chemolog

chemolog

Meditations while battling Cancer

arisamuel

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I was working and living in San Francisco. I had 3 kids under 6 years old at the time: Saul (6), Lev (4), Lua (20 months). Things were good: my wife Michelle and I were building our home and family, getting into rhythms of new schools, and quickly adjusting as new kid milestones emerged. All this was against the backdrop of working long hours as an e-commerce Product Manager downtown. I'd bike to work first thing, lock up and walk upstairs to my hip tech office overlooking the shimmering SF bay. I'd get to work with some of the most talented people I'd ever met each day. I'd get to solve hard problems with smart people.

At my last physical just a month prior my doctor said I was told my blood work was perfect. Some of the best of any patient my doctor had seen. Then in the June 2018, a month later, I went back to him. I complained about some discomfort in my abdomen and an odd lump. I was blindsided. The diagnosis: stage III Non-Hodgkin's Lymphoma. Left untreated it's fatal in 6-12 months. I had just turned 40.

This book started as a small blog to keep family, friends and colleagues updated. From there it grew as interest increased extending beyond my immediate circle to others that were going through various hardships. My aim with this book is to share my personal experience battling cancer. I hope to share not only the (gritty) details of what it looks like to go through this kind of ordeal, but also the mindset that helped me cope with it, ups and downs.

In going through the posts and writing this book something occurred to me. One of the dominant themes in our society is that we have control over outcomes. As a Product Manager that's one of the things I'm accountable for, the buck stops somewhere: spread the credit, shoulder the blame has been something of a mantra for years. I understand the basics of probability and statistics, that there are certain things not in my control. And that good decisions do not necessarily lead to desired outcomes.

We're told that if we eat the right foods, follow the right diet, workout 20 minutes per day 4 days per week, stop smoking and etc., that we are destined to live a long and healthy life. Well, I don't know for certain but I can say that in my circle of 30-50 year old healthy, successful professionals living in San Francisco with every material privilege, that I was most definitely among the healthiest, top 10% to put a number on it. This isn't talent by the way. I had crippling asthma as a kid that I had to overcome through lots of effort. That instilled in me an attitude that with right effort come positive outcomes. I believed in the idea of personal control.

I've run several marathons including the Boston Marathon 3 times. I won my age group for at least one half marathon. I workout 4-5 days a week. I meditate daily. I eat a mostly pescatarian diet (bit of meat here and there), minimal dairy and sugar. Lots of fiber. etc. etc. I also have an incredible family with a wife and 3 beautiful kids. I have an incredible social & professional network working as a Product Manager in Silicon Valley. I bring this up because I've tried to live intentionally and in a mostly balanced way, mostly avoiding extremes.

But in going through this experience I've shifted this thinking. No, we only control a small piece of the outcomes. But we control much in terms of how we respond to changes, good or bad. We live in a lottery system. This runs counter to our cultural narrative and collective psyche of control. I bought that story my whole life. Our genes control more than we want to give them credit for. We only control a small , part of the outcomes in our lives. Luck needs to be weighted more heavily than most people give it credit for.

This account is my attempt to come to terms with this reality. This is meant to be an empowering message though maybe it doesn't seem that way at first blush. As a 40 year old diagnosed with aggressive Non-Hodgkin's lymphoma, I'm part of a 'lucky' group – the median age is somewhere between 65 and 70 years of age.

What we do control our response to adverse events. Indeed I think think this shift in mindset is useful. Life is suffering and bad things happen to good people. As far as ideas go it's probably one of the least controversial ones regardless one's leanings.

One of the benefits to dealing with hard things like cancer is the opportunity to share that experience, to help support others that might also be going through something hard. That doesn't need to be cancer. Life is full of challenges across every conceivable dimension. We're all dealing with hard things. Some of them are on display for others to see. But I believe the majority of personal hardship remains hidden from view, somewhere below the surface. Sometimes we don't even know it's there. I think in our age of always on media and distraction it's increasingly easy to ignore these kinds of issues and just keep on scrolling through the latest newsfeed or watch another show. I went off social media and really took a step back to focus on being as present as possible with this treatment, to feel it more.

We're in 2019 and the technology of medicine is evolving rapidly. This industry needs to change. With it I see a new generation and mindset regarding medical advice and treatments. Gone are the days where people blindly listen to doctors. We are rapidly transitioning into a world of increasing complexity such that, let's be honest, doctors don't understand the full picture either. The practice of medicine should be a collaboration. The way I've approached this is in thinking that I'm the CEO of my body (I decide) and doctor's are paid consultants. That seems like a healthier approach than being a passive consumer. There's a shift such that Medicine: it's less about dispensing drugs (that's part of it) and is increasingly about information. Medicine is deciding what the right thing to do is under uncertain conditions. How do you decide? As a patient, who do you trust? As a physician inundated with exponentially increasing information to consume how do you know you are right?

My hope in writing this book is that it might provide a perspective, and maybe some concrete tactics to help you find a wellspring of strength to face your issues, whatever they are, head-on.

I

Diagnosed

I get diagnosed with stage III non-hodgkin's lymphoma

1.

I've got a 10cm mass in my small intestine. The diagnosis is non-hodgkins lymphoma but I'm not sure what stage it's in. This week will consist of another battery of tests to pinpoint the diagnosis: ct scan, pet scan, bone marrow biopsy (which I hear is awful). From there we'll start discussing the treatment specifics. So far from my initial call with the oncologist I'm facing 6 months of chemotherapy, possibly with radiation.

This is all quite an interesting mental exercise. It helps that I've tried at least to ponder these scenarios being a fan of war films, stoicism and generally living a disciplined lifestyle. But this is way different because it's real. There's a weight involved here that is really hard to simulate in one's mind without the pinch of reality.

I've always found solace in reading and thinking about hardship (Shackleton's expedition, Lincoln's presidency, anything related to world war II and the holocaust, etc.). This is because these kinds of stories recalibrate my reality and I become thankful for all that I have…*at least I have food! I could be stuck in some Siberian Gulag!*. For the past few weeks I've been recalibrating my reality on a daily basis.

And I find myself coming back to a single question: *what is precious?*

I could here cite thousands of mini vignettes and observations (Lua's 4 top teeth + that wild twinkle in her eye grinning at me at 3:30am "*datita*!").

This diagnosis so far is a gift. It seems like everyone says that. But I really believe this in my core. Feels like a wind of clarity blowing through my soul. The image in my head is one of fall trees in New England. There's so much crap in those tall trees deep into Autumn: birds nests, sticks, branches, rotting leaves. With the approach of winter shocks of wind clear that out in a hurry, leaving beautifully stark silhouettes of trees against the clean backdrop of winter. Only the essential bones remain, ready to live again when the conditions improve.

From behind these eyes the unfolding of nature and universe is processed, understood. Consciousness is nature reflecting on herself. A noble way forward is to be clear in these reflections, decent in our dealings, giving in our nature.

If nothing else the idea of cancer clears the cruff of day-to-day normal. I feel like a dusty window is getting cleaned.

2.

I try to read when I have free time but lately I've kicked the fluffy stuff to the curb. Shits real! The other day I re-read one of the most powerful books I know, Man's search for meaning. If you haven't read it I highly encourage you get a copy (heck I'll buy it for you – shoot me a note!). I've read this book probably 10 times and skimmed it many more. I like highlighting and annotating whatever I read. That way I can go back and skim when I have a few minutes (or months:), sorry – cancer humor. I find it comforting to understand the experiences and mindset of folks that have had it SO MUCH HARDER than I do, to understand what ingredients helped them pull through. The basic idea behind the book is that camp prisoners could roughly be broken into two groups: those that could find a larger purpose/ meaning to the experience vs. those that languished in the suffering. The former tended to thrive if they made it out whereas the latter did not. There's a common thread here with the writings of Elie Wiesel (another holocaust survivor) who found his purpose in the experience as bearing witness to evil so it never happens again,

> Never shall I forget that night, the first night in camp, which has turned my life into one long night, seven times cursed and seven times sealed….Never shall I forget those moments which murdered my God and my soul and turned my dreams to dust. Never shall I forget these things, even if I am condemned to live as long as God Himself. Never.
>
> -Elie Wiesel

This idea of finding purpose has special resonance for me today. Over the past week I've undergone a battery of tests, the final one is today to understand what stage this cancer is in. From there we come up with a treatment plan. I'm grateful for the people that have come before and contributed to our collective understanding, scientific and emotional. Consider these men that lost quite literally everything, including their humanity, emerging as saplings from the ashes to then impact millions with their attitude and learnings. I'm inspired and overwhelmed with gratitude.

Quick note on the title. Last night I read the classic Dr. Seuss book, Oh the places you'll go to the kids. My favorite part is called the waiting place,

You can get so confused
that you'll start in to race
down long wiggled roads at a break-necking pace
and grind on for miles cross weirdish wild space,
headed, I fear, toward a most useless place.
The Waiting Place…
…for people just waiting.
Waiting for a train to go
or a bus to come, or a plane to go
or the mail to come, or the rain to go
or the phone to ring, or the snow to snow
or the waiting around for a Yes or No
or waiting for their hair to grow.
Everyone is just waiting.
Waiting for the fish to bite

or waiting for the wind to fly a kite
or waiting around for Friday night
or waiting, perhaps, for their Uncle Jake
or a pot to boil, or a Better Break
or a string of pearls, or a pair of pants
or a wig with curls, or Another Chance.
Everyone is just waiting.
NO!
That’s not for you!

the waiting place!

3.

I'm finally done with my diagnostic tests. This week consisted of a CT scan, a PET scan and a bone marrow biopsy. Oh and a visit to the sperm bank because these chemo treatments basically ruin your swimmers (I'll save that for a separate post). The doctor was great, numbing the area with lidocaine and having faith enough in me to skip any anxiolytic. That was fine with me but I think a mistake for him. I spent the next 5-10 minutes channeling the pain into primal screaming. You've got to envision the scene – I'm in a room outside the chemotherapy infusion area (it's quiet) and yelling like like a leg was getting amputated without anesthetic. When it was over…

Me: *Fuck, that *really* hurt.*

Dr. L.: Pats me on the back, chuckling. *You did great… Though I guess you* ***were*** *more anxious than I realized.*

Me: *Well alright then. I'd like to at least see what my marrow looks like after all that. Can I?*

Dr. L.: *Sure – take a picture. Looks good so far. we'll have results in about a week.*

In case you want to see what my bone marrow looks like here you go!

waiting for my bone marrow biopsy

A core of my bone marrow

Lua offers me saltine crackers

4.

Have you ever wondered if you've exhausted the set of emotional states available to you?I never really have until now, assuming I've known them all. Hardly. In processing all this information it's clear that I'm charting new emotional territory. Or maybe something is different. This now resonates:

> *We shall not cease from exploration, and the end of all our exploring will be to arrive where we started and know the place for the first time.* – T.S. Eliot

In parallel some of my previous anxieties seem to have fallen away – day to day stuff. Or at least they've been replaced by a single, larger, more immediate & looming concern. It crowds out the others as the noon sun crowds out the other constellations. It's been a weird place to be.

In practice it seems that facing one's mortality occurs as a bi-phasic process: the first is coming to the realization that one will eventually die; the second is actually processing that knowledge when shit gets real. This was definitely the case for me. In retrospect a much better approach, the one I'm currently working on, is

a single-process in which one visualizes death in great detail. Spending time actually feeling the emotions one will encounter; thinking the thoughts one will encounter.

There are two death scenes I recall, both from circa second grade.

The first one I remember threw me for at least a week and made me sick that day. I went to the back of the room and grabbed a book off the shelf. I still remember the title, my brother sam is dead, (I just checked it to ensure I wasn't mis-remembering). As was my habit back then I started at the end. The final pages described an execution scene in which a potato sack was placed over the head of the man about to be killed. It described his thoughts. It was horrifying. Why? Because the cruelty of man was made manifest in a way that I hadn't directly experienced in my somewhat sheltered life. Also, my country was built on this foundation – this was about the civil war after all, something I didn't quite grasp at that age except that it happened early in the founding of the place I lived.

The second scene I don't recall except it was a read-aloud in class. The whole story took probably 30 minutes. In the end it became known that this whole long scene occurred in the space of a few seconds in which a man fell to his death. This story we just read described a magic. That magic was the slowing of time as a person approaches death. So I figured this compression of mental time was available to everyone only if they are about to die. So I was fascinated with this idea. Indeed I realized that I've been holding onto that notion until recently as it was unexamined – just kind of sitting on the neural shelf somewhere. Can we experience this business without dying? After all if that's true we only get to use this once!

I've always thought that great art is not wholly dissimilar from math/science: the latter while the former is an emotional proof of sorts. The evidence is written on the faces and emotions of the viewer (we can argue numbers; is great art that which elicits the greatest emotions in the greatest numbers or is it the depth of emotional resonance in merely a few keenly attuned, sensitive humans? I'll leave that one to someone else).

about the civil war.

And as with any sporting event there

is no real limit to how granular the vision can get. Ideally visualizing one's mortality should be a true simulation versus some abstract conception. This is not easy.

Of course the obvious alternative to this, and one favored by many, is simply to not bother. After all that's time and energy that could go into living. Also, some might argue this whole conversation is a major downer. But I'd argue the opposite; as with most planning exercises the majority of the value lies in the actual process of planning, and less with the actual output. In this case the value is that by visualizing death in great detail would be the key to living more fully. That's been my experience anyway. The mindset that tends to produce the worst outcomes (for me) is the simple avoidance of the topic – that's when I tend to watch (metaphorical) cat videos.

But that would be to miss the key point that life is an energetic process and energy is NOT infinite. Whatever those limits are (let's just say, at a cellular level) that there is merit in the practice of visualizing. One might ask: <i>What merit specifically – would that make the difference between dying well or not dying well? Who cares – you're dead!</i> But as with most planning exercises a good part, if not most of the value lies in the actual process of doing it, less with the actual output. In this case the value is that by visualizing death in great detail would enable living more fully. That's not an idea to take lightly.

So it would seem that if one is taking this stuff seriously then a simulation that gets onesself as close to the actual process is important. How else can you know if phase I is working, or you're just deluding yourself? As <person> said <quote>the only way to know a person's true character is to theow them into hardship</quote>. If I can claim any sort of expertise in this area it's directly a result of my own personal phase I being frankly out of sync with the reality. Because of my current circumstance I've had to basically deal with this

5.

It’s kind of bizarre to ponder one’s mortality while looking at a sink full of dirty dishes and sippy cups. The contemplation of death (if you want to get fancy about it, memento mori) always seemed more tastefully done on some epic landscape than in the home. But I guess the idea of epic is what we make it. The power is in us to suffuse our surroundings with the nobility that is our human existence. We create reality, if we want to. Perhaps the hardest thing is to parry the deceptive mirage of the mundane with the noble truth of our mortality.

6.

> …there is nothing either good or bad but thinking makes it so…
> – Hamlet

Improving one's quality of life requires expanding the space between stimulus and response (I picked that up at a buddhist lecture years ago and it stuck). For me the tool for doing this is reflection of some sort. This can take the form of sitting meditation, which I love, but more typically occurs while walking, running, swimming in the freezing pacific ocean!

Lately though this most occurs between sets of heavy weight lifting. I used to think of strength training in terms of the lift itself. But I've recently come to appreciate the space between sets as my favorite part. You get mentally pumped – an excellent way to prime.

This space between is where life's inputs get *synthesized and non-obvious connections made*. It's where I can decide how to act in an authentic way to life. I think that's because that decision would have passed through the imagination – probably because I do a lot of daydreaming/visualizing between sets (I'm the guy with the spaced out look staring off in the distance, if you see me say hi). It's where I tend to make hard decisions.

And for me this space is where free will lives (never mind for now if G-d plays dice!). Regardless the circumstance we find ourselves in there always exists the possibility to decide how we will respond. How that response is shaped and executed offers a strong indicator on the quality of one's life. Enough rambling for now…

7.

So many emotions flowing through me as I prepare mentally for chemo treatment, which starts 8:45 am tomorrow…

First off, I consider all the things I won't be doing much of for the next 6 months: no shipping products, no long runs, probably not much energy to handle the little ones, likely not a lot of focus for deep study (but I'll try), no awesome meals because my taste buds are shot, not much socializing because I'm immunocompromised, etc.

But I choose to focus on what I will be doing. For now my singular focus is on healing. I've mentioned before that getting cancer is like a great wind of clarity. As the distractions, myriad possibilities, dreams and fantasies blow away in the urgency of battle and I ask, *what's left*? What is that purpose that sets me on fire and will provide meaning for the remainder of my days beyond this bump in the road? Will it change from my current vista?

Battling cancer is a form of training. But this is not a competition with others, rather it's the purest form of gaining mastery over myself, body and mind. In that regard it does resemble long-distance running.

So what's great about this? I get to connect with people on a different level with a new awareness. I get to really – *REALLY* – face my demons, my mortality in a way I likely wouldn't have for decades. You might say facing it later would be better. NO! In ignorance we (ok at least I) sleepwalk through this precious life. I'd submit the ultimate clarity of our purpose on this great sphere comes in our facing death. So what's great about this is I get to face my fears now, head-on. And I will move past them. I'm hopeful that will make me more grateful, and less fearful human moving forward. I've always found there to be an incredible power in humans that find this clarify. Perhaps I'll join their ranks.

II

Chemotherapy in 6 parts

I go through 6 rounds of R-CHOP chemotherapy

8.

I've been thinking a lot lately about possession. What does it mean to own a thing? What can be owned and what cannot? It seems that the conventional ideas about ownership (e.g., my car, my house, my land) are just fine so long as we don't really believe them, seeing them them as legal/social constructs they are.

Ask: do *I own my kids? Do I own my body? My mind, identity, feelings, thoughts…*? An interesting exercise to try is sit for 30 seconds and try to not take each of the above personally: don't take thoughts personally, don't take ideas personally, don't take body/pains personally. Can you do it?

I have no interest here in some esoteric contemplation of non-dualism but to say that in contemplating mortality this topic becomes relevant. Most of us identify with our bodies and our experiences – which I've seen firsthand can lead to all sorts of issues and complexes. The fundamental issue it seems to me is one of attachment in a fleeting universe. *To what do attach – what exactly are we anchoring to? What is healthy attachment?*

Thought experiment: What would it be like to relate without bodies? And I don't mean on slack:). I mean what is the really essential part of you that relates? Is it actually your body, your ideas? So I've been interacting with my kids on a different level lately and in the moment asking myself what it might be like to relate to them on some separate, disembodied plane of existence. It leads to some interesting outputs:

> *Would age matter? If not does sequencing become irrelevant (i.e., who came first). And if true we would then be entities floating around without a parent-child relationship… so then do we become equals? What would it be like to erase roles with one's child. Of course this would go all the way back to one's parents, grandparents etc. After all, it seems there's not much that gives one the power in the relationship beyond that. So then we are humanity and the differences stem from embodiment. I'm left only with respect for the process of life of which we're a part, including of course, and the idea of sequencing which cannot be eliminated (else chemistry/physics stop working – things only go in one direction).*

The approach I try to take is that my body and possessions are on loan. That my kids are on loan. That actually helps me bypass feelings of over attachment (everything goes in the end, might as well get to terms with it). I've come to the conclusion that ownership is a word I'd like to use sparingly. Instead I'll default to stewardship, to me it seems more truthful. Why does it practically matter? All of our molecules get recycled, dust to dust and all that. As Carl Sagan rightly noted, *we are made of stardust.* Thus

Let's get out of the clouds and apply this to real life. I'll try this on for my current situation:

- Case 1:
    - **framing** -> *I am/I own this body and I get cancer. I must save it or else I die and everyone around me suffers.*
    - **motivation** -> scarcity; pushed by fear. Action born of fear to save the body because I'm attached to the body as it's my identity.
    - **commentary** -> You see, my identity is inseparable from the body. Hence the

cancer is me. To me that provokes fear and negativity that I find non-helpful and actually it doesn't resonate with truth. Moreover I'm attached to my family, friends, etc. so there's a downward spiral of fear and increasing stakes that can easily (for me anyway) lead to paralysis, which is clearly unhelpful.

- Case 2:
    - **framing** -> *this body is on loan (stewardship!) and it gets cancer. I must save it or I'm deprived of the opportunity to care for this amazing machine and all the good it can do.*
    - **motivation** -> abundance; pull toward opportunity. Positive action born of the opportunity to heal this body, do good in the world, for my family and serve the future. Purpose
    - **commentary** -> Note that 'I' am disembodied. I act as the transcendent carer of things. Way more helpful attitude.

