many people care is a singular gift.
Love…
Richard
Posted by greenpoet at 08:47PM (-04:00)

Comments

- BeJae April 20, 2010

Okay, do you have any extra greenies? They sound good to me. Actually, I have some cat treats called Greenies. Maybe I'll try some of those tomorrow and see if they give me a boost of energy.

Reading about your coffee indulgence makes me remember that we should never take our moments of enjoyment for granted, but instead we should savor them.

My friends in the band Brother Trucker do a cover of the Dead's Bertha. Wish you could hear them as you're Little Banging away. The guys in Brother Trucker have been hugely inspirational to me. Andy Fleming is a great songwriter. Lyle Kevin Hogue, the bass player in the band, is going to play for me in the June Iowa shows that Jackie can't make. I subbed on lead guitar for Brother Trucker one night in Dubuque, IA. I learned so much about playing guitar preparing for that show. It was way over my head … but, what I learned changed me forever as a guitar player. I think that this experience is your Dubuque. I think you'll learn as much about yourself as any experience has ever taught you. I think it will change you and that you will know more than you have ever known about yourself. I think you'll be grateful for the experience, if not for the Alien. Don't get attached to the Alien. The Alien is leaving. The Alien is possibly already gone. Little Bang and her friends, chemo, smart medical folks and good fortune, rule!

- TaDa April 21, 2010

You have an awesome wife... you said patients.. is she a counselor? NOSEY.. don't answer if you don't want to... When I found out I had cancer.. the first thing I did was enlist a counselor for the whole family... smartest thing I did.. As you know... you are not just the victim, the family is too!

Hugs... Hope the rest the week is easy for you...

- greenpoet April 21, 2010

BeJae, have Brother Trucker's "Something Simple" and a track from a sampler "Pleasure & Pain." I could bring them in while Little Bang is doing her thing! Not Bertha, though, but that's ok. Not with BeJae, that I'd love to hear!

Don't worry - I'm not attached to the Alien - awaiting the formal detached & destroyed. Little Bang & I are good friends, though. She moves her arms in time to the music (or maybe that's the techs, naw - it's her!)

Don't think you'd like these greenies. Yes, they keep you awake, but steroids (and these are mega) do weird destabilizing things to the mind & body.

Had coffee again today...   oh, sheer delight!

- greenpoet April 21, 2010

Laura, Ann is a psychiatrist certified in Cognitive Behavioral Theory. I'm very proud of her and the work she does.

Our kids are launched adults and make their own decisions. I'm proud of my sons' reactions and how they jump in to help and fill every gap. I see a psychologist to smooth my edges and maintain perspective (mostly when I'm too hard on myself.) Yes, cancer affects the entire family and it's real important to be aware of that. You were very wise to seek counseling.

Hugs, back. This week will be easy, next week we have a bunch of medical appointments and the feeding tube insertion surgery.

April 21, 2010 – Radiation 6 [29 to go, under 30!]

Wednesday, April 21, 2010

The greenies washed out of my system and I slept well last night. Woke up feeling strong and rested even after yesterday's activities. Alan picked me up at 6:30 am and we drove to Boston. The ride was a real pleasure. We had a chance to talk without distraction, to catch up on the small details that define the edges of our lives. Traffic was light, only a few snags on The Mass Pike, and we arrived at Dana Farber about 7:40 am. I was the first patient to scan in at nuclear medicine and was in the room with Little Bang before 8:00 am. Before I got on the table, I snapped five shots of this magnificent machine. Here's one, the full five are at this link:

Please note my mask sitting on Little Bang's radiation arm awaiting my arrival. As soon as I lie on the table, the mask gets snapped on so I'm immobile, the music plays, and Little Bang dances all around me firing the green lasers and the red radiation. Today's music was from Boston's own (though now living in LA) Laurie Geltman's first album *No Power Steering*. Tracks played were "Saddle Up Sally", "Red, Green, Black & Blue", "Bloodline", and "Growing Down". I had "Bobby Called From Texas" cued up but the tech hit the wrong line on the iPhone. No problem, there isn't a bad track on the CD.

It was a few minutes after 8:00 am when I returned to the waiting room. While I was being treated, Alan didn't have time to finish the crossword puzzle and start the Boston Globe Sports section. Before getting back in the car, we walked over to The Longwood Food Court (by way of the Boston Marathon corridor near the Lance Armstrong Center) and grabbed some coffee. Oh, java delight, I have my taste buds back for a little while! Café Americano rocks.

After today's treatment, my neck felt warm for the first time. I don't know if it was a little leftover flush from the greenie steroids or the start of the next stage. My dry mouth is definitely accelerating. I'm going to enjoy this break when food and drink have marvelous flavor and my mouth and swallowing are pain free.

Alan & I had an easy ride home, no traffic to speak of and more time for conversation. We'll have another round trip to Boston tomorrow and I'm looking forward to the time and talk.

A little while after I arrived home, Ann came home for lunch. We ate (I had a massive lunch, lots of protein and Iron), caught up on our days, and relaxed until she had to go back to work. Feeling strong, I headed out on errands to the post office and the pharmacy. I was considering a LifeCycle ride (that would be two days in a row) on my return, but my body told me I needed a nap. So, Rudy & I hopped up, laid down on the couch, and fell into deep naps. Mine was deeper; Rudy got up at one point to check out someone walking past our house. I can nap with ease knowing he's on alert!

Got wonderful news from Cousin Betsy today. Her PET/CT Scan was clean and she is free from cancer! Now, she can focus on recovery and getting stronger. It's a year long process, but she'll be able to return to teaching come September. Mazel Tov, Cousin Betsy! Make you go from strength to strength.

Thanks for all the emails, phone calls, and cards. I really appreciate how you all reach out to me and raise my spirits. The support and comfort make my days easier and my motivation firm.

Love…

Richard

Posted by greenpoet at 06:43PM (-04:00)

Comments

- Nancy April 21, 2010

That machine looks amazing! And so are you!!!

- TaDa April 21, 2010

Boston Globe I am so jealous !!!!

Keep it up Richard your doing great..

God Bless

Laura

- BeJae April 22, 2010

I'll tell you what, that Little Bang is a good lookin' gal, isn't she? The thing I like best about her is that she hates the Alien and loves you. That right there makes her okay with me. Another thing I really like about Little Bang is that she's very good at her job. I like that a lot.

Hooray for great coffee. I know it will probably start to taste funny again. But, once all this is over, it'll taste great again. I wonder how this whole experience will change your relatioinship with food. I'm thinking that, in the end, this experience will make food and delicious, strong coffee even more enjoyable for you.

I realize that Little Bang will get rougher and tougher as you two get to know each other better. But, she's on your side. And I'm on your side.

Love to you, my friend.

April 22, 2010 – Radiation 7 [28 to go] – Little Bang delay

Thursday, April 22, 2010

Alan drove me to Boston again today. The traffic was quite light. We reached Dana Farber around 7:40 am. All week, I've arrived early, just as the nuclear medicine department opened, and completed my radiation treatment before 8:00 am. When I scanned in today, the display showed a fifteen-minute delay on Little Bang (my Novitas Tx.) We walked over to the waiting room and found it filled with patients in johnnies. So, we had to wait. My appointment is 8:40 am and I was called right on time. But not early, I've become *so spoiled*. Today's music got the techs a rockin' – from Brother Trucker's *Something Simple*, "Side by Side", "Harold's Barber and Beauty", "She's in Texas", "For J", and a taste of "Who's Got Your Back?"

Today was treatment number 7, officially 20% through radiation!

I'm beginning to feel mild side effects from the radiation treatment. My dry mouth is a bit more pronounced each day. When I eat a sandwich, swallowing is little uncomfortable. My cheeks (interior of mouth) are lightly pitted. Fatigue is gradually increasing. For now, I can still eat with abandon (or what one might call normally.) I'm going to enjoy my meals this weekend and splurge at every opportunity!

Alan dropped me off at home around 10:30 am. We had another day of wonderful conversation, though fatigue slowed me down a bit. I had a few phone calls to make and my swallow exercises to do. Then I lay down on the couch for a rest that turned into a deep nap. Ann took her lunch break around noon. She picked me up and we went to Friendly's to eat. I had a hankering for French fries, which I fulfilled. When we returned home, I went back to the couch and slept until 3:30 pm. My need to sleep today overtook my desire to ride the LifeCycle. That's ok. I'll listen to my body and ride tomorrow.

I've run through the swallow exercise routine for three days now. The routine needs to be done three times a day. I'm quite familiar with the rhythm of physical therapy. The big challenge is learning the exercises and the order of performance until it's second nature. I plan to maintain the muscle tone of my tongue and mouth muscles. No free weights are involved though a spoon is.

Thanks everyone for being on this roller coaster ride with me. Your comfort and support light up my days.

Love…

Richard

Posted by greenpoet at 05:29PM (-04:00)

Comments

- BeJae April 22, 2010

I'm so glad you listened to Brother Trucker today. I often listen to Brother Trucker when I do yardwork. They make me glad to be alive.

Little Bang ... worth the wait. I know that these treatments are starting to have side effects ... hard ones. But, it's all going to be so worth it. With Little Bang it's swallow, swallow, swallow. With intense chemo it was spit, spit, spit. Soon it will be over. Free, free, free.

Love to you, my friend.

April 23, 2010 – Radiation 8 [27 to go] – tired boy!

Friday, April 23, 2010

Eight radiation treatments down, twenty-seven to go! Bring It On! Though I must admit I'm happy to have the weekend off. I remember thinking that 35 straight days without a break might be better. Uh-uh, which I will say with more conviction as the side affects ramp up. Between five straight days of the drive to and from Boston, the treatment plus whatever other appointments I have that day, and I guess getting up at 5:30 am to be at Dana Farber on time, I'm kind of worn out. Was exhausted today when I woke up. Slept on the way in (don't worry, Ann was driving!), I think napped during the treatment, and slept from 9:30-11:30 when we got home. I may have napped all day, but we have an appointment (at the house) this afternoon and papers to sign, so I needed to get up. Still hope to ride the LifeCycle this afternoon, think it will give me a burst of energy. Moderate exercise is that way for me. And is recommended by my medical team to improve the speed and efficacy of my healing.

We left Worcester around 6:30 am. Despite encountering a temporary parking lot on the Mass Pike due to a van accident, we arrived at Dana Farber around 7:45 am. I scanned in, dressed in a johnny, and got called in before I sat down in the waiting room. Music for today was from The Nields' *Bob On The Ceiling* – tracks played: "Be Nice To Me", "James", "Just Like Christopher Columbus", "Merry Christmas, Mr. Jones", and a little of "Ash Wednesday". This CD is one of a group that is special to me, the hot recordings when I first started doing my radio show back in the 1990's. Odd to think of how long ago that really was. My life was enriched by all the wonderful artists I met in studio, by the friends who remain friends over the decades.

I'm ready to enjoy this weekend. We have plans to go out to restaurants with friends and family. The side affects from radiation are kicking in and I won't waste any time anticipating them. I'll just eat my way there! With vigor!

Thanks everyone for your support and comfort. I never feel alone and look at all the cards piled on the windowsills and at all the email messages sitting in the "Alien" folder on my MacBook and realize how lucky I am to have you in my life.

Love…

Richard

Posted by greenpoet at 03:27PM (-04:00)

Comments

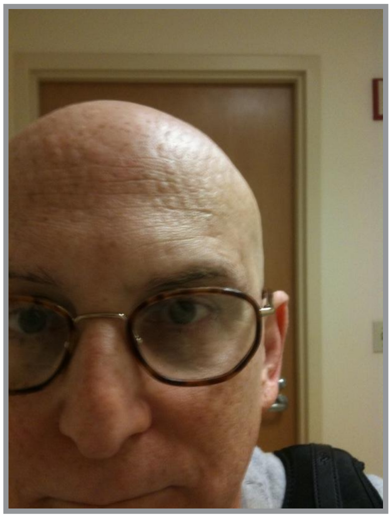
- BeJae April 23, 2010

It's hard for me to believe that your Zero-Dark-Thirty-Let's-Get-Up-and-Play-Records radio show was so long ago. It was the beginning of our friendship, which made getting up early, driving across the country, playing shows and making CDs all seem very worthwhile. As I was packing for the move to Ohio, I ran across the tapes (that's right, I said tapes … cassette tapes … I don't miss the cassette tape era, I really don't) of the show I did with you live on the radio. You introduced me to some wonderful music and musicians during your radio days. I will always appreciate that.

I read your blogs and realize how lucky I am to have you in my life.

April 23, 2010 – Second post of the day: Meshface

Friday, April 23, 2010



Am I tired today? I forgot to post this earlier on the blog – Meshface:
I rode the LifeCycle for 12 minutes at half intensity. Smooth ride. That pogged my memory. Yeah, let's say that did it!
Love…
Richard
Posted by greenpoet at 04:38PM (-04:00)

Comments

- BeJae April 24, 2010

Meshface. Adorable. I can't believe you think you could scare people with Meshface. It's just cute. Cute.

April 24, 2010 – Tired boy, take 2 (3, 4, ?)

Saturday, April 24, 2010

Slept until 8:30 am this morning, had my Boost breakfast, and did my morning computer thing. Ann got up around 9:00 am and we ate breakfast and talked about the day. The sun was already pouring into the house. I did my first set of swallow exercises. One of the exercises involves yawning. Didn't need to fake that! Around 9:30 am, I fell back on the couch. Next I knew it was 11:30 am and mandatory time to get up, wash up, and get dressed. We had company coming! I took one longing look at the couch and got myself going.
The condition of my mouth is changing day to day from radiation in a way different than from chemo. With chemo, the mouth sores and breakdown of the cheeks happened quickly and seemed to focus on particular spots. Today, I continue to feel the gradual breakdown of my entire mouth. It's a little sore, an indication of what's to come.
At noon, Ann's Dad Bill & his girlfriend Mary arrived. Dan came into the house a few minutes later. Dan and Mary were meeting for the first time. We sat and talked for a half

hour or so and then drove to Uno in downtown Worcester for lunch. Neither Bill nor Mary had been to an Uno restaurant before. We had a lovely meal. Between the four of us, we managed to take advantage of the diverse offerings on the menu. I think the highpoint was the shared dessert, Chocolate Malt Cake accompanied by two scoops of ice cream all covered with chocolate sauce.

During my meal, I discovered that my taste buds had decided to head south. I couldn't taste my salad or vegetable soup. Uno vegetable soup is a favorite treat. Both the salad dressing and the soup burned my taste buds, not so bad I couldn't eat, but enough to make me aware of what's to come. I've had a nice food "vacation" the past weeks. I've enjoyed tasting my food and looking forward to eating different meals. As I head into the next steps of radiation side affects, I will anticipate the full taste of food. The past weeks are a real motivator as I look to the future.

After lunch, we returned home and sat and talked some more. Bill & Mary set off for home in mid-afternoon. I did my second set of swallow exercises, and then the couch beckoned. I caught another deep nap. My body is telling me that I need both sleep and exercise. Next week will be busy, five days of radiation mixed with other appointments at Dana Farber. Monday is chemo day with five stops on the agenda. Friday, after radiation, the insertion of my feeding tube is scheduled at Brigham & Women's Hospital. Sleep and exercise sound good.

Oh, I wondered how it would look if I did my swallow exercises at a restaurant. What would people think? And would I empty the room?

Got wonderful news via Cousin Arlene yesterday. Darlene's CT/PET scan showed that she is cancer free. That is beyond wonderful!

Thanks everyone for the messages of comfort and support. I feel the love and it brightens my days.

Love…

Richard

Posted by greenpoet at 06:03PM (-04:00)

April 25, 2010 – The nap king, not the napkin

Sunday, April 25, 2010

First of all, a couple of clarifications. Dr. T. is not my radiologist but my radiological oncologist. Big difference. BeJae has named the Novalis Tx linear accelerator that radiates me "Little Bang". I've adopted that name, but began using it without explaining it. BeJae is brilliant when naming cats, dogs, and apparently linear accelerators.

Dan stayed late last night and we ordered in from Blue Jeans. He had the penne marinara. Seeking more protein, I had a large tuna grinder (grinder is Massachusetts talk for a sub sandwich.) I discovered that in addition to my taste buds going south, the interior of my mouth had continued to degrade. It hurt to eat the bread! Realizing that this may be my last grinder until June, I balanced the pain with sheer enjoyment of eating. All that for fresh baked Italian bread, tuna with low-fat mayo, lettuce, tomato, onions, and pickles? Hey, you take your treats when and where they're available. It's all perspective. The PET feeding tube gets installed on Friday. The tube will be my new friend.

Slept in late this morning, until nearly 9:00 am, and did my usual morning things. I figured that Cheerios are out for now and opted for soft and smooth Cream Of Wheat, the hot cereal that carries childhood memories. I was concerned because Cheerios has a lot of Iron, which I need. Turns out, a single serving of Cream Of Wheat has 50% of the Iron RDA and I eat a double serving. So I'm better!

Ann & I hung out reading, watching our HGTV home improvement shows (we have lots of tips saved up), and talking. I did my first set of swallow exercises and found them less comfortable than yesterday. I see a trend. Rode my LifeCycle for twelve minutes at half my normal resistance, drank a bottle of water, and had lunch. It was about 12:30 pm. I lay down on the couch and asked Ann to wake me if I still was asleep at 2:30 pm. We planned to visit my parents this afternoon.

Ann woke me at 2:30 pm, but it took me fifteen minutes to reach the sitting position. Rudy Dog napped with me and suggested we remain curled up on the couch. I found my feet and walked around waking step-by-step. Then it was time for swallow exercises set two. Ann & Rudy & I soon left to visit my parents. As is the norm for a Sunday visit, we watched sports while we talked. Dad was none too happy with the TV. The Celtics lost but lead the series 3-1. The Red Sox were ahead 4-1, when the knuckleballer Wakefield was pulled from the game and the reliever promptly gave up three runs to tie the score. Conversation easily won out over sports! Rudy is always happy to see my parents, even happier when Mom takes him into the kitchen and spoils him with a little chicken (white meat only for Rudy Dog.) Ann & I teach our dogs not to beg. The lesson is a bit looser at Mom & Dad's home.

Tomorrow is a busy day at Dana Farber with five scheduled appointments: blood draw, radiation treatment, meet with Dr. T. the radiological oncologist, meet with Dr. H. the oncologist and team leader, and chemotherapy infusion. Sounds like a fun day! Last Monday, Dr. H. noted that my red blood cell count and protein levels were lower than he liked. I've spent all week watching my Iron and being certain that my meals maximized my protein intake. It will be interesting to see where my blood levels are tomorrow. I've been quite fatigued since Thursday, which goes hand in hand with the worsening condition of my mouth from radiation. Fatigue is also a sign of low red blood count. I hope my red blood cell count is up in the normal range or at least shows significant improvement. I would like to avoid a blood transfusion. But whatever I need, just Bring It On! Knew this whole treatment process was not going to be pretty when I signed on. Also was very grateful to be able to sign on, that a successful protocol is available. We live in amazing times.

Thanks everyone for notes and good wishes. You are a constant well that I draw on for comfort and support. You make this journey gentler for me.

Love…

Richard

Posted by greenpoet at 05:19PM (-04:00)

Comments

- BeJae April 25, 2010

I initially named the Novalis Tx "Little Big Bang." It was a nod to that old Dustin Hoffman movie (that I keep meaning to see again), Little Big Man … And a nod to the other kind of accelerator I found online, a particle accelerator in which a team of scientists are trying to recreate the Big Bang by smashing protons together. They don't know exactly what will happen if they succeed … a contained Big Bang, maybe? Anyway, you shortened the name to Little Bang, so that one's yours. I think it's a very good name for our friend the Novalis Tx. It's very comforting to me to think of Little Bang as an entity intent on heroically keeping the world of your body safe from the Alien. This is how myths develop. My current position is that I get to tell myself any comforting story as long as it doesn't get me or somebody else into trouble. I feel that the Little Bang story is benign, so I'm sticking to it.

The pictures are so great, Little Bang, Meshface, Sockfoot, Blankie, Infusion Room, View from the Window … They make me feel so much more a part of this experience. I suggest someone tippy-toe in and take a picture of you and Rudy in Dreamland. What a very good companion that Rudy is.

Just to be in sync with you, I stayed up till 3:00 AM the last couple of nights, so I'm tired, too. Sometimes Jackie and I feel we're getting too old for this music-in-bars thing … But, we go right on with it anyway. Sometimes ya just gotta keep on going even if it seems too hard or too preposterous.

These are amazing times indeed. I, too, am so grateful for the successful protocol and for the very good prognosis. I wish you didn't have to go through this. Since you do, I think you should give up the low-fat mayo. I'm for high fat all the way … just for now, of course. I realize you can't completely ignore your arteries. Ah, the body is so complex with so much going on at once.

I am sending you love, my friend, and wishing you well with the big week you have ahead of you. Say hey to Little Bang for me. Tell her I said thanks. I always imagine that the Tx part of Novalis Tx stands for Texas and that its message to the Alien is: Don't mess with Novalis Tx.

Perseverance is worth it. You are teaching me that. Thank you.

April 26, 2010 – Radiation 9 [26 to go] – Manic Monday

Monday, April 26, 2010

I am a real doofus when it comes to pain medication. One of the suggested uses for Percocet during radiation treatment is to reduce mouth, tongue, and swallowing pain. The concept is that the patient takes the med an hour before a meal. Last night, I undertook the utilization of this complicated correlation and was able to eat my dinner with ease. Doofus is the technical term. My picture is in the dictionary.

Mondays are manic days for Ann & I at Dana Farber. Throughout the radiation treatment cycle, I will have at least five appointments that day.

Today, I got started at 8:00 am. My port was activated (a tube was put in for chemo) and blood was drawn. We haven't had a port issue until today. The channel flushed and seemed to be fine, but the nurse was having trouble getting blood out (usually it flows easily.) She used different syringes and vacuum tubes without much luck. Then, a series of flushes was tried. That seemed to do the trick. The nurse thinks there was a small piece of coagulation that acted like a flap when she tried to draw blood.

Our next stop was down in nuclear medicine. First, we met with Dr. T., the radiological oncologist. He checked out the condition of my mouth, tongue, and throat. I seem to be right on schedule. Dr. T. discussed what the coming week will be bring, both with treatment side affects and the insertion of my feeding tube. We talked a bit about pain management. I told Dr. T. my Saturday night grinder story and he advised me that it might be a few months before I can swallow a sub roll comfortably. But, it's something to look forward to; it's always the simple things.

We walked across the nuclear medicine lobby to Little Bang's waiting room. After a short wait, I was called. I took off my glasses, hearing aids, and undid the top of my johnny. The radiation techs saw my enabled port and decided that my mask needed a little customization. They placed the mask lightly over my face and chest to mark off a rectangle where the port's needle and tube sit. Then they got out scissors and cut the rectangle away. The techs assured me that the mask felt no pain. When they locked me in, the mask felt as tight as ever. I wished Little Bang a good morning and she started running my radiation program. Today's music was from Richard Buckner's first recording *Bloomed*, tracks played were "Blue and Wonder", "Gauzy Dress in the Sun", "Rainsquall", "Surprise, AZ" and bit of "Daisychain". There's nothing like the sound of a yearning pedal steel in the morning.

I changed out of my johnny, which means I took the johnny off and put my t-shirt and sweatshirt on, and we went to the next stop of the day, Head & Neck Oncology. I checked in and my vitals were taken. My weight clocked in at 149.8 pounds. I expected to be a few pounds heavier after the week's gorging, but I'm still within six pounds of my pre-cancer treatment weight. Our appointment was with Dr. H., oncologist and team leader, and the other Dr. H., the hematology/oncology fellow. They started with a physical exam of my mouth, tongue, and throat. Next was a review of my blood profile from today's draw. My red count is still low but it improved over the past week. The intensive chemo is still in my system, likely causing the lower counts. I told the doctors that I added fish to my diet to increase my protein intake. Unfortunately, my nutrition numbers weren't available from the lab (those tests take longer) so we don't know where my protein level is. At this point in the radiation treatment, my daily medications were evaluated. Dr. H. decided to simplify my daily intake and stop most of my non-cancer related meds until radiation is completed. A related goal is for all daily meds (cancer treatment and general health) to be administered in liquid form either orally or through the feeding tube. Dr. H. asked me how I tolerated my first booster chemo treatment last Monday. Other than hiccups, fatigue, and chemo brain (I left out the shopping trip story), I was fine. Dr. H. alerted me to potential side affects as we move forward.

