

Not Everything Will Be Okay, But Some Things Will



(Pictured: "Not Everything Will Be Okay But Some Things Will" by the artist aka Stanwyck)

First things first: My one month old immune system seems to be humming along just fine, thanks. Blood counts are all close enough to normal to be considered normal. Once again I am free to shake hands and go about in public without that silly face mask.

That's plenty okay.

I am still avoiding children as I have not yet received my childhood re-inoculations, and besides, your little dearies are seething vectors of all manner of petri dish horrors. And if we meet and you have the flu or ague or catarrh, please give me a friendly wave from no less than six feet away, thanks.

There are no apparent signs of lymphoma recurrence, and that's plenty okay, too. The real test on that comes in December when I go in for CT and PT scans. If I notice any lumps or swelling before then, the game board changes, but so far none of that, so okay okay.

The brain and physical stamina are still gone all spritzandpoppin. But that's just a time thing, so okay.

My appetite is back, but my taste for coffee has vanished. Bet

short on coffee futures. But the one beer I've had tasted GREAT, so okay.

Not so much okay: When we were given clearance to leave Gainesville and return home – well ahead of schedule – we were elated. Finally, a chance to return to normalcy, whatever that might look like after all this kerfuffle. But less than 24 hours after returning home, an air quality assessment we had done on the house came back with sirens and flashing lights: Get out now, especially the guy with the new immune system.

Not so much okay so much.

The Universe is demonstrating a very sick sense of humor. We have a toxic mold issue that is dangerous to a healthy person, and life threatening to a brand new immune system. We vacated the house until we can have remediation work completed. Me and Stanwyck and the dogs are piled into my Mom's 2 bedroom condo for nearly two weeks now, with at least another 2-4 to go.

Definitely not okay. But tolerable.

The repair work for this is stupidly expensive. Best case is that the worst of the infestation is under the house and that the mold in the living area itself is relatively mild. After scrubbing and spraying and sealing the crawl space under the house, the remediators will run several refrigerator-sized air scrubbers in the house for a few days in hopes that a re-test will come up mold-free. If not, we will have to have every item and surface in the house hand cleaned, and that includes books, and that means every surface in every book, meaning every page, one at a time, and etc. If it comes to that, the expense jumps exponentially and several hundred books are likely headed to the landfill. And the Moms will get to enjoy our company for another 6-8 weeks.

This is all so not okay I can. not. even.

But hey, not everything will be okay, but some things will,

and eventually other things will sort out, too. And then the Universe will throw another spanner and you'll either deal or you won't, and if you don't you'll be dealing anyway, just without exerting the choice of sifting the ashes to find the nugget that sparks the gratitude. And really, that may be all the choice you get in some situations, so why give it away?

Ya win some, ya lose some. Whaddyagonnado?

Day 10: Well Hello, Cousins!



If you arrived here from my article in today's Bitter Southerner....

Welcome! Come on in.

If you are new here, this is my home base for rambling, witterings, rants, laments, and other such. Lately things have been focused on my stem cell transplant, because what could possibly be more captivating than details about, well, me?

I'm pleased you dropped by. Stay as long as you like, come and go as you please. But be careful about the one-eyed cat. Trust me.

If you are regular here at the shack, you know the rules. Wipe your feet. No spitting. Be kind. No cussing unless cussing is all that will do.

Now on to business.

When I posted on Day 5, I told you that “I feel pretty bad, but not terrible.”

Let’s just say that sunny outlook changed right damn quick. Day 6 was the proverbial long dark night of the soul, albeit one that lasted about 48 hours. I’ll spare you details of the suffering, but it was dark and frightening and helplessness-inducing and all manner of dark mojo. (And still, none of it has been as specifically awful as the Tick Apocalypse of 2014.)

So let’s blast through Days 7 and 8 as if they never happened. Day 9 found me awake at 6.30 a.m. with three pitch ideas, a scheme for reorganizing the home office, and an itch to play a damned guitar. For the next five hours I interspersed these endeavours with some robust physical rehab action. I was a World Beater.