VERY IMPORTANT: note that to fight like fucking hell happens in either situation, no difference there. The key distinction is the motivation, the energy source, the fuel. While this setup works for my particular disposition, setting the conditions for great outcomes is a personal matter. I've always liked the image of a musician tuning a guitar – music comes from strings pulled to the right tension; too tight or too loose results in noise. I've never done great work when my motivational strings have been pulled too tightly in the direction of fear. Rather I've always preferred a fire under my butt (e.g., stakes) but disproportionately biased toward play, freedom and pleasure in the fight (10% fear, 90% play if I had to guess). So it could be this is all just a mental psych. Then so be it!

I'll echo a sentiment from a great local dharma teacher, Eugene Cash.

Does this cancer bother me?

On one level yes, I do not like it. But on another level it really has nothing to do with *me*.

9.

Holding on

We clutch our ideas, notions and feelings like my 1 year old daughter grasping her toys and walking around the house. It's cute sometimes but you have to eventually cleanup the mess. The difference lately is I'm aware of just how much I carry around in my head. Lately though I've been able to bring an awareness toward addressing this. The feeling is one of lightening. I put down these notions – baggage – and breathe in what is, right here and right now. I'm confident that should I need one of these ideas I can pick it up and then interact with it from there. No need to carry it because I know it's there if I need it. An odd and liberating feeling.

Stressful roots

Tracing stress back to grade school it really began when I went to middle school. I was in a Jewish day school until 7th grade. From there the transition to elite (no, elitist) prep school was jarring as I was thrown into a highly competitive situation that I didn't fit into at all. The kids were overall cliquish and mean spirited, faculty blind to bullying, sports were the dominant mode of popularity, and the pecking order, while technically invisible as it's a social construct, was evident in the clusters of bodies aggregated in various areas of the lounge area. It really was lord of the flies. Same as most middle schools.

There was really no emotional support system since my family was being literally ripped apart at the same time. As the oldest kid I tried to hold things together (unsuccessfully). All that is to say that stress has been a fixture in my life for a long time. So I've tried to make friends with it. My way of coping was to go towards instead of away. In retrospect there was much good in this decision. But it was a really hard road.

Mindfulness during stress

It really feels trite to be writing this. Everyone talks about mindfulness these days. It's taken on the same dismissal tone (to me) as talking about calories, budgets or well-meaning family telling you to put on a jacket if you go outside. But this one I've been taking seriously because it's so close to my current day-to-day existence.

The other night I went to a Sunday night meditation with my brother Eli. If I feel up to it (and not in my super low immunity phase) I've been trying to go. It's held at a Unitarian church near the tenderloin in SF. It's not the nicest area but I do find it to be a comfortable spot despite the hideous concrete architecture (sometimes called "brutalist" for obvious reasons, which is both hilarious and kind of spot-on). Last Sunday it was led by a German monk and we did something different than the usual 45 minute sit. Instead we paired up and did some exercises meant to bring us into the moment. These are simple (but not easy) exercises: active listening, and 3-5 minute intervals of 'mindful' speaking – punctuated by long pauses/silence as we think about what we want to say instead of doing it habitually. We are so attuned to filling the silence with words that this is hard. It's interesting to practice 'applied' meditation in that it more easily transfers to daily living. I don't know of a more helpful kind of practice than being fully present. It's kind of like doing wind sprints uphill – the flats are so much easier in comparison.

For example one exercise had us pair off and sit facing one another, just making eye contact for several minutes. Just! If you can think of a more uncomfortable mental practice I'd love to know. All kinds of stuff tends to come up when you're staring into a stranger's eyes from a distance of 2-3 feet, for minutes without looking away. Try and do that while at the same time remain centered, present and mindful. Talk about a spinning mind: it's like a ping pong ball of what I'm thinking about you, to what you might be thinking about me, back and forth and back and forth.

Being at ease when doing this is an awesome mindfulness exercise because it's real – it's not artificially sitting with eyes closed pretending to be centered; you're forced to be active and present. Generally speaking I'm drawn to applied practices that have connection to the real-world. After all, what we call 'reality' has stood the test of time so it's the appropriate starting point.

Anyway I paired up with Eugene, the founder and leader of the Sunday group (an inspiringly humble, insightful and wickedly funny mindfulness teacher). At one point we were asked to take turns speaking for 5 minutes on the topic of generosity (speaker 1 is the one with more hair, so that was easy). Specifically we were asked to talk about how we've recently shown generosity in our lives. I wasn't sure how much to go into detail on my situation – didn't want to feel like I was dumping. But I quickly decided if ever there was an appropriate context this is probably it. So, while holding direct eye contact and pausing to consider each phrase:

I felt like it was important to first set some context. *I'm in the middle of chemotherapy… I was diagnosed a few months ago with cancer… I have 3 kids under 6 that I try to spend more time with… I'm taking a break from everything to focus on healing and removing any extraneous stressors from my life so I can be with them as I go through this… I'm optimistic for a positive outcome but I don't know how much time I have, none of us do really but it's more visceral when going through something like this.* **Then, turning to the actual topic I continued**. *As much as I want to believe that I am a giving person, lately I've been on the receiving side of that equation and it's totally out of balance. Any generosity I've shown lately is completely overwhelmed by that of my community/social circle…It's completely disproportional to anything I might do…I have food on my doorstep most nights/daily calls/emails/blog comments/texts/visits – I'm overwhelmed with kindness…being the recipient of so much generosity from others is hard for me and I have no idea how I could ever be able to pay it back…I'm coming to understand the idea sometimes called grace, which is just letting it be and appreciating things as they are…that said I feel both a shift in my values toward contribution as the highest good…figuring out how I might pay it back to those in my community, family, social circle, colleagues, humanity is a constant topic of thought…then again that in the end all of it – everything – is upside…we are here because of the gift of life…we are owed nothing… all of life is generosity…* ***BELL!***

I notice a shift in my values toward contribution as the highest good

I now believe that that defining what meaningful contribution looks like is one of the most important questions in my life. He was gracious in telling me I was doing the right thing and expressed admiration for my approach, which was really touching coming from him. And he offered to help in any way he could – again this never loses it's power – simple gestures of helping. I get the same feeling as I did in sports at the end of a game when the teams shake hands. I always felt that shaking hands embodied all that was good about humanity – I know it sounds crazy but I looked forward to that all during high school sports. I actually cried a few times thinking about it. Which is crazy because I spent a lot of time in the penalty box playing lacrosse, was awarded most versatile player on a high school championship team for playing most 'downs' in football (offense, defense, special teams etc.). But the juxtaposition of moving from enemy and combatant to someone you could shake hands with, in the space of a moment, at the blow of a whistle was astonishing. Popping up a level still is our ability as a species to devise games – levels of experiential abstraction – to which we abide. But then those rules can shift as we exit one space in favor of another. So that transition always fascinated me. Our psyches are so malleable as to exist in different contexts in the space of a moment. In this lens it seems not so hard to comprehend the quick shift in extreme social situations, even from say a peaceful Germany (center of learning) to Nazi Germany (center of planned death). Games are perhaps

Links between cancer and stress

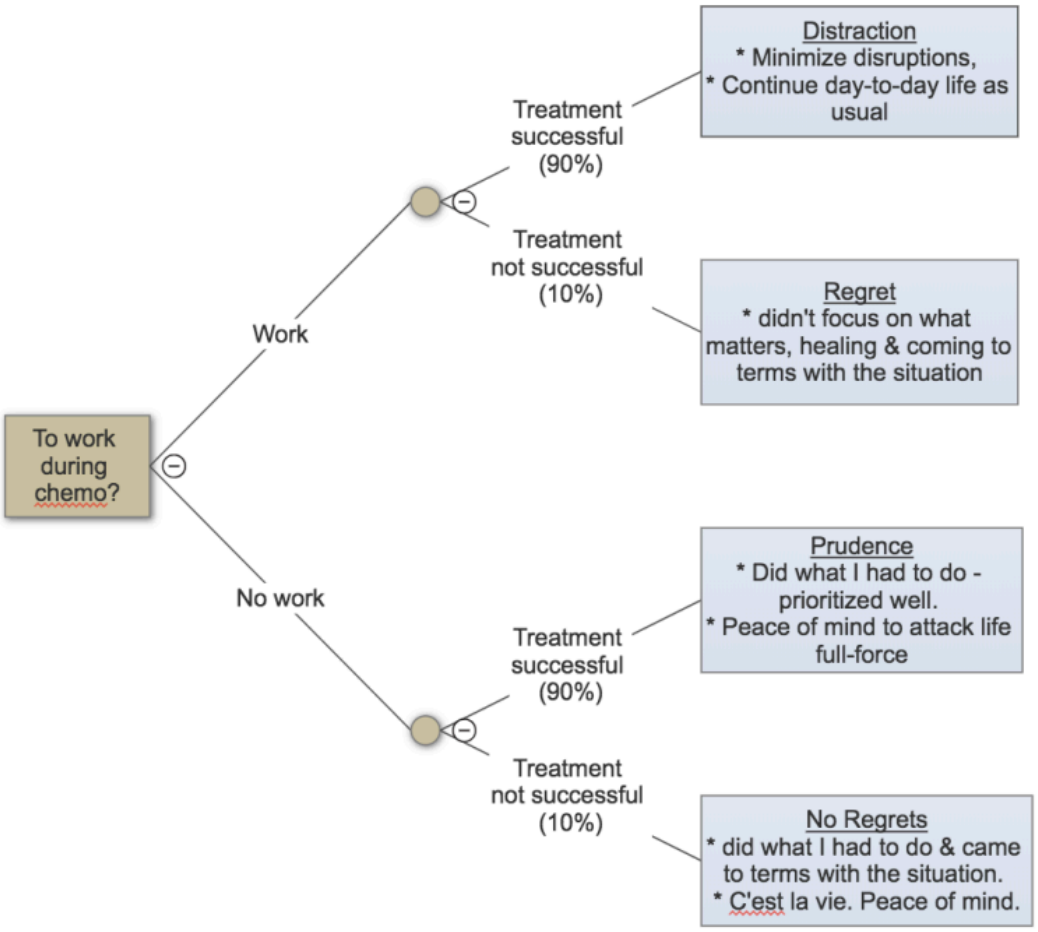
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3341916/

> stress can decrease the activity of cytotoxic T lymphocytes and natural killer cells and lead to growth of malignant cells, genetic instability, and tumor expansion (Reiche et al., 2004[88])

My view is that stress and anxiety are to be avoided while healing from something of this magnitude. Especially since I'm neutropenic I need to avoid opportunistic infections. Those kinds of infections rely on compromised immunity. Immune function is related to stress.

One question I resolved early on in this whole ordeal has been whether I ought to work during this chemotherapy. There have certainly been days when I felt up to it. But predicting this has been elusive – several times I've felt like I was in the clear several times only to get knocked back. I often find it helpful to structure the pieces in some type of framework to wrap my head around it. For example when I was deciding if I should work I used a decision tree – optimizing on regret minimization (typically you'd add expected probabilities and payoffs to optimize some output, say revenue). It's really just an emotionally-based decision tree. While simple I think it captures the essence of the first order decisions required. Note that the treatment success numbers are crude estimates (and in-fact they don't really change the outcome, I could just as easily have used 1% as 10%). Also even if the treatment isn't successful there's alternative therapies – that admittedly I don't understand yet, and I'm not going to try unless I have to. Anyway it's clear that one branch leads to peace of mind whereas the other has potential for regret, hence my decision to not work. Again this was all emotional and didn't even take into account my actual ability . Living with regret is bad.

Essentially the way I see it is I want an airtight psychology so ensure I'm treating body as cleanly as possible. I don't want worry, stress, anxiety to interact with the physical healing process.



decision tree: to work during chemo?

10.

The other night I went to Sunday night meditation with my brother Eli who is visiting to help out. If I feel up to it (and not in my super low immunity phase) I've been trying to go. It's held at a Unitarian church near the tenderloin in SF. It's not the nicest area but I do find it to be a comfortable spot despite the smooth concrete architecture (which I happen to like) and background thoughts that my car might get broken into. Regardless, this Sunday it was led by a German monk and we did something different than the usual sit. We actually paired up and did some exercises meant to bring us into the moment. These are simple (but not easy) exercises: paired listening, long pauses/silence and 3-5 minute intervals of 'mindful' speaking on various topics. It's interesting to practice 'applied' meditation in that it more easily transfers to daily living.

For example one exercise had us pair off and sit opposite one another, just making eye contact. All kinds of stuff tends to come up when you're staring into someone else's eyes for minutes without a break. Try and do that while at the same time remain centered, present and mindful. It's hard at the start and it gets to feel normal quite quickly. Being at ease when doing this is an awesome mindfulness exercise because it's real – it's not artificially sitting with eyes closed pretending to be centered. You really need to work at it when someone is staring in your eyes.

I paired up with Eugene, the founder and leader of the Sunday group (a tremendous mindfulness teacher by the way). At one point we were asked to take turns speaking for 5 minutes on the topic of generosity. Specifically we were asked to talk about how we've shown generosity in our lives. In the allotted time between bells, when it was my turn to speak I told him:

I was recently diagnosed with cancer; that I have 3 kids under 6 that I try to spend more time with and teach what I might; to focus on them right now while I go through this experience; that I don't know how much time I have despite that I'm hopeful for a positive outcome; but nobody knows how much time they have; this experience is a gift in helping me face mortality so I might live more fully for my days ahead…and that my recent experience with generosity was actually being on the receiving end of it; that any generosity I've shown lately has been utterly overwhelmed by the disproportionality of how much I've been receiving: food on my doorstep most nights / daily calls / emails / blog comments / texts / visits… that getting comfortable with being the recipient of so much generosity from others is hard for me (still); that I have no idea how I could ever be able to pay it back; that figuring out how I might pay it back to those in my community, family, social circle, colleagues, humanity at large is a constant topic of thought; I started gushing about how grateful I am for my situation; how much worse it could have been/it could be; that in the end all of it – everything – is upside; we are owed nothing; all of life is generosity, a gift; AND that I notice a shift in my values toward contribution as the highest good.

I now believe that that defining what meaningful contribution looks like is one of the most important questions in my life.

11.

I was able to get a biopsy scheduled for this wed, the day after Christmas. It's a balance between getting the surgical 'b-team' vs. expediency of getting results fast. I'm assuming this is a routine enough procedure that it shouldn't matter (this might be a foolish idea and I should perhaps wait for the best). Those results will gate a second opinion and everything that comes after so I'm biasing towards speed. I'll meet with the surgeon this morning to discuss details (way to spend x-mas eve, right?). If my spidey-sense starts tingling about some level of incompetence I may delay it or try for another surgeon.

The family is flying to Boston tonight but I'll plan to stay behind until I get this procedure done. Then hopefully I'll feel well enough to join them there. Lua turns 2 years old on 12/29 so I can't miss that! Either they'll fly back here or I'll go there.

In this holiday season where everyone is celebrating I find myself both wanting to join in and be festive, and at the same time I feel quite apart, separated from it all. While I don't feel like celebrating based on the context/seasonality, I do feel a form or meta-revelry. I'm adjusting to different expectations and immersing more fully in the moment. If past, present, future each carried a certain mental weight to them (say measured in terms of time spent in those places, supposing you could) the present is taking on much more weight than it has previously. I'm spending more time there which is quite great. They say anxiety/depression are to some extent related to spending too much time in the non-present and I think there's something to that. I tend to bias towards future more than past. But I'm spending less time there unless I decide to. This is an interesting lever to try and adjust explicitly. Typically our subconscious holds the reigns but I don't think that's the case by definition. I suspect it's more by default and habit.

12.

Attitude clearly matters in fighting cancer. We don’t know why (from my old-style materialistic perspective, I suspect that mental states feed back upon the immune system). But match people with the same cancer for age, class, health, socioeconomic status, and, in general, those with positive attitudes, with a strong will and purpose for living, with commitment to struggle, with an active response to aiding their own treatment and not just a passive acceptance of anything doctors say, tend to live longer. A few months later I asked Sir Peter Medawar, my personal scientific guru and a Nobelist in immunology, what the best prescription for success against cancer might be. “A sanguine personality,” he replied. Fortunately (since one can’t reconstruct oneself at short notice and for a definite purpose), I am, if anything, even-tempered and confident in just this manner.
-Stephen Jay Gould (From The Median isn’t the message)

13.

The past few posts have been hard. I'm trying to keep a level head on an emotional situation. I'm sure they've been harder to read. When things get hard and I'm short on time I tend toward getting to the point in an unvarnished fashion – so apologies for the firehose but you're getting it straight up. That's where I've been living the past week.

I've run the Boston marathon 3 times. I was thinking about this yesterday as I've been getting stronger in anticipation of my next battle. Anyway my training has never been ideal for lack of time (NO lack of commitment!). For each one I offset this lack of training with mentally hard runs (unscientifically, foolishly). Weeks before the race I often would run to the top of twin peaks in SF just outside my house, at night in the cold fog with a headlamp. I avoided doing it for a long time because it was hard and not very appealing. Then I decided to make friends with it. It was pretty dumb and no substitute for preparedness. But I will say the mental hardship is something I can certainly carry forward into this situation. Really it's not about physical though that seems to be what dominates the conversation. Anyway I just did that run for the first time yesterday since completing chemo. I'm gearing up for an even harder battle, the drugs are getting more powerful. Today I went to the gym to test my strength and see where I'm at with my one-rep max to bodyweight ratio (my normalized standard of personal strength). I pulled off a 1.8 (meaning I can deadlift 1.8 times my bodyweight). That's pretty good for me and where it was pre-chemo so I'm feeling physically strong now.

I had a long and interesting conversation with my sister Ilana yesterday. We were comparing notes on some hard times our family suffered when we were kids. She fell off the world for several years and only somewhat recently have we reconnected. It's really deep. I was the oldest, 12 when my parents started arguing (a lot) and 13 when they finally divorced. During that dark period we all responded in our own ways to the challenge. My sister observed that I was always focused and kind of above it all, that I withdrew into a world of introspection. I recall also responding by turning all that energy I saw as wasteful splashing at the water's surface (arguments, yelling, acting out) into something useful. In contemplating this tough time in my life I realize that I've had a mentality that may not be all that healthy. I've been contemplating this little guy below (that's me at, maybe 7 years old) at the time his world ripped apart at 13 with the collapse of his family.

That time is kind of a blur but pieces stand out. In response to those feelings I started writing and I've really been doing it more days than not ever since. Always for myself and with the purpose of processing things objectively. I'd go into our basement, sit on the floor and just pour out my thoughts and emotions into a journal. Like for hours. The first journal was memorable. It was a creamy white, velvety spiral-bound drawing book. Nothing special, just musings of a 13 year old boy. Perhaps not a lot has changed – here I am doing the same thing in response to challenge! At one point I had several full boxes of these journals (high idea-phoria will do that!) and years later I dispatched them all to the junkyard. I stand by that decision, interesting as they would be to retrieve. Life is ephemeral and don't forget it!

What I can say is that something in that kid decided to turn within instead of railing against the world. That's been his attitude since then: I can turn that energy into myself and improve, learn, do something that might make things better. I was talking with some friends the other day about focus. I'm not sure if that's something I was born with but regardless my response to chaos has always been focus and in that regard it's been a coping mechanism to hardship. And to be frank I like that. I like being focused and aggressive as that puts me in my element. I wonder if I sometimes engineer situations to elicit that feeling. That's probably why comfort is so bothersome to me; because I let my guard down and lose focus which brings me into a non-ideal mental state. Perhaps, if I were to speculate, there's something stuck inside him that is screwing with the immune system as my sister suggested. Now we're on the edges but immunology is complicated and anyone pretending to understand the relationship between one's mentality and immunity is probably lying, except to say that positive beats negative. My friend Geoff reminded me of Stephen Jay Gould's excellent essay, the median isn't the message on just this topic the other day, here's an excerpt:

> *Attitude clearly matters in fighting cancer. We don't know why (from my old-style materialistic perspective, I suspect that mental states feed back upon the immune system). But match people with the same cancer for age, class, health, socioeconomic status, and, in general, those with positive attitudes, with a strong will and purpose for living, with commitment to struggle, with an active response to aiding their own treatment and not just a passive acceptance of anything doctors say, tend to live longer. A few months later I asked Sir Peter Medawar, my personal scientific guru and a Nobelist in immunology, what the best prescription for success against cancer might be. "A sanguine personality," he replied. Fortunately (since one can't reconstruct oneself at short notice and for a definite purpose), I am, if anything, even-tempered and confident in just this manner.*

me as a boy

14.