We took the stairs next to Head & Neck Oncology down a flight to the infusion room. I checked in and Ann & I sat down to wait for my slot. It's fortunate that we enjoy reading. Waiting time becomes reading time. Chemo time becomes reading time. My name was called and I was directed to my favorite chair in a corner with windows on both sides. It's the same chair I was sitting in last month when cousins Al & Darlene arrived at the next chair for Darlene's infusion. As the nurse began to set up, my iPhone dinged. I checked the phone and there was an email message from Darlene in my Inbox. Cool! I love serendipity! Of course, I replied immediately and told her where I was. The nurse handed me a cup of pills including three greenie mega-steroids. We'll see if the insomnia gnome visits tonight! I was hooked up and the chemo booster was delivered in under an hour. It was still before noon, five appointments/treatments in under four hours – very slick!

Ann & I decided to go to the food court for lunch. Being aware of my doofus tendencies, I took Percocet around 11:00 am in anticipation of chewing and swallowing activity. Ann chose Subway. I was looking for a wrap, but Subway replaced the wrap with flatbread, which looked soft. I had tuna with veggies. Ann picked her favorite, a 6-inch Sweet Onion Chicken Teriyaki grinder on wheat bread. I was able to eat the flatbread sandwich with just a little discomfort (had to suppress my habit of eating fast.)

I think our ride home was easy. I closed my eyes on Storrow Drive (Boston) and opened them on Route 146 (Worcester.) Once home, the couch beckoned. Rudy and I assumed the position and napped while Ann ran a series of errands. I'm feeling good today, even after the pace of the morning.

This week, we'll have help on commuting to and from Dana Farber. Our friends Jesse (Thursday) & Susan (Tuesday) will drive and hang out with me during my appointments. We really appreciate this. Ann will be able to schedule two full days of patients. The pace of her work and my illness is a lot to manage. Wonderful friends are a true blessing. Thanks, Jesse & Susan.

I've got the rhythm of my swallowing physical therapy down. I did a set on the way to Boston and another set on the way back (wait – we stopped for gas – I just remembered that! I must have woken up.) Did anyone in other cars catch me doing the exercises?

They involve weird stretching of the face and sundry ways of sticking the tongue in, out, up, and down. I should notice the other drivers.

Thanks everyone for your kindness and consideration. Your comfort and support make my days brighter and my treatments lighter.

Love…

Richard

Posted by greenpoet at 06:05PM (-04:00)

Comments

- TaDa April 26, 2010

hang in there.... you are doing great..

- BeJae April 26, 2010

It is the simple things. It always is. Eating the grinder without pain, eating the grinder with enjoyment. This pain will make you so aware of the enjoyment. It makes me more aware of the enjoyment. I am more conscious when I read you. Thank you for that.

I just want to say that I think Ann is the most amazing partner. I have always admired your devotion to her. I'm now seeing her deep and abiding devotion to you. She has a busy life. I know that she cares so deeply for her patients. And yet, you are the most important one to her. That's what makes her a really good psychiatrist for others: She knows without question who and what is most important to her. I remember that she gave up much of her practice to be a fulltime parent for Dan and Adam during their teenage years. I remember she told me that she went through med school, in part, to be sure she could always make her own way, so that she would never be dependent. It was hard for her to give up her independence and to rely on you for support … But, she thought that her presence was important to Adam and Dan … So, she did it. She took a few years off. Of course, she did. I feel so grateful to her tonight. I admire her more than I can tell you. You are lucky. She is lucky. Adam and Dan are lucky. Life is good.

If your picture is in the dictionary under "doofus," well, that's what I want to be. Sign me up.

April 27, 2010 – Radiation 10 [25 to go] – Swallows

Tuesday, April 27, 2010

Today marks 10 radiation sessions in the book, twenty-five to go. It's good to be in double figures! We're on the new Little Bang time, moving from 8:40 am to 10:40 am. Jeff (& Nancy) has the block after me. It's always good to see Jeff looking well and he says he feels good. He's about two weeks ahead of me on the same treatment protocol. Today's music was from SONiA (of Disappear Fear)'s recording *Almost Chocolate* – tracks played: "Fallin", "Tattoo", "13", and "November Or Nothing". I have a special request for Little Bang via email that I'll play for her tomorrow.

This is a special drive to Boston week by Susan & Jesse (Tuesday and Thursday.) They've have been friends with Ann & I throughout our married lives. Our children grew up together and remain close. I've known Jesse since I was in diapers (no jokes, please.) We grew up a street apart and his backyard was on the way to my Nana & Zady's home.

Jesse's Mom would wave to me as I passed by on my walk to or from.

Today, Susan drove me to Dana Farber. We had a fun ride in heavier than expected traffic (then again, is there such a thing as expected traffic in Boston?) I warned Susan that many of the people working in the clinics are "kids", i.e. the age of our children. We talked all the way into town. With nearly thirty years of history and a pretty interesting now, we barely skimmed the surface of topics. We did get enough political venting in, complete with accents.

The first appointment was with the Speech & Swallow Therapist. Susan is an Occupational Therapist. I asked if she wanted to sit in on the session and she did. As we began, M., the Speech & Swallow Therapist, brought in a Clinical Research Coordinator, who presented me the opportunity to participate in an acupuncture trial. The trial will attempt to determine whether acupuncture can make swallowing easier during treatments (radiation and chemo) and whether it can facilitate the healing process. Ann & I will sit down and figure out if the scheduling is doable. I am ready and happy to participate in any research at Dana Farber. Whatever makes if easier for the next person coming in the room is meaningful. After the presentation, M. ran through her series of weekly benchmarks, checked my mouth and tongue (what's a trip to DFCI without a tongue depressor invading my oral cavity?), and watched me swallow. She prepared me for the coming changes in swallowing as I move forward with radiation treatment. Susan and M. talked a bit about their training and clinical experience. I was glad that Susan had a bit of the day.

After Speech & Swallow, we headed down to L2 to the radiation department. After my treatment, Susan checked me for fresh meshface. Yup, forehead to chin to neck.

We had a nice ride back to Worcester, time for more conversation. When I arrived home, Ann was already here on her lunch break. Lunch sounded good, so I made a tuna salad sandwich. Sandwiches are getting to be more of a challenge even with Percocet. Ann left for work. I did my swallow exercise set #2, then hopped back onto my Kindle and read more of Mariantes' *Matterhorn*. Fed the dogs dinner and took them out for a run. Then, I rode the LifeCycle for twelve minutes at half resistance. Ann returned from work and our friend Pam brought in supper from El Basha, babaganoush with pita bread and lentil soup. We've known Pam since our children were in preschool. It's a real blessing to have friendships that span decades, so much life in common.

Tomorrow is a light day at Dana Farber, just a radiation treatment. That's good because Thursday and Friday will be busy days. Hey, by the end of the week, I'll have 12 radiation sessions and one feeding tube in!

Thanks everyone for being here with your support. It's your company and comfort that makes this journey much gentler.

Love…

Richard

Posted by greenpoet at 08:20PM (-04:00)

Comments

- TaDa April 27, 2010

Richard... I sure hope it is easy for you and I am praying..... I breezed through it with minor burns on my back and minor irriatation to my eusophagus (spell)..but nothing that liquid loratab couldn't cure and the magic mouthwash..most of my damage was after with the scar tissue..but as you know my case was different...

Your strength amazes me... keep it up...

- greenpoet April 27, 2010

My strength comes from all your support.

- TaDa April 27, 2010

You are one tough Cookie... I have seen many buckle under not even half of what you are going through....I have been following you right along... You have the WILL and the strength and the awesome attitude... those alone will see you through (not to mention God shining down on you)

Hugs..

- BeJae April 27, 2010

I completely agree with TaDa. You are amazing.

I am so grateful that you have such good friends along for this ride. History is important when we face the really difficult challenges. It seems particularly significant that Susan and Jesse, your longtime friends, join you as you navigate double digits with Little Bang. I know it’s still a long way home … but, you’re a long way in now. The gas tank is still full and you’re not alone.

I send you love, my friend.

April 28, 2010 – Radiation 11 [24 to go] – for Tx

Wednesday, April 28, 2010

I think I'm into my radiation pattern: Monday when I get chemo with the greenie steroids and Tuesday, I have plenty of energy (it's also after a weekend's rest.) Wednesday to Friday, fatigue sets in and all I want to do is nap, nap, nap. This weekend I'll be sleepy and maybe a little sore after having the feeding tube surgery on Friday. It's an easy procedure; I take a "nap" and wake up with a tube. Simple, huh?

Jeff, who is going through the same treatment protocol for throat cancer, had his 20th radiation treatment today. He's a good model for me. We both don't smoke or drink, love to exercise, and eat healthy. Yeah, he's 40 and I'm 57, but we have a lot in common. His attitude mirrors mine. Bring It On! So, I ask him how he feels and I get an upbeat answer. He also tells me about some stuff he's hit that I will hit soon. For instance, the tube will be sore the first week until the surgeon pulls it out and manipulates it. After that, it’ll be much more comfortable. I feel fortunate to have my radiation treatment back-to-back with Jeff.

Ann & I left Worcester around 9:00 am for my 10:40 am slot. I went to sleep early last night and my alarm went off at 7:30 am. Took me almost four minutes (one song on the CD I have cued as a wake up tune) to drag myself out of bed. Big shock, I napped on the rides to and from Boston! Radiation treatment went fine. Today’s music was from Ray Wylie Hubbard’s *Growl* – tracks played were “Rooster”, “Screw You, We’re from Texas” (the special request for Little Bang, my Novalis Tx), “Rock ‘n’ Roll Is A Vicious Game”, and “Stolen Horses”. I think the techs like Texas.

When we returned home, we had lunch. Ann left for work and I got some errands done and answered a few emails. Rudy Dog & I took a nap, or tried to. Lacey kept whining for dinner – an hour early! Rudy and I were not amused.

Last night, I finished Mariantes’ *Matterhorn*. Thought the author found a satisfactory

ending for the book just when he seemed to have written himself into a corner. Started (still on my Kindle) Seth Grahame-Smith's *Abraham Lincoln: Vampire Hunter*. Ok, after *Matterhorn*, I need a bit of fluff and this book sounds like intriguing historical fluff.
Tomorrow, Jesse will drive me to Dana Farber. We'll have lunch in Boston. I'm looking forward to a fun day.
Thanks everyone for your messages. Your support and comfort keeps me rolling through these days. I appreciate every zoom you send my way.
Love…
Richard
Posted by greenpoet at 05:48PM (-04:00)

Comments

- TaDa April 28, 2010

It is good you have Jeff but remember every body is different... what he is going through yours might resist...

Onward ~

- BeJae April 28, 2010

I knew Hubbard (slightly, not well) in the seventies when I lived in Dallas. I worked at a legendary folk club called the Rubaiyat where Ray was part of the regular rotation of performers. I swear he's better now than ever … And Screw You, We're from Texas seems perfect for Little Bang. I also like Hubbard's Snake Farm. It's produced by Gurf Morlix and it's eerie and dirty and swampy … everything that Ray has always been, but Gurf captures that so well as a producer. I'll bet Little Bang's techs are having a real fine time with you and Ray and electric guitars and lasers and radiation. Gurf puts out great records his own bad self.

I'm so grateful for Jeff, who is your age corrected for good behavior: forty. It's so great to have a pathfinder. Your experience won't be exactly like his, of course, but you have such a better idea of what to expect because of Jeff. Please tell him I said, Thanks, and tell him how glad I am that he's most of the way through.

So, swallow, swallow, swallow … nap, nap, nap … You've got the rhythm. Rudy's got the rhythm. Groove is most of everything. Groove moves time along. Time does not fly when you're in treatment for cancer. But, it passes. Someday we'll look back on this, my friend. I'll be thanking you forever for your steadfast posts that inspire me and inform me and entertain me and comfort me. I'll be thanking Little Bang for being such a good and rowdy Tx girl. Yee-Hahhhhhh, boy howdy wow!

April 29, 2010 – Radiation 12 [23 to go] – riding with Jesse

Thursday, April 29, 2010

It's a sunny but windy day in Eastern Massachusetts, good traveling weather. Jesse picked me up at 7:15 am; we wanted to allow some extra time in case the traffic on The Mass Pike got dicey. The ride in was straight into the sun. Jesse packed some jazz, a Steven Colbert audio book, and a few CD's for the trip. We really didn't need much diversion. When you've known someone as long as I've known Jesse, there is a deep well of conversation open and waiting. We talked about our families, especially what the kids, now adults, are doing; and how quickly that transition from toddlers to adults swept by. Jesse & I are small business owners in Worcester. Discussing the challenges of operating a company in this city in this economy always occupies us. This year brings added complications and with them, a search for new solutions. Wherever our conversation leads us, we return to family. It's the ultimate destination. Qvelling is good for the soul!

We arrived at Dana Farber with plenty of time to spare. First stop was an appointment with Nutrition, part of the preparation for tomorrow's feeding tube insertion surgery. The nutritionist reviewed my current food intake and approved of it. She talked about the transitions I may go through over the next month due to the side affects of radiation. Some patients are able to eat sufficient amounts of soft food and use the tube only for booster calories and protein snacks. Others have more pain and difficulty swallowing and the tube becomes the primary source of nutrition. I will meet with the nutritionist weekly both for training on using the tube and for adjusting the mix of my diet. Some the meetings will also include the Speech & Swallow Therapist; the two fields have a large overlap.

We had a little spare time before radiation, so we went up to Head & Neck Oncology to straighten out a snafu in appointments. With that resolved, we took an elevator ride from the 11th floor to L2, land of nuclear medicine. I scanned in and we headed over to Little Bang's waiting room. It was empty. I changed into a johnny and checked the waiting room's monitor. Little Bang, on time at scan in, was now in a 15-minute delay. An older gentleman came into the waiting room, dressed for radiation. He has the slot before me and is the veteran of our group. After today, he has three treatments left. We have brief conversations and his sense of humor shines, but it's obvious that his throat is painful. He wished me well on the tube insertion. I congratulated him on being short. After he went into radiation treatment room, Jeff arrived. Today was radiation #21 for him, #12 for me. We talked tube a bit. Jeff asked me if I am a stomach sleeper. I replied, no a back sleeper. He smiled and said one of the worst parts of the tube was changing from his regular chest down sleeping position (which pushes on the tube) to his back. Soon, my name was called for radiation. I passed the older gentleman and wished him luck. He wished me the same on my tube surgery. I noticed the raw burn marks on his neck. As I rounded the corner to the radiation treatment room, I heard Jeff congratulating him.

My radiation treatment followed its now familiar rhythm. Today's music was from one of Boston's seminal New Wave bands during the punked out period of 1977-1982: Robin Lane & The Chartbusters. From their self-titled first recording, I played "Don't Cry", "When Things Go Wrong", "Without You", "Why Do You Tell Lies", and "I Don't Want To Know". Ann & I used to catch Robin and the boys live often, before and during the early days of our marriage. Those early 1980's styles were rad. The techs liked the tunes, got them dancing a bit!

On my way back to the waiting room, I passed Jeff (he has the slot after me) and he patted me on the back and wished me good luck with the tube. I wished him the same on his treatment today. We're members of an exclusive club and understand what lurks in the spaces between our words. The waiting room was full on my return. It ebbs and flows. Jesse & I left Dana Farber and headed around the corner to where his nephew Mark lives. Jesse & Susan are going to take care of Mark & Jen's dog Beso for the next week and we were picking the pup up. We decided to have lunch before driving back to Worcester. Mark recommended Charley's Diner, a neighborhood landmark that opened in the 1920's. (I wonder if my grandparents ever ate there?) Charley's was great. The food was excellent, the portions large, and the décor and ambience were from another era. After lunch, we packed Beso into the car and drove west through light traffic.

Jesse & I had time for more conversation on the ride home, amid my swallow exercises (I checked out other cars – no one noticed the odd movements of my face. I was disappointed!) Beso was quiet for the entire ride. Good doggie!

This morning, I was a bit apprehensive about the tube surgery. Kind of odd; the thought of it hasn't bothered me. Go into day surgery, take a nap, wake with a tube. Seeing Jeff and the DFCI staff today eased my apprehension. Maybe today, I'm being a bit normal.

Please note: if I'm coherent after the anesthesia, I'll post to the blog tomorrow. It's possible that I'll just sleep all day and night. So, please don't worry if I miss a day. I will try to at least get a few words up here.

Thanks all for your support and comfort. Having you along with me on this journey makes the path clearer and the footholds softer.

Love…

Richard

Posted by greenpoet at 05:29PM (-04:00)

Comments

- BeJae April 30, 2010

Hello from Denver. Jackie is at a conference here and I'm just long for the ride.

Happy stomach tube day to you! While you're there, would ask the stomach tube people if they have a tube for subtracting calories? I'm pretty sure they don't, but Dana Farber seems to be right in the forefront when it comes to helpful procedures, so I just thought I'd ask. I hope you end up not needing your stomach tube for additional calories, but I'm glad you'll have it in case you do.

I hope you'll sleep all day, if you can. There is great power in sleep, I'm convinced of it. You have been so faithful with these posts and I appreciate that so much. But, I can wait till tomorrow to hear about the stomach tube adventure.

I think of you every day and send you love and good wishes. Thank you for being such a wonderful person. I know you come by it naturally, but I know that it also takes a certain amount of work sometimes. You are an abiding inspiration to me.

April 30, 2010 – Radiation 13 [22 to go] – Tubular!

Friday, April 30, 2010

I'm tubular. I can eat and talk at the same time. I'm also passing out from the lingering anesthesia as I type. Here are a couple of tube photos:

The folded white piece on top of two bandages is a Velcro holder. It keeps the tube in place when not in use. The clear piece with a cap above the yellow connector is where the formula (via the syringe funnel) is poured.

Over on the left in the second photo is the Velcro holder. In photo one, we saw one

end of the tubing going to where the formula is poured. Here we see the other end of the tubing going through a white clasp and then into my stomach through a hole anchored by two bandages.

Ann & arrived at Dana Farber around 7:45 am. While she parked the car, I went down to radiation oncology and scanned in. I was called in, locked down with the mask, and ready to go when the mask was unsnapped. The table was malfunctioning; the techs couldn't control its height. They sent me back to the waiting room while Little Bang and the table had a heated conversation. After a five-minute wait, I was back on the table, mask locked and loaded. "Time to rock 'n' roll" I told the tech. "Time" she replied. Today's music was from Squeeze's *Argy Bargy*. Tracks played: "Pulling Mussels (From The Shell)", "Another Nail In My Heart", "Separate Beds", "Misadventure", "If I Didn't Love You", and "I Think I'm Go Go".

After radiation, we walked over to Brigham & Women's Hospital and checked in at Day Surgery. The whole process was very smooth. The pre-op staff checked all my details, physical and personal, and moved down to the prep ward. I changed into a johnny and was covered with hot blankets (yes!) Three people ran me through a checklist of questions. My port was activated. The anesthesiologist and surgeon introduced themselves and joked around. I was wheeled down to the operating room, given some happy juice through the IV, told a joke, heard a joke, and woke up in recovery.

The recovery staff was friendly and helpful. After checking my bandage, incision, and vitals, I was moved to a release area. We (or rather Ann, I wasn't about to remember anything!) were given after surgery care instructions and information on a surgical follow up. We left Day Surgery with me on foot and walked over to the Dana Farber patient garage. Our ride home was easy, at least for me. I fell fast asleep as soon as we hit Storrow Drive and woke on our driveway at home.

I'm now over 37% through radiation, will be over halfway next Friday. My tube is in. These benchmarks underline my progress. I'm sitting in Ann's recliner, currently the most comfortable seat for me. Getting in or out of bed or off the couch does seriously sting. I figure this will ease over the weekend. Some time next week, the surgeon will peel off a rubber washer (sits below the tube nexus) and move the tube about an inch to relieve the pressure and discomfort. I feel good and my attitude is very up, very Bring It On! I do understand that the second half or radiation treatments will be much harder than the first. But every treatment brings me that much closer to the finish.

Thanks everyone for your words of comfort and support. I carry you with me, especially on days like today, when the challenges are greater. I'm so grateful for all y'all.

Love…

Richard

Posted by greenpoet at 06:44PM (-04:00)

Comments

- BeJae April 30, 2010

Tubed! It sounds like summer and a slow-flowing river. It sounds like such a good thing. And look at you, typing instead of sleeping all day. Superman.

Over a third of the way through radiation. Amazing. Fabulous. Yes, I know the second half is worse than the first. I've heard that. But, the finish line is better than the starting line, even though it's more difficult and even though you'll be worn out and you'll have less energy and you'll need to do some healing. It's triumphant, the finish line is. Triumph makes up for a lot of discomfort.

I'm glad that Little Bang was able to sort out her table today. Sometimes a gal just has to do a little sorting out. I have no doubt that Little Bang has got the stuff to sort out any number of things.

It snowed again today in Denver, faux snow, air snow, the kind that disappears before it hits the ground, but swirls while it's falling. But, it's warmer today, more comfortable than yesterday … At least, it feels warmer to me. Maybe I'm just warmer today, getting used to Colorado and this unfamiliar town. The pedestrian mall downtown is busting with musicians and hustlers and tourists and fashionably down-and-out hipsters and convention-goers. We have walked and walked this afternoon … and I have wished you well with each step.

Is it Friday? (I don't know, I'm on vacation.) Do you have the weekend off? Woohoo!

Kiss your pretty wife for me. I send you good Rocky Mountain vibes, my friend.

May 1, 2010 – Pause…

Saturday, May 01, 2010

A short posting for today. Last night, I discovered positions in bed where the incision didn't hurt. Between the anesthesia and the busy Friday, I slept well. Then, I napped most of the day. The incision is much less painful now. However, I was quite constipated all day due to the pain meds and anesthesia (my best guess.) The constipation caused me the most discomfort. When I imagined this weekend, I saw myself working to deal with the incision's pain. Big surprise! It's my lower GI that had all my attention.

I'm feeling better now. Drank a Boost and will have supper soon. Have eaten very little today. This whole treatment process has many lessons. Just when I think the tube would dominate the weekend, my body turns around and surprises me. Ok, not all surprises are fun!

Dan's coming to visit tomorrow and we hope visit my parents. It's a short ride to their condo and a short ride will get me ready for the longer rides on Monday and the six appointments at Dana Farber.

Thanks everyone for your love and support. Knowing you are here with me was a great comfort today.

Love…

Richard

Posted by greenpoet at 10:12PM (-04:00)

Comments

- BeJae May 02, 2010

Not all surprises are fun ... Yeah, I hear that.

Thank you for being so amazingly steadfast in these posts. You are steadfast even during the not fun surprises. I have so much to learn from you.

Here's to some fun surprises at the end of all of this.

- drjj May 02, 2010

You amaze me and keep me strong in my own struggles - had shoulder surgery last week - calcified tendonitis - extreme pain for months, well, 3 years on and off but the last couple months seemed to get worse by the day. Less than two weeks after surgery, that pain is gone and I'm starting to stretch. I need to be in the ocean by June 1. Our darling niece Katy is graduating and we're taking her to Maui. She's going to Macaulester next year. Late at night I catch up on you, several days at a time. You are my hero, and Ann as well. Whatever strength and healing power I possess I send it to you, my friend. I am doing some mindfulness training as well as cognitive therapy - also, Foxy, have had great enjoyment coloring with fine point Sharpies. My writing class colors mandalas then writes, back and forth and it's lovely and mellow and the drawings are beautiful. I had uncovered an old anatomy coloring book from the 70's, though you can easily order them from a bookstore, and have had a ball with my alien color choices. When/if you can't write, color. Surround yourself with color and art and look at colorful things. I think that will help. I send you all my love, my friend. I'm holding your hand.
I love you, and Ann,
Janie

May 2, 2010 – Breathing

Sunday, May 02, 2010

Last night was an up and down night, up and down every hour to hour and a half. I slept well in between. Around 5:00 am, the constipation seemed to have resolved itself. All the meds were out of my system and my GI tract calmed down. After spending Saturday and early Sunday sorting out my digestive system, morning was welcome.

I had a breakfast of Boost and Cheerios with blueberries and vanilla soymilk. While I ate, Ann reviewed the post-op instructions on cleaning the tube incision. I finished breakfast and lay down on the couch. Ann removed the dressing and cleaned the incision site with a Q-tip. It didn’t hurt, but as Ann circled the site, she hit something that triggered a stomach muscle to spasm. That wasn’t fun but was pretty funny. The incision site is supposed to be left open to the air, so I’m going shirtless. Good thing the sun is out and temperature is 83F.

Dan arrived a little after noon and boosted my spirits just by being here. We sat around talking and watching “Scrubs” on TV.

I started getting hungry (good sign) and Ann made me scrambled Egg Beaters. Dan made himself a sandwich. My parents called and asked about visiting. They arrived soon after to the delight of the doggies, and the humans. We watched the Red Sox – Orioles baseball game as we talked. Mom & Dad admired my tube. I currently have two appliances in place (port is the other) and lead the family in that category. My parents left and Ann & Dan & I watched via DVR episodes of “Modern Family” and “Big Bang

Theory." I was hungry, again, and had a bowl of Campbell's Vegetarian Vegetable soup. When we were kids, I think there were more letters in the soup. Oh well.