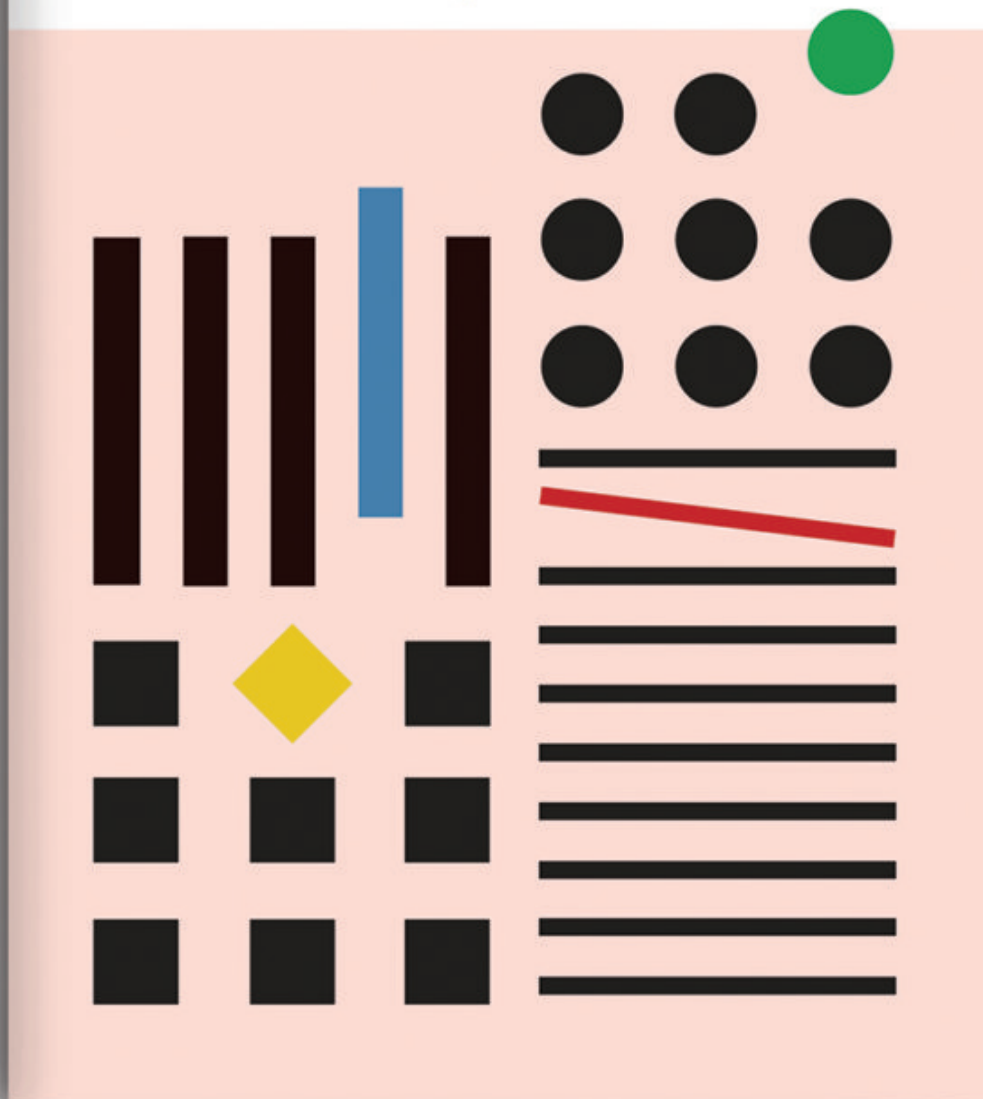
Then I crashed to Earth with just enough energy to watch the US Open final.

Today, Day 10, I awoke at a more sober hour, but no less enervated for achievement. More writing, more rehab, and devouring a huge chunk of Nate Chinen’s terrific new book *Playing Changes*.

PLAYING CHANGES

Jazz for the New Century

Nate Chinen



Buy this, read this, write in it, love it.

I have not managed 50 pages in a sitting since before we came

to hospital. I am very encouraged.

I kept up the snappy pace, doing laps around the nurse station, hailing all good fellows and ladies well met.

And then a nurse said "Hey, looking good."

Was I ready with a snappy comeback? Is the Pope an enthusiastic outdoorsman?

"Pngr diung shkr," I parried.

It was clearly time for a lie down. A long one.

There's this thing everybody in Cancer Land calls 'chemo brain'. Signs and symptoms of chemo brain may include the following:

- Being unusually disorganized
- Confusion
- Short attention span
- Difficulty concentrating
- Difficulty finding the right, uh,
- Difficulty learning new skills
- Short attention span
- Difficulty multitasking
- Feeling of mental foggiess
- Short attention span
- Short-term memory problems
- Short attention span

In short, dumber than a box of hair.

