Everything, everything gonna be alright this morning….

Muddy sez it’s gonna be alright.

When last we met, an unexpected recurrence of lymphoma in my neck derailed plans for a stem cell transplant, which is really the only viable option I have for any kind of long term remission. No sure thing, to be sure, but in this situation you gotta grab the best bet and push your chips onto the table.

They sent me home to have another surgical biopsy, but by the time I met with the surgeon the entire “recurrence” had disappeared. Quote…

> *There really isn’t anything there for me to take out.*

(Fun fact: Five years ago – six months after the Summer of Tick – this same doc was gobsmacked when I showed up for a fourth biopsy and had miraculously shed all trace of swelling. His comment then: “There really isn’t anything there for me to take out.” He was sure I had lymphoma then. He was probably correct.)

Anyhoo, we spoke to our ace oncology pharmacist at Shands, who then spoke to the transplant doctor (the one who said “You have a very aggressive form of cancer, and no good options.”), who then decided that I should come back to Shands straightaway for more scans and tests &c.

The outcome – revealed this afternoon – is that I am clear of any sign of recurrence. Onward and upward with the transplant!

But the big thrill of the past couple of days has been the several sessions of nurses and doctors reciting the possible negative outcomes of stem cell transplant.

Yesterday, the nurse presented this info with a terrifically inappropriate kind of chipper happy talk. Imagine the following in an octave higher-than-normal-sing-song voice you might use to coax a toddler into taking a nap.

“So, first thing is, the transplant could, um, take your life.”

She went on from there to describe tingling fingers and lips; lack of fine motor coordination; fatigue; mouth, throat, and intestinal lesions; confusion; bone pain; skin rash and itching; dizziness; constipation and/or suddenly explosive diarrhea; and organ failure. She averred that she had never seen *any* of these unpleasant outcomes in her whole career, which upon questioning stretches all the way back to 2016.

Alrighty then.

All of this pleasantry was delivered in a sing-song punctuated by reminders to tell the nurses if anything feels wrong, the admonition that “we do not play ‘suck it up buttercup’ around here” recurring at disturbingly frequent intervals. It was like a sitcom tagline, Steve Martin shouting “Well Excuuuuuuse Me”, or Fran Drescher laughing.

By the fourth time she said it, I was ready to scream. By the eleventh recitation, unpremeditated manslaughter was on the menu. I restrained myself, but only just.

Today, we had to endure the same litany from the Head Honcho Doc, followed by me signing documents attesting that yes, indeed, I understand all the crap things that could happen.

Now this is a guy that might be considered ‘on the spectrum’ (as ‘they’ say). In contrast to the nurse’s delivery, Dr. H spelled it all out in a largely affect-less delivery. Same info, but no buttercup happy talk. As Sgt. Friday would say, just the facts.

Funny thing. After the nurse’s chipper presentation, I was a fucking wreck filled with dread and premonitions of disaster. Terrified, really. But after meeting with doc today – just the facts, ma’am, no happy talk assurances – I felt reassured and ready to go.

So then. For now, we are back home with the dogs, a cold IPA at hand, the Sons of Kemet blasting Go listen to this scorching set from this year’s Big Ears. NOW! while we wait for the next chapter(s).

On Saturday, we begin the stem cell harvesting process, aka *apheresis*. For four days, I will receive twice-daily injections of a bone marrow stimulant (*neupogen* for the detail oriented). On the third day (oh, poetic portent!) they will install another port in my chest, this one with three dongles, a sort of Cerberus of access to my internal jugular vein.

On the fourth day we will harvest stem cells. I will be attached to a machine that takes blood out, spins it like a motherfucker (paging Dr. Brakke!), and then returns it to my system. Six hours, no detaching. The worst side effect of this process is boredom.

Then they send me home for a week. And then the real shit starts.

When I return to hospital, I will not step back out into sunlight and unconditioned air for at least 4 weeks, maybe as many as eight. First step in this is chemotherapy program (BEAM, for the curious) designed to pummel my immune system into nothingness. After six days of this (and this is where many of the more unpleasant side effects are likely to begin), they will reinject my stem cells to kick start my immune system from the proverbial ground up. My new birthday will be August 30.