I kickoff my first chemo session in an hour. Feeling very calm overall. The one thing that's surfacing for me above all others is a conversation with my son Lev last night. Actually it wasn't so much a conversation as him telling me his thoughts.

Daddy, when I grow up I want to be a surgeon. Because the world needs more surgeons. And surgery is important….yeah. And I also want to be a baseball player. And a construction worker….

Fuck yea Lev! Why didn't I do all those things?! Basically it was fear, apprehension. Self-doubt, thumb sucking (to borrow Warren Buffett's terminology). Oy! Whatever it is we commit to we have a choice. We can tip-toe or we can tap-dance through this world toward our goals and dreams. No tip-toeing moments will be missed. And I hope to have fewer of them moving forward. Today certainly is not a day for apprehension. The path forward is clear. Let's do this!!

15.

Have you wondered what chemotherapy is like? I had never seen it first hand, just in a few episodes of Breaking Bad. Here's a recap of my experience.

9:05am. The nurse places a heating pad on my forearm to get the vein ready. She hands me 4 pills for nausea and I forget what else and takes my vitals. I'm then walked through what'll happen in terms of the day and details.

The chemotherapy protocol I'm on is called R-CHOP. This is a cocktail of 5 drugs each with a different function to combat the cancer. The tl;dr is CHOP targets fast-dividing cells (including healthy cells), while Rituximab targets the cancer (B-cells) more directly.

Before we get going with the real drugs we start with an infusion of benadryl. *Benadryl*? Turns out the first drug, Rituximab causes severe allergic reactions, hives, rash, hot flashes, in 30-90% of patients (gotta love the precision, anyway turns out I'm in the non-reactive group). What I noticed was a burning sensation in my arm when the benadryl was infused. They slowed the drip rate and that seemed to help. I then got loopy/drowsy for about 20 minutes as was expected.

The nurse was ribbing me for not taking the "chemo class" which is kind of mandatory/strongly encouraged prior to starting treatment. These happen every Wednesday. I decided if I have a week left of pre-chemo strength I wasn't going to waste my time on a class – I'll experience it soon enough. So I googled it and read the pdf in 10 minutes. Still, she didn't react well to my breach of protocol. I do appreciate medical professionals following protocol so no issues, and she turned out to be great otherwise.

She leaves the room for a bit while flushing the line with saline. A moment of solitude. Then it just happened. I'm overcome with a tsunami of emotion and break down weeping like a child. Why – here's a dissection of the layers:

- ***Poisoning a strong body I've built from scratch***. Friends who know me as an adult know me as a healthy guy, intense competitor. But they don't know that I suffered horrible asthma as a young boy and spent my life after age 12 setting up systems to overcome really severe asthma. I recall the day vividly. I was running home in my brown dockers, a white gap short-sleeve button down with one of those old school damp orange life-vests slung around shoulder from a sailing camp I was taking (I was quite a sight back then). Panting I lunged through the door and collapsed on the sofa, staring lightheadedly at the white ceiling, gasping for air as if through a cocktail stirrer. I ran about a block. The sense of vulnerability and weakness was awful, terrifying. I resolved never to feel this way again. I didn't know how I would do it but I resolved to just get stronger. As part of this new mindset I would oftentimes do things just because they were hard, to remind myself that life is struggle. I don't value convenience and comfort, in fact being in these situations makes me anxious (like being in people's homes where they just sit on the sofa and watch TV). Another aside here, if you want to get under my skin you should call my physical abilities "talent" or genetics, or some other BS. I get why this happens because sometimes people think I get a lot done with little effort (like I'll sign up for a race last minute and do fairly well). But what they don't realize I'm relying on decades of hard work to have built a baseline that allows me to quite foolishly train less than my peers . And I do it more for the sense of struggle and competition than for actually breaking a record. I like to think of it as the physical equivalent of living off of compound interest vs. working harder day-to-day to make ends meet. Nope. whatever I've done physically is purely the result of decision and commitment at a young age. That's the secret. Commit.

- ***Relinquishing control*** to doctors. I don't do well with not understanding every detail of a plan, with blind faith. But I have no choice here regardless how much I want to read up on things. The alternative emphasized by two independent medical opinions is that this is fatal within a year.
- ***Admitting I'm sick.*** I took prednisone as a kid for my asthma to reduce lung inflammation. Whereas for decades I felt like I reached escape-velocity on medical issues it was like I was pulled right back to the hard earth. Whack!
- ***The dance of weight and lightness of being.*** My universe exists within the dark confines of this body, this skull. When I go then the universe as I know it goes too. I feel the gravity act on my body, pulling me into the chair. Of course I know the world will continue without me. Nevertheless my cosmos will die if this plan fails. It all hinges on this imperfect protocol, on messy medical statistics. If this fails all of it goes away: *no more newtonian physics, space, electric purple flowers, hugs, language, songs, Saul's golden locks, Lev's joyous screeches, Lua embracing my leg, Michelle's sweet voice saying 'Ari'…no more grand ideas, tasting food, smelling thanksgiving, strategizing, breathing fresh air, walking through gardens…no more hypnotically staring at dust particles diffusing in a ray of sunlight. Game over for me, and a wake of hardship/sorrow for my family and friends. Ugh!*

So I'm now literally injecting myself with poison to kill the cancer faster than it kills me. It's real and it's a needle prick. This flies in the face of everything I know, all I've built, all I love. It's as counter-intuitive as it is rational and necessary. The paradox and the reality of it hit me like a punch to the stomach.

Staring at the floor I see those distinctive black nurse clogs through my teary peripheral vision. She backs away tactfully. I take another moment to compose myself. Then I look up. *Ok, let's do this.*

Nurse hooks up the Rituximab. I pick up some literature she printed out at my request. I pick it up and the second line reviews the side effects. I fixate on the second line in what seems 94 point font "***SIDE EFFECTS CAN INCLUDE DEATH***…". I stop there, putting the sheet down. My inquiries aren't helping the current situation. I try to relax.

The next few hours were really quite dull. The drugs didn't hurt. Actually I could feel them acting on the tumor site as kind of a sharp tingle which actually was a good feeling. Maybe it was working. The nurse mentioned at the outset that some patients have this sensation.

Michelle takes the nurse aside. She heads to the pharmacy and returns with some ativan to ease the anxiety. I've been aware that my hand has been mostly clenched in a fist for the better part of the past couple hours. I shake my head no, I want to feel. I've always broken distance runners into two types: dissociative vs. associative, the key difference being focusing on the body vs. on other stuff to distract from the pain. I tend to be in the strongly associative group, I like to know what's going on and feel the experience.

And now I'm feeling my bladder so I head to the bathroom. I walk very slowly, not because anything really hurts but because I'm just uncertain about everything. What the fuck are these liquids going into my body, what are they exactly doing, what should this feel like? So I amble to the bathroom wheeling the IV pole with all the beeping machines, no doubt looking like a cancer patient. I make eye contact with the other patients – we're all in this together. our looks communicate a lot, no words. It's a nice feeling to connect.

As I sit back in my plush chair I figure now's a good time for some external stimuli. I put on my headphones and throw on a spotify meditation playlist. I brought a few books not knowing how I'd feel. I pick up The heart of understanding by Thich Nhat Hanh. This book has been with me a long time but I always find some snippets worth re-reading.

There are three kinds of gifts. The first is the gift of material resources. The second is the gift of knowhow, the gift of the dharma. ***The third, the highest kind of gift is the gift of non-fear***….he continues….*In Buddhist meditation we do not struggle for the kind of enlightenment that will happen five or ten years from now. We practice so that each moment of our life becomes real life. And, therefore, when we meditate, we sit for sitting; we don't sit for something else. If we sit for twenty minutes these twenty minutes should bring us joy, life.*

So that's what I tried to do the rest of the session. Be present in the joy of the now, the joy of doing, of being. I breathe and send positive energy to my body. Try to feel the drugs working on the cancer. Be in the moment. Easy to say and hard to do. If I can face this fear I can face anything in life – what a gift to face it. Really.

3:30. The nurse pulls out the IV. You're done. I take a great breath and sit for a few minutes taking stock of my body. Doesn't feel too out of whack. No nausea, just tired. I put on my shoes it happens again. No warning. I weep. I don't even try to fight it. Michelle hugs me tight. Again, those same mixed emotions but this time with some amount of satisfaction for getting through… whatever it is I just did. An ironic sense of relief on top of it all.

Round 1 done. 5 to go.

Reading while I get infused


11

16.

The opportunity in facing cancer, especially being as young as I am, is that I get to face my mortality directly. There is no wriggling free when it gets hard. This is not an abstraction. This is the work. And it's a gift.

Batting cancer is a two-front war, it's physical and it's mental. The physical dimension consists of the treatment regimen, interacting with doctors, making decisions. I'm fortunate that for now the plan of attack is straightforward and I've got a second opinion confirming it. So that feels great. The mental dimension is where I'm spending my downtime.

We talk often as a society about living standards and quality of life. If I had to choose a single variable to enhance the quality of my own life it would be the removal of fear (including self-doubt & limiting beliefs). For that reason I'm really taking my time to be with this process.

Within this mega equation there are variables within my control and many more that are not. Attitude, mindset and approach to this process are all within my control. Facing and conquering fear is within my control. The payoff I see is that if this treatment is successful and I come out the other side intact (and even if I don't) I will have faced and conquered my fear. I'm sure I'd have gotten around to it at some point, probably decades down the line. But I'm convinced that doing this work sooner than later will make me a much better person. For me that means living with greater sense of purpose, intention and joy. That carries benefits to the people around me, my family, friends, colleagues, community.

My wise friend/coach David Lesser called me the other day and named my situation as *getting catapulted into a higher sense of awareness*. That rings true of the situation. There are two parts to this. The first is acclimating to a mental space which feels very different than a normal day-to-day existence. The second part is maintaining that standard over time once I'm on the other side. For now I'm focused on the former. Looking forward to the latter.

17.

I did a tai chi class the other day. What struck me about this is a feeling of rootedness. You aren't moving much, certainly not compared to running a marathon. That said there's something interesting about mastering one's own 'frame' as it's called, basically what's in arms reach. In Tolstoy's *how much land does a man need* the protagonist seeks all this land/fortune, but in the end the punch line is:

> *His servant picked up the spade and dug a grave long enough for Pahom to lie in, and buried him in it. Six feet from his head to his heels was all he needed.*

So there's something great about going the opposite direction to this idea of more and moving toward the bare minimum, taking the essential amount of land we need in a given moment and bringing a total awareness to it. I find myself doing tai chi as I walk around, helping me be more mindful in the day-to-day.

18.

We think of quality of life in a physical plane. And it is to a large degree. But one thing to bear in mind is that feelings/emotions are the true value of the physical.

As I prepare to enter chemotherapy this idea is top of mind. Quality of life over the coming months will to some degree be dictated by an absence of nausea and pain, of good energy. But the quality of my thoughts is the main piece that I can control – good physical with bad feelings is probably not much better than great feelings and bad physical. I'll do my best to have both.

One clean way of braking up mindset is into two groups: scarcity and abundance. It's clear that emotions tend to be of a lower quality when under the influence of scarcity thinking. Conversely feelings of freedom result from an abundance mindset. Actually let's call it gut-set (I'm making that up because it resonates more); if your gut knows then your mind follows.

So practically speaking one change I'll make is to hang more art on the walls. My place tends to not have much by way of art as I like cleanliness. These will serve as emotional anchors to remind me that emotion is what matters most. There is no success without fulfillment. Fulfillment is an emotion. The goal is to feel fulfilled each day. Emotional mastery is achieving this to ever increasing amounts per day, regardless the circumstances.

19.

My brother Eli and I worked out earlier today at my local gym. I've been trying to get as strong as possible going into this battle so I have reserves to draw on. He had a great suggestion while we were doing heavy deadlifts to track this over time. So basically I plan to science the shit out of this (stealing from one of my recent favorite movies, the Martian).

I've decided to monitor 2 aspects of my health as I go through chemo. The first is monitor my weight and body composition with a wireless scale over the course of this treatment – I'll be using this one. The second is to track my strength loss during this period. I don't want to overthink this process so what I'll do is track one key lift, the barbell deadlift, since I think covers 80/20 on total strength. I've established my baseline 1 rep max (238 lb). Since I'm likely to lose some weight I'll normalize this looking as percentage of bodyweight (1.6x) and calculating the theoretical 1rm moving forward. I say theoretical because it's probably not advisable to push hard enough to do an actual 1rm during chemo. For reference here's the calculator I'll be using.

I'll establish a stable baseline over the next few days and track this as I go. Here's the spreadsheet I'll be using:

20.

I splurged on my wedding. My rationale was that there are only two times you get close to having your whole network in one place, your wedding and your funeral. I'll now amend that to include a third event – getting diagnosed with cancer. For all that's horrible about this there are benefits to having cancer if you know where to look…

First, the amount of support I've received in the past few weeks, not only from friends and family, but friends of friends is inspiring. I am deeply grasping the power of this force – it has a life of it's own and inspires me.

Second, openness to pain and sadness allow us to connect in a deeper way with our fellow humans. Not only do I resolve to win this battle with strength & grace, but in victory to re-orient toward giving & contribution (less me, more we!). I'm touched by Clayton Christensen's note in How will you measure your life, *"I've concluded that the metric by which God will assess my life isn't dollars but the individual people whose lives I've touched."*

21.

Commitment to a purpose will result in success, or at least a worthy failure. Proactively defining that purpose is the key to moving in a great direction. It's also the hardest part. And there should be little fear if the vision is crystal clear. Failure is always possible no matter what. For me I think it's important to keep fear in check and use it as a tool to produce better outcomes. Bruce Lee is quoted to have something I've always really liked… ***Not failure, but low aim, is the crime. In great attempts it is glorious even to fail.***

Where I've found fear in my own life is in the times when that vision was unclear. Fear creeps in as the twin of doubt: muddy vision -> doubt (problems take on disproportionate weight) -> fear. By analogy, an example of unskillful conduct would perhaps be running a marathon and focusing on one's shoes instead of the finish line. The fear sets in because then your mind starts spinning on how many more steps you have to go, how hard it is etc. For me now I'm focused on getting healthy and kicking the shit out of this cancer. Looking at my shoes here would mean focusing on and getting paranoid about infusions, pain, losing my hair etc. These things matter a bit but are just steps toward getting better. I embrace it because I'm committed and because it serves the end result.

Actually navigating the problems as they arise should not produce fear. Speaking personally they produce a form of elation because I'm getting better at work worth doing! In this case I'm fighting for my life – I'd say getting good at that matters quite a bit.

The captain calmly navigates uncertain terrain.

In The Hunt for Red October the defecting Russian sub captain Ramius offers a nice metaphor. In the film he hunkers the nuclear sub into a well described trench full of twists and turns pushing the crew to move faster while avoiding detection.He calmly does the mental calculations on when to turn to navigate the terrain, evade oncoming torpedoes etc, while he sits in a chair, emotionlessly sipping coffee (aside: I imagine Mr. Buffett making his fortune in similar fashion). As one sub engineer Kamarov wryly notes in the film, *Stop pissing, Yuri. Give me a stopwatch and a map, and I'll fly the Alps in a plane with no windows.* Ramius had clearly done his homework to understand the trench layout and focused on that which was in his control. Clearly he had been here before in his imagination. Beyond that he committed to the end result and and remained cool and focused as he executed the plan. There is no fear because the mission (in this case defection from Russia) was clear. He was committed. The specific details unfolded as they always do in real-time with unexpected surprises. But they did not take on unwarranted proportion, which I think is key. He saw them for what they were, details to get through toward the vision. Nothing more. There was no stress about it! He offers an example of proper conduct for the captain (or any of us) in that he: a) defines the vision, b) skillfully solves the issues that arise along the way…. turn by turn.

22.

I pulled out the clippers. I don't need hair where I'm going. And why hold onto it anyway – it's just going to fall out sooner or later. Last thing I need is clumps of hair coming out of my head. So I decided to shave it off in one decisive moment. This'll happen on my terms.

There is no commitment without surrender. It's interesting because committing to an action seems on the surface to be the opposite of surrender. Surrender implies defeat whereas commitment suggests aims toward some success/desired outcome. But the reason commitment is also surrender is because alternate paths and options are cut off. And paths are seldom linear things – we must surrender to the unknown obstacles that we'll encounter while moving toward the goal. The only options left are to work the problem minus distractions of alternate paths – which helps focus on creative solutions. Only a singular focus on the mission remains. Surrender to the path.

A historical example I always loved is that on invading Mexico Cortez is said to have told his men to burn the ships so they could not retreat (I think it's accurate but I'll stand corrected if my history is off). They would conquer the land or die trying. This move constitutes a brilliant pre-emptive strike. But instead of attacking the enemy it's an attack on one's own psyche, on team morale, toward maintaining clarity on the mission. No surrender. No alternatives. Success or death.

Lest this get too abstract I think a concrete exercise might help illustrate.

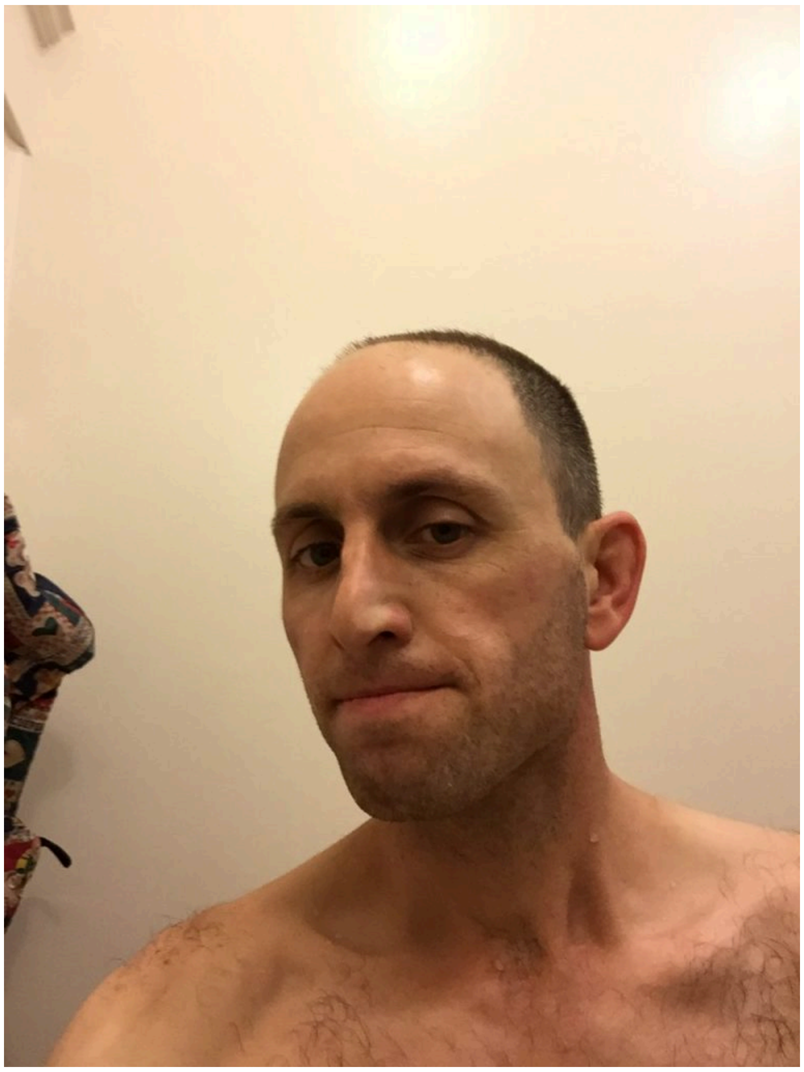
Here's something I've done over the years, maybe it'll work for you (it's not for everyone): If you live by some body of cold water, say the Pacific ocean as I do, commit to going in. New Englanders – this will work for you too, especially effective if it's not summer:). And no wetsuits either. Go in and cover your head. Stay in for 2-5 minutes or longer. MANDATORY DISCLAIMER: check w/your doctor first if you have medical issues!

It's scary to jump into 55 degree h20. Your body will say no. But if you truly commit then your mind will say YES. And you will be proud when you're done.