As bad as I felt last night, today I feel good. In a while, I'll take a shower, first shower since the surgery. I have to be clean for all of Monday's poking and prodding. We have a busy schedule: blood draw, radiation treatment, appointment with the radiation oncologist, appointment with the oncologist/team leader, chemotherapy, and the nutritionist. The nutritionist will teach us how to flush the tube and feed formula. I can eat and talk at the same time!

Thanks everyone for your support and comfort. I look at my windowsills covered with cards and my Alien mailbox full, and feel you all here with me.

Love…
Richard

Posted by greenpoet at 04:56PM (-04:00)

Comments

- BeJae

May 02, 2010

What? Fewer letters in the alphabet soup? Okay, this won't do? Which letters didn't make the cut? How will children learn to spell with fewer letters?

Isn't it amazing how some things bring us close to other people so quickly? It's like that for touring musicians. We're out there on our own in your town, not knowing anybody, just hoping to meet some kind people who are open enough to take in what we do. Sometimes, we find very generous people who not only take in our work and reflect it back to us so that we can understand it better, but who also take us into their homes and into their lives and care for us and make us almost part of their families … like you, Ann, Dan and Adam did for me all those years ago. I will always appreciate that so much. But, I also appreciate those people who very briefly come up to me after a show and talk to me and wish me well and help me feel like this journey of making music is a rich one. I doubt that those people will ever know the importance of what they give me and how close I feel to them in those moments. I feel that sort of closeness to the people in the infusion room and to the people who have appointments with Little Bang at times close to yours. I feel so grateful to them for their lightheartedness and for their attempts, in the midst of their own challenges, to make the people around them feel better, reassured and comforted. I will miss them when this blog has served its purpose and is done. Through you, they have really gotten to me.

It seems like Mondays are very demanding days. I hope you get lots of very good sleep tonight so that you'll be all ready to take on Little Bang and the various humans. This week will see you halfway through this part of your treatment. Keep moving on and know that I am cheering and that I am so very impressed with how elegantly you are running this marathon.

- TaDa

May 02, 2010

I am sorry you had to have that put in... but in the long run it will be for the best and will be out before you know it...

Hugs from FL..

May 3, 2010 – Radiation 14 [21 to go] – 40% there!

Monday, May 03, 2010

Ann & I are exhausted. It was a long day. We got up at 7:00 am and left the house at 8:30 am. Traffic on the Mass Pike was frenetic. We pulled into Dana Farber around 10:00 am, in time for my 10:15 am blood draw. Ann dropped me off at the entrance and I zipped up to the 11th floor and registered. I got my Dana Farber wristband for the day and sat down to wait. Just after Ann arrived from parking the car, a nurse called my name. The nurse accessed my port, drew blood, and set up the tubing for chemo.

Our next stop was radiation oncology. We went down to L2. I scanned in and donned a johnny. The older gentleman who has the slot before me walked into the waiting room and held up a single finger (index) to me. He finished his thirty-fourth session and has one more to go. He paused to ask me how the tube insertion went which I appreciated. The radiation tech called me in and got me set up for my radiation session. Music for today was from one of my favorite jazz concert recordings, The Carla Bley Band's *Live!* Tracks played were "Blunt Object", "The Lord Is Listenin' To Ya, Hallelujah!", and "Time And Us". When my session finished, I heard and felt the mask being unlocked. When the mask cleared my vision, I saw it was Jim, the head tech doing the unlocking. Jim is generally in the control room at this point in the action. He is also the largest and strongest tech. Putting his hand under my back, he gently raised me off the table. With my tube still new and healing, sitting up from the table by myself would have been painful. The radiation techs are very aware of tube insertions and I think Jim was there because he could get me off the table smoothly. It's the little things that count and Dana Farber racks them up.

I returned to the waiting room and saw Jeff. As he was being called in for his session, he asked me how the tube surgery went. It's like I said last week, being a Dana Farber patient is like being a member of a club. I doffed my johnny and Dr. T.'s (the radiation oncologist) nurse came to bring us to our next appointment.

Dr. T. checked out my tube, looked at my mouth, tongue, and throat, and asked the standard questions. At this point, my mouth, tongue, throat, and swallowing muscles are incrementally degrading with each treatment. Dr. T. told me what to expect in the near future and discussed long-term pain control strategies.

Our next stop was back on the 11th floor for my checkup with the oncology team. When my vitals were taken, they noted that I lost three pounds. I know when that happened, Saturday through the wee hours of Sunday. Lesson learned: I will never have anesthesia again when constipated. My oncologist and team leader, Dr. H., was away, so I saw the other Dr. H. (hematology/oncology fellow) and another attending oncologist Dr. L.. My blood numbers were reviewed and it was a positive report. My red blood cell count is stable and my protein level is significantly higher reflecting the changes in my diet. Everyone took a turn poking and prodding my tongue, mouth, and neck. Again, we talked options for pain management as we move forward. Dr. H. gave us a new factoid. The side effects from radiation will continue incrementally for a week following my last treatment. But, the healing process will start soon after and progress at a faster rate.

From the 11th floor, we walked down a flight of stairs to the 10th floor and the infusion room, stop number five. I registered there and was told that infusion was running behind. I had a noon slot but it was more like 2:15 pm before my chemo started.

Brooke, the nutritionist came by with the idea of doing my tube instruction at the same time as chemo. Since we had a delay, she found an examining room and we worked there. Brooke looked at my tube assembly and asked me how it felt. I told her that the discomfort was minor; but when Ann cleans the crusting around the plug where the tube enters the abdomen, there is one spot that spasms and makes my leg and foot bounce up and down. At first, I tried to suppress the bouncing, but that made the cleaning more uncomfortable. So, now I bounce. The dogs think it's pretty funny, but they understand. Brooke had me unhook the tube's nozzle from the Velcro holder and uncap the nozzle. She then inserted a 60 ml syringe (which is used as a funnel) into the nozzle. Next, I released the clamp that sits halfway on the tube. We were unlocked and primed. Brooke filled the syringe with room temperature bottled water to flush the tube (whenever I eat, gravity pulls stomach contents into the tube.) Then she opened up a can of formula (unflavored 'cause it's going straight into the tummy, no tasting involved!) and filled the syringe. The formula is thick and I had to raise the tube to get it to drain. It's fun to watch the chocolate color seep through the tube. The last step was to flush the tube with water. I found that if I hold the nozzle high and keep my mouth shut, the water easily drains below the clamp and I can secure the clamp without any trouble. Brooke's plan is for me to ingest one can of formula a day while I'm still eating orally. Two cans of formula equate to a meal, so as my oral food intake decreases I add more formula. Brooke checked in with the infusion room. There was still a delay, so she brought us out to the waiting room. Around 1:45 pm, my chemo nurse came out and apologized for the long wait. Mondays are always busy, being after the weekend, and midday is the time in most demand. I was brought to a bed, not a chair, a first. All the chairs were full. It turned out that the bed was handy for napping! Around 2:15 pm, she returned with my fresh brewed Carboplatin and hooked me up. I read a bit until I began to drift. Put the Kindle down, closed my eyes, and slipped into a nap. Before I knew it, the IV machine began to beep. It made an excellent alarm clock.

Ann & I hit the road around 3:15 pm. We ran into pockets of heavy rain, otherwise the ride was ok. The doggies were real glad to see us. Dinnertime is 3:30 pm and we were forty-five minutes late. Tomorrow, Lora is driving me to Dana Farber; I'm looking forward to a fun trip. It's an easy day, a radiation treatment followed by a trip to the 11th floor to sign the papers needed to join the acupuncture research.

Thanks everyone for all you do to make my cancer treatment gentler. Your support and comfort is a cherished gift.

Love…

Richard

Posted by greenpoet at 08:30PM (-04:00)

Comments

- BeJae May 04, 2010

40%. Wow!

That Jim ... He's a good one.

I'm packing to leave Denver. Today I will be flying and thinking of you.

May 4, 2010 – Radiation 15 [20 to go] – Riding with Lora

Tuesday, May 04, 2010

This morning I woke up with my first case of “Sahara Desert” mouth. The radiation nurses warned me of this wake up phenomena. Beyond normal dry mouth (and I sip water every nighttime pee break, about every ninety minutes) large areas of my mouth were coated with a thick sludge. I gargled water, no luck. I ramped it up to Biotene mouthwash, better, broke up a lot off sludge, but ouch! More water, then time for a Vanilla Boost. We are progressing with radiation therapy. Do the math; I’ll have less than twenty to go after tomorrow’s session, but that also means the side effects are picking up. I saw Jeff today as we passed each other between consecutive slots on Little Bang. He gave me thumbs up and wished me well. His voice was hoarse but his attitude great as he asked how my tube was feeling. The Dana Farber Club!

Our friend Lora picked me up at 8:45 am. We had an easy ride in. Somewhere past Natick, I noted the lack of traffic and Lora said don’t jinx us. We came around the next corner and yup; the backup from the I-90/I-95 interchange slowed us right down. I should have kept my mouth shut. Nonetheless, the tie up was minor and we arrived at Dana Farber in plenty of time.

Riding with Lora was a lot of fun. Conversation never hits a lull with good friends. We have a plethora of topics: adult children, aging parents, why children & parents won’t do as we suggest (isn’t the sandwich generation always right? ask me in 20 years or so), our common friends, and three+ decades of history and stories. Yes, Cousin Betsy, we talked about you. Were your ears ringing? (Not to worry, all we said was good and true.) Larry & Lora have two daughters; we have two sons. Both older children live in the Boston area and have established professional careers. Both younger children are Ph.D. candidates and live far from home; travel is part of their world. Mostly, Lora and I had a lot of laughs. The funny stories won out, but we touched the serious ones, too.

Today was a “light” day at Dana Farber. After my radiation treatment, we met with two Research Coordinators to sign me for the acupuncture trial. A doctor’s signature was also required. Dr. H., my oncologist and team leader walked in the room. He gave his view of the study (a positive one) and we signed the paperwork. It’s always a treat to see Dr. H.; he exudes competence and confidence. The Research Coordinators brought us down to the Zakim Center, the home of acupuncture and similar therapies. We scheduled the twelve sessions, which start this Friday and conclude in September. I may be in a “sham” (control) group or may be getting the real therapy. If I’m in the sham group, I’ll get six certificates, each good for a treatment at the Zakim Center. I won’t know which group I’m in until after the twelfth session.

Lora and I left Dana Farber for Worcester, but made a stop at Whole Foods in Newton. There isn’t a Whole Foods near Worcester; sadly our old mill town doesn’t attract new businesses especially diverse food markets. So going to Whole Foods for me is like going to Disney Land with even better eats! We meandered through the market, department by department, selecting soup & sandwiches for lunch, freshly prepared foods (an incredibly varied and creative assortment), and items to cook later that are not available in regular food supermarkets. Lora and I have a similar shopping pace. We like to stop and look at everything, take our time. And we did! We ate our lunch, got back in the car, and headed west down the Mass Pike. Lora, thanks for the ride and the great conversation and shopping.

When I got home, I greeted the doggies and put away the groceries. After that, I spent the rest of the afternoon doing chores and paying bills. Tomorrow will be a light day at

Dana Farber. The only appointment is radiation. It will be good to have some quiet time and maybe nap time when we get home.
Thanks everyone for all the greetings and good wishes. Your comfort and support makes my days easier and serve as a font for strength.
Love…
Richard
Posted by greenpoet at 07:34PM (-04:00)

Comments

- TaDa May 04, 2010

Whole Foods is new here..I can't wait to get into one.. I blasted of another attempt at dieting yesterday (Ugggg) I need to lose this weight... I be damed if I beat cancer to lose my health to overweight issues...

Hang in there.. You sound good... keep the spirit up..

If the love of your friends and family could kill the cancer you would be a zillion times cured by now.

Laura

- BeJae May 04, 2010

Ah, so you're still eating the old fashion way. That's very good, very good indeed. I wonder if acupuncture is good for sludge. I hope so.

Twenty sessions to go … So, four weeks and you're done? Amazing. I know that four weeks seems like a very long time when you're facing mounting side effects. But, it still seems mighty finite. I'll be heading to Iowa in just about four weeks to play a few shows. It seems like only a short time left to polish up those songs … but, I'll bet we'll both be ready to roll when the time comes.

I'm back in Columbus. I swear, the yard grew half a foot during the six days we were gone. It's as energetic as your healing will be once you and Little Bang part ways.

I'm so grateful to the friends and family who provide all of this conversation-filled transportation. Car time can be so wonderful.

I am thinking of you tonight, my friend. Four more weeks …

- drjj May 05, 2010

You sound so intentional with everything you do, every moment important, very present in the moment. I'm working on that currently. My show got moved to Monday nights from 9-10 a couple months ago and last night we interviewed Tracy Sugarman, author of We Had Sneakers, They Had Guns about the Freedom Summer of 1964 in Mississippi with voter registration. One of the guys that taught in a Freedom School is local and was also on. A bit of a departure from our usual purely literary show, but it's creative nonfiction and reads like a novel. It was so intense, especially coming while I'm writing prose, maybe a memoir, too soon to tell, about Mary and me. I'm not nearly done with that story. So, I recommend the book, very moving. I was 14 and you were younger and I was growing up with a black "help" so it was intense. The book is beautifully

written. I don't read history but this was written in such a way that I could.
I think about you every day and am sending love and healing energy your way. It's so great to be able to keep up with you because of your writing. Thank you so much for doing this. I'm sending you a huge, gentle hug so as not to bump the tube.
kisses and love to Ann,
janie

- greenpoet May 05, 2010

Laura,

Have fun with Whole Foods. Hint: the first time you experience it, don't go in hungry! It's the Disneyland of food!

Thanks for your notes of comfort & support.

- greenpoet May 05, 2010

BeJae...

Wish I could join you in Iowa. Always wanted to meet them Trailer boys! Road trips in moderation are fun. Great way to get to know someone or renew old ties...

- greenpoet May 05, 2010

Hey Janie...

Put "We Had Sneakers, They Had Guns" on my reading list. Seems this job of going to doctor's appointments and treatments is busier than I thought, so the books are taking longer. But that's ok. I rather read slowly and reread passages; drink in the author.

You're writing prose these days? Along with poetry? I'm really looking forward to seeing the Mrs. Noah and Friends manuscript.

Glad your shoulder is feeling well. Being free from pain is a gift. Stay loose! Enjoy Maui with Katy! Special times. You'll make memories that will fill you for years.

Love to you and Sondra!

May 5, 2010 – Radiation 16 [19 to go] – Less than 20.

Wednesday, May 05, 2010

I seem to be in a pattern. Monday and Tuesday, I have plenty of energy. Monday makes sense despite the six appointments; it is after the weekend. Tuesday, perhaps I'm still feeling the jolt from Monday's pre-chemo steroids. Wednesday and Thursday, I am fatigued even with a light Dana Farber schedule on those days (or maybe because of the light schedule?) Friday, I'm tired, but shake it off. It's the last day of the week. "It's Friday and the streets are ours." – old Boston 1980's Punk/New Wave proverb. Today is a tired day, but hey: I have less than twenty radiation treatments left!
Ann & I left the house at 8:45 am. We drove into the sunshine, a beautiful Massachusetts Spring morning. Traffic was relatively light until we hit the Cambridge/Allston exit off I-90,

but that's a short tie up. We arrived early for my radiation treatment. I scanned in, donned my johnny, and we pulled out our books. While we were waiting, one of Dr. T.'s nurses came over and checked in on my progress. Things are stable for now, but it's good to know the staff is watching.

My radiation treatment went smoothly. Today's music was from Annie Gallup's *Backbone*, tracks played were: "Fight The Devil", "Max", "John Llewellyn", "The Girl With Flyaway Hair", "April 22nd, Somerville, Massachusetts", and "The Truth About Disguise" [perfect mask song!] Jim, the head radiation tech, asked me who the artist was, so I introduced him to Annie.

In the waiting room, I said hello to Jeff before he headed in for his treatment. Dealing with the side effects is getting to him, though he's trying not to show it. But Jeff is short. His last treatment is two weeks from today! When he finishes, I'll have nine left. We all move forward, from newbie to seasoned (Little Bang helps.)

We had an easy ride back to Worcester. When we arrived home, Ann took a quick nap while I caught up on phone calls. An hour later, I laid down on the couch to nap just as Ann was getting up to go to work. I had a long nap, woke to two doggies imploring me to feed them supper. Fed the pups, then took them out for a run (while I watched. Running is a ways off for me.) Got together the PEG tube supplies and fed myself a can of formula. Yum! It's kind of weird to be drinking water through my mouth while for the formula is draining through the tube directly into my stomach. The plan is to take it really easy tonight and get a lot of sleep. Tomorrow night, Adam arrives from Colorado. He'll do the bulk of the driving to Dana Farber over the next three weeks; take a lot of the pressure off of Ann. Ad can do his research from here. The Internet makes the world smaller.

Thanks everyone for your emails. I'm behind on replies, but working on it. Thanks for all your comfort and support. Walking this road is much easier when not walking alone.

Love…

Richard

Posted by greenpoet at 06:08PM (-04:00)

Comments

- TaDa May 05, 2010

Richard... do not hold Jeff in your glory.. every body is different.. what he goes through may never effect you... or vice versa... hear me there? ... every body is differnt.... example ..... when i was doing mine there was a girl (4 yrs older than me) similar cancer in the lung.. she suffered major burns on her body.. and i though "oh great... that will be me" .. it never happened....hence.. EVERYONE IS DIFFERENT... hang in there... you will be fine. and that feeding tube will be out before you know it.. (know why... cause I pray every night for you)...

- drjj May 06, 2010

My week, at least this week, is opposite - I'm teaching tomorrow, Friday and Saturday. Starting June 14 my Gifted Writers summer camp could have me working 6 days, or portions, but for me it's feast or famine and most of the year it's been famine, so I'm grateful for whatever comes.

I am writing prose. I finished the Mary book and am submitting it to contests, but the poetry just didn't finish the subject of growing up with a black maid, so I'm trying different angles and just writing anything write now. Otherwise, new Mrs. Noah's keep coming. I can send you the manuscript, Both Wings Flappin', Still Not Flyin' and send you the messy out of control The Little Mrs. in process when I get back. Throw me your address

and I'll get the first one to you. Did I tell you the latest two titles? Mrs. Noah - The Monkey Doodle-do, and Mrs. Noah Chats with Simba. Hope I'm not repeating myself. The second is another sestina; I have a ton of Mrs. Noah sestinas - very weird, but I'd love to have you see them and I'd love to finish the book and start sending it. I've had a couple published. I'm sure we will be seeing more of her in volume 2, not to worry.
I just feel so much love for you, Foxy. I'm the one staying up deep into the night watching over you, my dear sweet friend. Glad to hear Ann will get some driving respite. Give her my love.
Thanks for the daily updates; makes me feel closer.
love,
janie

- BeJae May 06, 2010

I'm so grateful for your posts and for this internet that makes the world smaller and brings me closer to you. I imagine you right now with Boost in your belly, flying along the highway unimpeded to your date with Little Bang.

Jim, the Head Banger, showed his very good taste in lyric writers when he asked about Annie Gallup's work. I love the songs on Backbone. I haven't heard Annie live in a very long time, but I always connect her work with my memories of you and your time at the radio station.

It's so good to read your words and to know that, despite the challenges, you just keep moving on.

May 6, 2010 – Radiation 17 [18 to go] – Counting…

Thursday, May 06, 2010

Ann & I set off for Boston at 7:30 am today. We often have the fifteen-minute debate (should we leave at 7:45 am?), but end up allowing the extra time. Today, we needed it all. Don’t know why, but we hit two big snarls on the Mass Pike.

The first appointment of the day was with Maria, the Speech & Swallow Therapist. We went over my swallow exercise program and current food/liquid intake. Breakfast has been a challenging meal for me this week. I wake up, take pain meds, have a Boost, and wait forty-five minutes before eating. It’s still hard to eat over the night’s dry mouth and general soreness in my mouth and on my tongue. And while fighting off early morning fatigue. Maria suggested that instead of eating orally, I just “do a couple of cans” of formula through the tube and let my body wake gradually. I think that’s an excellent plan.

Next, we went down to L2 for my radiation treatment. We were about a half-hour early and someone must have been late. They took me in immediately. I asked the techs if they liked Austin Blues and they said heck yes, so today’s music was from Sue Foley’s *Walk In The Sun*, tracks played were: “Try To Understand’, “Give It To Me”, “Walk In The Sun”, “The Snake”, and “Lover’s Call”.

My appointments finished early, we decided to stop and do a few errands on the way home. I napped most of the way into Boston and napped most of the way back, too. Thursdays are high fatigue days. Don’t know if it’s the sequencing of chemo and radiation, the schedule of treatments, or what. Thursday, I crash.

Ann watched me sleeping on the ride home cut our stops to CVS, a quick lunch at El Basha (lentil soup still smooth), and Petco where she picked up food for Blaze, Adam’s

Labrador Retriever.

And yes, that's the big news. Adam and Blaze arrive from Colorado tonight! Ad can work from here and drive me into Dana Farber daily. That takes a lot of pressure off of us, especially off Ann's schedule.

Renee is driving me tomorrow. I have radiation, acupuncture, and the follow up for my tube surgery.

I'm afraid I'm fading. I took a three-hour nap this afternoon, but my body wants me to lie down on the couch again. I will listen to my body.

Thanks for your comfort and support. You all light the way for me on this journey.

Love…

Richard

Posted by greenpoet at 05:43PM (-04:00)

Comments

- BeJae May 06, 2010

So great to hear about your day, even the more difficult "crash" days. I am learning so much more about this process than I have ever known. Thank you so much for that.

Jackie left for Asheville after work today. It'll be just me and the kitties for the next couple of days. I'm so glad I have you to keep me company.

Tomorrow is Friday. The streets are ours!

- TaDa May 06, 2010

Adam n Blaze (son)? I am glad you have company and they can pitch in..this will all be over before you know it and you will land on your feet!

Laura

- greenpoet May 07, 2010

Blaze = sweet Black Labrador Retriever!

May 7, 2010 – Radiation 18 [17 to go] – Over halfway, Particle (ap)...

Friday, May 07, 2010

Adam & Blaze dog arrived around midnight last night. Ann picked them up at Logan Airport while Rudy Dog, Lacey Dog and I slept. It's good to see Adam. We talk often but nothing is like flesh to flesh. Blaze has grown since we last saw her, not only physically, but also from a rambunctious puppy to a mature dog.

Got up this morning after a deep night's sleep. Decided to go with the two can plan for breakfast. Yesterday afternoon as a test, I downed two cans of formula without a problem other than a little bloating. (It is a weird feeling when I pour water in the tube and have the feeling in my stomach of drinking water but my mouth is bone dry.) After the first can this morning, I decided that a second might not be a good idea given that I was about to go on a ninety-minute car ride. Instead, I grabbed a Boost for the road.

My sister Renee picked me up at 8:45 am. She came in and said hello to Adam, Blaze, and Ann. Then we were off to Dana Farber. Traffic was steady until we hit The Allston/Cambridge exit, which was backed up beyond the tollbooths. Renee was a student and teacher in Boston and knows that corner of the city well. She drove us around the Cambridge gridlock towards Allston and double backed along side streets to Dana Farber. We arrived in plenty of time.

First stop was radiation oncology. I saw one of the nurses and asked her to look at a rash on my upper back. After donning my johnny, she examined me. I didn't realize that some of the radiation is shot through the back of my neck and upper back. I need to treat that area with Eucerin Aquaphor as well as the front of my neck. When it was time for me to go in, Renee was offered a quick tour of the radiation treatment room. Today's treatment went smoothly. Music was in Renee's honor, Particle from a live soundboard recorded at The Paradise Rock Club on 11/15/2003. Track was "Lost Child>Ed & Molly". My nephew/Renee's son Eric is the bass player for the band.

From radiation, we went to the Zakim Center for my first acupuncture appointment. The research coordinators gave me a survey to fill out. One of the questions was "Do you feel ill?" My gut answer was no. I may feel fatigued with a sore mouth, tongue, and throat, but I don't feel ill.

I was brought back into an examining room and introduced to the acupuncturist. He's Chinese and trained in his native country. We went over my cancer treatments and their effect on my pain level and swallowing. I got comfortable on the table and was blindfolded; to be sure I didn't get a hint as to which group (sham or real) I'm in. The session was gentle and relaxing. I couldn't feel the insertion of the needles. With Chinese music dancing in the background, I drifted on the table for a half hour. The acupuncturist returned and removed the needles, again without pain. My next session will be in about a week. First impression is very positive.