But the super most excellent thing about chemo brain is that one minute you might be expostulating like the third-act Scarecrow in *Wizard of Oz* and in the next blink of an eye you revert to Act One Scarecrow.

Best estimates on shaking chemo brain range from six months to a year or perhaps even more. (That 'perhaps' is doing a lot of

work right there, and not especially well.) Apparently it is, as they say, just a matter of time.

Before I checked in, I removed myself from our car insurance. One reason is to save a little money. The other is that I do not want the temptation to hop in the car and joy ride down to the malted shop to hang with Reggie and, um,

Never mind. Forget I said anything.

I also have really intense dreams in which a conversation in the dream will cause me to respond out loud, which wakes me up, which scares the shit out of me because the person I was talking to has been replaced by one or more severely alarmed observers puzzling whether to get the restraints on me before I get spagiggady, and yes I know that is not a real word, at least not yet, and since the word I want won't come I will devise its replacement.

All this to say: Things are well and truly on the upswing here. Blood counts are where they should be, my physical/mental condition is ahead of the curve. There is a good chance I will get out of here next Monday. (They don't do transplant discharges on the weekend, and Friday is likely too aggressive a target.)

From there it's 2-3 weeks in the halfway house – though some beat the odds and get out quicker. Again it all depends on bloodchemistry and how I am tolerating the transplant.

So far, so spiff.

In the meantime, y'all introduce yourselves to each other and please tidy up before you leave. I'm late for a chat with Jerry Garcia and AP Carter. I hope I can keep it to myself.

Til next time...

LOVE EACH OTHER MOTHERFUCKERS!

It matters a difference.

DAY 5: Zippos in the Jungle Somewhere



We have arrived at the Great Decline, the leading edge of the Great Divide, beyond which is the Great Resurrection where Robo v2.0 either hums like a fine Swiss watch or reminds everybody of Windows Vista.

I am effectively stripped of my immune system at this point. The technical term is neutropenia. For the med tec(k)s among us, the details are: WBC<0.1; ANC=zero; Hemeacrit 33.7; and platelets at 19. This last number means that I will receive a platelet infusion over the next hour.

As my old pal Frankie told me about his chemo a few years back:

Basically they have to get you as close to death as they can without actually, y'know, killing you.

That is some hardcore torch-the-hamlet-in-order-to-save-it mentality right there.

As much as I resist, current conditions lend to metaphor. I am filled with a polyglot of chemicals and isotopes and re-jiggered stem cells and antibiotics and probiotics and stem colony growth factors. There is a system wide negotiation at play on multiple levels. Cells and mitochondria are at war. Molecular conflict is rampant. Organ functions are under close scrutiny to ensure no unexpected rebellion. System interactions are unreliable: One minute fine, the next as weak as a kitten. Treason and treachery may be afoot.

To be honest, it feels as if I am just a bystander to the whole shooting match, kind of like when the swells in DC took a day tour to watch the Civil War get decided in an afternoon.

“Oh, look there, Jedediah, those stem cells are skirmishing up the left flank.”