What I love about this is the levels at which the exercise works. First off there are **real stakes involved** (physical pain, though transient and tolerable). There's a **decision** to do this. There's **fear/apprehension** and of course **surrender** when you shut the car door and are left in your undies/swimsuit staring at the freezing cold water. There's **stages of entry**: feet, knees, waist, head – all **potential fail points** as each step gets progressively "harder". Once you're in there's the shock of cold and the body's **withdrawal reflex** to get out asap! Then there's the battle of the body against the mind. How strong is your will? Here's where you test your **mettle**. Are you tough enough to stay in and do as you said? Or **will you give in** to the desires of the body. Finally, there's the payoff, the **satisfaction** of executing your plan. For this example the satisfaction works on 2 levels: a) the **mental satisfaction** of doing a hard thing, b) the **endorphin release**. Speaking personally this is among the most sure-fire methods for getting high naturally. I'm not sure if this is the case for everyone but I feel reborn every time I do this. There's nothing like it.

Try it out. Let me know how it works for you.

The moment of truth. Let’s do this.



the new do

Uh, daddy, looked better the other way

23.

I thought I was in the clear. It had been about 14 days, 2 weeks exactly post-infusion and I was feeling strong, close to normal. I even worked out in the morning. Hours later I was in the ER being told I might die.

How it went down was I had family in town from Israel. This was the last day of their visit. Given I was feeling good I decided to take them to Muir woods, see more California. We left 12:30 and I was driving. I don't typically mess with AC when driving but I was hot and turned it on. The only reason I remember this is because when we were on the golden gate bridge I thought how ironic it would be to die in a horrible traffic crash fucking with the controls – no doubt earning me a darwin award. While walking in the forest I started getting cold and tired. I had to stop 4 times to sit down. On the way back I was blasting the heat with a hood on. Thermoregulatory issues noted. I decided to lay down for a few minutes. When I woke up I was sweating and flushed. I reached for a thermometer and then realized it might be a toddler one (and you know how we measure temp in babies:). Michelle gets me a new one and the temp is quite high. I call a lyft and rush out of the house.

The line in the sand requiring immediate ER attention for folks on chemotherapy is a fever above 100.4, very specific. Mine was 101.5 when I left home, 101.7 by the time I was admitted 30 minutes later — very high. Aside: if you want to cut to the front of the line at the ER turns out telling them you're running a fever while on chemo works well. The ER was 3/4 full and I was rushed to the back in less than 3 minutes post check-in.

By 4:00 I was in the ER and diagnosed with what's called neutropenic fever. Basically my white blood counts are, to use the oncologists terminology, "*in the toilet*". What he specifically means is:

> *An absolute neutrophil count of 1,000– 1,500 cells/mm3 defines mild neutropenia, 500–1,000 cells/ mm3 defines moderate neutropenia, and <500 cells/mm3 defines severe neutropenia. Source*

So a healthy absolute neutrophil count (they're basically cells that respond to infection and destroy it) should be around 1500. On ER admission mine was 84. My neutrophils are basically gone. That's part of the problem. But the immediate issue requiring attention is that I had a tiny blister or abscess on my thumb that developed the day before. It was something I barely noticed and no idea how it got there. *Was it Lua's blowout? Did I get scratched? Forgot to wash my hands? …* Due to my severely compromised immunity even this tiny infection required swift and massive action. The reason for the concern is when a patient is this severely immunocompromised small issues blow up fast. In this case it could result in sepsis – sudden organ failure/death. I had this surreal red line running up my arm originating at the thumb, up the fleshy part of my forearm and the inside of my bicep racing toward the heart. This is apparently a classic sign of progressing disease. It got as far as a few inches from my armpit – freaky.

I'll save writing about the ER experience for another time as I still get worked up thinking about it. In short it was really scary and horrible and it had little to do with my condition. Rather there were obvious systemic inefficiencies. What made this infuriating is the preventable nature of this – simply unacceptable. To draw a thumbnail sketch these issues stemmed from, poor lines of communication (nurse-doctor, doctor-patient, doctor-oncologist), lack of strategic thinking (e.g., nurse setup an iv on the same arm as the infection they were monitoring – so she had to poke me twice!), all on top of a bedside manner that was lacking. And the lancing procedure basically destroyed my thumb – I'll get to this. I'll stop here for now on the ER piece.

Anyway they pumped me full of antibiotics. They took an X-ray of my chest to monitor organs (I think). They took an X-ray of my thumb to verify the disease hadn't spread to the joint (it didn't). They also lanced my thumb to culture whatever bacteria was in there. This turned out to be the most painful procedure I've ever experienced. It was worse than the bone marrow biopsy. I think this explains why – basically the density of sensory neurons in the thumb is much higher than in the back. Pretty basic.

Just before he started injecting my thumb with lidocaine I knew how I would do this. I decided to get singularly focused on my breathing. I would count and not break focus on numbers. If I lost my place I told myself I need to start over. It looked like this:

> *1-in: 1-out, 2-in: 2-out, …87-in: 87-out ("keep going")…117-in: 117-out.*

My eyes were squeezed shut into darkness. I was so focused on the breath and counting that the searing pain shifted to a secondary level of awareness. It was in the background and I was observing it objectively. My body and mind were 100% in sync. I don't recall ever feeling this. Between breaths I distinctly recall thinking that if he were to amputate my thumb I could handle it (that's actually what it felt like). A strange serenity overcame my mind. The entire procedure took exactly 117 hard in/out breaths (at 2.5 sec/breath that's a a bit shy of 5 minutes). Oddly meditative.

Latest status is I'm in the hospital at least through Sunday getting IVs of powerful antibiotics every few hours.

- I've started daily injections of G-CSF to stimulate white blood cell generation in the bone marrow.
- Continue collecting daily labs to monitor white blood counts
- Continue IV infusions
- Culture the extracted pus and blood and switch from broad spectrum antibiotics (basically dropping a nuclear bomb on my body) to a more specific antibiotic, ideally something oral.
- push round 2 chemo out a week so I can recover
- Get on a neutropenic diet
- Whatever else they tell me:).

The infection needs to subside before I continue chemo. For that reason they're pushing my next treatment out a week.

Silver lining? It wasn't my stupidity/pushing too hard that caused this. This was a direct byproduct of the chemo. For a few hours I was kicking myself a bit for venturing to the woods with my family (I should have been resting!) but turns out that was fine. And we got a nice memory out of it in the end.

Taking a break with my sister Jacky in front of a giant redwood. 13:30 – feeling mostly ok.

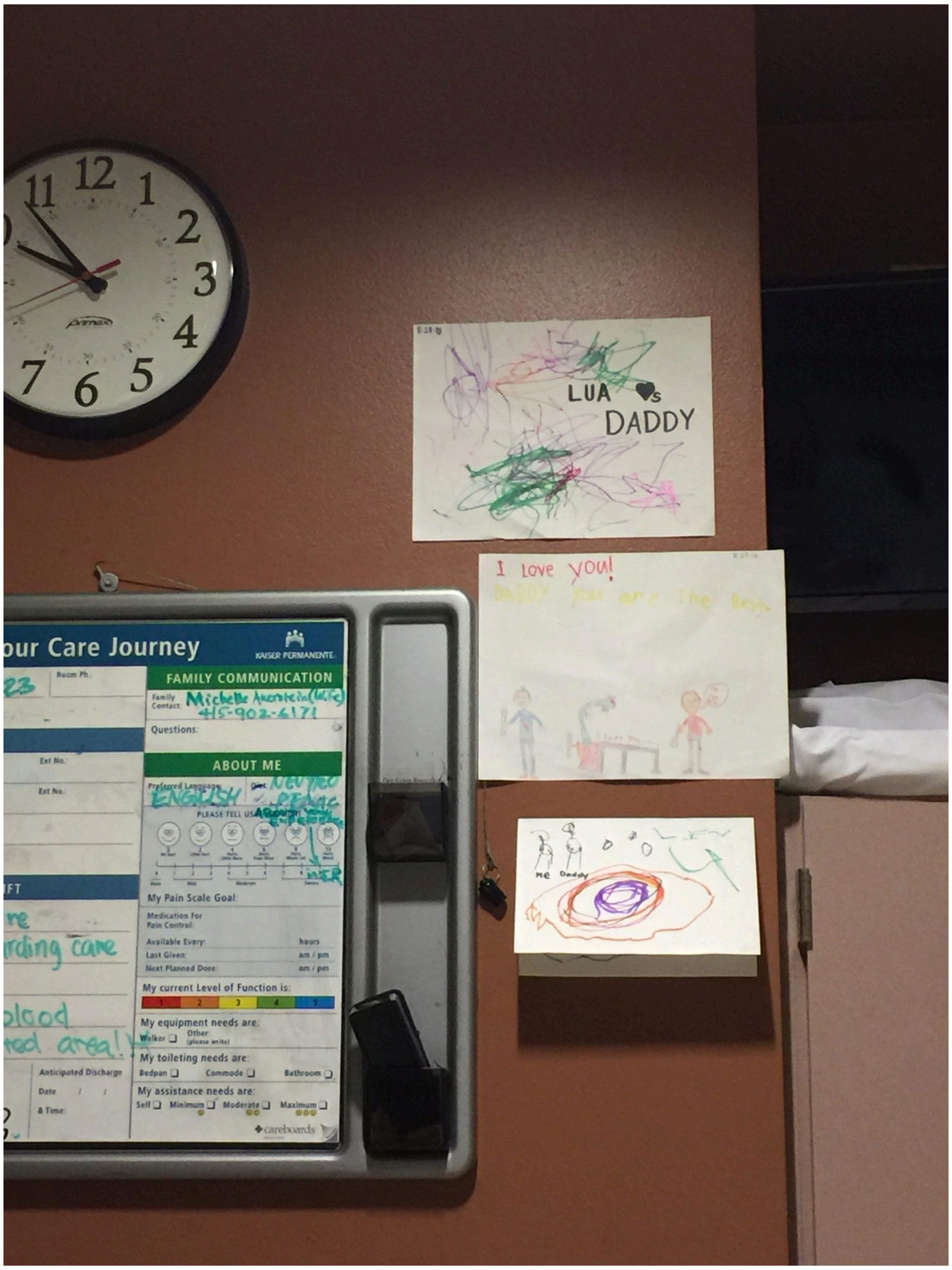
16:00 – in a Lyft to ER and frantically checking my temp.

Thumbs down to this ER visit. 23:00, channeling Saul when he’s angry with the “mad truck” face.

01:00 – checked into the hospital inpatient room for the next few days. Way better than the ER.

Lev: you can do it, daddy! This kid inspires me every day.

Lev and I share a moment



Endless hours staring at this wall. Kid pics can brighten any wall

Michelle is really the one taking the brunt of all this. She’s my rock and my hero.

the sign outside my door "neutropenic precaution". Visitors need masks, gowns optional.

Really its you not me. Visitors need to gown up because my immunity is so compromised. Dr. Kim you’re looking good.

24.

I’ve been back home since Saturday pm. I slept all Sunday and most of Monday. As of Tuesday I’ve been feeling mostly back to normal.

The G-CSF worked incredibly well to stimulate the growth of neutrophils. My counts shot up from a dangerously low <100 to a healthy 1000 within 48 hours, then to 3000 within 72 hours. Apparently my bone marrow is very healthy. So I’m no longer neutropenic. Apparently this severity of immunosuppression affects under 10% of folks going through my chemo protocol (not sure underlying causes). It’s also unclear to me why they didn’t check for this since post chemo infusion white blood counts reach their nadir around day 7-10. This would have been actionable information. I’m assuming it’s because 90% of patients don’t experience this though I’ve been asking around and haven’t gotten a good answer yet. Will be digging into this piece w/oncology team. I’ll likely need to supplement my chemo with these g-csf injections to ensure I stay out of the neutropenic red zone. I’ll pickup chemo next week.

Also my hair has started falling out. This really would have been more troubling had I not pre-empted by shaving my head. Literally every time I touch my scalp I get a clump/handful of hair (see below). I took a shower yesterday and the tub was literally filled with hair. I lost about 30% of my hair in the space of a 5 minute shower. It’s a reminder that despite feeling fairly ok I am sick and these drugs are doing their thing.

I’ve always associated the start of the school year with freshness, opportunity and potential. In a strange way I still feel that way despite the circumstances.

Get me outta here

Phyllis, my next door neighbor tells it how it is

hair everywhere. Every time I touch my head it looks like this.

hair in the tub

Bald and splotchy is beautiful

25.

I'm one week out from the first infusion – that's 5% of the way to completion, assuming no complications. The first few days were ok, better than expected actually. I slept a full day after getting home from the hospital that first day. On Friday I got up early and actually did a pretty hard workout (my doctor wasn't pleased but I felt really good).

That feeling of strength continued through the weekend. I was able to get up early a few other days and do some light exercise. My appetite was hearty, sleep was mostly fine and no nausea. There were two minor side effects. The first was heartburn/acid reflux, something I never get. So I started taking prilosec to help (hard to tell if it's working so far). The other is what I can only describe as cramping in my stomach. It's basically a burning sensation in pockets around my abdomen that I take to be the cancer. While not comfortable there is a satisfaction in being able to feel some tangible effects. The tumor is perceptibly smaller already, which blows my mind. This is further supported by the fact that the constipation I was experiencing (due to the size/location in the abdomen) has improved. This story is corroborated by my doctor who says this is normal/to be expected for the ~10 days post-infusion and that the drugs I'm on have the effect of "*liquefying the cancer*". I like that image. Medicine is a marvel.

The elevated energy had a lot to do with the prednisone (it amps you up and increases appetite). On the days after stopping the pills I've felt very different. I stopped taking them on Sunday, and starting Monday I've basically been in bed sleeping/too weak to get up with a somewhat suppressed appetite. I clawed myself out of bed to take a walk around the corner and write this post, feel normal. I tried taking a walk yesterday and I had to turn around after a few blocks. Imagine your energy during the worst flu you've had – that's my energy for the past 2-3 days.

Everyone told me I'd be watching more tv but that hasn't been the case so far. With whatever attention I can muster I've been doing more reading. And I've rebooted my meditation practice in earnest, shooting for 30 minutes daily. I've started re-attending a group on Sunday nights that meets for 2 hours. That's felt really important actually. We'll see if my strength permits as I continue in this treatment.

What I should expect over the coming months is a progressive weakening as the cumulative effects of multiple rounds take their toll. I'll start losing my hair in a few weeks. That's in the back of my mind but the immediate goal is to understand what the trajectory of a single round looks like. From there I should be able to better anticipate what to expect. The primary issue right now is that my energy is way low. Let's see how this piece progresses.

With all the sleeping I've been having some vivid dreams. Last night my body was like a wind-up clock running out of energy – kind of an obvious extension of my afternoon walk. Typically dream time for me is non-linear, but this one was different in that the cadence of my gait started fairly normal towards the beginning. By the end of the dream I had to use my arms to pull on nearby railings and fixtures to proceed. I was moving in molasses. Each step took about 20 seconds. I was counting. My legs were failing, a progressive paralysis.

I got up at 2:30am in a cold sweat feeling like total shit. My back felt like it was used for batting practice. But I broke a smile when I rolled out of bed and was able to make it to the kitchen for a glass of water. I did it quickly!

I think my mind was trying to tell me something:

Never mind the limitations. Focus on what you have.

Still got some hair, for now.

26.

I’ve been meeting with and talking to many cancer survivors lately. It’s inspiring and confidence building to speak directly with people that have gone through the fire. But as I hear more success stories I’m left with mixed emotions. There’s an obvious bias at play in that I’m hearing from and talking to survivors and successful cases. At times the disease can seem almost like a mundane abstraction since it seems so curable. Something that later will all seem as a bad dream.

It reminds me of a well known WWII story in which the British military is trying to save pilot lives. They specifically wanted to know where to reinforce their war planes to protect them from German anti-aircraft fire. The data clearly showed gunshot holes littering the wings of returning bombers. The military wanted to armor the wings. But the statistician Abraham Wald when given the data instead asked a better question, roughly: *returning planes can survive holes in the wings. Why don’t planes with holes in the fuselage return? Those planes are not represented in the data suggesting they don’t survive. Wings do not need more armor since they survive the gunshots.* He counter-intuitively recommended reinforcing the areas that were not represented in the data – a great example of survivorship bias.

I haven’t been looking for those narratives of unsuccessful battles, from those souls who didn’t return, who didn’t survive. The tendency is to look away. I prefer instead to forge the strongest character possible from this crucible of disease. It’s odd to explain but I find myself often oscillating mentally between success stories and the normal day-to-day existence that is life with kids, and the crushing weight of knowing I have CANCER. I notice this oscillation happening multiple times per day, lightness vs. weight. It’s disorienting but I’m getting better at maintaining my equilibrium within the turbulence.

I want to look towards instead of away.

The truth is I’m also prepping for another battle, the one that comes after cancer (not if, when!). That is the battle of living a purposeful life, every day. How do I leverage this experience to live the most purposeful, meaningful life possible? No, I don’t want this to be a distant memory. I want this to be a reminder so I make better decisions. I find myself stripping things down to the studs, the essentials values, like packing a rocket ship. I suppose this blog is an attempt to create that reference document.

Chemo round 2 – tomorrow.

27.

Yesterday we took a quick excursion to the SF Japanese tea garden to bring in the weekend. About 10 years ago I made a decision to ask Michelle to marry me – and yes it was the best decision I ever made. I asked her on this bench. Below are 3 pretty darn good subsequent decisions. Put one step in front of the other; good decisions tend to create virtuous upward cycles. Here's the proof.

28.

Round 2 was fairly smooth. I was less preoccupied and had more going on this time around me. It's been a few days since the infusion and I feel pretty good. Based on the first round all this is the prednisone talking and I'll likely start getting super fatigued in a few days. Here's what made the infusion experience better.

First off it was faster – 3 hours, not 6.

This was mainly due to the fact that the Rituxin infusion started off at a fast rate. On the first infusion the nurses needed to verify that there's no strong reaction, so they started me off slow, 50 mg/hr, incrementing by 50mg/hr each 30 minutes, ending at something like 350mg/hr. This time we jumped straight to 400mg+. Also we skipped the benadryl IV since I had no reaction last time. I took plain zyrtec in the morning and started back on the 100mg prednisone. We jumped right in.

Distraction with process improvements

My infusion nurse and I have developed an interesting relationship. She pesters me about not going to the "chemo class" (despite that I repeatedly demonstrate I've memorized the .pdf when she quizzes me, but she's a stickler). In return I enjoy frustrating her with detailed oncology questions she can't answer. To her major credit she is honest enough to tell me when she doesn't know. And she's curious enough to want to find out the answer once the question is posed. More than once she's gone to research the answer with colleagues, or pull in a doctor/oncologist to come discuss with me – which has been fun.

While satisfying for my innate curiousity, there's a deeper reason for this. In medicine, probably more than most fields, the difference between a positive and a poor outcome is often the result of a single decision, or a mere 2mm movement in the wrong direction. I'm insistent that my doctor/nurse can to a reasonable degree explain to me the rationale for their decisions. And that they are focused. One wrong move can quickly result in a cascade of downstream effects leading to permanent injury or death. Trust but verify. I've seen first hand how one small issue can derail treatments & outcomes. I saw this with my neutropenic event a few weeks ago. I would have taken more precautions, been more vigilant had they measured my labs earlier. Knowing my counts were as low as they were would have been actionable information. But they didn't because only a small minority of patients wind up this severely compromised (<10%). I get that. Then again I spent 4 days in the hospital as a result. Had I known to ask I'd have pushed for earlier testing. Anyway they'll do that moving forward now that we've established I'm not "average". But again, only because I'm pushing.

A few other top of mind examples:

- My grandfather my hero as a kid (still is), died young after heart surgery when he was in his early 60's, and I was just 12. The surgery was successful but he developed a preventable infection that ended up killing him. And ripping apart my family – another story.
- My father had what was supposed to be a routine surgery for acid reflux. In the process the surgeon damaged his vegas nerve, forcing him into an early retirement. He will likely never recover his energy levels or ability to properly digest food. After most meals he needs to lay down for 30 minutes or he'll get stomach cramps.

A key distinction that I'm drawing is that of the practice of medicine vs. the medicine itself. The drugs

I'm on reflect the best of humanity – saving lives with science, innovation etc. Absent this treatment, and going solely based on the statistics I should be dead in six to twelve months. Therefore I will owe my days beyond that horizon to these drugs and this care. While we're here let's put a date on it: based on my best estimates I'd die by April, 2019 (12 months after we suspect it started). I'll owe my life to the unaccountable, anonymous hours of basic science research & insight born from a commitment to make life better. It's humbling. And it makes me keenly aware of how our survival, as individuals, as a species, is a function of our interconnectedness. It's so easy to lose sight of this plain fact.