Renee and I next went over to The Longwood Grille for lunch. My Longwood meal is becoming like Garp's name. The Tuna Salad Grilled is now down to a couple scoops of tuna salad and French fries! The fries will be next to go. Renee had one of the Longwood's featured salads.

My last appointment was at Brigham & Women's Hospital Day Surgery, the follow up from last week's surgery. The nurse practitioner examined the tube placement, turned it 360 degrees, and cleaned the site. She pronounced me ready and able for non-contact sports, i.e. I can ride my LifeCycle again.

Renee and I walked from Brigham & Women's to Dana Farber. It was a beautiful day, warm and lots of sunshine. We made our way to the car, and began the drive to Worcester. Our day together was a lot of fun. With time for uninterrupted conversation, we laughed a lot, pulled out vintage memories, and got caught up on the details of our children's' lives. It's a real gift to share the day just with my sister. I feel very grateful for today.

When we arrived back at the house, we all visited a bit and then I went in for a long nap. I had good reason to be tired; it was a busy day. But I think the radiation is catching up with me and I'll need to be conscious of my rest and sleep time.

Dan arrived after supper. The four of us are together for the weekend! Ann's Dad & Mary are visiting us tomorrow and Sunday; we'll head over to my parents' condo.

Thanks everyone for cards and emails of support. As I enter the stretch run of radiation, your love, comfort, and support are an anchor for me. This is tough part of the treatments, but the end is in sight! I'm over halfway through radiation; raise a toast!

Love…
Richard
Posted by greenpoet at 08:58PM (-04:00)

Comments

- BeJae May 08, 2010

Ah, Particle. I knew they'd be in the rotation and I wondered when. Eric is an amazing bass player. I noticed that they're on the summer schedule for an outdoor show in Des Moines. I hate to miss that. I need to check and see when they're playing Columbus.

I'm so happy that Adam and Dan are both home this weekend. The boys are back in town. Yeah!

I hope you have a wonderful, restful weekend. Over halfway through: This is just so great. The days and the weeks roll by, and you and Little Bang accomplish miracles. Life is good! The streets are ours!

May 8, 2010 – Here comes the weekend

Saturday, May 08, 2010

Sweet Saturday slept in late and just woke from my third or fourth nap! I must need the rest!
For breakfast, I drank a Boost and then did a can of formula through the stomach tube. As I lay back bloated, I realized the opposite order would have made much more sense!
It's fun having Dan and Ad and Blaze dog visiting. The doggies all get along, well sort of. Adam's Blaze is a black lab; she's very sweet and gentle but big, one tail swipe can clear a table. Lacey, our geriatric Bichone, is also sweet and gentle, though happily dealing with a bit in dementia. Young toy poodle Rudy is a jealous doggie! He growls when ALL the attention is not headed in his direction. Rudy will survive. Hoping these three weeks with Blaze will be a good learning experience for Rud-a-boo.
Ann's Dad Bill & girlfriend Mary came by for lunch. We ordered lunch in from Blue Jeans, all except me. I had a bowl of Campbell Vegetarian Vegetable soup with sopped crackers. The visit was a lot of fun. Mary is very sweet and makes Bill very happy. Which in turn makes us all very happy.
Tonight, Dan & Ad will pick my Mom & Dad and meet Renee & Marshall at Romaine's Restaurant in Northborough. It's an early Mothers Day dinner.
Ann & I will take it easy (I feel another nap coming on) tonight. It's a weekend of celebration.
Thanks for the cards, notes, and email messages. I never feel alone.
Love…
Richard
Posted by greenpoet at 05:16PM (-04:00)

Comments

- BeJae May 09, 2010

I'm all for celebratory naps … Just the ticket … And no one naps like Rudy dog. He's king of napping, hands down, no growling necessary.

Jackie is out of town. My friend, Jae, and I went out to hear a couple different acts at a couple different venues. I took a page from your book: hard listening; wide open listening. Such a pleasure to hear live music.

I'm so happy that your family is together. Your sons are strong and true, just like you raised them, just like you showed them. I celebrate the mothers: your own mom, your sons' mom, the mother of that great bass player, Eric. There are extraordinary mothers in your family. What a lucky bunch you are. Here's to the mothers. Here's to you. Here's to Little Bang, the mother of destruction and healing, and here's to over halfway through. Cheers!

May 9, 2010 – Happy Mothers Day!

Sunday, May 09, 2010

Short posting for today, been napping a lot. My parents and Renee & Marshall had a lot of fun last night with Dan & Adam. This morning, the doorbell rang and beautiful flowers for Ann from the boys arrived. We went to visit my parents this afternoon. The flowers we ordered for Mom didn't show up. There was a snafu at the florist and they will deliver (with a bonus) on Monday. We had a fine time with my parents, and then returned home. I'm going to hit the couch for another nap soon as I finish blogging.

I'm quite fatigued this weekend and my mouth-neck-throat are becoming increasingly sore. Tomorrow is a six-appointment day at Dana Farber. I'll see all of my med friends! And likely, sleep in the car both ways!

Thanks everyone for your notes of comfort and concern. Your support helps me through these increasingly challenging days.

Love…

Richard

Posted by greenpoet at 04:40PM (-04:00)

Comments

- BeJae May 09, 2010

Over halfway through … The marathon is difficult now. The body is tired, pushed far beyond its normal limits. And still the finish line is not close. It's still out there in the distance. This is not the brightest time, not the most comfortable. And there is the knowledge that it may get even more challenging. But, soon you will be able to see the finish line. Soon the effort will seem entirely worthwhile. In the meantime, I am with you, thinking of you, sending you my love and my best wishes. I wish you didn't have to do this … but, I absolutely know that you can and that you will. Courage, my friend. I admire you more than I can tell you.

May 10, 2010 – Radiation 19 [16 to go] – Little Bang rocks!

Monday, May 10, 2010

Today is busy Monday. It's catch as many naps as you can on Saturday and Sunday to be ready for Monday, Monday. And you can't trust that day, or at least some appointment times that day.

We woke up early. As soon as I washed up and took my meds, I set up the PEG tube and did a can. Northing like the aroma of formula in the morning (sigh… coffee.) Ann & I left for Boston around 6:30 am. It was a rugged ride on The Mass Pike, lots of stop and go and snaking traffic.

We arrived at Dana Farber a little after 8:00 am. While Ann parked the car, I went up to the 11th floor lab to have blood drawn and my port prepared for chemo. When I came out of the lab, Ann was there and we walked over to Head & Neck Oncology. With an hour before my next appointment, we sat down next to windows streaming sunlight and read.

At 9:30 am, it was time to meet with the two Dr. H.'s. I reported increased fatigue and pain, both normal for this stage of radiation with booster chemo treatment. My blood numbers continue to be good. After a mouth examination, we discussed pain control. The Percocet are less effective than they were a week ago. My mouth and tongue have large sores. The doctors decided that the best option is moving to a patch. We'll start small and work the way up (by using liquid Percocet to supplement) until the right level of pain control is reached. With the patch, there are (of course) new side effects to consider. Oh, boy!

At 10:00 am, we took the elevator down to L2 and the radiation oncology department. I scanned in and donned a johnny. One of the nurses came out and said Dr. T. (radiation oncologist) was ready to see me. Dr. T. examined my throat and noted some potential fungal growth on the inside of my mouth and on my tongue. He started me on a med to address that. We also covered much of the same pain management conversation (as with the Dr. H.'s.)

Next stop was a visit with Little Bang, session 19 – 16 to go. Today's music was from Barbara Kessler's second recording *Notion*. Tracks played were "Jane's Last Day", "That Hurricane", "At My Age", "The Date", and "Kathy". Barbara is a Boston songwriter and graduate of The Old Vienna Kaffeehaus.

The day was really rocking along as we headed up to the infusion room. My slot was at 11:30 am and we were there at 11:00 am. There was confusion in infusion. The details are not relevant. Our experience at Dana Farber has been so wonderful and caring. Short story is that we had a two-hour wait, but the chemo was well delivered. While we waited, the nutritionist met with us. She was happy. My weight varied by 0.1 kilograms this week to last. We reviewed my diet for the coming week.

Our ride to Worcester was smooth and easy. I napped part of the way. Once we returned home, I napped the rest of the way. I started the day wary about my fatigue level and increasing pain. At every step, someone at Dana Farber has a proven solution to deal with the problem. The next three+ weeks aren't going to be easy, but I feel confident that with the care at Dana Farber, it will all be manageable.

And because of you, family & friends, I feel at ease with the coming month. Your support and comfort will see me through. You are the best!

Love…

Richard

Posted by greenpoet at 09:14PM (-04:00)

Comments

- BeJae May 10, 2010

Infusion Confusion. Sounds like a late sixties rock 'n' roll song.

Management. It's a wonderful thing. Chemo and radiation are a lethal combo. The amazing thing is that the good cells recover from it. The bad ones don't. That's the way we like it.

There's a lot to management, I see that now. One thing you've taught me is that it's so important to reach out. It's as important as pain meds and getting though the time. It's as important as seeing Little Bang as a friend instead of an advisory. It's important for all of us, even for those of us not fighting an unwelcome alien. Sometimes the Alien can be nothing more than our own doubts. It can feel like no one is listening. But, they are. Sometimes they let you know and sometimes they don't. But, they are. You have taught me that. And, in so many ways, you've taught me to listen.

Sleep the good sleep tonight, my friend. There is a whole week ahead of you … and then it will be down to two plus. Two plus sounds manageable to me.

Love from a four letter state.

May 11, 2010 – Radiation 20 [15 to go] – Blog query

Tuesday, May 11, 2010

Remember how excited you were when you turned 20? (Ok, the drinking age in Massachusetts was 18 then.) A new decade for that "age" line on forms, the end of the teenage years (like right! Whatever.) Today was radiation treatment #20. Big psychological push; I've made it this far and overall feel good, certainly better than anticipated (by me.) Today's music was from Rilo Kiley's *More Adventurous*. Tracks played were "Portions for Foxes", "A Man / Me / Then Jim", "It's a Hit", and "Does He Love You?"

Adam drove me in for the first time this morning. Traffic on the way in was light as far light is defined in Boston. Going home, it was a breeze. Both legs, we listened to music (Ray Wyle Hubbard's *Growl* and Various Artists' *D.I.Y.: The Modern World – UK Punk II (1977-78)*. Mostly we talked. Ad & I have our best conversations when it's one-on-one, no one else in the room to intrude on a flow we have going. Fun rides!

Oh, and Adam got the 25 cent tour (as opposed to the normal 10 cent tour) of the radiation control and treatment rooms. I think the combination of his warm personality and Applied Math career gave him a leg up.

I'm writing this post mid-afternoon. Lately, many of my posts are written after dinner. I'm tired, less focused, and try my best. But the posts feel formulaic: a list of the day's treatments and appointments, a little about the commutes, and a little about home. I write with what feels like little flow. Little flow does not do Little Bang justice! I don't know how the posts feel like on your end. Hopefully, not a yawn. In the future I resolve to, whenever possible, write earlier in the day when my mind is clearer and there are not extraneous activities (TV, supper being made and devoured by humans with functioning taste buds) going on in the background. I really care about YOU and want to give you the best I have. And I care about writing, hate being sloppy, and prefer to avoid responses like the one from Mr. Ramsey, always communicated most eloquently with his eyes, "and why did you give me this to me to read?" I think that look was the precursor of the "now I have 15 minutes I'll never get back" line from current pop culture.

I know I write this everyday and there are a limited number of ways to express it, but I do so because I really mean it. Your support and comfort get me through the days, especially the dark hours. Today, the sun is pouring in through the living room windows and it makes me feel very happy. I think of you as the sun.

Love…
Richard
Posted by greenpoet at 03:00PM (-04:00)

Comments

- TaDa May 11, 2010

You are doing so good... sailing right through it... I did too! Piece of cake right? ... I am cheering you on for the last leg of the what is you call that machine...(Little Bang).. I was to focused on the good looking dude that set me up everyday to name the machine... LOL .. (kidding, well not! LOL but I am happily married)... This will soon just be a bad memory..

God Bless Richard... you were ment to BEAT THIS...

- greenpoet May 11, 2010

Thanks, Laura. You're making this day even brighter. The thing about cake is that it gets smaller & smaller slice-by-slice until the plate is empty. I hoping for no more of this variety of cake, though!

I talk to the techs. I talk to Little Bang. I'll remember her name!

- LibbyMcK May 11, 2010

Richard,
Even if your posts are similar, there's nothing routine about what you're going through, and I feel privileged to be included in the story-telling. I've never been this close to the process, though my next door neighbor went through throat cancer treatment 2 years ago. (She's fine now.)

You are in my thoughts every day. My parents have you on their prayer list. (They do morning devotions and have asked me if there's anyone I want them to pray for.)

Thanks for sharing.

Libby

- BeJae May 11, 2010

Happy 20th! Can we change “Portions for Foxes” to “Potions for Foxes”? Little Bang is one powerful potion, both magical and poisonous, destructive and productive, a potion that changes so much.

As I’ve said many times, I love and appreciate your posts. I cherish them. And I am amazed (except that it’s you and this is so like you) that you keep at them day after day whether you feel well or not. I understand that the writing doesn’t feel to you like it has enough “flow” to it. But, it has great discipline and it’s very concise. It is the flow of life … which, some days, may feel mundane, but only because you’re so close to it. It is a journal. The flow will come as you look back at what you’ve written. You will write from a different perspective then and experience the kind of flow I think you’re talking about. Right now, you are writing just exactly what you need to write and what we need to read. You let us know what your days are like, days in this remarkable challenge, days in this difficult miracle, days that are ordinary and fantastic at the same time. I have never known what this is like. Now I know … Day by day, I know. I’m sure that some of the people on this list who have been through similar treatment protocols are reexamining their own experiences as you write about yours. They probably feel those past challenges very deeply as they read you. To write with the kind of flow you’re talking about, you'd have to feel this experience very deeply right now … And, right now, that depth of feeling might mire you. And it might mire me, too, if you wrote from that place of flow that I think you're talking about. You are skating over the top of this experience, gliding along with elegance and purpose. And you are taking me right along with you and I feel the breeze of motion on my face and I don't think about what's underneath the ice or how thick it is and I've forgotten that I don't even know how to skate. I am just gliding along with you. I'm not frightened or anxious. I'll be frightened and anxious when it's safe to be frightened and anxious: went we get where we're going and we're safe and warm and looking back. We will both feel the flow when it's safe to feel the flow … very soon now. Your writing is perfect just as it is, perfect for the flow of things right now.

I am traveling tomorrow to Gainesville to spend a week with my longest friend. I've known her since I was six. We plan to drive the Florida panhandle, explore the odd flora and fauna, and think of our long lives together. You will be with us. I may be out of internet reach for writing, but I will be reading you. And you will be with me. It should be an interesting ride.

- greenpoet May 12, 2010

Libby...

Thanks for all those kind words, for reading the blog, for keeping me in your thoughts. It's all greatly appreciated. Thank your parents, please, for adding me to their prayer list. I have great faith in the power of prayer.

Love to you & Sarah...

Richard

- greenpoet May 12, 2010

Hey BeJae...

Sounds like a fun road trip - only no Thelma & Louise'ing, ok?

I've had a hankering for a Worcester-St. Louis-Worcester road trip. With some likely Webster suspects who still live in MA. Columbus would be halfway. First I gotta finish with Little Bang!

Thanks for the kind words on the blog. I think your analysis is spot on. When I reread this mess a year(?) from now, I will see it and feel it much differently.

Long day today and I'm fatigued - just typing and putting words together. Blogging will be challenge but it'll come later. One word after the other.

Love to you and Jackie...

Richard

May 12, 2010 – Radiation 21 [14 to go] – 60% in

Wednesday, May 12, 2010

The pattern holds true. Monday and Tuesday, I have energy. Wednesday (and Thursday, uh-oh), I am fatigued. So here I am blogging when my fingers won't type and my brain looks longingly at the couch. We'll give it a go!

Last night, Ann wasn't crazy about how my stomach tube looked. At the same time, I had a problem; it was clogged. I finally snaked the top (where the funnel connects) with a round toothpick and got the liquid flowing. Ann called Dr. H. the fellow and discussed the tube. Dr. H. decided that we could wait until the next day when the radiation oncology nurses could examine it. This morning, Ann thought the incision looked redder and the discharge yellowier (puss like?) I tried to use the tube, found it clogged again; only this time snaking didn't clear it out. Ann decided that she would drive to Boston, so she could be at the examination. Adam stayed home with the doggies and took on the errands.

We left Worcester around 7:30 am. After doing my swallow exercises (now my car ride routine), I fell fast asleep. My first appointment was acupuncture at 9:30 am. We arrived in plenty of time. While I was getting needled, Ann went to the food court for a snack and the optician to look at glasses. (She was successful at finding both a snack and new frames.) My second acupuncture session was more relaxing than the first and the first was calming. It seemed I was on the table longer, but that was all perception. We got into the treatment with little conversation and time stretched out. I drifted in and out of sleep. The acupuncturist returned, eased the needles out (cannot feel them going in or out), asked me some questions related to the session, and wished me a good week. I like him; his presence alone is soothing.

Ann & I walked over to radiation oncology. I scanned in while Ann located a nurse. I was next on Little Bang, so the nurse went to set up an exam room. Today's music was from *Bob Dylan The 30th Anniversary Concert Celebration*. Tracks played were "It Ain't Me Babe" (performed by Johnny Cash & June Carter Cash), "What Was It You Wanted" (performed by Willie Nelson), "I'll Be Your Baby Tonight" (performed by Kris Kristofferson), and "Highway 61 Revisited" (performed by Johnny Winter). I saw Jeff on the way out. He looked a little haggard but well. He has five treatments left after today and is very happy about that. We agreed that once you're past twenty treatments, you feel like the end is in sight. For Jeff, the light at the end of the tunnel is bright!

After radiation, the nurse took us to an examining room. She looked at the tube area with Ann and didn't think there was an issue (e.g. infection) but decided to call in one of the resident physicians. Next, she fiddled with the tube itself and showed us a couple of tricks to get the fluid flowing. While I was doing a can, the resident arrived and began to examine the tube incision. Ann pointed out her areas of concerns. He didn't see an immediate problem, but decided to check it for the next two days now that he had a baseline for comparison. He also suggested using Desitin and pads that will cushion the tube to help the healing.

Our day at Dana Farber complete, we headed back to Worcester. In the car, I did my swallow exercises and then fell into a deep nap. When we returned home, Ann & I went back to napland. Wednesday equals fatigue. I tried to return a few emails/postings but kept falling asleep. So, I took another nap. Now, I'm yawning, spacing a bit, but managing to write.

Thanks to the folks who wrote about the current nature of this blog. It truly helps. And thanks everyone for your prayers, comfort, and support during these challenging days. You smooth out the bumps in the road and keep a smile on my face!

Love…

Richard

Posted by greenpoet at 08:23PM (-04:00)

Comments

- comadre May 13, 2010

Sending you all the energy and strength of this long beautiful spring toward your healing and renewed Being.

Many thanks to All who are with you body and mind on this journey... Including Little Bang.

May 13, 2010 – Radiation 22 [13 to go] – zzzzzzz

Thursday, May 13, 2010

The pattern holds true. Monday and Tuesday, I have energy. Wednesday and Thursday, I am fatigued. Today I slept in the car. I slept traveling near. I slept traveling far. I napped lying on the couch. I napped sitting on the couch (and Adam had a whole conversation with me without realizing I was out.) The doggies snuck out my Visa card and were ordering treats and toys off the Petco website when I woke up just in time.

Ok, a bit of exaggeration but I'm slaphappy.

Today was a light day at Dana Farber. Adam drove and traffic was reasonable. I had radiation early. Today's music was from Jim's Big Ego's *Don't Get Smart* recording. Tracks played were "This Message", "Ahead Of The Curve", "Ambition", and "Love Everybody". Then we went upstairs to see the Swallow Therapist. She went down the set of benchmark questions and declared me on track. The ride back to Worcester was easy, or so Adam told me. I slept.

When we arrived home, I camped out on the couch and slept. I did wake to do a few cans of formula. The key was to stay conscious until the can was empty. That was my afternoon and early evening. Ad wants to watch the Celtics-Cavaliers basketball game with me. I'll try to stay awake!

Not an exaggeration; it's taken an hour to write this post. And my eyes are sleepy.

Thanks everyone for your support and comfort. I never feel alone on this journey.

Love…

Richard

Posted by greenpoet at 08:03PM (-04:00)

Comments

- TaDa May 13, 2010

my husband is watching the game ... Celtics are up.... I just love that you are so upbeat ! keep it up..

Laura

- comadre May 14, 2010

Sweet healing dreams and/or ballgames in your nappings.

Zoe

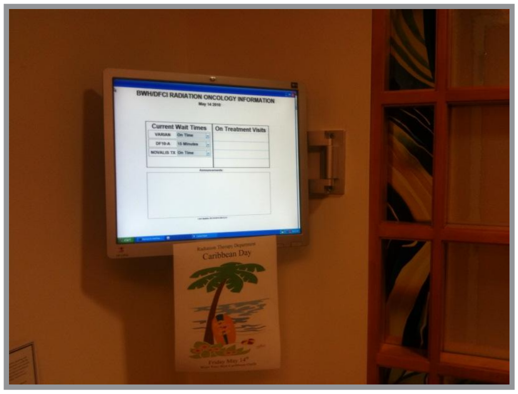
- greenpoet May 14, 2010

Went to sleep before the 3rd quarter ended. But I dreamed the Celtics won and they did.

Thanks Laura and Zoe!

May 14, 2010 – Radiation 23 [12 to go] – tick tick tick

Friday, May 14, 2010



Adam & I had a slick ride into Boston today – no traffic! We walked into Dana Farber and even the building seemed in “holiday mode” – comparatively few people around. Did I miss something? My best guess was “nice weekend to head to The Cape, The Beaches, NH, VT, ME, or Newport”. But, uh, was there a holiday?

It was festive down in radiation oncology. Today was Caribbean Friday. The staff dressed up in colorful garb and leis. Reggae music (without lyrics) was pumped into the department. The staff danced and hula’ed while finishing the setup of Little Bang. I was locked down in place and the radiation began. At some point, I noticed that the treatment was taking longer than normal. When the techs returned, I asked and was told that they had to reboot the machine mid-treatment. Happy Holiday!

After I changed out of my johnny, one of the radiation oncology nurses checked my incision. With the care changes (Desitin, Excilon drain sponges), the wound is healing cleanly.

After Adam drove us home, he packed up the car. He & Blaze dog are spending the weekend up in Burlington, where he did his undergrad work. It’s an opportunity for him to see friends he rarely gets to see. When Ad said he was coming out to visit for three weeks, it seemed like such a long visit. Now, he’s been here over a week and the time seems to be flying by.

Speaking of flying by, as of today I have twelve (12) radiation treatments remaining. When I started radiation, I didn’t know where I’d be mentally or physically when two-thirds the way through. It’s not fun, but I’m feeling better than I ever anticipated I would.

Ann & I have a quiet weekend planned. I’m hoping to get caught up on sleep before manic Monday.

Thanks everyone for your support and comfort. I am feeling better than I ever anticipated I would because of you. You all are my anchor.

Love…
Richard
Posted by greenpoet at 08:31PM (-04:00)

May 15, 2010 – Weak end stomach slip

Saturday, May 15, 2010

Had a real surprise this morning. Ann slipped Rudy Dog under my arm and went to take a shower. I patted Rudy and dreamed about being dizzy and throwing up, until an epiphany came about. Thus – if I didn't make haste to the bathroom sink, I would vomit in bed. Not a nice vision, even at 9:15 am.

I haven't vomited throughout the whole chemo / radiation experience. I haven't needed the anti-nausea drugs. So what was going on here?

In the interest of full disclosure, I can count on one hand the number of times I've vomited. There were times I'd wished I could vomit, but was inept and unsuccessful. At such times as the legendary bad spicy Polish sausage in Pittsburgh, I watched friends relieve themselves of food poison using a single finger, after which I lay in a crumpled heap for days.

My last memory of vomiting before this morning was the week after one of my pre-(grammar-)school birthday parties. Renee was conducting a scientific experiment: how many plums could Richard eat? Results were inconclusive; I finished the bag and the bag finished me. I was wearing my favorite pajamas given to me by Nancy F. my favorite babysitter. Mom said the pajamas were finished, too. That bothered me the most, the PJ's going into the trash bucket. Sigh…

At any rate, this morning I made most of the way to the bathroom sink and was able to finish there. Nice early vision of the day, right, glad you stopped by?