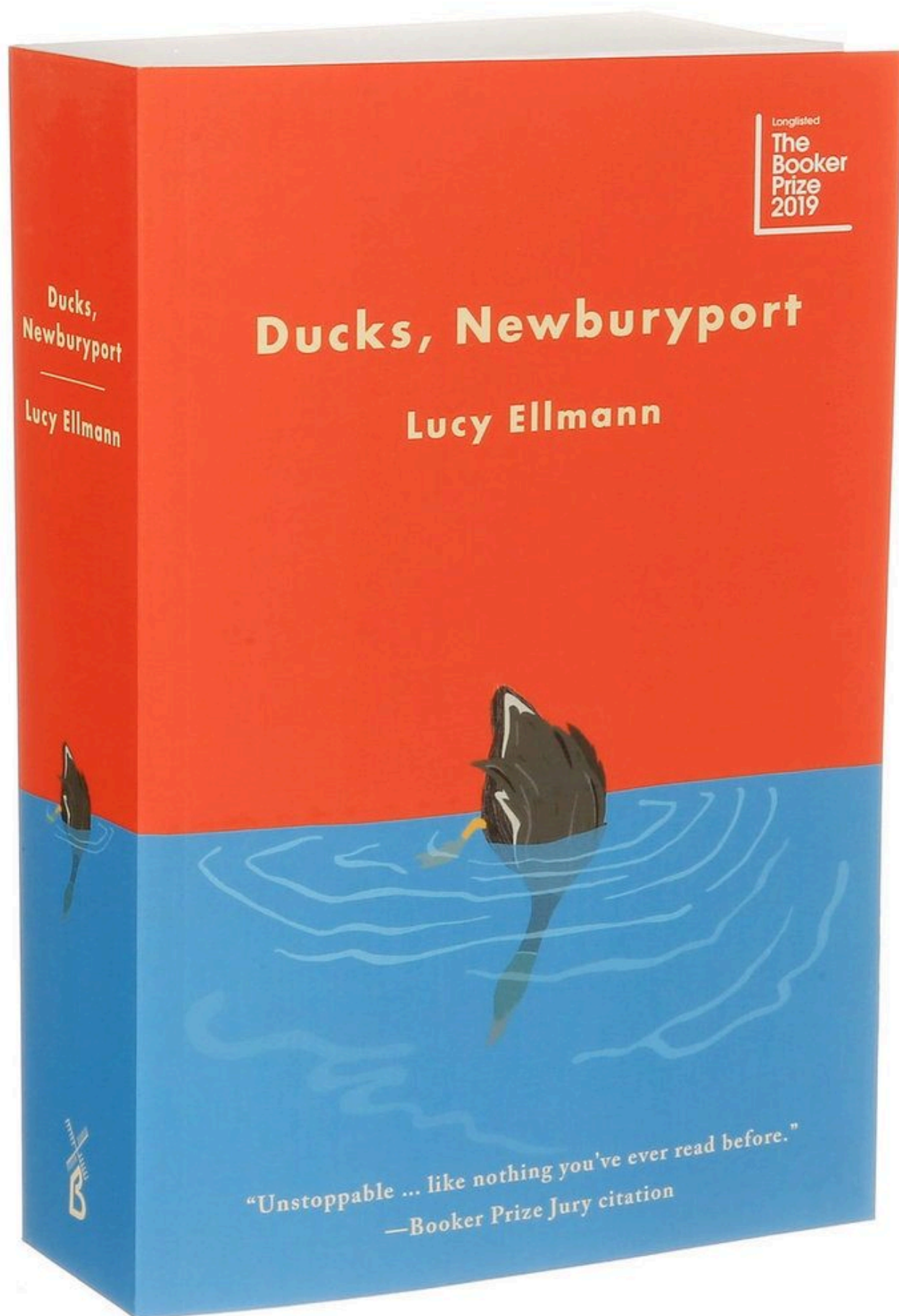
“And what ho, Sweet Nellie Constancy! Look at the way those cancer cells are on the rout! War shall be over by Christmas, most certainly.”

Twas that it were true. Recovery will be a many months affair, no matter how soon I blow this chicken shack.

The calendar looks more or less like this: I will likely remain neutropenic for another 4-7 days. My system will slowly begin to recover over the following days until, the good Dog willing and the stem counts rise, I might get out of here as early 9/15. After that, it is the Cancer Halfway House for 1-3 weeks so the team can have me close at hand in case anything goes all spritzinpoppin. Best case for getting home to dogs is late September.

That’s aggressively optimistic, sure. But I just executed an act of purest optimism by ordering this book, described by NYT as “a 426,100-word sentence that stretches over 1,000 pages – occasionally interrupted by a more traditional story, albeit

one from the point of view of a mountain lioness.”



Aside from *the fact that* this kind of thing is pure catnip to me, I ordered this with the old Vaudeville joke in mind.

I'm so old I won't even buy green bananas.

The low down here is that I feel pretty bad, but not terrible. FWIW, the Great Tick Apocalypse of 2014 was far more physically grim. I am starting to develop the mouth and alimentary canal irritation that I was warned about. Nothing tastes or smells good. One sip of coffee this morning and I nearly wept at how bad it tastes. I am flat down zero on energy, and reading or typing for too long tends to make me woozy.

So here I sit, the boy in the bubble and the baby with the baboon heart, a prime demonstration of what the amazing minds of medical science can come up with. FWIW, that whole 'bubble boy' thing was a short-lived approach and is exceedingly rare these days. It turns out that while external agents can cause an infection or sepsis, it is far more likely that that which is already within me will serve as the source of aggravation. My usual biome may well loom as the greatest threat. Only time will tell.