That being said humans, doctors & medical professionals can be fallible, careless and stressed out creatures like everyone else. Vigilance and patient advocacy is a necessary part of the outcomes equation – I'm not shy about getting aggressive about this in my own care. It's too bad there isn't more systemic patient advocacy built into the system, at least I haven't seen it. So I figure while I'm receiving all this medical attention the least I can do is try to fix some issues I've been experiencing for those folks that will come after me.

So far:

- **Nutrition –** I'm fighting weight loss and hyper vigilant about not getting below 140 lbs. When I was admitted to the hospital they put me on a "neutropenic" diet but the food they were giving me was truly un-edible and low in calories. The only food I could get down was canned syrupy peaches. After a few meals I told them to skip everything else and just bring that "6 cans of it – bring me as much as you've got". Anyway I was lucky in having awesome friends/wife smuggle me food (canned sardines, sandwiches, salads, fruits) – not everyone is so lucky. I could have lost 10 lbs in that hospital, setting me up for issues on my next chemo round. So while I was getting infused I was asking the nurse *is there really any evidence for this diet they had me on*? *Seems kind of outdated/unsubstantiated when I read the white papers…* The nurse was surprised they still were doing this and agreed. So she brought my question to the head of programming (or something, I can't keep the titles straight) who has been there over 20 years to discuss with me. Turns out she was at a symposium a few months ago in which this very topic was discussed. She was also surprised the hospital was still were following this practice. Apart from not eating raw fish/meat and washing fruits/vegetables well there is no convincing data that it supports better outcomes. So she is now updating the guidelines and protocols. Progress! Hopefully the next person in this situation won't have to deal with this (I hope that person isn't me).
- **New resident bedside manner**. Turns out my episode in the ER coincided with the first year resident trainings. By the way my thumb is still swollen with lack of full mobility and numbness from a minor lancing procedure. So the pushback I was experiencing in the ER was very likely a case of first-year resident bravado/ego. I filed formal feedback with Kaiser and one of the managers will also discuss this with the head of the resident program (likely this will go nowhere but who knows). Maybe it'll help them at least be aware of the issue and tone down this kind of behavior in the future.

Some good news from the Oncologist

My oncologist came by to the chair for a visit. He felt my abdomen and was somewhat taken aback at how much the tumor had shrunk after a single treatment, noting it was quite a lot smaller than he would have expected. So he is pushing the mid-way checkpoint from after the 3rd, to after the 4th infusion owing to his confidence in the treatment protocol I'm on. That said I can't believe how far off that still feels!

And friends sitting with me…

Did you know you can sit with people as they get infused? It's a pretty intimate experience to be there with loved ones while you get pumped full of toxins. At one point when they were infusing the doxorubicin ($20k/dose in case you were curious – thank g-d for insurance), aka red death, my friend Mike reached out to hold my hand. It was appropriate given my obvious wincing and shifting in my seat when they hooked it up. Mind you none of this really hurt physically – more of an eerie coldness flowing through the veins as they manually infuse at a rate of no more than 5ml/minute. My squirming really came from the knowledge of what's happening at the molecular level. Yes, I was visualizing the drug acting on my cells. There's incredible physical, topological complexity involved in DNA replication. Basically what happens is the drug interferes with topoisomerases, enzymes that interact directly with the DNA helix to manage supercoiling during replication. By interfering with enzymes responsible for the physical structure during division, DNA double-strand breaks are introduced making the genetic material non-viable. This in-turn drives machinery initiating programmed cell death. It's endlessly weird to think about the fact that such complexity lurks beneath each of our surfaces. Butterflies and rainbows don't really do it for me.

Apart from that Michelle and Sean took turns sitting in the single chair next to me (the room can only accommodate one visitor at a time). At one point Sean turns to me and quite rightly remarks that scenes like this are where superheroes are born (think Marvel comics, e.g., Deadpool, though I haven't seen it).

… just a normal Wednesday in San Francisco… a cancer infusion center…there sits a normal looking young bald guy. He's tense. They're infusing him with some crazy red serum…THEN ONE DAY…

Maybe we'll soon find out what this serum is *actually* made of. Hmm, what will be my superpower?

My new ritual of staring at the street below as I mentally prep.

The Doxorubicin infusion (aka, red death). Yes, this is the actual color.

Wife + green/ginger tea. Does a man really need more?

Mike, Sean – thanks for being there to support me!

29.

The past two days have been awful. Much worse than the first round. Last night I didn't sleep. I've been having severe headaches for the past few days. At one point I was literally sitting up in bed just punching the mattress in vain attempts to deal with the waves of pain shooting through the top of my head.Apparently this is the result of G-CSF growth factor (more on this below). I have an entirely new appreciation for the daily tribulations those who suffer migraines endure – thankfully it's not an issue I've really had to face until now. It's debilitating. Last night was a new low point with the following set of issues presenting at various points, often in combination:

- Burning in my stomach (chemo targeting the cancer cells, I think)
- Heartburn/acid reflux
- Shooting headache – waves every 1-2 minutes and lasting hours
- Swollen knees – suspect I'm retaining of water in my joints for some reason
- Possible nerve damage in my thumb from a few weeks ago. I was reminded of it when trying to rub my head at weird angles
- Bronchial infection/coughing – the past couple days I've been coughing up yellow mucus from somewhere deep in my chest. I was basically up every 5 minutes stumbling to the bathroom to spit up phlegm

Despite the above I'm a lot stronger and healthier than most people that go through this (again, median age is closer to 65 for this disease) so what I'm describing above is likely on the mild side of what people go through. But it's not easy.

As noted above I'm now supplementing my chemo regime with self-administered injections of G-CSF to stimulate neutrophil growth. This is a subcutaneous injection into the stomach. This is why I'm not in the hospital right now with this bronchial infection – the thinking is I should be able to fight this on my own.

At the hospital they showed me how to do it, walking through how to pinch the skin, hold the needle etc. Great I told them – I got this. No issues. No questions. I hadn't really considered but turns out that I've never actually given myself a shot…

What happened when it was time to actually stick myself fort the fist time caught me off guard. You're probably thinking this was no big deal. That's what I thought. I've been stuck with needles more in the past month than the sum of all needle pricks in my whole life. I don't flinch. But when I took out the syringe and the time came to stick this needle into my own body I froze. I would touch the sharp needle to my skin and just stop there. I really could not do it. I could not envision breaking the skin.

I tried every technique I could think of: music to get pumped, silent stoicism and deep breathing, Michelle in the room, Michelle not in the room – all to no avail. It was just me and the needle. It was really surprising. I was frozen, paralyzed, incapable of action.

I paced the room for over 45 minutes, picking the needle up, putting it down, swabbing the area around my belly button with alcohol prep, repeatedly. I took a nap to clear my head – I was getting stressed out actually. Lev had a 102 fever and was vomiting. I really could not afford to have low immunity in this context. Anyway when I got up had anything changed? Not a damn thing. Still couldn't do it. I finally gave up, realizing no good was coming from this business. My inaction had gained momentum.

It was clear I wasn't going to get this done on my own. Defeat. I needed support. I put my ego to the side and called my friend/neighbor Rafaela over (a nurse – but I didn't realize what a kick-ass nurse she is!). She sat with me, assured me it was ok and talked me through it. *On the count of 3 we're doing this. Commit on 3. Eye contact. Seriousness of purpose (Bedside manner!). Do you want to count or should I? …No it's all good, I got this.*

And that was it. I stuck the needle all the way in and plunged the syringe. It was oddly satisfying to put that paralysis behind me. I need to do this each day for 5 days each round, so this is a necessary skill to master. Feels good to be on the side of action. I've done this three times so far and as you would expect, each one has gotten easier.

Small wins.

30.

I’ve been taking time off work for the past few months to focus on cancer treatment. Healing is my singular goal in life. If all goes perfectly g-d willing I’ll be done with all this by end of December. That I could have such a tight timeline on something like this still blows me away. It’s is an incredible testament to the power of innovation & technology. So that’s my Q4.

In this time it’s been interesting, therapeutic even, to take a step back from the day-to-day and settle into a slower pace. On a typical “good” day (i.e., getting out of bed) I’ll feel strong in the morning. By noon I’m usually foggy & zombie-like. It’s weird but that’s how my body is reacting – I’m adjusting. I feel pressure to optimize those good hours. So I’m trying to be more intentional about how I spend my precious, limited attention.

Try this thought experiment to get a sense of what I mean:

Today you no longer have 16 hours (or say 8 working hours) to complete whatever is on your plate. Instead you have 3. Go!

How would you approach that?

If you’re anything like me you would likely re-assess what it is you’re doing in the first place; do you really need all those items on your todo list? You’d possibly re-prioritize your list to ensure the first ones get done instead of keeping it an unordered list. You’d likely be more vigilant about protecting your attention, e.g., reconsider the use of various social media, apps, news consumption habits etc. while the clock runs down.

I’ve basically followed the above steps. For better or worse (I’m not sure which it is yet, and it might change) I’ve mostly avoided the socials since getting diagnosed. I’ve turned off slack notifications, pulled back from reading the news. My media consumption is more oriented towards longer-form essays and books. Lots of books. Often I’ll just turn off my phone (I don’t think I ever turned off my phone before cancer except to restart it if there was some issue). In terms of communication and socializing, I’ve biased towards more intentional, high-signal forms: email, blogging, phone calls, spending time with kids, meeting face-to-face. More intimacy and actual connection. More full sentences and eye-contact, fewer emojis.

You might think it stressful to jam everything into a few hours. I think if I was fully functional right now that would certainly be the case. But lately I’ve been at peace with going the other way, resigning myself to the value in doing less. Right now less is definitely more. I’ve had to find a new perspective to come to terms with this reality. And besides, living life with stress is like driving stick and grinding the gears – makes for a bumpy ride, and the car won’t last.

Meantime clearing my plate and doing deeper work has had another interesting and unexpected benefit; reclaiming playfulness. It sounds trite but over the years I’ve come to realize the value in it and how easily it’s tossed by the wayside. One thing I’ve definitely noticed in myself is an inverse correlation between how busy I am (or am making myself) & playfulness.

Why is this important?

First, authenticity. My grandmother likes to remind me that when I was 5 I told her: Grandma, *I’m a player, not a worker*. I actually remember this, wishing my grandfather was around more (he worked a lot and in a pressured way from what I understand). Those words, that sentiment still rings true. This has nothing to do with work-ethic. It has everything to do with suffusing joy into how we spend our time while getting shit done. Work without an element of playfulness is drudgery. Play might not be the best word to convey what I mean but it feels right ('lightness', 'joy', or 'flow' could work too). Basically there's a minimization of internal baggage, preconceived notions, ego – a loss of self. There's right perspective.

Second, it's deeply satisfying. I think this quote from Isaac Newton sums up what attention well spent looks like:

> *I do not know what I may appear to the world; but to myself I seem to have been only like a boy playing on the seashore, and diverting myself in now and then finding a smoother pebble or a prettier shell than ordinary, whilst the great ocean of truth lay all undiscovered before me.* -Isaac Newton

Third, examples from history support play as an engine of deep insight – important for knowledge workers. When I think about some of my favorite characters from the past (the eminent dead, to borrow a term from Charlie Munger) many of them had in them a golden braid of deep curiosity, playful whimsy, and the skill to put that obsession to good use. That these folks had every right to conduct themselves with pre-occupation, stress and anxiety (and some did that too); they were shaping the future of humanity with big ideas and I think they knew it. What I appreciate most is how many amazing insights resulted from this playfulness, full immersion, the simple joy of doing. Pursuits were pursued as playful obsessions.

Some examples I find inspiring:

- Ben Franklin and his experiments on electricity, overturning millenia of religious superstition (counter arguments were put forth asserting that god's will is for people to get struck with lightning!) with detailed experiments resulting in the ability to understand, harness the force. Plus he would float on water getting dragged by a kite, making him I think the first kite surfer by a few hundred years.
- US president Teddy Roosevelt taking a few hours in the middle of the day for boxing to recharge the batteries. Apparently he would roughhouse with visiting dignitaries inside the White House.
- Einstein taking breaks from developing his theories to play the violin.
- Leonardo DaVinci throwing boxes off balconies to understand how they shape shift during free-fall and how to render it on the page. He was full of these kinds of seemingly whimsical pursuits. This ability for deep and direct observation enabled him to develop his ideas about fluid dynamics and how hearts pump from first principles (quite accurate and 100s of years ahead of his time). Amusingly, he would also invite some of the ugliest people he could find to dinner, get them drunk so they were animated and then sketch their 'grotesque' expressions from memory when he got home. The beauty of Mona Lisa no doubt was the result of this willingness to explore (playfully!) the full continuum and principles underlying the representation of beauty on the page; yin/yang.

The enemy is distraction. I'm concerned that we're breaking our attention into tiny increments. I certainly do it and recognize it in myself. It's tempting because we typically get a feeling of satisfaction and mistake activity for work: an email composed, a tweet reply, a quick SMS, reading a news story. We're basically splitting our attention into infinitesimal chunkst. Not only is it ineffective but it's expensive. The opportunity cost is a lack of deep focus on the things that really matter to us, that would bring us true pleasure, gratitude, awe.

This really matters for today but also for the next generation. I see my kids playing without interruption all the time with legos or drawing – they're young enough that they don't have phones. If you have kids I'm sure you see it too. It's a great reminder on how to be. It's inspiring to watch true absorption and think about how valuable that is. I'm concerned they will lose this ability (or at least do less of it) once they start getting phones and immersing more fully in the technology of 5-10 years into the future. Personally I'm happiest if I get a good dose each day. So I've been biasing strongly towards whole blocks of attention as much as possible on these days. It's been nice to have the luxury of putting down the phone for a while – the bologna slicer of attention.

Here's a quote I've always loved from one from the great physicists Richard Feynman – it's long but including the whole thing since it's so classic. Just think, he might have been checking his email instead!

> *When I was in high school, I'd see water running out of a faucet growing narrower, and wonder if I could figure out what determines that curve. I found it was rather easy to do. I didn't have to do it; it wasn't important for the future of science; somebody else had already done it. That didn't make any difference. I'd invent things and play with things for my own entertainment. So I got this new attitude…I'm going to play with physics, whenever I want to, without worrying about any importance whatsoever. Within a week I was in the cafeteria and some guy, fooling around, throws a plate in the air. As the plate went up in the air I saw it wobble, and I noticed the red medallion of Cornell on the plate going around. It was pretty obvious to me that the medallion went around faster than the wobbling. I had nothing to do, so I start to figure out the motion of the rotating plate. I discover that when the angle is very slight, the medallion rotates twice as fast as the wobble rate – two to one. It came out of a complicated equation! Then I thought, "Is there some way I can see in a more fundamental way, by looking at the forces or the dynamics, why it's two to one?" I don't remember how I did it, but I ultimately worked out what the motion of the mass particles is, and how all the accelerations balance to make it come out two to one. I still remember going to Hans Bethe and saying, "Hey, Hans! I noticed something interesting. Here the plate goes around so, and the reason it's two to one is …" and I showed him the accelerations. He says, "Feynman, that's pretty interesting, but what's the importance of it? Why are you doing it?" "Hah!" I say. "There's no importance whatsoever. I'm just doing it for the fun of it." His reaction didn't discourage me; I had made up my mind I was going to enjoy physics and do whatever I liked. I went on to work out equations of wobbles. Then I thought about how electron orbits start to move in relativity. Then there's the Dirac Equation in electrodynamics. And then quantum electrodynamics. And before I knew it (it was a very short time) I was "playing" – working, really – with the same old problem that I loved so much, that I had stopped working on when I went to Los Alamos: my thesis-type problems; all those old-fashioned, wonderful things. It was effortless. It was easy to play with these things. It was like uncorking a bottle: Everything flowed out effortlessly. I almost tried to resist it! There was no importance to what I was doing, but ultimately there was. The diagrams and the whole business that I got the Nobel Prize for came from that piddling around with the wobbling plate.*

Yes, sometimes we need to just get things done, put our heads down, do hard things, command & control, hit a deadline etc. More often than not though I think it's helpful to take a step back and make things a bit lighter, find the fun in what we're doing. Maybe this is the key to eternal youth; retaining that childish twinkle in the eye and infusing some good old-fashioned playfulness into the focus of our attention.

31.

Chemo round 3 is tomorrow morning.

The past week has offered some much needed respite. I've been feeling strong and reasonably healthy. The G-CSF injections have been working; I've been able to fight a pretty significant bronchial infection on my own. There were some touch-and-go moments as I did have light fever about a week ago but it never exceeded the 100.4 degree threshold that requires an ER visit. But that's now gone, just an innocuous dry cough remains.

Physically I've been able to get in a couple jogs (slow with lots of walking, but still). My weight is up a couple of pounds. My deadlift strength/weight ratio – the benchmark I've set to gauge strength – is a solid 1.7. I even felt strong enough to fast for Yom Kippur. So I've felt more comfortable getting out more and seeing friends etc. to take advantage of the window.

But psychologically it's a real challenge to feel healthy one day, sick the next (or often that afternoon). Not just that but there are also systemic reminders in place to reinforce the reality of my situation, lest I get too comfortable! The most annoying of these are the routine labs. Generally the phlebotomists are great and the blood draws are smooth. But every so often I get a terrible one that stabs me at an unlucky angle, leaving me sore and clutching my arm for hours. The pain isn't the issue. Instead it's the feeling of aloneness that can stir up the emotions.

Take last night, for example. I put the kids down at 8pm and headed out the door into the darkness to get pre-chemo labs done. We need to know that my white blood counts are at a safe level to proceed with the next infusion tomorrow. I drove to mission bay cutting through the thick SF night fog. I parked in the lot, one of only a handful of cars. Some kind of parking lot robot/drone was roaming the lot. The Caltrain horn echoed off the concrete walls. The whole parking experience felt dystopian.

I entered the Kaiser building. I walked through the white fluorescent hallway and realized I was the only person there except for a couple of night shift workers. Just me and the medical system. I felt totally out of place like the whole thing was a mistake – *why on earth am I here!*? I take a number at the waiting room entrance and have a seat. A moment later the automated system, "*now serving number 72*". The guy at the counter and I acknowledge the oddness of the hollow announcement. We're the only two people in this huge room and I was literally two feet away from him. It's like medicine can't happen without coldness.

Anyway he checks me in. I walk to the back room. I fumble with the receipt, license and medical card and shove them into my pocket. I extend my arms straight out to check the veins and decide which will be the lucky one. With a smirk he says, "*Good veins you decide, bad veins I decide*". I have good veins so I go with the left one. He ties the tourniquet. Here goes, "*small pinch*". A few minutes later we're done (this guy was great). He puts the tape and cotton gauze on the vein. I keep the pressure on for a few minutes. Then I walk back into the empty hallway. Just me and the questions swirling in my head: why am I here? how did this happen, and other equally useless lines of inquiry. Mostly feeling like I'd rather be at home with my family. I felt a bit sicker, my steps were slower, my shoulders and back were more stooped, looking down…

It's vital to remain aware of how these little insults can impact one's psyche; water eroding rock. Awareness enables the opportunity to replacing subconscious patterns of thought like doubt, fear, self-pity with something more hopeful. So I pulled myself together out of that funk, straightened up and walked out the building.

Tomorrow morning I’ll again submit to the chemo drugs. I will get knocked back down to the ground. Then I’ll fight my way back, likely emerging weaker than today as chemo effects are cumulative; a backwards ratcheting effect.

We’ll see.

32.

The round 3 chemo infusion was the smoothest yet. I had a new nurse and she was great. The whole affair took about 4 hours. Now that I know what to expect I'm a fair bit more relaxed about the whole thing. Also they made an exception where I could have 2 friends (vs just 1) sitting with me – Geoff and Abe – which helped. We were basically talking the whole time. I knew this was against the rules but the nurse looked the other way. She then "reprimanded" me (going through the motions to say she did, it was cute) for having too many visitors. Very tactful.