Let's talk about writing a bit. I've been using computers professionally since 1977. I'm a touch typist. A touch typist who is off just a bit because of the treatments? The fatigue? Bottom line is that it's getting increasingly difficult for me answer email and write these postings. At the same time, it's really interesting to watch my brain and body misfire. Just so you know, my output is seriously down. I'll keep trying. If one day this is all gibberish, assume I am conducting the monkey typing experiment. Also, if my email replies are slow in coming, it's because I'm sleeping.

Sleeping is what I did most of this fine day. The nap is in and with it I am out. I'm about to do my fourth can of the day. It's an infant like existence.

Thanks everyone for your comfort, support, and prayers.

Love…
Richard
Posted by greenpoet at 05:06PM (-04:00)

Comments

- TaDa May 15, 2010

awwww Richard it is the chemo...it happened to me... Never got a stomach ache.. never felt it coming... I just be sitting or doing something and up it came (no warning).. We were once in a country western place enjoying the music and my husband saw my look and said oh no... it was up and out and in my shirt before I could run... I whipped my shirt off and ran out of the place in my Bra...(now I know you are laughing) hang in there ... I was so grateful the old days of throwing up morning noon and night during chemo were fixed with mondern meds..

- greenpoet May 15, 2010

Ok, I'll feel grateful about this then!

Thanks, Laura!

May 16, 2010 – Sunday lives up to its name

Sunday, May 16, 2010

A short posting is appropriate for a slow sunny day. I slept in late with Rudy Dog while Ann & Lacey Dog and Pam & Samson Dog & Lily Dog went on a walk through Institute Park.

Dan arrived a little after noon. He & Ann & I watched an NCIS episode. While Ann went in for a well-deserved nap, Dan & Rudy & I visited my parents.

My Mom has successfully taught Rudy the words “CHICKEN” and “KITCHEN.” He demonstrated his increased vocabulary soon after arriving. Mom asked Rudy if they should go to the latter to get him some of the former. He bounced up and down and then sprinted ahead of her when she took her first step kitchen bound.

After we returned home, we relaxed the rest of the day. I got in a couple of naps and four cans of formula. Dan’s going to hang out with us until the evening. Adam is having a good time in Burlington. Ann suggested he stay another night since he won’t be driving to Dana Farber tomorrow. Monday will be the standard six-appointment start to the week. That’s cool; it’s all good.

Thanks everyone for your comfort and support. We’re entering “the home stretch” not only for radiation but entire initial treatment plan. Having you along on this journey makes these long days softer and bearable. So Thank You again. You are appreciated!

Love…

Richard

Posted by greenpoet at 05:46PM (-04:00)

May 17, 2010 – Radiation 24 [11 to go] – Speed appointing

Monday, May 17, 2010

Another Monday, another six-appointment day is in the books. It’s late. I’m tired. The rest of this week appears to be light (so far, just radiation Tuesday-Friday). I’ll summarize today in this posting and then write in more detail about the appointments tomorrow.

Let’s see, traffic was real light both to and from Boston. My first stop was at the blood lab for a port activation and blood draw.

Next, was a trip to radiation oncology on L2 for treatment 24, which leaves 11 to go! Thursday, I go below 10 treatments remaining! Music for today was from Dar Williams’ *Out There Live*; tracks played were “As Cool As I Am”, “Iowa”, and “When I Was A Boy”.

After the treatment, we saw Dr. T. (radiation oncologist) and his team.

We went up the 11th floor for my appointment with the nutritionist and then with the medical oncologists, the two Dr. H.’s. Finally, we walked down a flight to the infusion room for chemotherapy.

In the next chair, was a man getting chemo boosters for brachial cancer. The goal is to keep him in remission until a better approach to dealing with his tumor is developed. Ann was running errands while his wife and daughter were getting lunch, so he and I had time to talk about cancer, how we approach treatment, and our new perspective towards life. When I was ready to leave, we wished one another best of lucks and God Bless You's. It was an uncommon moment in life. It was a common moment at Dana Farber.

Ann & I got home around 4:00 pm. Adam & Blaze dog beat us home. We all decided we needed a nap. I napped a long time, even after everyone else was up. Ann told me I was making "strange noises" – she couldn't describe them and may set up a tape recorder! One common thread for the day was the need to hold my weight where it is and put some more on. I'm down ~7 pounds since beginning radiation. Much of my pre- and post-nap activity involved cans of formula. Gonna do my best.

Thanks everyone for you support and comfort. I am so fortunate and so grateful to have you in my life.

Love…

Richard

Posted by greenpoet at 09:05PM (-04:00)

Comments

- TaDa May 17, 2010

Keep chugging.. you are doing AWESOME..

- LibbyMcK May 18, 2010

Richard,

I thought of you last night, music wise, when Jeff Beck's name came up in conversation. Maybe you should play "Constipated Duck"during one of these sessions??

Loooooove,

Libby

- greenpoet May 20, 2010

Thanks, Laura!

- greenpoet May 20, 2010

Libby - The card is gorgeous - Ann is going to frame it. Thanks!

- greenpoet May 20, 2010

Blow By Blow is one of Beck's best for certain!

May 18, 2010 – Radiation 25 [10 to go] – Graduation days

Tuesday, May 18, 2010

Ten to go; I like the sound of that!

Adam & I left Worcester around 8:45 am, arrived in the lobby at Dana Farber around 10:10 am. Stopped in the lobby so I could take a Bacliphen – chemo hiccups on the rise. Went down to L2, so I could work on relaxing the hiccups away. Sequenced well, too. Three people jumped slots for me and when the waiting room was empty, my hiccups were gone. (Or rather, Jim told me they were gone and they were.) Music for today was again from Dar Williams' *Out There Live*; tracks played were "The Christians And The Pagans", "If I Wrote You", "End Of The Summer", and "Spring Street."

On my way out of radiation, I ran into Jeff & Nancy. Jim's last treatment is tomorrow! (My last is two weeks from tomorrow! Why does Wednesday suddenly sound so sweet?) We'll keep in touch by email, but have had a month (plus) of unique bonding. Today, we compared radiation burn on the neck (oh, how motivated am I to somehow find a way to add an Aquaphor neck treatment to each day! Jeff was told that the neck heals in about two weeks), swallow therapy results, and diet/weight trending. More, we checked on how the other was feeling. Jeff is very upbeat, ready for these next steps, which do not involve a daily ride to Boston, much as we truly love and appreciate Dana Farber. I felt like my older "treatment" brother was graduating and I had to wait another "class year" for all the cool stuff at the next level. While Jeff was getting zapped for 34 of 35 times, I talked with Nancy about our families and future plans. Thursday, I'll feel like the senior on the job. But I will officially be short.

The other main factor in Monday's speed appointments besides weight (message received, doctors!) was pain control. Medical oncology (Dr. H.) upped me to the next level of low term pain patch. Radiation oncology (Dr. T.) suggested, when eating is difficult, to take 3 oral pain meds up from 2. This will be an ongoing "game" between pain and the meds over the next two weeks. In this case, I am the playing field, but certainly not the bored.

Thanks everyone for yours words of support. Today is an up day, so the words feel sweeter, but on the down days, they are my constant comfort and source of strength.

Love…

Richard

Posted by greenpoet at 06:11PM (-04:00)

Comments

- TaDa May 18, 2010

drum rollllllll let the count down begin...

- BeJae May 19, 2010

OMG, I go away for a few days without interent access, come back and read that there are ten treatments left to go. Ten. TEN! I am amazed and thrilled.

I need to go back and catch up on your posts, but please knonw that I am so happy that things are progressing so well and I have missed you terribly. I have taken you with me into the strange wilds of the Florida panhandle, have told all sort so of stories on you and have felt your presence as I have traveled.

I am so very happy to be back with you.

May 19, 2010 – Radiation 26 [9 to go] – Wednesday worn

Wednesday, May 19, 2010

Nine to go, that's less than ten, single digits! I was effusive when I got up off the radiation table. Now, I'm just tired, real tired, working real hard to stay awake tired.

That was a fifteen-minute three-line paragraph. I'll catch up with you later, when my eyes are open. Probably tomorrow, because I'm ready for bed after my third nap today.

Thanks all for your messages of support and comfort. Today was a really good day overall. Will try to get caught up asap.

Love…

Richard

Posted by greenpoet at 08:24PM (-04:00)

Comments

- BeJae May 20, 2010

Single digits. I can hardly believe it. I'm so happy.

Thank you for being willing to admit how hard it is to write right now. You have made all of this seem way easier than it is.

I have enjoyed catching up with you today. I hated missing your posts while I was away and without internet. Short posts are fine, I promise. Thank you for making this herculean effort day after day.

The end is in sight. You're my hero.

May 20, 2010 – Radiation 27 [8 to go] – Thursday

Thursday, May 20, 2010

This will be another short posting. Was knocked out even more this morning than yesterday. Could barely feed myself one can. Taking a shower was against the currant. The cause is likely the combination of the upgraded pain patch and the new anti-fungal meds as we ramp up for the final EIGHT radiation treatments.

I'm finally reaching a reasonable level of coherency. Hope that by tomorrow morning enough of the chemicals will have washed themselves out of my system (or at least stopped fighting one another) that I can do my 12 minute swallow exercises in under a half hour! Then again, 45 minutes is better than falling asleep 3 minutes into the routine. Again! (As was the case today.)

I actually feel better knowing that this is not all fatigue but rather a mix of meds with some fatigue tossed in. It's great to see the countdown at eight and to feel as well as I do (discounting the med waves.) I'm not going line dancing but I'm not miserable. I'm real grateful.

Speaking of which, today's music was from The Grateful Dead's *Road Trips Vol. 3 No. 2 – Municipal Auditorium, Austin TX, 11/15/1971*: "Beat It On Down The Line" and "Dark Star>El Paso>Dark Star".

Yesterday' music was from iF's *iF 2*, tracks played were "Your City Is Falling", "Sunday Sad", and "I Couldn't Write And Tell You".

I won't be answering emails until sometime this weekend and then slowly and succinctly.

Libby - thanks for the beautiful watercolor card (by your hand). Ann's gonna frame it!

Thanks everyone for your support and comfort. Having you with me on this ride makes this journey seem so much shorter than I ever thought it could be. Onward!

Love…

Richard

Posted by greenpoet at 05:15PM (-04:00)

Comments

- BeJae May 20, 2010

Tomorrow is Friday. The streets are ours. You are so amazing, so brave, so steadfast ... and you're nearly done. You are nearly done with this very difficult dance with the lovely Ms Little Bang. She's a tough one, but she's a good one. She's doing her job ... and her job is nearly done. I'll bet the techs are gonna miss the music ... and the music man.

Thank you so much for posting even when it's really hard. It's such a great gift to all of us.

The end is in sight. Keep on reaching.

- TaDa May 21, 2010

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you are amazing and you are just about done.... and you did all standing up! with an awesome attitude...

May 21, 2010 – Radiation 28 [7 to go] finally Friday!

Friday, May 21, 2010

And I am officially exhausted. Fatigued to the max! My friend Larry drove me to Dana Farber today. I'd looked forward to the ride with a lifelong buddy, but fatigue/drugged up feeling took over. We had a lot of family "gossip" to catch up on. I slept most of the ride both ways.

I was so wiped out that I misplaced the iPhone with "my" music queued and ready for radiation. (Hid it in my sweat pants pocket!) The techies played vintage Motown for me. Nice techies.

So, thought I'd feel better today but am a little worse if anything – that's the short view. The long view is that I have SEVEN radiation treatments – SEVEN – left. That's cool.

I'm happy the weekend is here. I hope I do better than sleep. Adam & Dan are visiting.

We'll see. Time to be strong in a different sense. I could easily sleep all day, but must get my body in motion.
Hope you all have a wonderful weekend. Enjoy the beautiful Spring weather. Enjoy friends and family. You are my anchor and I am so thankful that you are a part of my life. I never feel alone with you.
Time to write blog: 1:28:48. (hr:min:sec)
Love…
Richard
Posted by greenpoet at 08:51PM (-04:00)

Comments

- BeJae May 22, 2010

You are my anchor, sweet friend. It's Friday and the streets are ours ... mostly because we're lying in them, but they're ours. Ours.

I hope you will rest deeply and profoundly. Your body is doing what it needs to do to plow through the challenge. It's good that you push to move, but also very good that you sleep and sleep. You're a good listener. You'll know just what to do.

I hope you have a wonderful weekend of dreams. I am thinking of you.

May 22, 2010 – Saturday

Saturday, May 22, 2010

Spending the day resting. My throat has been quite sore. Pam & Mark are coming by to visit tonight. I will spend this weekend catching up on sleep. I plan to ramp up the postings on Monday.
Thanks everyone for your comfort and support. As we round the final posts, knowing I am in your thoughts keeps me strong.
Love…
Richard
Posted by greenpoet at 05:27PM (-04:00)

Comments

- BeJae May 22, 2010

Good, my friend, a very good choice, the resting. I'm fixin' to do that myself, but I just wanted to drop by and say hi and tell you that I'm thinking of you and that I am so grateful for your endurance, your devotion and your inspiration. You are an amazing example of courage.

Okay, it's hard right now. It is. Keep at it, though. Not much further.

Here's to you, my friend.

May 23, 2010 = Sunday + 7 and holding

Sunday, May 23, 2010

A weekend of sleeping and resting, days spent trying to heal the body and mind. My throat is sore on the inside and scratchy & itchy on the outside (radiation burns.) Seven radiation sessions remain, this coming Monday – Friday and the following Tuesday and Wednesday. The radiation suite is closed for Memorial Day.
Then, I heal.
Thanks everyone for staying on this trip with me. It hasn't been easy, but we are so close to the end. We'll walk hand in the real future. And dance together…
Love…
Richard
Posted by greenpoet at 05:48PM (-04:00)

Comments

- TaDa May 23, 2010

Look at how far you come and you are just now hitting a bump with the sores and burns... 7 more counting down with you.... On an up note... My lower esophagus got sore durring radiation (burns on the inside) ... lortab (pain med) comes in liquid syrup ... I was shocked when it was perscribed to me seeing it in liquid but it worked and there is also a med out there called magic mouth wash... it has a form of numbing med in it and works good too! Hope that is helpful... how many more chemo sessions do you have? When will they take that thing out of your stomach?

So happy the radiation is just about done for you. you took it like a champ! Pat yourself on the back buddy .. I didn't hear ANY whinning from you...!

talk to you tomorrow

Laura

- greenpoet May 24, 2010

The tube is my friend. It comes out when I can eat & drink enough by mouth to gain weight.

Intensive chemo finished in early May. The Chemo I get now is a "complimentary chemo", non-intensive makes the rad work better.

My neck itches. Diverting.

Time for another can and then bed.

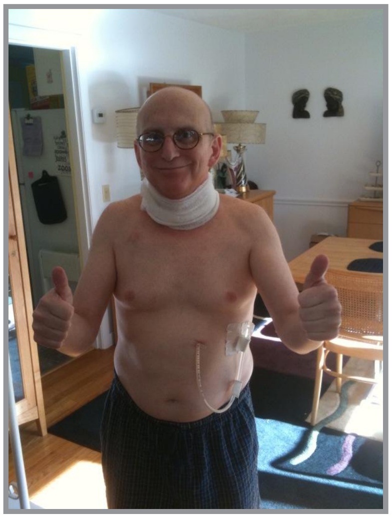
Thanks, Laura!

- TaDa May 24, 2010

Well I hope you don't have to have that tube in long... praying for you

May 24, 2010 – Radiation 29 [6 to go] : 6 and counting

Monday, May 24, 2010



Today the traffic on the Mass Pike was heavy but the traffic on L2 for Little Bang was light. The staff drummed on the dressing room door "are you ready yet?" I was #1 on the runway to my favorite 'lil linear accelerator.

Ready-to-roll: Power Port nestled just outside of right shoulder. ConMed 20 F PEG Tube (second 18mm feed) feeding tube assembly. Aquaphor neck wrap.

Today's music was from an old classic live album The Rolling Stones' *Get Your Ya-Ya's Out*. Tracks played were "Jumpin' Jack Flash", "Carol", "Stray Cat Blues", and "Love In Vain". Had intended to play different tracks ("Midnight Rambler", "Prodigal Son") but setup time was short.

Oh well, got off the table with the call of SIX TO GO! Oh yeah!

Adam & I went to meet to Dr. T.'s (radiation oncologist) team. They examined my teeth, throat, and tongue. My pain med and calorie/protein level were checked. The skin on the directly irradiated areas of my neck was compared to last week and it was decided that an exterior Aquaphor throat dressing is now appropriate. My mouth shows the war that going on has neared its peak of collateral damage. My weight and diet numbers made Dr. T. happy. He said I'm doing all the things they've asked of me. We briefly reviewed the post-treatment schedule. Then, Dr. T. and the team left Ad & I alone with nurse Christina. She cleaned my neck, opened identical sterile plastic transparent pads. Christina loaded the pads with Aquaphor and form fitted them to my neck. Then, she rolled a gauze bandage around my neck covering the whole thing. It's prime in the photo above. I will wear a couple of these a day (maybe three) until the end of treatment.

Shortly after Ad & I returned home, Rabbi Seth came for a visit. Ad had been looking forward to seeing Seth. The three of us had an insightful conversation about the nature of disease and its effects on family life. We looked at this nexus from practical, emotional, and spiritual angles. I cherish my conversations with Seth; they leave me feeling lighter and stronger.

Tomorrow is the balance of my "normal" Monday. I'll have blood drawn, get radiation, have a rad wrap put on, see Dr. H. and the medical oncology team, and get complimentary chemo.

I'll be a tired boy by tomorrow afternoon!

Thanks everyone for your comfort and support. This has been a very long road and I couldn't imagine traveling it alone. Friends and family are nurturing and healing.

Love…

Richard

Posted by greenpoet at 07:22PM (-04:00)

Comments

- TaDa May 24, 2010

Geeezz Richard you are always so techinical... LOL I always have to look words up from your blog..(not your fault LOL mine) well I sure hope that ointment helps.. from what i read on it when I googled it ..it should... and you only have six more to go (well four this week) which will give the soreness a break over the long weekend... hang in there.. you are almost done..

Laura

- BeJae May 25, 2010

Okay, I love the phrase "complimentary chemo." It sounds like something you'd be offered on a plane for no extra charge ... Like peanuts (which are no longer complimentary) and a soft drink ... "Could I offer you some complimentary chemo?" "Uhhhh ... No thanks."

Oh, you look so cute in all of your medical gear. Nobody else sends pictures like these. But, you've always been good at knowing what to photograph. I remember when we first met in person in San Francisco. You photographed the street in front of our hotel first in one direction and then in the other. I thought that was strange at the time. But, those pictures made that trip very memorable for me, memorable in way that it would not otherwise have been. I loved the other pictures you took, too, of course, pictures of Ann, Adam and Dan, pictures of Jackie and me, pictures of the lovely, elaborate gardens we visited. But, those pictures of the street where we stayed made my memories of that trip so vivid and enduring in a way that I can't completely explain.

I am happy to be able to see as well as hear what all of this is like for you. It's an amazing journey and you are taking such good care of your passengers. Thank you for that.

May 25, 2010 – Radiation 30 [5 to go], Dreams.

Tuesday, May 25, 2010

Little Bang's arms elegantly dance to Rebecca Coupe Franks' horn and the sweet purr of hydraulics. It's the same dance for all thirty-five gigs, one I've decided *not* to learn by rote. Every time I experience it, it's new to me. (Though to be honest, I kind of know the finale.) Maybe my gift to L. Bang could be to learn and dance in common on my last visit (to be honest, though, Ms. Bang is too surreptitious to let that one slip by, but has a kind heart.)
Today, I spun some funky jazz, Rebecca Coupe Franks' *Check The Box*, tracks played: "Life Has Just Begun", "Thursday", Exposure", "Starting All Over", and Check The Box". If you haven't checked out Rebecca, stretch your ears! On *Box*, she adds slick vocals to her mix of medium horns (trumpet, flugel) and keyboards.
5 radiation treatments to go! FIVE!
Rest of the day went off well. We're gearing up for POST-treatment recovery. Sounds good to me!
Thanks everyone for your comfort and support. Your love and grace especially helps me on long days like today. Onward!
Love…
Richard
Posted by greenpoet at 07:13PM (-04:00)

Comments

- BeJae May 25, 2010

You always bring the music for the Little Bang dance, each tune meaningful to you. Though the movements are the same each time around, they have a different relationship to the music. It's that relationship that changes everything. Always the relationship.

Five to go. Five. And there is a lovely long weekend before the last two.

Recovery. Healing. You'll find a soundtrack for them. You always do.

I just realized that I rarely think of the Alien anymore. I used to think of the Alien a lot. Now all I think about is you and Ms Bang and the countdown and recovery and healing and the dance and the music. I think that the Alien is already gone. That's what I think. I think that Little Bang, bless her accelerator soul, is only doing "just to be sure" clean up work now. I think that the Alien is already gone. I think we've won.

Here's to you, my friend, and to Ms Bang. Five to go.

- creativeminds June 02, 2010

Richard,
I'm happy u enjoyed my new release! I wish you all the best and hope you feel better soon. Thanks,
Rebecca Coupe Franks

- creativeminds June 02, 2010

Glad to hear Rebecca's new album "Check the Box" is helping during your treatment and healing process. The album is dedicated to her father who she lost last year. I know it means a lot to have a listener out there who understands the challenge of surviving cancer. Looks like you are doing great.
Be well. Hillary Wilson(RCF Management, www.rebeccacoupefranks.com)

May 26, 2010 – Radiation 31 [4 to go], books

Wednesday, May 26, 2010

Question of the day: What books are not safe to display on your desk at work?
My answer: Books can be very dangerous, especially when reflecting contagious ideas, but I've never met a book that I'd be afraid to have on my desk. Of course, I have the luxury of owning my desk for the past twenty years so it's a bit of a cop out answer.
Your answer: (option in comments)
Today, with the music pumping (or bluesing) out "Four" (as *fo-wah)* at the perfect moment in time, I felt my mask being unbuckled. I held up my right hand with four separated fingers and thumb at 45-degree salute pumping! "Fo-wah!", I croaked in my very best and loudest croak. "Fo-wah!" I waved. Today's aptly timed musical choice was from Roy Book Binder's *Live Book… Don't Start Me Talkin…*; tracks played were "Black Dog Blues" and "Candy Man". This is a contest. I'm not going to explain the significance of the second track and *Fo-wah*. That's up to you and again in the comments section and again very optional.

We saw a burning car on the Mass Pike, on the way into Boston.
My appointments today were with the acupuncturist, nutritionist, and radiation. Aced them all.
"…I felt my mask being unbuckled…" - the lights are low during radiation and the music is LOUD (by request!) Through the mask mesh and without my glasses, I see shadows. Occasionally with Little Bang set on safety, a tech will come in and make a physical adjustment to my position, to the table, or places I cannot tell because I have not seen (glasses, mesh – see above!)
With the sessions' length in time being inexact, it's always a mystery as to when it's over. Ok, ok, ok, I know the last routine, probably the whole thing, but there's GOT to be some mystery! Like my Montreal cousins say *Ey!* ? I do know the length of the songs, though, and today's session didn't just seem to fly by, it was under fifteen minutes. Nice job, rad techs!
Thanks everyone for your support and love. I'm told that I look great for someone in his last week of radiation. That's because of you, sweet family & friends!
Love…
Richard
Posted by greenpoet at 06:05PM (-04:00)

Comments

- BeJae May 26, 2010

Fo-wah! Fo-wah!

I remember that Roy Bookbinder used to travel in a motor home and fish during the day at gigs on rivers and lakes. I played right after him at a venue in Oswego, NY years ago. They told stories of his guitar playing and his fishing. They took me to the edge of the great lake at midnight and I felt its power even when I couldn't see it.

Fo-wah! Fo-Wah!

No-no books: See. I own my desk, too, so I can put anything I want to on it. The books that are on it right now are Mystic River, by Dennis Lehane (just because I loved Any Given Day so much) and I Married a Communist by Philip Roth. The book I'm reading right now is The Help by Kathryn Sockett. I recommend it.

Fo-wah! Fo-Wah!

I love and admire you.

Fo-wah! Fo-Wah!

- SunIra May 27, 2010

Most recently I was teaching in Vallejo where the students could not be trusted to NOT attack anything of mine in the classroom, so, sadly, no books were on the bookshelf.

- Purple May 27, 2010

Counting Down with ya Foxy.

Fo-wah! Fo-Wah!

- comadre May 29, 2010

My old copy of the The Rape of the A.P.E (American Puritan Ethic : The Official History of the Sex Revolution, 1945-1973 : The Obscening of America, an R.S. V.P.) by Alan Sherman survived cross country and forestry work travels where we used to take turns reading aloud on breaks from tree planting in the mountains of the NW and SW. What it didn't survive was being borrowed in the early 80's by a friend who left it on his desk where his dog found it and ate it.