These are the recited facts. Please do not feel bad for me at this time. There is way worse suffering out there than my own, and the fact is that I am damned near drowning in gratitude and love right now. It means so much to me to see that people are starting to visit this site regularly and spend some time with my witterings. If you know or are a writer, you know that kind of this means more than it might should. But no matter. Thank you all. If friends are wealth, I'm at Croesus level accumulation here.

Besides, I am indeed the world's luckiest boy. Stanwyck is by my side throughout, and while the circumstances are grim, we have enjoyed some of the deepest and most rewarding time in

our 36 years together. We are starting to talk about plans for after: Trips, activities, physical fitness.

This saga – perhaps the Greatest Story Ever Told – is ongoing and exceedingly rich. Something deserving of extended rumination and belletristic treatment.

I have begun each day here with Sister Mavis’s version of “Hard Times.” It is a solid reminder that our troubles may be plenty, but this too shall pass. And while we are at it, there are plenty of people around us who need compassion and a helping hand.

So you know what comes next, right?

LOVE EACH OTHER MOTHERFUCKERS!

It matters a difference.

Day Zero



After six days of preparatory chemotherapy, I arrive at Day Zero. Today marks the system upgrade to Robo 2.0, download to commence shortly. It’s my New Birthday.

There are five bags of stem cells, harvested week before last from my own recalcitrant and glitchy old OS, now thawing in an Igor-esque laboratory down the hall. Around 3.3M stem cells,

give or take, yessir yessir five bags full to be mixolydianed in with my diminished strain.

The Days Minus-6 through Minus-one were largely uneventful, which is really the way you want things in a joint like this one. No drama. Decent sleep. A distinct lull before the storm, as it were. Dorian afoot, and not so minor as its name might suggest.

We are perched seven stories above ground in a building constructed to the strictest brick-shithouse code, a designated shelter for storm pummeled locals. We have an expansive view over Paynes Prairies to the south, where we trust the storm will travel after it blows Mar A Lago straight to where it belongs. A little concerned about the storm hitting our dedicated house/pet sitters, but whaddyagonnado?

Plenty of time to think and ponder, especially after the 4 a.m. vital signs visit from the attending. Time enough to arrive at this: I am in the best part of *It's a Wonderful Life*.



I'm alive, Bert! I'm ALIVE!

Yeah, it's one of my favorites. I'm a sap. Deal.

It is too bad it takes a brush with mortality for me to twig to the immensity of my own Wonderful Life. I know I've had it good: vis Stanwyck and the amazing kids. That alone is more riches than Ozymandias ever knew.

But also too: There have been notes, emails, missives of all sorts from people reminding me of kindnesses I have done over the years, small things that I might not remember or maybe did not even realize were actually happening at the time.

I cannot express how much this means to me.

We wander through our days, often, in a grey haze, not always careful in how we act towards each other. All too often, that leads to carelessness and, sometimes – like right now when my laptop will not behave properly – nasty bits of temper that lead to simple acts of unkindness or even cruelty.

Funny how those events tend to stick in memory. I've often wondered if my life has not been a string of accidental or intentional unkindnesses punctuated by the occasional accidental kindness.

But lately, the outpourings of thoughts from my many friends lead me to feel a little like George Bailey. A string of random events, perhaps, that actually add up to my having done something good in this world, that I have had a Wonderful Life.

And that maybe, just maybe, I deserve to live it some more, if only to try to make sure the kindnesses outweigh that other crap. What would Anubis say if he were to weigh my heart against his feather?

I'd like to wait a little longer to find out.

A few minutes ago, I received the first of the pre-meds that will support the stem cell transplant. Some of this is a considerable jolt of steroids, something with which I do not

well deal. Between that and this damn laptop, I better sign off before I send the blasted device a-sail across the prairie. I'll post again when I can. Meantime, all inquiries, hail thee wells, and get-over-it-bubs are welcome via whatever messenger route you choose.

Sincerely, thanks for all the very real and tangible support. We are grateful for our friends and family, grateful to have been a part of your lives and you part of ours, and full of hope that we will all look back on this over some frosty adult beverages and have a good laugh.

Til then, and as always:

LOVE EACH OTHER, MOTHERFUCKERS.

Time is shorter than you think. Get Cracking.