If all goes well, I will then face 2-3 weeks in hospital and 2-3 weeks as an outpatient which requires me to stay in Gainesville. If all does not go well, my stay in hospital and Gainesville may be longer, or, if things go terribly wrong, I could find myself on the wrong side of the dirt at any point along the way.

Just the facts, yo.

Still in all, I feel more positive tonight than last night when I tossed and turned all night in our hotel bed, visions of explosive bowels and sudden organ failure dancing in my head.

Tonight my vision is of beating their estimates of how long I have to stay in stir. Tonight my vision is of putting this shit behind me and moving on like a beastly motherfucker, ready to kick ass and take names. That’s where I see myself going. I might be deluded, but it beats the alternative of figuring that shit is going off the rails.

So for those who wish to help: We have some of our time away covered as far as dog and house sitting are concerned, but we still have some gaps in the calendar. Get in touch if you or anyone you know might be able to help.

Also too, and as always:

LOVE EACH OTHER, MOTHERFUCKERS!

That is an order.

Turvy

In yet another turn of fate, the game board has been flung skyward.

I spent the first part of the week at the hospital getting tested for my fitness to endure an autologous stem cell transplant. The good news is that I am a picture of health, passed all my tests with flying colors.

The bad news is that I am experiencing an aggressive recurrence of the lymphoma. All bets are off.

This is not quite all the way back to square one, but close. There will not be a transplant unless we can get to remission. In the mean time, I will undergo yet another “salvage” regimen in hopes that we can get the cancer under control. There are two primary options to choose from once results from my bone marrow and neck biopsy come back.

The likeliest is a drug called Romidepsin. Unlike my prior therapies, this one will be done locally, one day a week for 4-5 hours. There will be two cycles of this, each cycle consisting of three weeks on and one week off.

The good news is that this therapy is supposed to be very mild on the side effects and is far less toxic than standard chemotherapy. (This is a newer generation of drug.) It has a good track record in general, though again, the rarity of AITL means that there is insufficient research to indicate whether my cancer will respond.

It is something of (another) leap of faith. The good news is that it will give me about two months to clear the previous chemo sludge out of my system. If I am not in remission after the two cycles of Romi – or if the biopsies come back with something unexpected – we will move to another chemo cocktail or perhaps a clinical trial of some sort. None of this is good news, though at least I still have some options for treatment.

Our transplant doctor was blunt: “You have a very aggressive form of cancer, and no good options.”

Thanks, doc. On the other hand, our oncologist is not quite so fatalistic, you should excuse the expression.

The odd thing is that I feel pretty good aside from some ongoing fatigue issues and a sore spot in my hip where they removed some stem cells and bone for the biopsy. (Not as bad as it sounds, but almost.)

So the saga continues. Thanks again for the music and books and cards and emails and such. I appreciate you all. I owe a couple dozen thank you notes and return phone calls and such. Damn, y’all are good friends.

I’ll post again when I have more news. Until then…

LOVE EACH OTHER, MOTHERFUCKERS!

Ask Not For Whom…

Life since the last update has been fairly routine, if by routine one means a seemingly endless succession of inpatient chemo sessions punctuated by deep exhaustion, malaise, and occasional mild bouts of tummy tumult.

The last round of standard chemo left me pretty well flattened, a piece of unidentifiable road kill sprawled on the sofa, incapable of following a thought for more than a few seconds at a time. It was as though I were looking at a huge, jostling crowd from above, everyone wearing big, yellow hats with nothing to distinguish one from another. Then, one person would take off their hat and I would try to follow that person/thought. But no matter how hard I would try to concentrate, the damned thought would put the yellow hat back on and start trying to hide. Then another would take off the yellow cap for a few seconds before hiding. Ad infinitum.

Then, everybody’s hat would turn red, and I would try to figure out what had changed, but there was no hope of ever remembering what that change could have been. Then I would forget anything had changed at all.

Rinse. Repeat.

Gah.

This lasted a solid week. Since then I have enjoyed a rare stretch of clarity and (slightly) elevated energy. Reading is again enjoyable, the words alive on the page and taking lively shape in my mind.

Alas, all good things must end.