May 27, 2010 – Radiation 32 [3 to go]

Thursday, May 27, 2010

Yesterday's contest question was ably handled by BeJae:
Fo-wah! Fo-wah!
I remember that Roy Bookbinder used to travel in a motor home and fish during the day at gigs on rivers and lakes. I played right after him at a venue in Oswego, NY years ago. They told stories of his guitar playing and his fishing. They took me to the edge of the great lake at midnight and I felt its power even when I couldn't see it.
Fo-wah! Fo-Wah!
Looks like code or concrete poetry. I need t-shirts to hand out. This is a contest. There will be a prize, of that you are apprised. That, and poor grammar!
As for today: I'm immersed in the Thursday fatigues. Ready to dive back on the couch.
Thanks all for your love, comfort, and support. I still hop up on the bench under Little Bang even knowing how I'll feel in a week. You give me that confidence. Thanks for being you!
Love…
Richard
Posted by greenpoet at 05:16PM (-04:00)

Comments

- TaDa May 27, 2010

Yeah one more this week and time off for good behavior... !!!!

Hugs...

TaDa ... (I go by TaDa on line .. can you guess why ? ~ cause I beat the cancer)! As you will too!

Laura

- greenpoet May 27, 2010

Thanks, Laura! for your wishes and your spirit...

- BeJae May 27, 2010

It is code. And it is concrete poetry. It is three. Three. It's unfreakin'believable. Three. A three-day weekend, a three-day rest, a three-day recuperation, a three-day break before the final two. And tomorrow is Friday and the streets will be ours.

I was telling a friend only a couple of days ago how very much this blog has meant to me. It is a tremendous comfort to know how you are from day to day. Even when the days are hard, and I know that these days here at the end are very hard, very fatiguing and painful … but, even on these hard days, it's a huge comfort to know that you are okay in spite of the difficulty and the pain. You're there. You're with us and you keep going.

But, besides the great comfort of knowing that you are moving forward even when it's hard, I have never been through this with anyone before. And now, if it happens, if I have to go through something similar or someone close to me has to go through something similar and they need my support, I will have some idea of what's going to happen and what it's going to be like. It won't be so foreign and unfamiliar to me. I won't be as lost and I won't be as scared. That's what you have given me and I am so grateful to you for that. I have never sat in the infusion room … but, I feel like I have. I have never seen the deliberate movements of Little Bangs powerful arms, but I feel like I have. And if I ever have to go through this or help someone else go through it, as the music begins, I will say to myself, "Oh, yeah, this. I remember this. This is hard, but it passes. This is difficult, but it will be okay."

Tomorrow is Friday. The streets are ours. The countdown continues. And you persevere. Here's to you, my friend.

- Nancy May 28, 2010

Counting down with you - I hope the fatigue will end and you can enjoy this beautiful spring weekend!

May 28, 2010 – Radiation 33 [2 to go]

Friday, May 28, 2010

You knew this wouldn't end without a challenge or two. Today, I woke up over heated and with a slight fever – fever due to the 90+ degrees exterior heat and a well-insulated house – and with diarrhea. We left early for Dana Farber so the nurses could kick my tires before radiation. I felt cooled off and better by the time we arrived in Boston. But Little Bang was sick and down - a bad bearing best my ears could tell! A machine in Brigham & Women's Hospital mirrors each machine in Dana Farber's radiation arsenal. Off we went, cross campus, to BWH, to meet Little Bang's twin.

I'm still wiped out and cannot do this story justice. Let's just say that Dana Farber gives Little Bang much nicer digs!

I forgot to list yesterday's music – The Beatles from *Rubber Soul* and *Revolver*. Tracks played were "Here, There And Everywhere", "For No One", "Good Day Sunshine", "And Your Bird Can Sing", If I Needed Someone", "In My Life", "Nowhere Man", and "Norwegian Wood".

Today, I introduced Little Bang's twin to Particle, playing a couple of soundboard live

tracks: “Little Wing” and “The Elevator”.
I don’t feel well and will cut this short. These moments of feeling yucky are expected. So I need to focus my view real short. The next two weeks may be a real roller coaster ride.
Here’s where YOU come in. Your support and comfort keep me going no matter how I feel. Today, I am leaning on you. And I so appreciate you.
Love…
Richard
Posted by greenpoet at 05:48PM (-04:00)

Comments

- TaDa May 28, 2010

hang in there.. Richard... TWO MORE TO GO... get rest and relax this weekend.... YOU GO !!

Laura

- BeJae May 28, 2010

Ah, the Bang sisters. I should have known. Sorry Other Bang's house is a little run down.

I'll echo TaDa. Rest. Relax. Restore. Roll on. And thank you so much for checking in even on the hard days. You inspire me every single day ... but, these days, the hard ones, you inspire me the most.

It's Friday. The streets are ours. Rest knowing that every one of us on this blog wishes you comfort and ease. We love you.

- comadre May 29, 2010

Sending gentle, cooling, restful ZOOMS, Richard. We so appreciate your posts. Love to you, Ann and All.

May 29, 2010 – Quiet weekend

Saturday, May 29, 2010

Dan & Adam just left for Cambridge. Dan will drive Adam to Logan Airport über early tomorrow. Ad & Blaze dog will fly to Colorado. Our sons make us very proud. They’ve pitched in and cared for us when we really needed them, pitched and cared without being asked.
I am beat, even after sleeping most of the day. At some point over the next three weeks, I will wake up feeling better than the day before and make daily progress from there. For now, I track through the mud and snow, understanding that I will warm again.
I will post very little lightly this weekend. I need to rest and recuperate.
But I walk around with a smile that YOU put on my lips. I know I can drive through these next weeks, because I have you by my side. Your love, comfort, and support raise my spirits.
Love…
Richard

Posted by greenpoet at 08:26PM (-04:00)

Comments

- BeJae May 29, 2010

And I walk around with a smile you put on my lips with your warmth, graciousness and your amazing fortitude. If I ever have to do this, you've shown me that I can do it and that I will do it. You have shown the way through so many challenges … Don't complain, just keep going, that's what you've shown me. Just keep going.

I'm so glad that you got a Particle session in this week. Eric Gould is such an amazing bass player. He's one of those musicians who got really good really fast. Particle's music is complicated, but Eric, with his superb bass playing, is the one in the band who keeps it all sorted out and discernable for me. He's the one I hold on to. He's also personable, friendly … a great guy. He's just an absolutely great guy. It seems to be a family trait. I remember stories of you dancing all night to the live Particle shows in MA. Soon you'll be dancing again. The Bang Sisters have taught you a lot about dancing. Dancing will never be the same. And another thing: Bass rules!

Rest, my friend, rest and heal. My thoughts stick close by you.

- TaDa May 31, 2010

Good luck tomorrow ..... hope you got tons of rest this weekend...

Laura

June 1, 2010 – Radiation 34 [1 to go] Day (s) (a)

Tuesday, June 01, 2010

What was once a day so far away, impossible to imagine, crunched in a spreadsheet, a Where's Waldo hidden digit, lo-ti-qued in a woman leaning against a wall in Dr. T's office, will be here tomorrow.

I am officially short. As of approximately 10:57:59 am, I will stride from Little Bang's haven, (LB's bearing still sounding worn), into the trainers' room for one more neck wrap and dream the taste of apples and know it is it not a lie but a time equation. I know the speed of post-Memorial Day mail and I want more at bats baby!

Our day at DFCI started with a flood draw and an appointment with Dr. H.. With the fresh blood numbers, H. decided that further chemo would be counter-productive. After having the port deactivated and getting a few prescriptions filled, we returned to Haed & Neck Oncology for a meeting with the Swallow Therapist.

Coming out of the Swallow Therapist office was Jeff. He looks great! We only had time for a few moments of conversation and a fist bump. Jeff said the recovery is as advertised: two more weeks of incremental side effects followed by "the day" when you wake up and realize that you feel better today than you did yesterday (that is apparently a beautiful day!)

I am fatigued. I know I have a rough two weeks head of me. But I see the recovery personally. Onward!

As for you, I held you in my dreams, sought you out in my nightmares, and understood minute-by-minute just how alive we are. Thanks for being here, for your comfort, and

knowledge of us.
Love…
Richard
p.s. – Today's music, Jeff Beck's "Constipated Duck" from *Blow By Blow* and "Acsension (Edition II)" from *The Major Works of John Coltrane*.
Posted by greenpoet at 06:29PM (-04:00)

Comments

- TaDa June 01, 2010

ONE MORE ONE MORE... did you think it would ever arrive? So happy that part will behind you after tomorrow..

Hugs

Laura

- greenpoet June 01, 2010

Thanks Laura - and thanks for being a rider all along this path...

- Stuart June 01, 2010

Fantastic! Proud of you, Richard. Wishing you many, many days on which you wake up and realize that you feel better today than you did yesterday ... and that they come soon and powerfully.

Much love,

Stuart

- BeJae June 01, 2010

I will imagine you on that last ride, down the hallway, port deactivated, your last dance with Little Bang, her arms waving; you, still as can be, listening like you do. I will imagine the technicians, wishing you well, glad for your sake to see you done, sorry for their sakes to see you go. You leave a sweet impression behind when you go. You always do.

Tomorrow is the last day of a very important journey; living in a hotel in a foreign country; getting the hang of the language at least enough to get by; learning the way to the small, best-in-town bakery, a long enough walk away to earn the calories; recognizing the kid who rides by on his bike at the same time every day. Then comes the jetlag: It'll take a while to get over that. But, you will get over it … at home … You'll remember the trip from your room at home. You will remember, but you won't be there anymore. Knowing you, you'll remember what was good about it.

I will imagine you on that last ride, the one that seemed so very far off, the one that is here now. I know it's not the end of the journey. There's still a lot to do. But, this part … This part is nearly over. Thank you so much for taking us all along. We are richer for it.

Here's to the last ride, my friend. And here's to the next town. Onward!

- comadre June 01, 2010

AHH HOOAAHHH!!!

- LibbyMcK June 04, 2010

Richard,
I imagine you in the mask, on the table, with Jeff Beck's Constipated Duck going in the background (foreground?) Is it hard to keep still with some of these tunes going? Probably not, at the level of fatigue you've been having.

I'm so appreciative of having a window into your journey that BeJae so poetically articulates.

Thank you for sharing. I do hold you close and send lots of zooms for the next two weeks to pass quickly and easily - from Strength to Strength, as you said (about Joanie) yesterday!

Libby

- greenpoet June 05, 2010

With Jeffie playing Duck, me & the mask be constipated brains. Can't move a tooth with the mask on, or tongue, or...

Isn't BeJae a peach? One of these years, I'll hijack her to a Webster gathering.

June 2, 2010 – Radiation 35 [treatment completed]

Wednesday, June 02, 2010

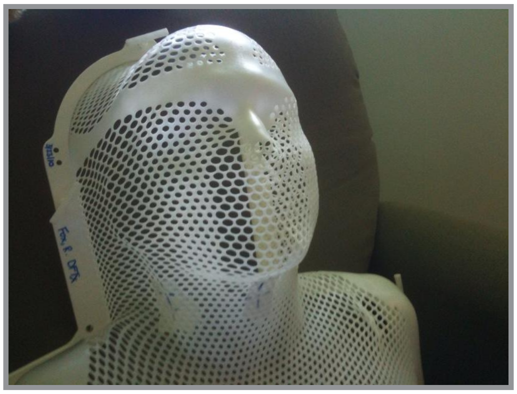
I'm wiped out but quite happy. Radiation treatment is complete. Music today from was Particle's live soundboard of the show at The Paradise Theatre on 11/15/03 - tracks played were "Make It Real" and "Simulator". My sister Renee drove me to and from Boston and baked one of her famous chocolate chip cake for all the wonderful folks on L2. A splendid time was guaranteed for all!

I get to keep the mask, now referred to masque as it has been deactivated. It's currently living on my bedroom chair! After radiation, a neck wrap, and a few minor repairs to the old feeding tube, we did the outpatient dispatch paperwork.

I can't keep up with email and phone call flow. Please understand that I love you all, and will try my best to reply to email after the next week or two; these next two weeks are supposed to be the most tiring and painful of the entire throat, neck, and tongue cancer treatment.

Thank you all for being here with me during this tiring and difficult battle with the disease. Your love, support, and comfort carried me through these days and will continue to carry me in the days ahead. I am blessed by your grace and presence in my life. I LOVE ALL OF YOU! THANK YOU!
Love...
Richard

Posted by greenpoet at 03:03PM (-04:00)



Comments

- TaDa June 02, 2010

YAY it is behind you ..... thank goodness... flying colors too! when does the tube come out

good for you Richard.. Praying hard it did its job.... good thoughts... good thoughts

- comadre June 02, 2010

Our hearts' zooms are rapt round you during these tough days.
Love the photos. That masque is HOT! ;-)

- BeJae June 02, 2010

I agree, Masque it totally hot. Along with Particle ... and the whole finished thing. Okay, okay, I get it that it isn't finished, that there are days to come when maybe you won't feel better than the day before. I'm sorry to hear that this is the most difficult, most painful part of the trip. But, I want to tell you this ... and I didn't tell you before now, because it was so discouraging: I have an acquaintance back in Iowa who recently went through this same protocol. He had to stop in the middle of radiation and take a week off. It was so difficult that he couldn't go on. But, now he's fine, feeling good, pronounced cancer-free. You and Little Bang have been so devoted to each other, keeping on tenaciously. And, even though you feel like s**t right now, you are healing. The process has already begun. It's not apparent yet in how you feel, but your smart, tenacious, efficient body is miraculously healing itself … Just like my over-nipped cuticle … Your body is healing itself. You should sleep through it, that's what I think. Okay, okay, I tend to be a slacker, but that's what I think. You'll be riding your three-wheeled thingy through Sanibel and doing spreadsheets and math at A and D soon enough. Take some time off. Your body deserves some time off. It has served you amazingly well.

None of us expect you to answer email. We expect you to rest and soak up our love. We expect you to learn to take as good as you give. Come on. Come on. This is a challenge.

I leave for Iowa tomorrow. I'm not sure what my internet access will be. But, if I go silent on you, I want you to know that I am thinking of you, I am wishing you well, I am grateful to you for including me in this amazing journey and I have faith that the Alien is gone. I have not abandoned you. I am listening.

Thank you for your resolve, your courage, your inspiration, "your sweet good nature," as our friend Annie once wrote. Please rest, recuperate and rebuild knowing that we all love you and treasure you and admire you beyond words.

Onward, my friend. Onward.

- Nancy June 03, 2010

I am in awe of your fortitude, cheerfulness and positivity in face of your most difficult life challange. You rock!!!!

Saturday June 5, 2010 - Back in Mobile with the Memphis...again

Saturday, June 05, 2010

I'm ok. The two weeks after my type of radiation treatment ends are the two worst weeks of the whole protocol (chemo + radiation.) Fatigue peaks as does the pain. Most often, I cannot read or write. It's almost over but not yet. Ann thinks I'm a little better each day. I'm hoping that a week from today, I'll feel weak but human - can then work on my recovery by eating soft food. That's where Jeff is.

I'm sorry I've been silent but I've felt like crap. I promise to get caught up when I can physically write.
Life is sweet. Treatment is complete for phase 1. I have three months "off" until another PET/CT Scan.
Thanks everyone for your comfort and support. I draw on your strength daily. I can't imagine getting this far without your love and help.
Love...
Richard
Posted by greenpoet at 07:52PM (-04:00)

Comments

- TaDa June 05, 2010

Hang in there buddy.. You feel human which is a good sign... I can remember days being dropped off and I would plunk right down on the couch with my sweatshirt still on (OCT) and lying right on the couch just not able to move and eyes wide open... Many times the girls came in and were like "Ma why is your coat on"..it does get better... The worst is behind you..and it does get better (although you may think so) it does each and every long day.. slowly but surely..listen to your body and do what it tells you to do..

Hugs from FL

Laura

- greenpoet June 05, 2010

Thanks, Laura. You are telling me just what I read to hear. Appreciate your friendship and the goodness in your heart...

Richard

- Nancy June 07, 2010

Richard,
You are something else! Going thru all this pain and suffering yet you have time to make a donation to Ali's favorite charity.
There are no words to describe your awesomeness!
And the children who have all gone thru treatments thank you too!
with much love,
Nancy & Ali

I am a patient.

Tuesday, June 08, 2010

The last three days have been been fairly quiet. My job is seeing doctors, nurses, technicians, and medical specialists. I am a patient.

My work load has pretty light lately, most of it home based (physical therapy, tube feelings, etc.) Light doesn't mean easy, just less road time and small machines.
Tomorrow morning, Ann & I hit the road for Boston and accupucture. It's a long ride for a 45 minute treatment, but it's research and well worth it for the next person who walks in the door.
When I get busy, I'll post daily. Currently, our goal is to balance pain, constipation, and mouth/tongue recovery. It's a lot of trail and error. Yeah, fun! As fun as watching paint dry. While my schedule is interminent, I'll post every 2-3 days.
Hang in there. I'm hanging in here with you. Thanks for being you. This is the tough part, being somewhat isolated, dealing with the pain and stuff while away from Dana Farber. I really need and bank on you now. I have my stack of cards to walk through when I'm feeling blue. Sam - thanks for the lovely and whimsical gift (a note is pending but writing is a challenge.) You are my support and comfort. I need you and you are here. Thanks, don't know what else to say, but thanks! The one word elegantly carries such a weight.
Love...
Richard
Posted by greenpoet at 08:57PM (-04:00)

Comments

- TaDa June 09, 2010

Is the pain that bad Richard? I suffered burns to my throat and had to take liquid lortab... I now control it with nexium so the acid don't bubble up and aggivate my throat and the scaring. Plumbing issues... those were the worst... Hang in there hmmm did I say that... I was so sick of people telling me "God doesnt' give you full plates if you can't handle it" I felt like saying "well here, you have the full plate" but I didn't.. This soon will be just a bad memory

Lots of Hugs

- greenpoet June 10, 2010

Thanks, Laura. I need this verbal hug today!

I must be patient.

Friday, June 11, 2010

Thursday's trip to Dana Farber for acupuncture was uneventful. I am enjoying the treatments.

I need to get on on a schedule to ramp my days up. I need periods for naps, exercise, eating, writing, World Cup matches, etc. A schedule serves as a disciplined framework for my day. It's too easy to sit back and develop bad habits at a time when I need to heal.

I'm feeling overall ok. My throat and mouth remain sore. At this point, I have to accept that soreness. It will fadeaway with time, most areas fairly quickly. I'm still fatigued and need extended naps. But I am ahead of where I was a week ago. It's a slow process, some days seems like I'm swimming in place.

This is a tiring process, tiring on me and on Ann. The doggies are are stressed out, too! We feel like we should be at the end (and are) of this treatment protocol. The depth of the recovery process is greater then we imagined, even after experiencing recovery signposts during chemo.

Thanks for being with me, these recovery weeks are difficult, and your support, love, and comfort help me through the bumps and grinds of this new road.

Love...

Richard

Posted by greenpoet at 07:44PM (-04:00)

Comments

- TaDa June 12, 2010

I have been sick Richard.. sorry I wasn't around to cheer you on.. I had some type bug that made my bones throb... glad your symptoms are giving you some relief slow that it may be it is an improvement...

ONWARD..

- greenpoet June 13, 2010

Hope you are feeling better Laura. Missed hearing form you, glad to know you are well.

Onward... Richard

Sprung impatience

Sunday, June 13, 2010

When I began cancer treatment, I had a finish date tacked into my mind. Three 21-day intensive chemo cycles, 35 radiation sessions, then a "two week" healing arc. During the roller coaster ride of the intensive chemo cycles, a two week recovery arc seemed reasonable. My mouth, neck, and throat were bouncing back and forth between pain and rapid healing.

Intensive chemo was in the books and I reached a couple weeks of happy eating that extended into early radiation. As I neared the end of radiation, the challenge ahead - the healing - loomed larger.

Now I pass my days with pain patches that make me drowsy and mostly do their job. I can't drive or read or follow complex text. I have my friends & family surrounding me with love, support, and comfort - otherwise I'd be very lonely and very blue.

I have yet to start solid food (we discuss that process at Tuesday's appointments) and must reach two weeks of maintained weight without use of feeding tube before the tube can be removed and healing accelerates. Average time is 12 weeks from last radiation treatment (June 2) until tube removal. I feel hungry and though the tube fills my nutritional needs, it's not the same.

Ok, these 2-4 weeks is a blue time. I was warned and warned about that. I AM feeling better, a little fire through the blue. I will heal and be stronger. It's just hard to see sometimes.

Thanks all for being my anchors. I rely on you in so many ways and appreciate you in every way. One day, sooner I hope, we can celebrate all this growth. Right now, your love is seeing me through.

Love...

Richard
Posted by greenpoet at 05:42PM (-04:00)

Comments

- TaDa

June 14, 2010

the pain meds are good.. Nobody should suffer...YOU WILL HEA AND GET STRONGER....

hugs

- Nancy

June 14, 2010

Sorry to read you are feeling blue. We are here for you Foxy- knowing that each day you will get a little bit better. Sleep, rest and heal. Ali would tell you that it does get better. One day at a time, and on really bad days one hour at a time.
Love you lots!

- BeJae

June 16, 2010

Hello, hello, my friend. I've been in Iowa staying at a friend's house: lovely, peaceful, wonderful … but, without internet connection. I have missed you so much, missed your adventures in healing, your inspiring words of persistence, patience and determination. I am back and I look forward to catching up with the story of your journey over these last couple of weeks.

I wish you could go through your challenges, your triumphs, your sweet, good life without a bit of the blues. But, none of us gets that. I know that this blue time will help you appreciate and embrace the healing that is happening right now as it manifests more and more each day. The blues will feed you in the end. I know it.

I am so very happy to read you again. Thank you so much for continuing on with this journal even when the days are difficult.

Here's to you, my friend, my inspiration. Onward.

- BeJae

June 18, 2010

I am thinking about you, wishing you well, knowing that this will be over with in time, the pain, the blues. I know that you are healing ... right now ... right now ...

Love to you, my friend.

Chicken or the egg?

Saturday, June 19, 2010

Yesterday, I swallowed three tablespoons of Tofutti Vanilla Frozen Soy Yogurt. Today, with my late lunch of two cans, I had half a container of Eggbeaters - about an egg, scrambled.

Progress.

This is the current step:
Eat, no matter what it tastes like, eat.

Spices will do you no good.
Can't hide flavor because flavor is nil.

My taste buds will rebound. For now, it's mechanical. At least I feel hungry at times!

Thanks all, for the cards, the love, the laughs. You are my fuel and motivation.

Love...

Richard
Posted by greenpoet at 04:06PM (-04:00)

Comments

- BeJae June 20, 2010

Eating! Real honest to goodness food eating. This is so great. Congratulations.

Thank you so much for the post, my friend. I know it's tough going these days. You're my hero.

- BeJae June 21, 2010

Hurray for stomach tubes! See, I never thought I'd say that. I haven't given much thought to stomach tubes before, but I'm thrilled about them now that I know how handy they are. I'm so happy that you can pour sustenance through your stomach tube while your throat is healing. Soon you'll be scarfing down tofu and beans and vegan chocolate cake just like you used to. But, for now, the tube is our friend. I won't miss it when you don't need it anymore, but I'm beyond grateful for it right now. Here's to the tube!

- BeJae June 24, 2010

Hello, my friend. I am thinking of you tonight. You and swallowing. Who would have imagined that swallowing would even be a thing to think about? And, yet, I'm thinking tonight of swallowing and about how wonderful and underrated it is. It's a miracle. Swallowing.

Here's to swallowing. Here's to you, my friend.

Is it bait and switch? Or just that I hear what I want to hear?

Thursday, June 24, 2010

I get a cancer treatment ending date and think it'll all be easy from that date on. As usual, life plays tricks on me. Finish the treatments out on an island far away from home, knowing that I will feel better but not exactly when. Still gotta get home and heal up. This is life teaching me a lesson. It's never as simple as it seems to be. But what should I concentrate on? Six-seven-months ago I was diagnosed with cancer. Today, my prognosis is excellent. I have a bad sore throat & throat & tongue, a stomach tube, and I'm still caught up in medication alley. Really, do I have room for any complaints? Look at the big picture, son!

I will get better; and probably faster than I can imagine today, or maybe slower. But I need to buck up, be a little tougher.

I write in this blog less often. That behavior mirrors my daily activity.

Much to think about.

The fan blew my cards off the long windowsill. I carefully and gently stacked them in a shoebox. I've been placing new cards on my sill and my sill is near full again. That sill is you. You never leave me unattended or alone. Thanks for the comfort and love, unending.