Anyway at one point Geoff turns to me and we talk about what's a life well lived. He tells me about his friend (a Stanford philosophy professor, also the one who officiated his beautiful wedding) who taught him an interesting assessment that Nietzsche wrote about. It involved a demon which makes it all the more compelling, Nietzsche offers:

> What, if some day or night a demon were to steal after you into your loneliest loneliness and say to you: "This life as you now live it and have lived it, you will have to live it once more and innumerable times more: and there will be nothing new in it, but every pain and every joy and every thought and sigh and everything unutterably small or great in your life will have to return to you, all in the same succession and sequence — even this spider and this moonlight between the trees, and even this moment and I myself. The eternal hourglass of existence is turned upside down again and again, and you with it, speck of dust!" Would you not throw yourself down and gnash your teeth and curse the demon who spoke thus? Or have you once experienced a tremendous moment when you would have answered him: "You are a god and never have I heard anything more divine." If this thought gained possession of you, it would change you as your are or perhaps crush you. The question in each and every thing, "Do you desire this once more and innumerable times more?" would lie upon your actions as the greatest weight.

I love this. You basically are asked as a thought experiment to re-live your life an infinite number times. If that idea is horrifying there's something there worth examining; if it brings joy then that's a great sign. I guess the prospect of getting cancer an infinite number of times doesn't sound all that appealing. That said getting this time to be more closely connected with friends/family/colleagues is pretty awesome. I really haven't felt this loved, maybe ever. That's pretty weird but it helps offset the hardship. I live in more gratitude than ever and this is a large contributing factor in my positive mindset. I cannot do this alone.

In contrast to round 2 I've thus far been more fatigued. I actually did need to sleep when I got home. And I've been more tired just in the past few days than in round 2. I can tell I'm a bit off. For example these drugs give me weird cravings such that I'm now eating like a 6 year old; the other night for dinner I ate 3 hotdogs on toast drenched in mustard and like 8 cups of apple juice – I was so lazy/weak that I drank it out of a lid-less sippy cup. Whatever. I'm trying to "be kind to myself" which is really not a strength, but I'm working on it.

It's apparent that I'm now living my life in 3 week cycles: so far it looks like the trend is basically a few days of good (thanks prednisone), just under 2 weeks of not so good, 1 week feeling ok in the lead-up to the next chemo. It's mentally taxing and disorienting. My 4th quarter of 2018 will consist of 3 more such cycles. Outside it's spring in SF with blooming flowers, warmth, sunshine. But the seasons I live by now are instead driven by the rationality of drug cycles rather than the earth's proximity to the sun. Takes some getting used to.

I’m now back into the 2 week hard part. I actually don’t feel as strong as I did the last 2 cycles on prednisone. I woke up this morning with a swollen gland in the left side of my jaw, ugh! I suspect my body is starting to fight something. I feel tired already and remain vigilant in paying attention to every physical detail at this point.

I didn’t sleep well last night so left this morning at 5:15 and did a very light workout (40 minutes mindless elliptical machine+podcast at local gym). I’m propped up on prednisone so that definitely helps with the energy. My immunity will fall off starting now and I’ll do all I can to keep from getting compromised. This consists of several parts:

- light workouts as I can for energy
- avoiding crowds, keeping distant from schools/other people’s kids as much as I can (obviously hard)
- G-CSF injections
- avoid some foods that may cause infection – e.g., sushi, root vegetables
- meditation – trying to remove stress, anxiety as that’s always been a trigger inviting opportunistic infection. I’m doubling down on this, especially as we enter flu season with 3 kids at home. I find this to be increasingly essential to my wellbeing.

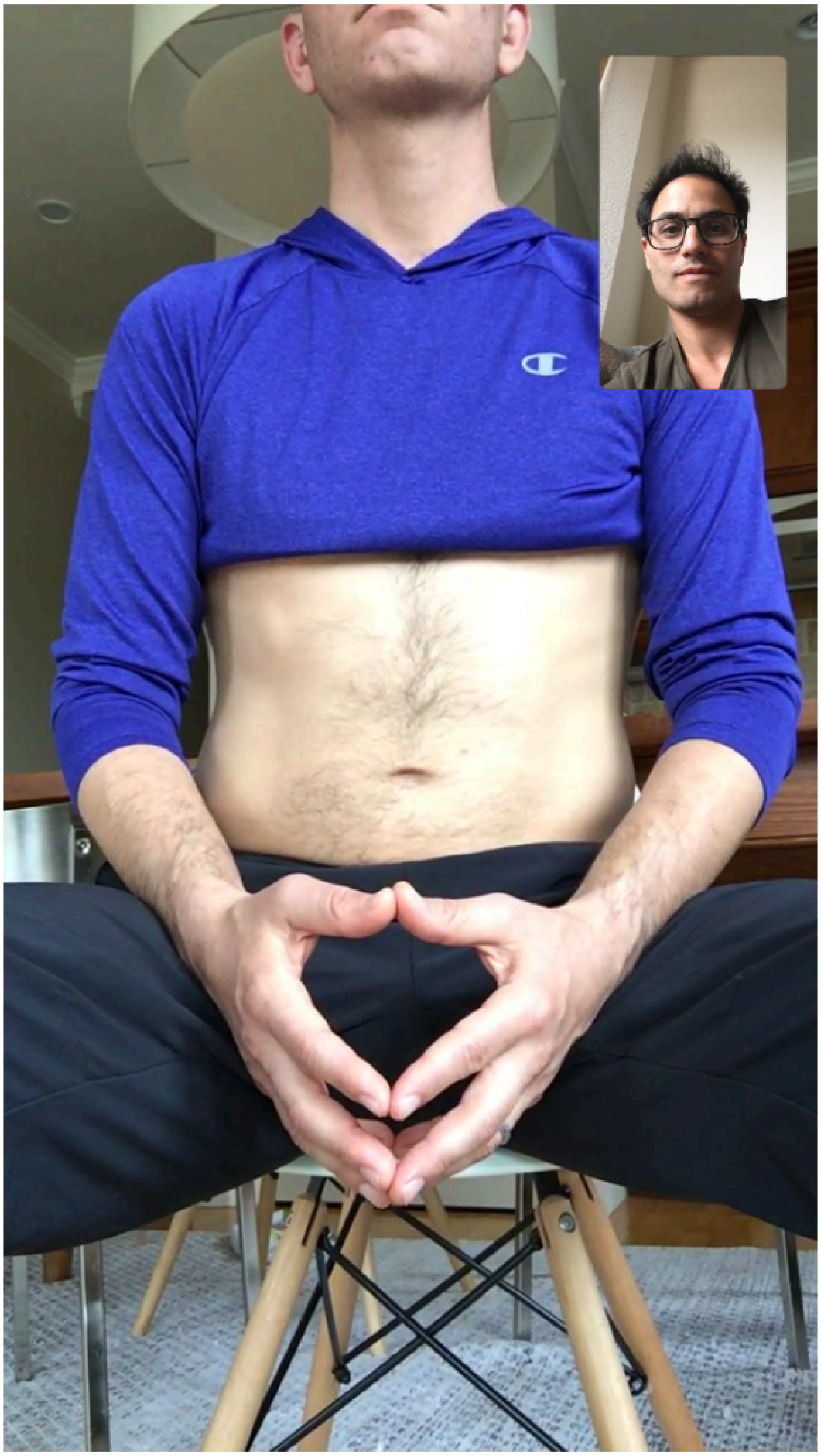
Today I started again with the zarxio injections (G-CSF). Quick note on the injection since it’s been such a blocker for me. For my first injection this round I got on a face time with my brother Eli in Colorado. He was (is) an amazing athlete – champion wrestler, diver, gymnast. In gymnastics one of the major causes of injury is mental lapse/hesitation vs. a lack of skill. So his old gymnastics coach taught him a great mental exercise that we walked through that was very helpful, and that I’ll share.

Before doing any “routine” his coach would make his athletes visualize the it from beginning to end, perfectly, 10 times in a row. In doing this it helps to actually move your body to rehearse the movements while keepig the eyes closed. So I went through the movements of injecting myself with the needle: picking it up, pinching the skin, positioning the needle, depressing the plunger and removing. When completed you then get tee up the action on a countdown, commit then do it. It’s worth emphasizing (and I screwed this part up) to include the fear and anxieties you feel in the context of the exercise. What happened was I went through the motions but when I opened my eyes I got up and started getting anxious. I picked up the needle then had to put it down. Fail.

Eli: “*YOU DID IT WRONG. Let’s try again.*”

So I visualized it again a few times end to end, this time including the feelings of apprehension. That was the key, factoring in the emotions, the fear & anxiety. When I opened I counted down 3-2-1 then I then just did it. Easy. Such a great technique. Thanks Eli!

Thanks for joining Geoff, Abe! it's odd but the smell of the blue tape makes me gag.



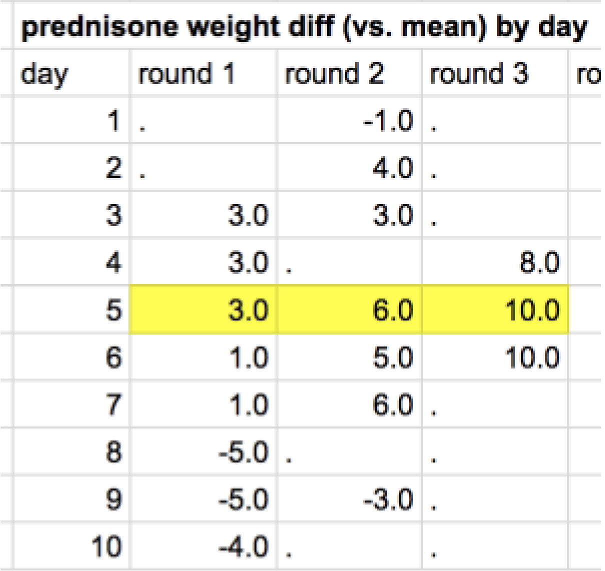
Eli guides me through a visualization exercise of the self injection on facetime

33.

October! Apple picking, halloween, pumpkin patches, crisp fall air. I typically love this time of year. Except that I'm now definitely into round 3 and I'm slogging through this thing.

Saturday I woke up really bloated. My normal weight is about 144. I got a shock when I stepped on the scale and it read 152 – up 8 lbs literally overnight – my highest reading yet. Then Sunday, 154! My face has been flushed and swollen. It's obvious this liquid is retaining in my skin, belly and joints.

I seemed to recall this happening last time but with less severity. So I looked back over my spreadsheet and noticed the same thing has happened each round. This gain is followed by a sharp loss in weight, dipping below average then returning to baseline days later (table below). Originally I thought it was the chemo but I did a bit of research and realized prednisone causes sodium retention & potassium imbalance. It's also clear that my weight gain due to water retention has been getting more severe by round. Specifically: in round 1 I gained 3 lbs; 6 lbs in round 2; now 10 lbs in round 3. The table below is looking at the difference between my average weight and my weight in the days following chemo (I take prednisone starting that day for 5 days). Not sure the cause of the trend here but I would expect this pattern to repeat such that within then next couple of days the weight falls off quickly to below my baseline, and then I struggle to return to normal.



prednisone weight diff (vs. mean) by day

day	round 1	round 2	round 3	ro
1	.	-1.0	.	
2	.	4.0	.	
3	3.0	3.0	.	
4	3.0	.	8.0	
5	3.0	6.0	10.0	
6	1.0	5.0	10.0	
7	1.0	6.0	.	
8	-5.0	.	.	
9	-5.0	-3.0	.	
10	-4.0	.	.	

weight gain due to prednisone water retention. Round 1 I gained max 3lbs; round 2 max 6 lbs; round 3 max 10 lbs due to excess fluid. Ugh!

In contrast to the first 2 rounds I've also been a lot more tired in the first days post-infusion. So the prednisone seems to be helping less, or perhaps there's some cumulative effect at play here. Anyway I spent most of Saturday in bed. Sunday I was really antsy/frustrated and felt a need to move despite my body's protests. In a moment of inspiration I decided to dust off my wetsuit in the garage. I threw it in the trunk and drove down to Pacifica to try and clear my head – fresh air, sunshine, water. I struggled to put on the wetsuit over my blubbery-feeling body and jumped into the Pacific. And I ~~swam~~ mostly floated in the water. It's was glorious! The cold Pacific water buzzed me with a jolt of sensation on my fingers and my bald skull. Did I mention that the chemo drugs have been causing me peripheral neuropathy. The drugs basically damage the nerves in my fingertips resulting in a persistent tingling/numbness. It's not terribly severe and is reversible but it's been yet one more small annoyance to contend with.

Later in the afternoon, still feeling this horrible bloating, I thought I might try jogging a bit to see if that helped anything. Bad idea. I could barely take a few steps before my heart felt it might explode – a very tight feeling in my chest. A bit scary actually. So I ended up walking for a bit to try and flush out that feeling of stiffness in my joints and resolve whatever that feeling was all about. Still tight chest and shortness of breath. I was moving so slowly – at one point in a crosswalk I literally had to signal the cars in the street with an outstretched hand like, *hang on, thanks for bearing with me, I can make it*. Not sure the deal there but I just accepted it and decided to not pushing anything further. Listen to the body.

34.

My weight is back to normal. I dropped 6 lbs overnight on Monday, then another 4 lbs on Tuesday. Easy come, easy go. I feel back to “normal”. Feels like a (small but meaningful) win to be able to predict my weight flux and the underlying cause. Data tames anxiety.

I’ve also finished this round of 5 self-injections. I’m happy to say that I haven’t had the headaches I suffered last time. I was really anxious about that. In terms of the psychological hangups of doing the injections I’ve turned a corner on this one. The visualizations I mentioned the other day were very helpful (and are a super practice anyway, especially for any physical/skill-based effort you’re undertaking, e.g., a tennis serve, bouldering route, surfing). But I think I’m now past the need for it in this context. For this particular skill the value of that practice was to serve as a scaffold to help build the underlying mental structure needed to prep me for the task. I’ve now removed that scaffold. For 3 days in a row I managed to do it quickly with minimal anxiety. Feels great to have mastered this one. Actually of all the support I’ve gotten from friends/family on this piece, I think my (not yet) 2 year old Lua is the one that got me over the edge. She walked into the room as I was prepping a few days ago. So I started babbling with her as one does with toddlers: *zippy (we call her that, short for Tzipora) want to see daddy get better? I’m going to inject myself with the big needle…wanna see? here let’s do it together…ready?* Boom! Definitely the fastest one yet. Less than a minute; thought is the enemy! So that’s how I do it now. My new practice is to incant a magic “*fuck you*“, then stick.

I’ve been sleeping 12 hours the past few days, laying in bed somewhat restless but too fatigued to get up circa 7pm. My fatigue levels tend to steadily accrue in the preceding hours, starting mid-afternoon.

In anticipation of this issue I bought some board games. This equates with roughly the level of coherence/energy I have at night to spend quality time with the boys. Two nights ago I made the mistake of promising we would play but I ended up too tired when the time came, despite promising. I felt really bad about that – if there’s one thing I can’t stand it’s breaking promises. Lesson learned; I now caveat everything with an, *if daddy feels up for it*. Anyway last night we finally played Battleship. Saul loves it! He even won his first game (though I’m pretty sure his winning in fewer than 50 shots with a >60% hit-rate is cause for suspicion). It’s already provided a nice opportunity to discuss bragging and cheating (the problems with, NOT the merits of). I’m not sure I can think of a recent $14 better spent. And I haven’t had this much fun since building rockets a few months back (that’ll be a separate post). I’m always on the lookout for cool shared activities.

Now that I’m on day 7 of the 3 week cycle I’m doing what I can to stay strong. I managed a few jogs and rediscovered glen canyon near my place which has fairly recently been re-landscaped and looks great. I’ve been doing some meditation there in the middle of my jog – a very convenient way to convince myself I’m being efficient, 2 for 1 – though to be honest I’m mostly catching my damned breath!

Meantime I’ve been super fussy about food. I’ve been an off and on pescatarian for years, but not eating meat has always been an ethical/rational decision vs. one of listening to my body (I tend to feel better, stronger when I eat meat). But in the past couple of days, and for the first time this treatment, I just couldn’t eat meat. The very idea of it disgusts me. Recall a few days ago I binged on hot dogs. I’m all over the place! My fussiness and unpredictability from one day to the next is maddening. On Monday, for 3 consecutive meals all I could manage was tomatoes that my neighbor Phyllis gave me + olive oil/salt/pepper + sauerkraut on top. I then literally licked the plate like a cat to get more calories from the olive oil. And that night I ate raw collard greens torn from the stem with frozen mango and popcorn while laid up on the sofa reading a book. Yesterday I ate pita and a tub of hummus for lunch. If I wasn't going through chemo your guess that I was an eccentric 85 year old man living solo would be spot on. It's amazing I haven't wasted away entirely.

So I'm doing what I can to force food down though protein has been especially challenging. My plan to address this is I'm going to make a concerted effort to start cooking; hard enough for me to understand what I want to eat, let alone inflict my fickleness onto those around me! The other day I started binge watching chefs table, which I've found to be really inspiring (which is saying a lot given my gustatory challenges. I've always joked that if armageddon comes I'll survive against the *foodies* because I'm so utilitarian when it comes to eating: energy in, energy out – feed the machine). Anyway maybe I'll join their ranks as this attitude of mine threatens to vanquish me in this personal armageddon. I've now gone through a bunch of my dusty cookbooks to find recipes that seem appetizing – I've taken up a full notebook page containing 30 that look good. I resolve to try each one. My strategy is to start cooking mid-afternoon before my energy levels dip too far below functional. I think the error I've been making is waiting until evening to prepare anything and by then it's too late – I'm not capable. And actually friends have been incredible, dropping off food at my doorstep more days than not – if not for that I probably would have skipped dinner entirely (if you're reading this THANK YOU!). These meals have been a salvation.

Historically days 7-12 tend to be the most challenging so let's see how the next few days go.

Saul learns battleship. This boy is a fierce competitor!

35.

This morning I'm back in the chair for round 4.

The whole thing is starting to take on a routine feeling: take my prednisone and anti-nausea drugs in the morning; head in to that familiar room on Geary st. for my infusion; head home and either sleep, or feel wired from prednisone.

I've been feeling pretty good for roughly the past 10 days. So I've loosened up a fair bit, jogging more, taking kids to the park, binge watching man in the high castle, at night. In fact it's been the longest stretch of feeling good this whole treatment which is both wonderful and a bit perplexing. Based on conversations with others that have gone through this, and my oncologist, I should be feeling worse at this point. Chemotherapy tends to have a cumulative effect, breaking the body down. I'm not complaining, more curious why the trend is going against expectation. And just when I think I spotted a pattern I got really tired the past couple of days, in bed at 7pm – go figure.

Meantime several of you have been concerned in not hearing from me – indeed my writing has suffered, as several readers have let me know with SMS nudges (glad people are reading and thanks, seriously!). There seems to be an inverse relationship between how good I feel and how much I write.

With this round I'm now crossing firmly into the second half of this treatment. At the end of this round I'll do another CT scan to measure progress. My sense is that things are working. The evidence is that the tumor is much smaller than it was – in fact I can barely feel it by hand anymore (I do still feel a strange and hard-to-describe fluttering in this location sometimes). Remember this tumor was the size of a softball, so something is happening! And my intuition is that I'm feeling better overall because the drugs are having their intended effect and the cancer is going away. That's what I'm telling myself. We'll see soon enough.

I'll be honest that I'm nervous anyway. I know I don't really control the outcome and wouldn't do anything differently than I have. Still, the prospect of the official assessment is pretty scary and I can't help but run through the scenarios which again, helps nothing, changes nothing.

So here's to a boring infusion.

36.

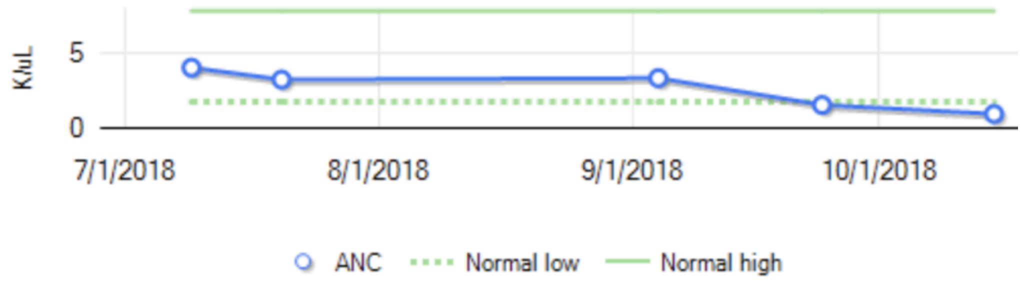
The infusion itself was smooth. These are becoming routine. Michelle joined me and I had a new nurse, also excellent. I must say I've been very impressed with my Kaiser infusion nurses – they're consistently great.