My PT Scan came back with terrific results and I have been off all meds, feeling pretty darn good. The scan showed that the chemo did its job. That means I am eligible for stem cell transplant. That process begins next Monday. Once more, unto the breach.

I am filled with hope and dread. Hope that the SCT will work as planned. Dread because the chemo I will receive for this will make the previous chemo look like child’s play. And dread because following a few rounds of outpatient testing and treatment, I will likely spend the bulk of August and September in confinement.

An essential part of the transplant process is application of chemo in doses sufficient to destroy pretty much everything I’ve got in the way of bone marrow, white cells, platelets, etc. The whole immune system has got to go, basically, and cell division – which is the basic characteristic of any living organism – will be nothing but a memory. Shorter: They want to get as close to killing me as they can without me actually dying.

The original begin date for this was July 23, and boy was I looking forward to the next couple of weeks. But somebody canceled their treatment, so I was moved up by 8 days. On the one hand, this is good. We get started on my treatment sooner and deny the AITL an opportunity to return.

On the other hand: Well, fuck.

Fun Fact: Because the transplant process will take my immune system down to zero, I will have to get all my childhood immunizations again.

Greatest thanks to all who have sent messages, books, food, music, &c. I have a universe full of amazing friends. Can’t wait until I can see you all and can give you a giant hug. This elbow tapping is a poor substitute for a heartfelt neck squeezing.

Locals: Hoping to set up an outing to one of our local drink spots before I once again disappear into the gaping maw of the medical-industrial complex. Likely Friday or Saturday. Stay tuned via FB/Twitter.

Also too:

Well I’m Accustomed to a Smooth Ride

Or maybe I’m a dog that lost his bite.

The first six weeks of chemo were relatively uninteresting. Fatigued, but not hammered in the fashion all those movies of the week and after school specials had me expecting. I thought I was special, that rare creature immune to the horrors. Everything would work exactly as planned, *mirabile dictu,* I am healed!

It seemed to be working, until it wasn’t, so the docs decided I needed to shift to another protocol.

May you live in interesting times.

First repercussion: Where my hopes for full remission via chemo were around 60%, the need to change protocols (due to aggressively resistant cells) means my chance of full remission via chemo are now around 40%. What that means is the marrow/stem cell transplantation is almost certainly going to be necessary.

Well fuck that. I followed my rules, all the precautions and shit. Whaddyamean that stuff isn’t working. I want to speak to your manager.

Second repercussion: The second line protocol is more systemically insulting, i.e., this shit is rough on the human body. Caustic. Fatigue and brain fog are way worse, and my immune system collapse landed me in the ER with a near-shock condition sepsis event. Three days in hospital during my scheduled non-hospital time. Who is in charge here, and may I speak with her straight away?

I’m accustomed to a smooth ride, goddammit. I would like a word with your supervisor. My consumer rights are not being adequately met.

A week later, I am feeling relatively okay. Tomorrow, back to Gainesville for initial consult with the transplant team. I have a feeling I will own more information than I would care for by tomorrow afternoon. Kind of like when I found a British website focused on AITL that concluded with the following cheery thought:

> *It is important that you and your family recognize that you are dealing with a fatal disease.*

Well fuck me sideways and call me Shirley. The Brits, they can be overly direct, no?

I am not quite prepared to accept that as definitive, and besides, life itself is a fatal condition, but I must admit that my thinking has had more than its share of morbid consideration since I saw this on the eve of my last treatment. The new one, because the first one was not working.

That.

We keep plugging. Our oncology pharmacist – our favorite member of the care team – says this: You keep going, even one more day, in hopes that they find the cure for this thing.

Also too: There are dogs and music and books in my day-to-day, and though reading is iffy with the chemo brain (It took me a full week to read *The Watchmen*, fer crying out loud), still, I persist.

Monday was our 35th wedding anniversary, me and Stanwyck. What an amazement this is, the rich history, the shared life. I really want to celebrate many more. So much more to say about this, but alas, the brain resists the intentional sequencing of words to create something whatever etc.

Greatest gratitude to all who send messages and love and books. It means more than you can imagine. Truth.

So as my bracelet says…Keep Fucking Going.

What else is there? Oh yeah…

LOVE EACH OTHER, MOTHERFUCKERS.

It matters a difference.