It's in the 80F's today! And muggy!

My short term goals remain the same: eat some semi solid food, walk 15-30 minutes a day, maintain my weight so I can get the feeding tube out.

Love...

Richard
Posted by greenpoet at 06:13PM (-04:00)

Comments

- BeJae June 24, 2010

You are choosing all the right cards, my friend, determination, courage, strength, kindness and a sweet, good nature. These are not new cards for you, not new at all. But, you are choosing different versions of them, versions tempered for unshakeable certainty and endurance. You are so generous to keep us informed on how all of this is going for you. The blog is hard right now, I understand that it is. Life is difficult right now in a real and significant way. And yet you continue on with tenacity and with more good cheer than seems possible. It's disappointing, of course, to get through the grueling protocol in such good shape only to feel ragged and done in once it's over. What seemed like such a triumph turns into an even more rigorous challenge. Relief will come slowly over time, not suddenly so that it is easy to celebrate. But, there is so much to celebrate right now: the good prognosis, the love of friends and family, that fact that you are so utterly amazing, the reality that you are healing and, best of all, the proof that you have not lost yourself in this very demanding process. You don't give in to the illness or its treatment and you don't give up your resolve. You are so very inspiring.

I am sending you all of my best wishes and I am feeling so very grateful that I know you. My money is always on you to finish best.

For once, adverts on TV for food are delectable!

Friday, June 25, 2010

For so many countless reasons, it's good that Ann is here. I could have/would have slept all day today without her encouragement. This wasn't a day that tracked well.

We slept in. Apparently, at 10:00 am, with clear diction, I shouted HELP! Ann came running, her heart racing. For me, it was a dream.

Ann had an early work meeting at the house, to I made myself scarce until after noon. The end of the scarce was lying in bed napping. As I said, I was ready to sleep the day away until Ann made some gentle suggestions. Instead, I

ate an Eggbeater (equivalent 1 egg)
road the LifeCycle (6 minutes @ 1)

At 3:30 pm, Rabbi Seth stopped by and we talked about me, cancer, and recovery. Seth helps me put things in perspective. It's easy to get lost in illness, it's good to have an experienced guide. Seth thinks that a component of eating food as opposed to formula through the tube is an element of being human. People eat to live but more as a social mechanism. The dinner hour pulls us together.

I need goals and a schedule to keep me moving. Napping is too easy. Adjusted for medical appointments, each day should include slots for the LifeCycle, real meals (as opposed to formula), formula, naps (start & end times), blogging (yes, you), and general email response. And it's time to start reading again. My focus is improving.

I need to take my life back. The schedule plus real meals seem to be the keys. Once I can eat real food in quantity and variety, I believe my recovery will be rapid. Oh, how I yearn for food that has flavor, doesn't burn, and swallows easily. That will come. I can move it along by forcing that eggbeater down each day until my recovery progresses.

For once, adverts on TV for food are delectable!

Thanks all for your support and comfort. You are my fountain and anchor.

Love...

Richard
Posted by greenpoet at 09:56PM (-04:00)

Comments

- BeJae	June 25, 2010

You got it. You've got your life back. You've uncovered the secret: Live.

Thank you, thank you, thank you ... For inspiration ... For keeping on ... Yeah!

Why one day is different than another

Sunday, June 27, 2010

Two days - yesterday and today.

Took a 30 minute walk each day
And a nap

Ate 3/4 of an eggbeater egg yesterday
Approaching that time now

This morning Ann got a call from her Dad and they decided to meet at St.V's E/R room. Ann's Dad is having a stomach test. Ann slipped taking a short cut from one parking lot to the E/R, fell, and broke her left arm in two spots.

It's going to be a fun few weeks!

Dan is on his way in from Cambridge.

If I fall behind in blogging, well, days are different.

Love...

Richard
Posted by greenpoet at 12:09PM (-04:00)

Comments

- BeJae June 27, 2010

Ah, geez, I'm so sorry to hear of Ann's fall. Well, now you both get to mend together at the same time. And I know that you are on the mend. I know it.

- TaDa June 28, 2010

sorry to hear about your wife's arm.. I hope she feels better soon... Sorry I haven't been around.. I have had some drama myself but all is good...How is your throat healing? You are in my prayers nightly...

Laura

- greenpoet June 28, 2010

BeJae - we love to do everything together, but this isn't what we are looking for. Thankfully, the pain is light. Next big question: surgery for a pin to be out in?

Laura - the throat is healing but it's a long process. I'm learning more and more about patience. Thanks for your thoughts and prayers. Hope the drama has it's laughing moments, too!

- TaDa June 28, 2010

Smile!

Ann says I'm doing better

Monday, June 28, 2010

so I must be doing better. This morning, she compared how I feel and act now to how I was doing just after radiation - then two weeks ago - and then a week ago. The further we go back, the more dramatic the differences. So, I can't dance and eat solid foods, can't chug water or any beverage for that matter, but I am moving forward. Albeit, (I guess) impatiently.

It's real hot & humid today so I did a LifeCycle ride instead of walking. I don't have a set in time schedule, but I am getting tasks done each day. When I can chug water or swallow solid food, I will be really happy. Have to take it one day at a time, though.

With Ann's broken hand, I'm doing all of my feeding and medicating myself. This is a sign of progress. There was a period of weeks when I couldn't keep track of meds (or time of day) and slept nearly round the clock. Don't worry - Rudy Dog cross checks me!

Thanks for your comfort and support. Now is an easy time to get lost, but you folks keep me honest and happy.

Love...

Richard
Posted by greenpoet at 04:41PM (-04:00)

Comments

- TaDa June 28, 2010

It is a slow process but does get better with time....

- BeJae June 28, 2010

You keep me honest and happy back. You do. You're amazing. And you're right: If Ann says you're better, you are. You really are. This is a day to celebrate. Your body is doing its miraculous healing ... Oh, I know, I know, not fast enough ... But, it's doing it. It's happening.

Oh, that Rudy is such a very good boy. I'm grateful to him for being such a good companion.

Here's to chugging fluids and swallowing solid food. It's coming, my friend ... It's coming.

I send you love from the OH state.

Busy week to come

Tuesday, June 29, 2010

Ann saw the orthopedic surgeon today. She'll have surgery tomorrow. A plate will placed in her left arm above the wrist. The plate will keep both arms the same length, add strength, and allow a quicker recovery.

Today, Renee drove me into Dana Farber for my acupuncture appointment. Traffic was startling light and we arrived early enough for me to make a stop down on L2 to see Maureen. Maureen is a radiation oncology nurse and would have done my discharge but our schedules got out of line. We touched base and I got the once over. My feeding tube is working well and looks good. My mouth, throat, and tongue are making steady progress. Maureen did a basic brain adjustment on me - I have to have reasonable expectations on the speed of my recovery from radiation. My swallowing will come back and my pain will lessen. I am getting closer everyday. I am getting stronger and better everyday.

On Thursday, I see Dr. H. & Dr. H. and the medical oncology team. Our friend Susan will drive us. (Currently, Ann & I are keyless per our doctors.)

Time to get ready for tomorrow. Ann appreciates the good thoughts and wishes as do I. You are wonderful.

Love...

Richard
Posted by greenpoet at 08:22PM (-04:00)

Comments

- TaDa June 29, 2010

i will say a prayer for you wife...

- Nancy June 30, 2010

Ann,
Sending zooms your way. Hope all will be well tomorrow and you have a speedy recovery!

Update

Wednesday, June 30, 2010

Ann's surgery on her left arm above the wrist was successful. She's home. We have a busy evening planned for us! Must get started...

Love...

Richard

Posted by greenpoet at 08:03PM (-04:00)

Comments

- BeJae July 01, 2010

So glad to hear that things went well for our Ann. Okay, I think you two should just settle down now, heal and give up all maladies for all time.

Love to both of you. Nobody should have to go through this much hard stuff, especially nice people like you two. I hope all of this will pay off your hard luck dues for eternity.

- BeJae July 03, 2010

Went to see fireworks tonight, an amazing, big city display. We were positioned in such a way that some of the fire and ash happened right above our heads. I wondered if it might set my hair on fire. I thought of you and of Little Bang and of your dance together, awesome and dangerous. The fireworks were beautiful, the crush of the crowd was scary, the two together were wonderous and disturbing. Afterwards, Jackie and I sat and talked a little in our very quiet, peaceful backyard.

After all of this spectacular protocol and its disturbing side effects, your body will soon be quiet again and at peace.

I am thinking of you tonight, my friend. You light up the sky with your determination and with your courage and with your kindness.

- BeJae July 05, 2010

Thinking of you and Ann tonight, hoping you had a relaxing (if not fun-packed) holiday weekend. I hope you avoided the crowds, but still had spectacular views of amazing sights and sounds. I hope you had beloved family and friends around you to remind you how important you are to us all.

Independence is near, my friend. Patience.

- BeJae July 07, 2010

Thinking of you and Ann as this heat wave blazes on. A line from one of my songs says: When the summer's over and the winter snow is deep, will our shivering bones cry out for this unrelenting heat? Seems like the too-hot is going to go on forever ... just like it seemed like the bitter cold of this past winter was going to go on forever ... But, they don't. And you and Ann will heal and feel great again and walk in the sand and be amazed by the beauty of a perfect day and by how good the salt air smells and by how good it feels as you breathe it.

Patience.

Hurry up and take my time...

Wednesday, July 07, 2010

Last week, I saw the medical oncology team, today the radiation oncologist. The message is about the same. The med_oncon folks cut my pain patch level in half (50 to 25) and placed the primary goal on eating semi-solid food (scrambled eggs, pudding, yogurt, etc.) The rad_oncon gilded the the pain patch up 12 to 37 because I've been hurting. This seems to be a good compromise. We'll drop back down to 25 in a week. Healing is a slow complicated process. I'm being sold patience and it's the only show in town. But one that makes sense.

My treatment started with curling as the background, then the general Olympics, and now the World Cup. The NBA Finals were in there somewhere, too. Sports makes an odd metronome!

My old plan is out. I'm not back at work in late-June to mid-July. The new plan is pretty similar - one day at a time - and follow the oncon rules. When I reach a milestone, act surprised! There's no book on cancer treatment recovery with set and dry times.

BeJae - our shivering bones cry out for this unrelenting heat - has always been a favorite verse. I hear your guitar echoing the truth.

I'll write when the seas are calm and I'm awake. My spirits are good.

Thanks everyone for your support and comfort. You draw the roof and floor on my days.

Love...

Richard
Posted by greenpoet at 05:20PM (-04:00)

Comments

- TaDa July 07, 2010

Yes Richard... every body is different when it comes to healing... you have done so great! Stand Proud ~ I didn't see you crying through this process! How is your wifes hand?

laura

- greenpoet July 07, 2010

Ann's arm is sore but healing well. She's doing her PT and it's paying off. Yesterday, they cleared her for driving. The surgery to put in a plate went gently and successfully. Thanks for asking!

R

- TaDa July 09, 2010

Glad to here that... Saw my oncologist today... I will be 4 yrs cancer free in Nov. I still thinks he is baffled LOL..anyways.. good report and good check up ! Hope you have a great weekend and it is not to hot up there... I hear there is a heat wave going on..

- greenpoet July 10, 2010

Four years - congratulations, Laura! May you grow from strength to strength. It is HOT in MA, cooler in FLA. Today was better and I got a nice walk in this morning (75 degrees!)

- BryceKrug July 21, 2010

Richard,

We continue to be inspired and impressed by your optomism and courage. Our best to you and Ann as you both regain your strength.

Bryce

- greenpoet July 21, 2010

Thanks, Bryce. Hope to see you in September.

Sorry promise

Sunday, July 25, 2010

Friends and family, sorry I have been inconsistent in my posting to the blog. And then I get concerned messages from folks worried how I am. So here's my new promise. I will post three times a week to the blog. I'm really sorry if I've caused concern with my negligence. To say that little has been going on, or that each day is like the one before, is no excuse.

So where am I? Still having little success with semi-solid/solid foods but am being patient. Have appointments with oncol, nutritution, swallow therapy on Wednesday. Maybe I need a kick in the pants, maybe I need to continue with patience. We'll see. This is getting tiring, just formula. If I need to toughen up, so be it.

On Friday night, Ann & I joined Jesse & Susan and Pam & Mark at Jazz At Sunset, a now twenty year series held at Worcester's Ecotarium (indoor/outdoor science museum). Ann & I stayed for the first set and had a really good time. The concert was a veteran big band featuring a young jazz vocalist. The vocalist's parents are close friends of the big band players. That added a special twist to the music.

Dan's in town today. We visited my folks.

Though I have not posted as often as before, I think about you, my support network, every day. You are my anchor and your love and concern keep me centered.

Love...

Richard
Posted by greenpoet at 07:28PM (-04:00)

Comments

- TaDa July 25, 2010

Oh good you are ok.... I havent' been online blogging much either..

it is not going to happen overnight.. you are doing wonderful... seems sucky but you will get there...

- BeJae July 27, 2010

Want me to come over there and kick you in the pants? You'd be a hard one to want to kick, you're so great and all.

I think you're doing exactly what you need to do. I know, I know, it doesn't feel like it. It feels like the getting better has somehow stalled out. But, it hasn't. I promise you, it hasn't.

We all love you and think of you whether you blog or not and whether you're able to eat solid food or not ... raw turnips and such. (Did you eat raw turnips before you got sick?)

It's happening. The healing is happening. And we're all on your side.

I'll be eager to hear (you probably won't want to do this right now, but somewhere down the road) how this process has affected your relationship with food. Does absence, in the end, make the heart grow fonder? Does it change everything. What will eating be like in a year, I wonder.

We send you love from the OH state.

- greenpoet July 27, 2010

Thanks, Laura. I'm just an impatient boy!

- greenpoet July 27, 2010

Hey BeJae,

My heart grows fonder for food. Advertisements (magazines, TV, etc.) make my mouth water even if it's for food I don't like. I am sooooo ready for REAL food - food with texture, juicy, mixture of flavors. Simple food sounds divine.

July Sliding By - what a song. Will take a bit longer!

Love from the Commonwealth...

Richard

Mirror daze

Tuesday, July 27, 2010

Yesterday and today are mirror days. Three formula meals, swallow exercises, attempts to eat semi-solid/solid food mixed in with a mall walk and naps.

Tomorrow would be very much the same except it is Appointment Day at Dana-Farber. There is a very busy day planned. I get blood draw, have an acupuncture session, meet with the Swallow Therapist, the Nutritionist, and see the medical oncology team. We have lots of questions centered on my swallowing progress.

I have no problem with the physical act of swallowing. The substance being swallowed burns and/or the tongue and throat muscles hurt (they are still healing.) I know that I must learn to swallow with comfort to fully recover, I know that I can. The advice is "keep trying". Plus, I have such hankering for real food!

Today, Dan started his day in town; his first appointment was here, so he stayed overnight, short commute, extra visit for us.

Thanks everyone for your words of comfort and love. I think of you, friends and family, when the healing is most challenging. I never feel alone.

Love...

Richard
Posted by greenpoet at 04:49PM (-04:00)

Comments

- TaDa July 27, 2010

Hey what of that magic mouth stuff... that might help by numbing the area so you can get food down... I had issue with my eusophagus (spell) none as severe as yours but they gave me liquid lortab... that worked ..

This soon will just be a bad memory for you... hope your wife is well...

Laura

- greenpoet July 28, 2010

Ann is doing well, thanks! She made the ride to and from Boston with ease.

I use the Magic Mouthwash twice a day, to help swallowing and teeth brushing. My main tumor was at the base of the tongue - where the radiation was aimed - all the tissue there has to regrow and heal. During the growth and healing, I have to keep swallowing no matter the pain - those muscles must be constantly be exercised, three time a day (which hurts, too.) See, I do have a job while healing!

Richard

- TaDa July 31, 2010

It is hard... I know..you did so wonderful through out this... That mask of yours scared me, I honestly don't think I could have done that over my face with out a panic attack....

if it is any consolation...I use to sit back and tell myself on my crappy days... "just remember, there is someone out there way worse off" I know that stinks but it helped me to distract it from me..and I got really sick of hearing "God only gives the full plates to those who can handle it" .. I always felt like saying "Well good you take the full plate for a change".. but I didn't.... LOL

- greenpoet July 31, 2010

I had to see the mask as my friend, not an alter ego. 36 sessions with the mask on - looked at it like sci-fi or spaceflight. At first, it sat on the bedroom chair. Good for nightmares???

Fountain of Youth

Thursday, July 29, 2010

Yesterday was a productive day at Dana-Farber, a day of reassurances. I hear that the traffic into Boston wasn't too bad (the car rocks me right to sleep). First stop was a dual appointment with Nutrition and Swallow Therapy. I have been concerned that my inability to swallow more than one to three "bites" of semi-solid food at a time was marking me behind in my recovery from the radiation treatments. Not so, I was informed. My primary tumor was located on the base of my tongue - an area of muscle that pushes food down the throat. It needs more time and work before it will have recovered enough. We went and made up a list of foods to try - eating builds strength. We reviewed the exercises and set up goals for the next two weeks. Oh, and my weight has been stable (+/- 2 kilograms) since the tube went in!

Next, I had blood drawn and my ports flushed, then headed down to acupuncture for a session. The only issue with having acupuncture in the middle of the day is that it makes me very relaxed and full of desire to operate on low speed.

Side note: my hair (top of the head) growing in from chemo is soft and baby like, though brunette and gray.

Our last appointment of the day was with Dr. H. & Dr. H., medical oncology. We reviewed my general state of being, pain and medications, and eating. Once again, I asked about where I should be eating-wise and got the same answer. Patience and work, boy. Dr. H. felt that having my stomach tube removed in October was a good goal. But the tube only comes out if the food coming in though chewing and swallowing (i.e. without out the tube) for a couple of weeks is able to do so without weight loss. My CT and PET scans are now scheduled for August 30th. On September 1st, we'll meet with the two Dr. H.'s and Dr. N. (surgeon) to review the scans. The senior Dr. H. does not believe I will need surgery on my lymph nodes but they want to be certain all remnants of the cancer are gone. If there is any doubt, they will remove a node or two. (I'm hoping for no surgery, but we'll follow the science.)

Thanks everyone for being here with me. Your support is carrying me through the tough days and making me laugh during the easy ones.

Love...

Richard

Posted by greenpoet at 04:46PM (-04:00)

Comments

- BeJae July 30, 2010

Eating builds strength: I'm going to chant that to myself every time I over do it.

I'm very glad you're making good progress. I know it must seem very slow to you, but it sounds like you're right where you should be under the circumstances.

Thought of you yesterday while visiting the Rock and Roll Hall of Fame. DJs have made a huge difference in the landscape of music and in the lives of musicians in this country. You sure made a huge difference in my life with your DJing. Spin one for me, won't you?

- greenpoet July 31, 2010

Eating builds strength: funny how perspective changes. Now, I should be excited about vanilla soy pudding in "large" portions (1/3 a serving).

Rock and Roll HOF in Cleveland - appropriate. DJ's play their ears, but it's real pickers that drive the music forward. I'll always spin for you!

Pattern of a day - with a travelin' twist

Saturday, July 31, 2010

Not much news on the health front. Still hurts when I yawn and do swallow exercises. It'll be that way for a time. I take meds through the tube (one of which makes it easier to digest and "move" the formula), wait a half hour, have my formula (yum-yum), then do swallowing exercises and east semi-solid food while the pain med is most effective. Today my lunch times match yesterday. Big whoop - I need something to find wonder in.

Ann is brilliant, ok you all know that! Yesterday, Ann realized that her vacation (week after next) and Dan's vacation (next week) matched an open week at one of the cottages at Wind-In-Pines on Sebago Lake in Maine. Dan moved his week to match and now we're going up to WIP a week from today through Thursday. The trip probably would be too much for Ann to pull off alone, but with Dan's help, we can make it a real vacation. Yum - more formula! The folks at WIP are going to do some stuff to make it even easier.

WIP (link one official site--- link two my photos) is a rustic cottage colony that the four of us (Ann, me, Dan, & Ad) have been enjoying for well over two decades. It is our place to relax. This is a surprise bonus this year!

Thanks for all your consideration and concern. I'll be carrying you up to Maine with me next week, we can revel together.

Love...

Richard
Posted by greenpoet at 01:59PM (-04:00)

Comments

- TaDa

July 31, 2010

That is awesome Richard... Bonus surprise is right... Just make sure your blood levels are good before you take off.... I am jealous ! but You more than earned it! I was always a White Mountain girl when I lived in MA... Someone just recently told me they re constructed the Old Man in the Mountain... What is up with that.. My parents always took us there when we were little and I carried on the tradition with my girls when I lived up there. My girls all did the Flume, Santa Village, Story Land ...LOL just Like I did when I was little...

Ok I am on the down side this weeknd fighting a major cold and trying to head it off before it settles in my chest where my scar tissue is and becomes a mess.... Hang in there ... You are doing wonderful...

Oh I wanted to share with you a book I just read... it is called "The Cancer Survivor's Guide (The Essential Handbook to Life after Cancer) by Michael Feuerstein,PhD, MPH and Patricia Findley, DrPh, MSW...

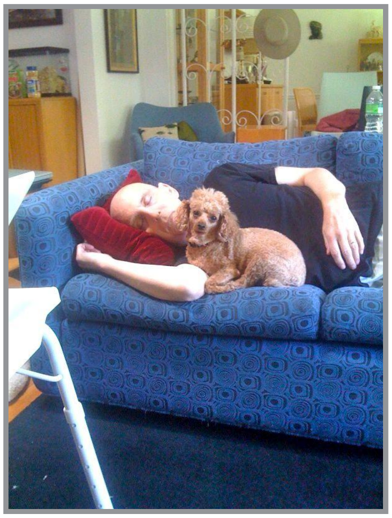
I had saw it at a store and then went to the library and took it out. Even almost 4 yrs later, I found it helpful... You may want to check it out at your library...

also if you go to www.curetoday.com you should be able to sign up for a free suscription of the Cure ~ I LOVE MINE and it is free and has lost of updated information ....jsut fill out the part that says free gift subscription..

Ok... talk to you soon enjoy the rest of the weekend..

Roster for Maine

Monday, August 02, 2010



Wind In Pines is special for our family. We called Adam to let him know what was going on and he quickly decided that he was in and ordered his plane tickets. Surprise family vacation in Maine! Rudy is also coming with - here's what he & I will be doing some of the time.

Had a great eating day yesterday as far as semi-solid foods; breakfast - baby food apple sauce, lunch - one eggbeater equivalent of one egg, dinner - soy pudding. Today, not so much, nothing went down. The nutritionist and the swallow therapist warned me about days about days like this. No bruises. Tomorrow, I'll wake up with a clean slate.

And days like today are days that I rely on you to keep me focused. Without you, I am lost. Thanks for your comfort and support.

Love...

Richard

Posted by greenpoet at 08:56PM (-04:00)

Comments

- BeJae August 04, 2010

Looks to me like you and Rudy are busy doing just exactly what you need to be doing right now ... Just exactly. I'm so happy that you all will have this time together at Wind in the Pines. There is a rhythm there that I'm sure will be very healing for all of you. Through the years, you have sent me photos and stories of your time at Wind in the Pines. I almost feel like I know it, even though I've never been there. I will wrap those stories and scenes around you as I think over you over this time.

Scratch Rudy for me. He's such a very good companion.

Ready for Maine

Thursday, August 05, 2010

The days are the same, getting ready for Maine. I tubed my formula, ate vanilla pudding and baby squash, did a number of errands. It was after lunch until nap time called so I napped the afternoon away. Sleep, sweet, sleep!
Posted by greenpoet at 04:53PM (-04:00)

Comments

- BeJae August 06, 2010

Miracles are occurring during those sweet naps. Healing is happening. Stuff is percolating and recombobulating and rearranging into something very strong and very fine.

I hope that the breeze across the lake will blow lots of sweet memories your way and remind you how much we all love you.

Will I Have WiFi?

Friday, August 06, 2010

We're off to Sebago Lake tomorrow. Charlene and Terry will be here with the animals. I will check in during the trip if I have Interent access (my guess is yes).

Thanks all and safe travels Oyra & Luis.
Posted by greenpoet at 05:20PM (-04:00)

Maine via iPhone

Tuesday, August 10, 2010

My computer lays in it's bag. Posting via phone from Lake Sebago.

The weather is beautiful and the breezes sweet. This is a happy place for us. There are moments when the challenges of the past six months fade and life is simpler again. At lunch today, felt extraordinary happy - here with Ann, Dan, Adam; no particular reason, just blessed and grateful.

Still don't have that texting a post down yet. Thanks for your comfort and support and love. Rudy loves Maine and I love you.