Current issues:

- I gained 8 lbs water weight after just 2 days of prednisone – up to 152. We'll see how the next few days go.
- My tastebuds are totally screwed up. I can't really articulate it beyond that my sense of salt and sugar are way off, and water tastes bad.
- Sleep has been an issue. I've been sleepy during the day then tossing at night. I get a second urge to sleep around 4:30am then sleep well from then on.
- Nausea thus far hasn't been an issue but I've been having this sensation I can only describe as the olfactory equivalent of phantom limb syndrome. Basically I smell this medical scent (specifically the medical tape) even if I'm outside in fresh air. It's not a particularly bad smell but clearly there's been an association made with the chemo infusions such that it takes me to the brink.

On a broader level what's more concerning is that my neutrophil counts are low, despite the zarxio injections I've been self-administering. I mentioned before that the cutoff for even having chemo is a concentration of 1000 (or 1.0 in the units below). My last lab results reveal that in my 'fully recovered' state (that is, after about 19 days), and with a regime of 5 injections I made it to 990. Close enough that they didn't delay round 4 but concerning enough that now I'm upping the injections from 5 to 7. Hopefully that'll do the trick and get me firmly above the line.

I asked the pharmacist about this and she suggested my bone marrow is weakening – there are only so many cells you can stimulate while in parallel destroying them with chemo. I asked the obvious question of why not just take this stuff every day, what are the risks/negative effects? She mentioned that patients that are even more compromised than I am (e.g., organ, bone marrow transplants) don't take this daily so there's probably something there. I'm sure there's a reason though I was able to find a few long term studies suggesting overall safety so I'm not too concerned.



my ANC counts over time (note the last 3 data points are during treatment). Dipping below dotted line is not good.

Separately last night Saul said at dinner that he misses being small. We were listening to the song "*you are my sunshine*" that Michelle would sing to him often. His eyes started welling up. It was so innocent and to be honest we all started getting emotional.

Seeing nostalgia manifest in the tears of a 6 year old both reminded me how fundamentally emotional we are as a species (despite how rational we think we are), and that he's definitely my kid. There's so much to process indeed!

Nostalgia. The desire to go backwards, to live in a moment, to revert to simpler times. He's adjusting to the challenges of first grade – so much more to deal with and so many social and emotional complexities to navigate. Kids have this wonderful way of cutting to the truth.

Nostalgia: I think there's 2 parts, (a) a desire to go backwards in time, and (b) the desire to correct mistakes we've made, to set things right.

There's value in feeling emotional pain but only in serving the future. But casting the mind back in fruitless wishes is the path to suffering if unaccompanied by learnings carried forward. It requires mental discipline to not get stuck there. There is a fundamental sadness in the fact that times arrow only travels in a single direction. I see it most clearly at dusk; can't take the day back. It always brings on these paired feelings of nostalgia and gratitude. I know how well the day went depending the proportion of each. Since I was a kid it's been this way. It's not like an inward-facing depressed sadness but rather it's the sadness that comes with realizing how finite our reality is. In ~100 years we, and all the humans we know and love will be gone and only the systems, learnings and structures will remain. What did we do, make and build that mattered? We are fireflies in the night; express then expire and never to fully comprehend what it's fully all about as we're stuck in our local realities. The colors shift perceptibly from second to second as photons hit the molecules in our atmosphere marking time in chemical reactions, not with clocks.

Regarding the desire to go backwards I've had the good fortune of not only having made many mistakes but *MUCH* more importantly of recognizing it. So I decided years ago that if I was to avoid spending precious hours stuck in regret race conditions I had to take active measures. So I instituted processes (I assure you, out of necessity not brilliance) to explicitly name errors and causes so I can be clear about correcting them, or at least bringing more awareness to the future. It's better to objectively assess than to subjectively judge ones self. If there's any magic in this simple practice it's that one realizes that the number of mistakes to learn from. Summed over years this is nothing short of astonishing – especially if you're anything like me. It's like sifting through dirt and realizing there's gold there!

When standing at dusk and taking stock of the day (I do it most days) it's helpful to spend it present in the glory of the moment and not spinning on mistakes or un-acted desires. I can say the proportion of gratitude to regret is highly favorable these days. Living with cancer reminds me that the ultimate wealth is to stand at dusk and not feel a need for doing things over. Even if I feel like crap if I'm standing with one of my kids it acts as a circuit-breaker on any such thoughts. Cancer reminds me that life is short (even if I'm cured!). We don't control the duration of life. We control our actions and hopefully, to some degree, this supports more positive emotional states.

People say health is wealth. I think emotional health is more important. Cultivate that.

37.

Yesterday was one of the worst days yet.

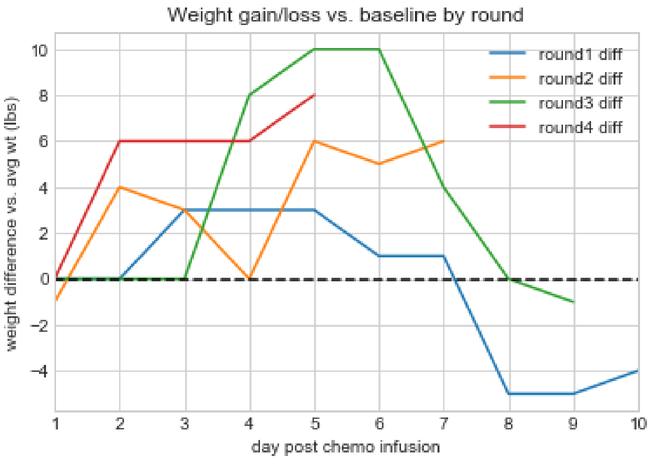
It started out great though. I got up 5:15am and drove to Kezar stadium to do a "track workout". Actually it was the best morning I've had in a long time. I parked in the dark night lit by a few yellow lamps and did a meditation for 15 minutes before getting out of the car. Then I got out and walked to the track. I was the only person there. I was cold so didn't bother taking off my jacket for the run. I did 2 miles total (including lots of walking), carefully monitoring my heart rate to stay in the 130 range as anything above for more than a minute or so makes me feel like I'm pushing too hard. Then I did a handful of 100 yard striders once I felt warmed up. It feels good to break in my muscles and chest a bit. It's interesting how strong my body signals are. I can barely pull off 100 yards at a heart rate of 150 beats/min without feeling my chest revolting against my will. So I would pull back to whatever I could easily tolerate. Just doing easy bursts of 50-100 yards felt really liberating.

Something about running in the lanes of the track is just so cathartic. Just being in the moment, in movement, one foot in front of the other while pondering the underlying complexity of our physiology that makes it all possible. I suppose I've picked an in-opportune time to get the running bug. I'll try to continue this practice of morning track workouts if I feel up to it.

But late morning I just crashed. Not only physically but mentally I was a mess. I was moody, hungry, frustrated, tired, hyper-critical and unfocused. My mentality has been rock solid this whole time so I don't like it when that gets perturbed. I'm fairly certain that the transitions on/off prednisone are a big part of it. I can't wait to be done with those. In addition I could feel the area around the tumor site acting up. I haven't felt this since round 2. It was like a little animal scurrying around – very odd and kind of scary. Hard to tell if this was this good or bad. To be honest it felt more like my anxiety acting up than the drugs, but who knows. I ended up crawling into bed early afternoon, then I got up and mindlessly ate some food, then I went back to bed. The kids were playing in the other room and it was a beautiful day outside. I wanted nothing more than to get up and just be with them. I couldn't help but feel like life was passing me by. But there was nothing I could do about it.

Let's end on a couple of high notes because today I'm feeling good:

I'm now off prednisone for this round. Below is what the weight gain situation has looked like thus far. I was concerned that round 4 would be worse than round 3 but that hasn't been the case. Let's hope it stays this way for the remaining 2 rounds.



Weight gain on prednisone by round. My baseline weight is 144 (dashed black line). Hopefully round 3 was the worst of it.

And I'm of course continuing with the zarxio injections. I'm no longer getting headaches. I'll brag a bit in saying I've achieved professional status as a self-injector! No more flinching or fidgeting. I don't even get anxious about it. Actually I now look forward to it. Why? I allow myself to look from a new vista onto how I was and how I am now – less fearful. It's a simple action yet a powerful reminder of progress I've made on a very simple and tangible effort. What took me at one point an hour now takes a minute (I now consistently am done in under 60 seconds, from alcohol swab to injection). Lua and Lev have been great motivators too.

I'll go further in saying that the process of self-administering these shots actually inspires me. They remind me that true progress is possible if only we stick with things and are willing to do honest work to improve.

38.

This Tuesday I'll go in for a CT scan. We need to compare this scan with the original from before the start of treatment. This will tell us if the chemo is working. At one point my oncologist mentioned that it's possible there are different cell types, some of which might show resistance. I actually don't want to know all the details of how this can go wrong. As with most things in life there are fewer ways in which things can go right and countless ways in which they break. For now I'm not interested in probing (what I hope are) low probability rabbit holes and freaking myself out. There's nothing I can do about it anyway. Let's stay positive!

In Judaism the holiest day is Yom Kippur – the day of Judgment in which it's said that G-d determines who will live and who will die in the upcoming year. It's an extreme mental construct meant to shake us out of our glazed-over walk through reality. And this test does bear some similarities in terms of what it brings up for me. Is this crazy path I've been on having the intended effect? Or is there yet something else lurking in the weeds? I'm doing what I can to visualize success and at the same time prepare for the worst case – whatever that might look like.

And while I'm optimistic about the outcome of this test (as is my oncologist) I've been doing a great job finding new things to worry about. For example over the past week or so I've had a mild cramping and what I can only describe as a fluttering sensation around the area of the tumor (kind of like when your eyelid spasms due to fatigue, but in my abdomen). I find myself holding those areas, as if clutching the uncertainty helps. It's weird because I've been thinking that this tumor has been shrinking – so why am I suddenly feeling it? When I sleep I try to place my hands on the area and visualize the tumor melting away.

In lighter news we're prepping for halloween. The other day we carved a jack-o-lantern, got costumes for the kids, and visited our local pumpkin patch. I may try to get out to walk around. I think I'll be be Heisenberg from breaking bad – good way to justify being in a crowd while wearing a mask without freaking people out.

Dose of cuteness: Lua tries on her Ruth Bader Ginsburg halloween costume

I Love Halloween! With Eli at the pumpkin patch. I need to cover up as much as possible. Chemo and sun do not mix well.

39.

Ok the CT scan results. Drum roll please….

First, the CT itself

This is pretty straight forward. They inject you with an IV contrast which causes a warm and flushing sensation, along with a metallic taste in the mouth. You then lay you on a table and raise the arms overhead like a military surrender. A large white machine fires up a terrible whirring sound. It then starts moving over the body. I close my eyes. A hollow recorded instruction: “Hold. Your. Breath”. I hold. The machine passes along my pelvis to chest area. “Breathe”. I don’t. Instead I continue holding my breath to slow down my pulse as I visualize packets of ionizing radiation ripping through my DNA.

At the end of it I thanked the attendants. The main guy was an older Chinese man. He remembered me from last time and showed kindness in the form of small gestures and smiles that can restore one’s faith in people. Anonymous hospitality and kindness are so important; rays of light from the void. I went back into the changing room to remove the gown. I sat there unwilling and unable to move. I was overwhelmed with the feeling of how little control I have in this situation.

More patient self-advocacy

I was told by my patient coordinator I would get results Tuesday evening. Two days later (yesterday) I was on the phone getting the runaround from her backup person. They wanted to schedule a call Friday evening because that was the only 10 minute slot they could find. Seriously? I tore into this poor patient coordinator letting her know exactly how unacceptable this situation was. Someone dropped the ball – or worse/more likely, didn’t care enough about the patient experience to follow up – and it was not acceptable.

Onto the results – some good news!

While I had been waiting for the results from my CT scan for 2 days, in actuality I’ve been anticipating this moment since the start of this treatment. Few things are as frustrating as pressing on in some direction with absence of objective data.

Finally yesterday afternoon I got some good news – an email from my oncologist.

He told me the treatment response is solid. There is no new disease and the tumor shrunk significantly. But there the cancer isn’t gone. It would have obviously been better if I was cancer free at this point. The issue however is I started with a high “tumor burden”, meaning lots of cancer cells (again, I started this in stage III). It would have been unreasonable to expect that good a result by round 4. So things are working but we need to press on.

Moving forward the plan is to stick with the original plan. So that’s 2 more rounds and we’ll re-assess then. The biggest change is we now have some objective data that we’re on the right path. And I have some peace of mind that the treatment is working.

Yesterday was Michelle’s birthday. I was concerned it was going to be bitter sweet if the news was bad. But it was good – so here we are double-celebrating at Chez Panisse.

Celebrating Michelle's birthday and some good news for me. Note to self: start using the anti-shine filters for bald heads moving forward.

40.

Round 5 tomorrow

It's hard to believe I'm heading into round 5. Still feels like a bad dream. I really want off this ride. I just got more blood drawn to check my white blood counts. I'll be curious what the level looks like as they were low last time. Worst case is we need to postpone the treatment because it's too low. But I don't think that'll happen as I've upped the number of G-csf injections from 5 to 7 (that should be enough according to the docs).

An emotional test

On the way over I stopped into the same coffee shop as where I got the news that I definitely have cancer. I was curious what I would feel now that I'm more than halfway through. Would I have PTSD or some negative emotions walking back in there? Answer: no. So what do I recall from spending a very tense 90 minutes here?

First, here's what I did that day after being told I have cancer

Amidst the obvious sweaty palms, shallow breathing etc. I first I got out some paper and listed my most pressing questions for the oncologist. Then I called Michelle. She was obviously very shaken but stayed calm. I told her I would head home in a bit. I called several folks at work to let them know. The kindness and empathy I felt when telling them the news was powerful; it was like ok, we're going to get through this together. Amazing. Next I wrote a list of people I wanted to let know immediately. Frankly it was less about letting them know and more about feeling I needed to talk to some people (limited to 5). I could tell I was starting to get worked up and needed perspective. I spent the next hour or so processing the news with cool-headed people I trust, admire, love. Note, cool-headed matters. I could not have conversations in which one side was spinning into a froth on getting the news (unless it was me). This was all hard enough without the additional anxiety of potentially stressing people out at the start of a workday.

You control your experience. Own it and make it good… even if you think it's horrible.

This all raises an interesting point of reflection. Events themselves need not dictate our experiences. I didn't control the news I got. But in retrospect I'm quite pleased with how I handled the news. It's incredibly empowering to consider that *holding ourselves to an inner scorecard of conduct is a good way to bypass the random insults of universe*. The test is asking myself if I had to do it over again, would I play it the same way? Answer: yes I would. So the retrospective emotions I feel from that morning are not about the horrible news I received. Instead I feel deep satisfaction and gratitude for:

- Having such amazing circles of colleagues, friends, family that I can lean on
- Staying reasonably calm, making a plan, and following through on it
- Having the good sense to get out of my head

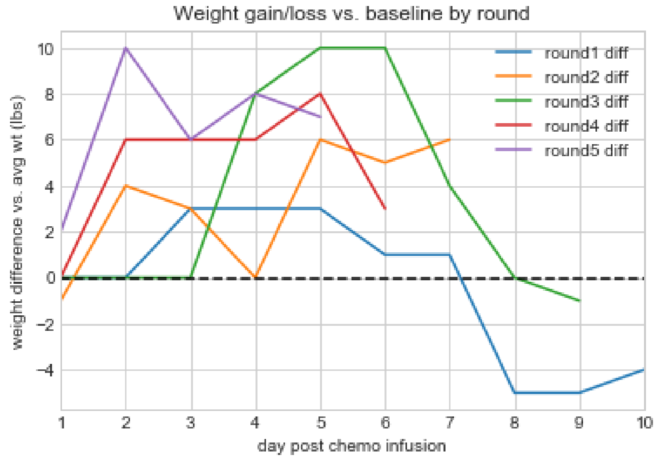
That's what I feel and what I remember. After those calls I felt like I had climbed – or got pulled – out of a very steep ditch. That got me into a better place to proceed.

As I stare down the barrel of round 5 this post is me taking a moment to celebrate a win.

41.

Feeling mostly ok in round 5

The past few days post chemo have been ok for the most part. Significant fatigue continues to be an issue. And I really haven’t been exercising much as I’ve been biased toward staying indoors as the bay area air quality is abysmal from the Chico fire. While we’re here other physical symptoms include: neuropathy (fingertips are tingly), taste is way off/most foods taste bad, periodic shortness of breath, I haven’t vomited but have been feeling nauseous at times (especially when I smell certain industrial things like printer ink or tape). Bloating on the days I’m on prednisone continues to be an issue (chart below) – I gained 8 lbs overnight again – despite trying to up my potassium and reduce sodium. And in the days post chemo I can feel the tumor site again; I think it’s the drugs acting on the site which I find encouraging. Oddly what I notice too is that if I find myself getting stressed, e.g., the kids or similar, I can feel some activity manifesting there, kind of a cramping, and I back off and try to relax. While perplexing it is an extremely clear feedback system – it’s like a warning system that I need to check myself. Bodies are sometimes smarter than we are and I listen to it.



weight gain due to prenisone is still an issue (round 5 in purple). I gained 8 lbs basically overnight

Round 5 was smooth

My friends Ali and Joseph joined me, along with Michelle and Lua. I also had my original chemo nurse, Thea, on point. As horrible as these sessions are for me I actually do cherish them as means to connect deeply with people. I’ve come to consider my chemo treatments as sort of sacred events.

These sessions really make the experience meaningful. It reminds me of the Western wall in Jerusalem. Whenever I go I’m struck by the same thought: it’s a bunch of ancient stone – what are all these people getting worked up about? But it’s not the stones or the site itself that matters so much as the community manifesting at a site and expressing their shared beliefs. You can feel the energy when you go. Shared meaning and community matters. I feel this meaning during chemo in the form of love and support. Each day in this treatment I’ve been totally overwhelmed with community. I’ve never felt such support – it’s life affirming.

Thank you for coming Ali! My hands have been swollen but that’s not my left hand across Lua in case you were wondering:)

Hanging with Ali

Full house: Joseph, Lua, Ali

Thanks for joining, Joseph!

Lua power to encourage me (her latest thing is making power moves when we say 'lua power!'). Lev and Lua help me with shots at home.

42.

This is a quick thank you note to Ruth Bader Ginsburg. Thank you for taking a few minutes out of your day to write in. You inspire me.

Michelle ran upstairs screaming over the weekend when she saw the envelope header – “Supreme court of the unites states”. Turns out RBG caught wind of this blog – we dressed Lua up as her for halloween – and she wrote in! I must say I was familiar with some of her work on women’s rights as a supreme court justice but wasn’t familiar with the details – or the breadth of her reach. So I went ahead and watched her recent documentary which is fantastic. So here’s what inspires me.