Richard
Posted by greenpoet at 03:24PM (-04:00)

Comments

- BeJae August 10, 2010

And I love you, my friend. I am so happy to hear that there are those moments when life is just what life was and life is everything that life was. Everything's gonna be alright. Yeah. Love to Ann, Ad and Dan, and to you, my friend, and to you. And to Rudy. What a good boy.

- TaDa August 12, 2010

life after cancer is wicked different... you will soon realize this.... enjoy your time and God Bless....

- TaDa August 12, 2010

BTW (by the way) I know that "no particular reason" feeling ! Smile!

- Amy August 12, 2010

ahhh...I love knowing that you are at WIP with your family..I love having a visual!! it is a special place! Heal and rest and enjoy the fresh air..love to all! oxoxxo

- greenpoet August 13, 2010

Thank, BeJae. All our love to you. And more words sooner...

Linda, isn't that "no particular reason" priceless?

Amy, saw the new camp on Fb. We had room this year. Last year was wonderful serendipity. First trip since treatment. Healing...

Light is relative

Friday, August 13, 2010

Maine was a wonderful break. We're all back at our homes. I napped most of the way on the ride to Worcester, when the city was announced I opened my eyes and everything seemed gray outside in the bright sunlight. The lake cottages are dark; that way they hold the cool air on hot days. We don't need the light away from the lake. Worcester is urban gray, such a change after days on Sebago. Funny how dark becomes light.

I'm doing my swallow exercises, eating semi-solid "meals", napping, trying to stay positive about my my solid food intake.

Thanks everyone for your words of comfort and affection. They are much appreciated.

Love...

Richard
Posted by greenpoet at 02:43PM (-04:00)

Comments

- BeJae August 14, 2010

So glad that you had a good vacation and that you are back home with your sweet wife ... Keeping on ... Keeping on ... We love you.

Sunday Morning

Sunday, August 15, 2010

Woke up around 5:00 am today, slept fitfully for an hour, then got up and coughed out my morning dry mouth which was a bit worse than usual. I generally sleep with my door open so air and moisture can circulate, but yesterday Lacey Dog decided it was time to play ball (with the bell in the center ball) around 4:15 am. Guess I have a choice of how to wake up. Good sleep is elusive. My best sleep is a deep nap. I don't know if it's a factor of the medication or the experience, but nighttime is often nightmare time. I did have a good walk yesterday, but don't/can't push myself to sleep with exercise.

Poor Lacey is likely senile at 4:15 am, wanting to start the day and play. Today, she sleeps - what does she dream? Dog dreams...

So I sit here at 7:13 am. Voluntary. It started as an overcast wet morning, but now the sun is sneaking out through the clouds. Guess I'll get up and see what the day brings. Hey, maybe I'll get one of those max naps!

I am wondering about Webster College/University Reunion 2010, the end of September, next month. When I started treatment, I though I was a lock to be there. Now it appears iffy. Fatigue is part of the equation, but so is eating. I don't think I want to go with a feeding tube still in place and the need to carry canned formula. I am eating semi-solid snacks three times a day which is good, better every week. But snacks of odd foods don't cover a recovering body's needs. I see the Swallow Therapist and Nutritionist tomorrow. Maybe they'll have some nice things to say.

Thanks all for your comfort and support. You brighten my day and give me balance.

Love...

Richard
Posted by greenpoet at 07:31AM (-04:00)

Comments

- BeJae August 17, 2010

I hope you got very good news from your Swallow Therapist and Nutritionist. This healing business is quite a project and seems, in many ways, the worst part of this experience. But, as you said a while back, there will come a day when you feel better than you did the day before and a day when you feel even better than that and the nightmares will fade and you'll sleep at night again. You'll still be awakened by Lacey the early riser, but that can't be helped ... and you'll fall right back to sleep one of these mornings soon.

I sat outside this morning and the air was crisp and I felt the passing of summer. This is like the healing process ... It will go on and on, but, at some point, there will be a change in the air, not suddenly, but gradually you will feel the passing of this difficult season.

I know someone back in Ames who went through treatment similar to yours. I saw him briefly in June and he told me that he (finally) had his stomach tube removed and was pronounced cancer-free. Your day is coming, my friend. It's coming. Not quickly enough, no, but it's coming just the same.

Courage, tenacity, patience ... Onward!

Thursday Afternoon

Thursday, August 19, 2010

Time to 'fess up.

Monday, I had an appointment with my Swallow Therapist and Nutritionist, the two disciplines are close, so they are scheduled together. I was doing well. My routine of meds followed by a half hour break to do swallow exercises followed by two cans of formula (720 calories) followed by a semi-solid snack of real food was working. I was eating three snacks a day. My weight was very stable. The next step given to me was to begin with my real food and in greater quantity, then fill in with how much formula I need to fill up. They gave me a nice yellow cookbook, too, filled with easy to swallow recipes.

Tuesday morning, I started out with great enthusiasm and a cup filled with Cheerios and soy milk. To my surprise, I finished the cup. I then followed it with a can of formula. The Cheerios swelled in my stomach and soon I was lying on the couch bloated. The rest of the day, I took it very easy with food. On Wednesday, I ate most of a soy pudding first and then followed with formula, still not having confidence in larger than snack real food portions. Again, the rest of the day, I took it very easy with food.

Today, I tried a cup of Cheerios for breakfast. I finished about a third of it. I had one can of formula, but did not feel satisfied. I should be doing better.

On the plus side: I am close to being off pain meds.

My short term goal is to get out of the house more. Today, we had repair people in all day. Tomorrow, I walk the park or mall (depending on temperature) and go grocery shopping. I need specific foods based on the Monday appointment to vary my meals. I need a change of scenery.

I am angry with myself. I can do better than this. I must do better than this.

On Monday, I was feeling great. I was with the program and progressing. Today, I feel off. It and I are not as bad off as I think. This is just a tough day. I have to bounce back. I'm stronger and in less pain than anytime since radiation. Cancer recovery is very challenging. Time for me to buck up!

Thanks friends and family for your support, comfort, and love. Special thank you to Renee who drove me on Monday - I stayed awake to and from Boston - a great sign that I am getting stronger.

Love...

Richard
Posted by greenpoet at 06:08PM (-04:00)

Comments

- SunIra August 19, 2010

Also time to be kind to yourself.

- BeJae August 19, 2010

Oh, my friend, you will do better. You will. You would even if you didn't try. You will do better faster because you try so hard ... but, it would happen either way. It's like that with guitar, too. It's mysterious. You try, you try, you try, seems like nothing is happening ... But, it is ... And you get better at it gradually ... and it doesn't feel like much ... but, it is. It's huge. It's huge. You are stronger. You are better. You are awake. You are sturggling. You are improving. You have bad days. You are improving. You can already eat more real food than you could. When you can eat all the real food you want it will feel so normal and natural that it may feel like no big deal. You'll be on to the next thing, the next challenge, the next thing you think you should be doing better. Highly productive and competent people are rarely satisfied with their progress.

It feels like crap. Yeah, it does. But, the fact is ... you're doing well.

Here's to you my friend, my hero.

- TaDa August 20, 2010

Awww Richard sounds like you are doing great.... How was Maine ??/

My highspeed was down... but you were still in my prayers....

I am back up and running

Laura

- greenpoet August 24, 2010

Maine was wonderful; moments of sheer joy with the four of us together. We've been going up to the same place in Maine for about 22 years. Every visit brings memories.

Thanks for the prayers...

Back in the hospital again

Saturday, August 21, 2010

Couldn't close my right eye yesterday and my smile drooped. So went for a brain scan - nothing wrong there. We're waiting for a maybe MRI. All tests show no sign of a stroke, so likely I have a case of Bells Palsy.

The hospital is so much fun. Gotta love those three hour sleep nights!
Posted by greenpoet at 12:56PM (-04:00)

Comments

- BeJae August 21, 2010

So good to hear that there's no sign of a stroke. I think that Bells Palsy half-smile is charming. Ralph Nader has it. All you need is a few deep Rudy naps and you'll be good as new. They should let you have Rudy in the hospital with you for sleep therapy ... but, I'll bet you'll be home soon anyway.

Back home last night

Sunday, August 22, 2010

Internet is down in the rain. Checked myself out of the hospital last night. Was waiting a second day for an MRI that my DFCI oncologist didn't think was necessary. My oncologist wanted a CT brain scan which was done out of the ER and showed no problems. There was no guarantee when the MRI would have been done if I stayed another day or another day or another day. I was admitted to have the MRI, frustrating.

Feeling tired but ok. Ate well today- half bowl Cheerios for breakfast and two Eggbeaters for lunch! So, progress.

Thanks everyone for everything.

Love...

Richard
Posted by greenpoet at 05:55PM (-04:00)

Comments

- BeJae August 22, 2010

Ah, progress is sweet! So glad you're home so that Rudy can help you with sleep therapy.

This is long and tedious and frustrating, this battling aliens. But, you are fighting the good fight, my friend, and I hope you know that I'm always on your side.

Learning to eat again

Tuesday, August 24, 2010

I'm doing much better with my eating. Each meal starts with real food followed by a can of formula. Two cans of formula three times a day has maintained my weight - so steady that the Nutritionist jokes about it. So, my weight will suffer but hopefully for a short period of time only. Food still doesn't taste good and Imodium is my companion. Eating is my job. I am grateful that I can eat with little discomfort - I'm off of pain medications - and that my swallowing has improved so much. Still a ways to go. I'll be happy when my taste buds bounce back!

I take a walk everyday. Getting stronger, on a good day my walk is 45 minutes. I hope to be over an hour soon. If the weather's bad, I head over to The Greendale Mall and walk there. I think of what a showplace it once was and how rundown (empty storefronts) it is now.

My CT Scan and PET Scans are on August 30th. I get the results (am I cancer free) on September 1st. Say a prayer, please.

Thanks everyone for your support and comfort. There are days I have the blues and knowing you are out there with me helps beyond words.

Love...

Richard
Posted by greenpoet at 05:39PM (-04:00)

Comments

- TaDa August 25, 2010

Always and you will get good results... how is the bells palsy ?

- greenpoet August 25, 2010

About the same. Will take a few weeks to subside. Thanks!

Big Week Coming!

Friday, August 27, 2010

Next week is a big week for me. On Monday, I have a CT Neck & Head Scan and a PET Scan scheduled. Wednesday, I find out if I'm cancer free. Say a prayer or commune with your spirits for me. I've started to eat solid food though it has little taste (my taste buds sill haven't rebounded.) My weight has been rock solid on the liquid formula diet (via stomach feeding tube), but now as I cut out formula for real food, my weight is dropping. We are trying to address this. Part of the problem is that my appetite is non existant. It's my job to eat and I eat when full. If my scans are ok, getting back on a solid diet and losing the stomach tube are the major challenge.

Today is Ann & my 32nd Anniversary. We walked Institute Park this morning.

If you'd like to help in the fight against cancer, consider a donation to Dana Farber Cancer Institute. It's the research facility where I'm being treated. I've joined the Team Head & Neck (the specific department where I get my care) for The 2010 Cancer Walk. Please view my page at:

http://www.jimmyfundwalk.org/2010/fox

Thanks everyone for your support and comfort. It means more than I can express.

Love...

Richard

Posted by greenpoet at 01:17PM (-04:00)

Comments

- BeJae August 28, 2010

I am honored to support you and the work of Dana-Farber Cancer Institute. Thank you for your courage, your kindness and your inspiration.

Happy anniversary to you and Ann. Here's to 32 more happy years together, cancer free.

Love to you, my friend, my hero. Walk on.

- greenpoet August 28, 2010

Thanks for your generous donation, BeJae. It means so much to me. The staff at Dana Farber is special. They treat the whole person and are very accessible. The famous doctors are humble and humane.

Thanks for your constant support. You brighten days that are challenging. I look forward to walking in the fields with you again sooner.

Love...

Richard

Scans

Monday, August 30, 2010

We're back from Boston. It just seems like a long day. We left Worcester around 8:00 am and arrived on time at Dana Farber at 9:30 am. My first task was to visit the blood drawing room. I know all the staff there now and each greets me as they walk by. Nice to have a friendly environment especially there. Because I was having a PET Scan, I needed an IV (the nuclear material needed for the PET can damage a port) put in. Since it was a month since my port was accessed, my friend had to flush both sides of the port. I had a triple stick! Though they are really good there. My IV was in a vein no one has been able to successfully set a line in before.

I'm still nuclear (watch out small children and pregnant women) from the PET Scan. They put me in a lead lined room, opened a lead walled pass through and pulled out a fat syringe coated with (yes) lead. Then they injected me with the stuff and had me spend an hour quietly. I listened to music on my iPhone and read the latest *The New Yorker* short story. Brother Trucker had just finished the song "Bobby" when they came and got me. It's 90 degrees outside, but in nuclear medicine it was about 65. I laid down on the PET bench and was covered (thankfully) by a warm blankie. Then, the scan started and I went in and out of this tube for a half hour or more. Typical for me, I fell asleep during the scan. They woke me and told me I was still and they got good images.

Next, I went to CT World for a Neck Scan. I filled out their paperwork, saw a screener with long red highlights in her hair. She asked me if I had a port or an IV. I said both. The IV was active so that's the way the contrast for the CT would be administered. I went back to the waiting room, sat, and waited to be called. Tim came out and called my name and brought me into one of the CT rooms. Just like the PET machine, the CT scanner was new and state of the art (nice machines!) I bet it could tell if I were lying! Again I laid down on the bench. They took a few "pictures" then let the contrast go through my IV. My whole body felt warm which was helpful given the cold temperature in the CT room and yes, they also gave me a blankie. A few more "pictures" and I was done.

Both these tests required fasting of at least 4-6 hours. I was hungry and packing formula and my stomach tube apparatus. I asked if there was a place I could feed myself - I thought I might gross someone out in the waiting room who'd never seen a tube feed. Hey - it's just a tube that disappears in my belly and opens to the stomach. They set me up in a nice holding room and I fed. Then, we headed back to Worcester.

Now we wait until Wednesday morning when we get the results of the scans. Dr. H. feels that I am cancer free but there is no guarantee. He projects a 20% chance that I may need surgery for a maverick lymph node. We're hoping I fall into the 80% cancer free range. Say a prayer or the spiritual equivalent. Thanks.

A side note: last Friday, Mom & Dad had lunch at The Wexford House, their usual Friday routine. Dad fell on the steps after eating and broke & dislocated his arm. Wexford is conveniently located across the street from UMass Medical Center (where Ann trained and) where Dad gets his medical care. He was ferried to the E/R where they decided that surgery was risky given all of Dad's health factors. The doctors were able to manually set/reset the arm. Later on that night, Dad's blood pressure dropped and he needed a unit of blood. He was bleeding internally in the arm, blood thinners complicating the situation. He is stable and will be released soon (whatever soon is). He may have to go to rehab though he prefers to go home. We'll see. So, we have this going on, too. Never a dull moment in our family.

Thanks everyone for the support and comfort over the past week. This can be stressful, especially the waiting, and the emails have really kept me focused and made me feel the energy carrying me. It means a lot.

Love...

Richard
Posted by greenpoet at 03:34PM (-04:00)

Comments

- BeJae August 30, 2010

I'm with Dr. H. I have a very good feeling about this. I think the alien has fled.

Please remember, through all of this, how very easy you are to love. We are with you.

Onward!

- greenpoet August 31, 2010

Thanks, BeJae!

Love...

Richard

Cancer free!

Wednesday, September 01, 2010

We're just back from Boston and Dana-Farber Cancer Institute. My scans were good. I'm cancer free!

They stuck a rubber hose up my nose (after spraying no pain stuff) and looked around. I avoided some of the potential side effects (the extreme ones) of the radiation, but still have plenty.

Now I need to work on my eating. I'm still dependent on my stomach feeding tube. Once I can consume the necessary calories (720 per meal, three times a day) orally, they'll remove the tube.

Anyway, great news today! Thanks everyone for your good wishes, prayers, and support.

Love...

Richard
Posted by greenpoet at 11:58AM (-04:00)

Comments

- TaDa September 02, 2010

AWESOME NEWS... I am happy for you...It is a wonderful feeling isn't it...

Huge hugs to you and your family...

Laura

- greenpoet September 02, 2010

Thanks, Laura!

Eating is the thing

Friday, September 03, 2010

We are lighter knowing the cancer is gone. It's been a long road since I started treatment on February 2nd (my birthday.) My big challenge now is eating. Since September 1st, I haven't used my stomach tube to feed. On September 22nd, I see the Nutritionist and Swallow Therapist and if my weight is stable, the stomach tube will be removed. On September 13th, my Power Port (a device that sits below my chest skin and hooks into a large vein - chemo, other medications, and blood draws are accessed via the port) will be removed. It's day surgery. My understanding is the stomach tube is just yanked out in an exam room!

Eating is a challenge because food doesn't have much flavor and I need to eat about 720 calories per meal. My body is still healing and needs the extra calories. My taste buds are still coming back and I still have areas in my mouth that are raw (sensitive to acidic food/drink). I have to be patient and keep eating.

I went to the dentist yesterday and had my teeth cleaned. Head and neck radiation is hard on the teeth (well, hard on every part of the mouth, tongue, and throat) and I was concerned that the cleaning would be tough and that I would have other dental issues. The cleaning felt like any other cleaning, probably easier because my mouth has gone through a lot. Dr. Jeff came in and checked out my mouth. It's in good shape, just an old filling that needs replacement (we knew about that before cancer treatment.) Radiation weakens the teeth and I need to brush twice a day with a prescription fluoride toothpaste, let my teeth "marinate" for half hour after each brushing.

Thanks everyone for your comfort and support, for your greetings and celebration of cancer free me. You all carried me through the chemo and radiation and recovery and I was heavy.

Love...

Richard
Posted by greenpoet at 05:26PM (-04:00)

Comments

- BeJae September 04, 2010

You were not heavy. You were and are light; our light and our inspiration. This journey is an honor for us tag-alongs.

Onward!

- greenpoet September 05, 2010

Thanks, BeJae. Yes, onward...

Real Food

Monday, September 06, 2010

Happy Labor Day!

Saturday, Dan visited and we went out to El Basha, a Middle Eastern restaurant here in Worcester. I was able to eat some salad (how I've missed salad!), a entire bowl of thick lentil stew, and some french fries. It didn't go perfectly but I was able to swallow the food. This is a pick-me-up!

Tonight, we're going to Pizzeria Uno with Larry & Laura. I hope to be able to take on more salad and pasta marinara. Keep you posted.

I'm having my Power Port out on September 13th - simple day surgery. If my weight is stable on September 22nd (same as my last weigh-in), I can have my stomach feeding tube removed! I'm working (eating) hard to meet that goal.

Thanks everyone for the kind words of support and comfort. I've never felt alone through this whole journey.

Love...

Richard
Posted by greenpoet at 04:13PM (-04:00)

Comments

- Mary September 06, 2010

So glad to see you are able to eat. I know it's hard work, but you are so strong and determined, I'm sure you'll win this battle, too. Hang in there.
sam

- greenpoet September 07, 2010

Thanks, Sam!

Penne bits

Wednesday, September 08, 2010

We went to Pizzeria Uno and my meal there was less successful. Found myself choking on penne with vegetables in a tomato sauce. Also had french fries and a little salad. (How I love salad - got to keep trying!) Last night, I ate the penne leftovers with a plan. I cut each piece of pasta into thirds and swallowed each third before trying another. It worked. I'm feeling better about eating and more confident. My swallow muscles are getting stronger and the food more diverse. Hopefully, on September 22nd, when I meet with the Nutritionist and Swallow Therapist, they'll ok my stomach feeding tube coming out. My weight has to be stable and they have to approve my diet.

My Power Port is being removed on Wednesday, September 15th (not the 13th as I wrote before) - it's simple day surgery.

I keep walking everyday. It's hard to see progress with my stamina, but I'm sure it's there.

Thanks everyone for your support and comfort. It's been a long process but I finally feel like I'm getting close to being normal again.

Love...

Richard
Posted by greenpoet at 04:45PM (-04:00)

Comments

- BeJae September 09, 2010

Hooray! Normal is great ... Well, sometimes ... I'm still fascinated by your Webster days and those yearnings to be something besides normal.

I so admire your tenacity in this process. It's a challenge to keep on when progress is apparent. To keep at it when progress is not as apparent is no less than amazing. I appreciate your warm spirit and determination through this process.

Just remember, in a year, like the rest of us, you'll be back to struggling to keep your weight down instead of struggling to keep it up. Of course, a year seems like a long time … and, of course, it's not. When Jackie and I moved to Ohio last year, I used the "one year" marker as a mantra. In one year, I won't feel so lost and every day won't seem like such a tragic upheaval. And I was right. It's been a year now and, though I don't feel like I've lived here all my life, I also don't feel like I don't know where (or who) I am. That year went by quickly … and slowly. I think this coming year will be like that for you. I think that, sometime during this year, you'll push yourself away from the table and say, "Man, I'm so full, I shouldn't have eaten all that salad."

Here's to you, my friend, as we go on.

Twofers!

Wednesday, September 15, 2010

Today we went to Brigham & Women's Hospital to have my Power Port removed. It is a simple day surgery procedure. We left early; we wanted to be sure to be on time. The traffic was beyond heavy. It took (perhaps) longer than any other drive into Boston. When we got there, a half hour late, I signed in and was immediately brought down to pre-op.

I was concerned about my stomach feeding tube and potential infection (that was an issue at St. Vincent's Hospital) and told my surgical nurse. The surgeon had a simple solution. "Why don't I just take that out too while you're under sedation? I won't even charge extra!" Ann said go for it. Normally, the tube comes out without sedation or pain meds - literally yanked out and covered with a dressing. I was concerned that we were making a decision without my oncologist's approval. The surgeon paged Dr. H. who said sure go ahead and remove it. I have an appointment next Wednesday at Dana-Farber with my Nutritionist and Swallow Therapist; they were supposed to authorize the tube's removal. They work for Dr. H. so no toes are stepped on. (Don't I worry about this stuff too much?)

The procedures went smoothly and quickly. I really liked the surgeon, she is compassionate and has a sense of humor. All the nurses and anesthesiologists were nice, too.

So now I'm portless and tubeless and just a little bit sore. I have to take it easy for a few days while I heal. The port is just an incision. The tube is an open hole the size of the tube. It will scab over and close on its own. Both have dressings.

My job now is to continue to eat, not lose weight, and slowly broaden the variety of foods I eat. I'm looking forward to sandwiches, but bread (being dry) is one of the last foods I'll be able to eat. Next Wednesday, the Nutritionist and Swallow Therapist will give me more suggestions on where to go (and how) food-wise.

I went into work yesterday and spent a few hours getting my workstation updated and more, my brain updated. Getting back into the swing of things will take me a while, but I'm ready. Next week, if I'm healed sufficiently, I'll start going in for afternoons daily and work my way back into a full day's schedule.

Thanks everyone for your support and comfort. It means more than I can say.

Love...

Richard
Posted by greenpoet at 08:26PM (-04:00)

Comments

- TaDa September 16, 2010

so happy for you.... great job you... !

- greenpoet September 16, 2010

Thanks, Laura!

- TaDa September 27, 2010

Richard don't leave us.......... looking for your post understand if you are busy getting better...

- greenpoet September 28, 2010

New post for you!

A little while later...

Tuesday, September 28, 2010

Sorry I haven't posted in a while. Haven't been spending much time with my computer. But there is a lot of news.

I went to Dana-Farber for my appointment with the Swallow Therapist and Nutritionist. They were surprised to find out that my stomach feeding tube had been removed. They weren't upset though. I gained four pounds in the three weeks since I stopped feeding using the tube. Generally, people lose weight. They were happy with my diet and progression of adding new foods.

My tube is healing well. While I was in seeing Swallow and Nutrition, I asked one of the nurses to check the wound. She thought it looked good. My steri-strips still haven't come off the incision where my port was removed. Ann's getting ready to pull them. Will be two weeks on Wednesday.

I get up at seven, eat breakfast, and take a nap while the food digests. A month or so ago, I couldn't ride my LifeCycle - my legs weren't strong enough to drive the wheels at low resistance. Started on the bike again last week. Am up to 24 minutes at level one. Before treatment began, I did 36 minutes at level four every morning. I am getting stronger. Plan to try 36 minutes tomorrow or the next day, then start gradually upping the level.

I've been going into work in the afternoon for the past couple of weeks. Still getting back in the swing of things.

My first followup appointment at Dana-Farber with my oncologist is next Wednesday.

Thanks everyone for your support and comfort through my illness and treatments.

Love...

Richard
Posted by greenpoet at 08:08PM (-04:00)

Comments

- TaDa September 28, 2010

So happy to hear this...

Rock on!

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