Justice Ginsburg,

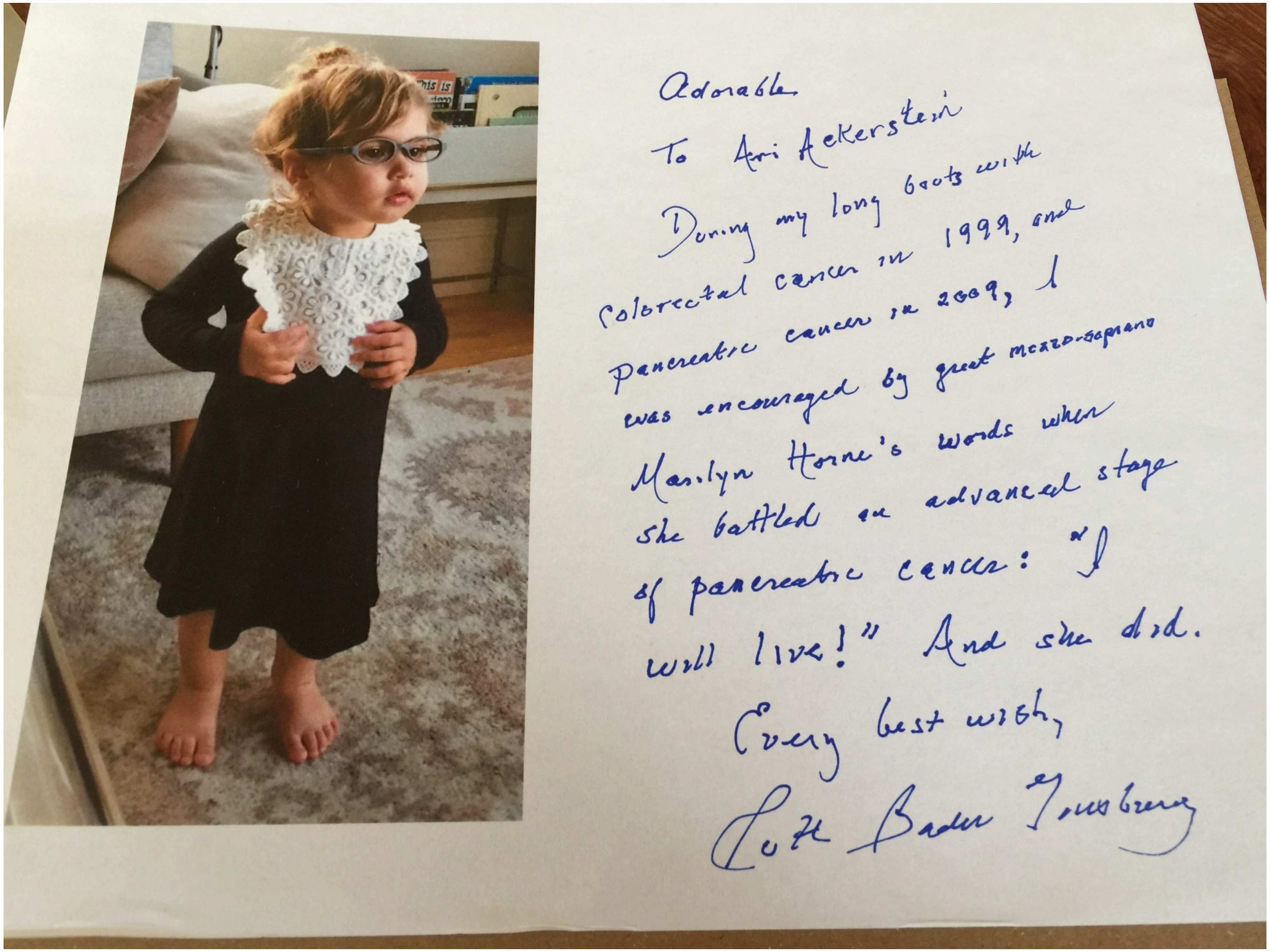
1. You embody a rare combination of humility and power. Your physical stature is no impediment to the clarity and resolve of your purpose which shines through in your work. Through that tiny frame you have changed the world.
2. You have clearly defined your life task and have not wavered from that orientation throughout your very long career. I cannot think of a person that better embodies the concept of Tikkun Olam. And thanks to your efforts my daughter’s opportunities will be significantly better than they otherwise might have been in this great country. You have changed our society for the better.
3. Your work ethic, working until 4am with prune juice and coffee at hand is fantastic and inspiring.
4. You’re down to earth! You certainly have more important things to do but regardless you took a few minutes out of your day to reach out. Thanks for reminding me (and my family) how little it takes – a quick note – to make a massive impact on someone’s life.

I heard about your recent fall. Wishing you a speedy recovery and thanks again.

– Ari

D. Ginsburg
SUPREME COURT OF THE UNITED STATES
WASHINGTON, D.C. 20543-0001

Official Letterhead from the supreme court. Uh oh!



Adorable

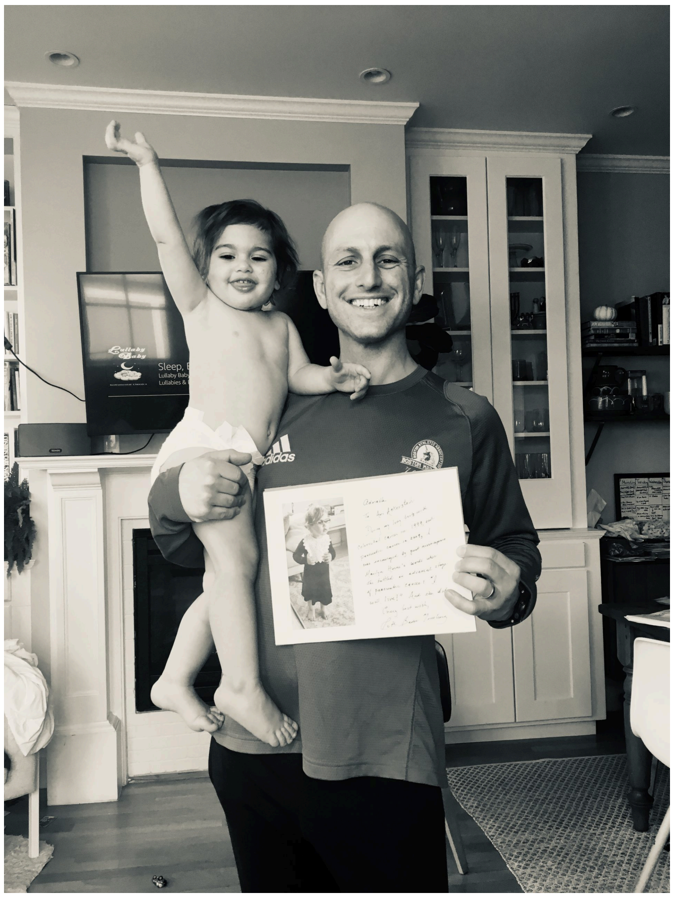
To Ari Ackerstein

During my long bouts with colorectal cancer in 1999, and pancreatic cancer in 2009, I was encouraged by great mezzo-soprano Marilyn Horne's words when she battled an advanced stage of pancreatic cancer: "I will live!" And she did.

Every best wish,

Ruth Bader Ginsburg

The letter from Ruth Bader Ginsburg!



Lua Power!

43.

Yesterday was my birthday. I find that as I get older these matter less (sounding like my grandmother). The past two days have been rough. Tuesday I spent basically the whole day in bed. My body ached and I could find no relief. I feel like my legs have lost all their strength and are now rubber. I think I figured out that it's the G-CSF injections. Basically those migraines I was suffering a few rounds ago came back but distributed to the rest of my bones. I'm fairly certain that's what was going on. And yesterday more of the same. Felt like a zombie and tried to just sleep it off. Started to feel better in the late afternoon. And just in time. Michelle brought Burma Superstar home for dinner (one of my favorites). But first chocolate cake and candles.

This stands in stark contrast to last year when we had a gigantic bash in the back yard. Obviously circumstances this year are different, not to mention the terrible air quality. So it felt like a win to actually get out of bed and enjoy it a bit. What has become apparent regarding expectations is that they are fully controllable (duh!). Satisfaction is found in a reduction of needs. It means feeling grateful for what one has and recognizing when things exceed that bar. This notion is not at odds with setting aggressive targets. Those are important. But I think it's about understanding one's perimeter of true needs and finding a base of satisfaction there; no sense getting upset about not winning the lottery! Recognize and celebrate it as upside. It's about the delta between actual and expected. One insidious cause of suffering that I know all too well is this idea of 'should'. Should takes a person outside of the here and now and flips this delta and for me at least results in the opposite effect – thoughts of scarcity. Something like this:

- a true needs mindset (gratitude, abundance)
    - what you have – true needs = high
- a *should* mindset (fear, scarcity)
    - what you have – what you should have = low or negative

I caught a second wind after dinner so Michelle and I decided to go to a meditation around the corner that she found. It was all I had energy for and it was questionable I even had enough for that. We donned our N-95 masks and walked around the corner. This must have been the most low-key birthday on record: chocolate cake, nice dinner, birthday cards from kids, meditation. I thought I'd be stuck in bed. This was extravagant.

44.

The SF bay area has among the worst air on our planet lately and it'll continue at least through most of next week from what I can tell. So we're leaving for Tahoe this morning. There's only so many days of being stuck inside that a family of 5 can handle – kids need movement, as does this parent. Also Saul is on vacation next week and school for Lev may be cancelled as well based on trends. And frankly we'll get a much needed vacation for a few days. We likely won't get another one this year so I'm justifying it as an excuse for some family R&R. We contemplated going to Boston for a week but I don't feel comfortable being that far away from my doctor or hospital in case of infection or fever etc. Also flying is out of the cards for me. Going to Tahoe is about as far as I think is reasonable given these extraordinary conditions.

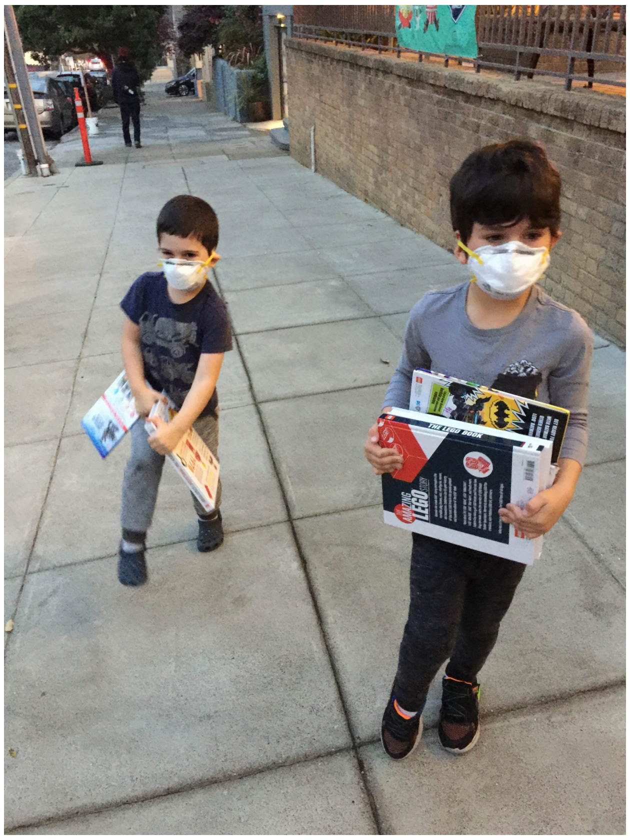
I've basically been stuck inside with barely any walking etc since these fires started and I think it's having an effect on my body too. While my lungs feel fine because I keep the air filter going full strength basically all the time, I did start getting some terrible back pain the other day, probably from lack of movement (it's certainly NOT from overdoing it on strength training – you have to actually strength train for that to happen – and that hasn't been happening lately). Felt like I slipped a disk but this morning it seems to be ok.

So with that decision made my main concern in leaving is the actual drive. It turns out that cars are only partially effective barriers against pollution (despite what I thought before looking into it). At least one study showed the most effective strategy for reducing in-car pollutants is to keep the AC on, cutting around 30% of the outdoor pollution; basically the cold surface attracts pollutant particles before get into the circulating air. So if the outdoor air quality index is, say, 180 as it is this morning ("unhealthy") that means inside the car it's ~125 (bad for sensitive groups like cancer patients and kids), better, but still worse than staying at home. So we'll want to keep the masks on while in the car. No, actually that's only part of it; leakage as a result of poor fit, as one would imagine, is also a consideration (with kids futzing in the back that'll definitely be an issue!). So let's say worst case the masks are only about 50% effective at cutting those pollutants because kids protest mid-way, adjust them etc. That brings us down to an in-car AQI of ~65 ("moderate"), for about 3.5 hours. Not great but I think tolerable. Likely it'll be a bit better than that. We're basically trading off a few hours of bad for hopefully very good on the other side. The key here will be keeping those masks on. So, bribery!

In a moment of divine inspiration I introduced Saul to "Pong" on the iPad. He's been playing it (or talking about playing it) nonstop for 3 days. He's also now totally into chess. Between those two games he can easily get through a car ride. And yesterday I took the boys to the library to pick out monster-sized star wars and lego picture books. I also took out a bunch of cd's to play in the car as kids music in the car really starting to wear on my soul*. As an aside here (it's Sunday morning, indulge me) I haven't taken out cd's from the library in so many years. As a longtime Spotify user I'd nearly forgotten the joys of physical cds: holding the plastic case, seeing the cover, making kids carry the objects home. The biggest benefit though is the *anticipation*. As much as I love online services like Spotify there is absolutely ZERO anticipation because I can have EVERYTHING RIGHT NOW. Ironic right? But it's true. I need to allocate brain power to thinking about those albums as I decide which to listen to, take them out of the case, insert into cd player, turn up volume etc. There is the design of an intended experience, and then there's the manner in which folks actually experience the edges surrounding it. Important to consider both.

So we have lego books, cds, old school video games: check, check, check. In short looking forward to getting out of here and being in nature for a bit. Keep you all posted.

*Really, who thought infinite plays on kid music was a good idea? I mean if you're going to donate then sure. But who does that with cd's anymore? Idea: introduce a *times-played* counter onto kids cd's. Some limit is set by the manufacturer, say 20 plays, after which the cd becomes unplayable. Or, maybe better still, the cd starts getting horribly scratched. Kids don't usually like horrible scratchy sounds (except when it's coming from their own mouths). So it'll be *their* idea to never play it again. And I'd submit that a scratched cd is no worse for the parent than listening for the 65th time to the music together hello everybody song. I want no proceeds. Just someone *please* make this happen.



Boys load up on library books for the trip

45.

We made it! Average speed was 90 mph. Lua refused to wear her mask so I just sped through. I was also feeling quite aggressive having been cooped up so long. And as one astute reader noticed in the previous analysis (this blog way over-indexes on astute readers) the 3.5 hour estimate was too pessimistic, it's more like 2.5 hours since the air cleared around Placerville as one ascends to the mountains. That turned out to be about right. When we go there I opened the windows and tore off the mask – AHHHHHHHH!!! I've never appreciated fresh air so much as the past few days.

3:12am the next morning. The steady hum of the heater soothes my mind in contrast to my otherwise inconsolable body. I crashed around 8:00pm last night. My lips and nose are severely dry from the combination of clear mountain air and blasting heater. I purse my lips them to minimize contact with the dry air. I've been doubled over with stomach cramps from, I think, the burrito I had from dinner (the black beans seemed undercooked but I let it go; perhaps someone didn't get the memo that black beans cooked at an altitude of 6k feet need to be in longer). I was huddled under the covers trying to get whatever warmth my body could generate: I had turned up the heater, put on a hat, breathed fast. Nothing was working. The only other time I had this inability to thermo-regulate I wound up in the ER. And I'm again concerned that's where I'm heading. It's been misery from 11:00pm. Every modicum of relief was a hard-fought battle. Every shift of my body was the dull ache of an old man…

The next day I tried getting out of bed a few times only to realize I was barely coherent and in a stupor. I stayed in bed basically the whole day through early evening. But my fears didn't manifest. I bounced back, slowly regaining my faculties. No fever! On reflection I suspect this might have been altitude sickness. Which would be odd because I've camped at higher altitude without issue. And I've run a race in Boulder just 1k feet lower without a problem. Perhaps it's the combination of chemo and altitude? I don't really care right now. Just glad that's behind me.

Apart from that the trip has been great. We've been with our friends Sean and Beth and their similarly aged kids. We head back today to hopefully cleaner bay area air now that the wind and rain are coming.

who just woke up from a nap? That’s right, Daddy!

driving out of this mess

46.

Let this shit be over.

I might have thought I'd be celebrating at this point. Nope. Been really tired the past few days and every day have woken up thinking I might be sick. Haven't had anything resembling a workout (nothing more than a walk) in 2 weeks. Have felt like my immunity is down (tingling in my jaw, fatigue, starting to get a fever blister, overall weakness). I'm oscillating between mindfulness, staying present to the experience, and anxiety to push hard to the finish line and to get on with things. Pushing is bad in my current condition; stress and immunity travel in opposite directions. I need immunity. Maybe it's the smoke and being cooped up too long, driving with a family to Tahoe, general life. But I'm ready for a change in conditions here. I'm ready to be strong. So – I take a deep breath and try to go the other way.

So one more *planned* round. I keep saying planned because who knows – tumor isn't gone yet. I'll meet with the oncologist on Tuesday to get a better sense of what's next and how to think about contingencies, e.g., what if the tumor isn't gone after then next CT scan? Do we tack on another round? Do we change the protocol? Something else?

More labs tomorrow. Then Chemo on Wed.

47.

A stone is thrown into the air. It splashes into the river below and sinks to the bottom. The speeding water rushes over it creating ripples and vortices. The rock remains unperturbed. Wounded animals find a cave and rest. They stop to fully recover then get back to it. So too with chemo. Pause and rest. Recover. That's been my internal mantra for the course of this treatment. In fact it's one of the harder parts in all this; remaining unperturbed while the river of society – perhaps best represented by the Facebook newsfeed – rushes by. There are days I feel ok enough to convince myself it's all a bad dream. *Chemo? I'm fine!* But I'm not. At least not yet. Knowing, committing to pause runs counter to my disposition. It certainly runs counter to the society we live in. We don't stop, we speed up! But a small voice inside tells me it's a good thing. It's necessary to support healing. So that's what I've been doing. Pausing for a while. Being ok with that.

48.

Yesterday I met with my oncologist. My body's response thus far has been extremely strong. He took a look at me and said that even for people my age going through this specific protocol I'm looking stronger than most. So that's great. We looked at the CT scan, at a cross-section of my abdomen, and saw the before and after images. Before: looked like I was pregnant with a large mass pushing all organs to the side (explaining clearly my back pain at that time). After: mass still present but significantly smaller – measured in mm's vs. something over 13cm across a side at the start. I started with so much mass in my abdomen that getting rid of it fully would be very unlikely in his opinion, despite the excellent response.

So there's a fork in the road coming up. Once this round is completed there are two dimensions to assess next steps: mass size and cell activity. These are measured by CT and Pet scan, respectively. Inactive mass is still ok. Think of it like scar tissue from the mass. And it's small, I can't feel the tumor with my hand anymore. But he has seen cases in which the mass actually increases in size toward the end of treatment (my jaw dropped when he said this). While we both consider that unlikely it is unnerving to consider just how complex these systems are – and how quickly we approach the brink of our understanding when peeling back the onion even just a layer or two. For all our knowledge, built brick by brick so to speak, in these conversations one can almost peer over the edge into the abyss of our collective ignorance.

Anyway, if there is still cellular activity post round 6 that means my current protocol isn't getting the job done and we need to evaluate other options. I'm trying to get that Pet scan scheduled for December but these machines are notoriously hard to get appointments for. At the latest I should know early Jan about the status.

Regardless, today will be the last round of this protocol. Yes there's a looming set of decision points up ahead. I left the office a bit unnerved as I fixated on outcomes. But that was short-lived as I reminded myself there's no point thinking about it too much. I'll focus on the happy path. And isn't it always the case that we don't know what's around the corner? How boring if we did! It's just that sometimes we are made aware of the complexity. So screw it. I'm ready to do round 6 and finish with this chapter. And I *WILL* celebrate. Never mind what's around the corner.

49.

It’s done.

I got home and felt like I was slammed by a wall. I just slept. Then I slept more the next day. The plan now is to recover from this last infusion for a few weeks. I just scheduled my CT and PET scans for later this month (17th and 18th). So I should know my status by end of Dec. I’ll fly east to be with family for about a week for the holidays.

Do I feel relieved? Yes. But that relief is eclipsed by a feeling of overwhelm at the thought of these upcoming tests. These will determine if I’m on the other side of this or not. Have I won the battle only to continue the war? Am I cured? Will I need to evaluate other treatment options if the cancer is still active? I’m on guard. It’s kind of a mental limbo that I’m contending with. Oy! But today I feel great so screw it. Now I’m back on the prednisone and zarxio injections to boost my immunity. The weight gain seems less severe than last rounds thus far. Lua and Lev helped me with my injection this morning. They were so excited; Lua said she wanted a shot too!

In terms of a recap on round 6 I couldn’t have asked for more. My colleague and friend Matt joined me for the whole time, taking time off of his insane schedule. Was wonderful to catch up and talk about deep life topics (as well as life sciences!) for a few hours. Matt – if you’re reading this your strength, resilience and attitude in handling adversity inspire me (I’ll leave it at that). It really meant a lot to have you there on this last round.

Thea, my original chemo nurse popped in a few times to say hello though she wasn’t my actual nurse that day. Towards the end, a nice surprise – all the nurses on the floor came in started blasting some music on someone’s phone and started dancing (really bad dancing!). It was a very sweet gesture. They all signed a certificate of completion – you know, the kind you get for doing nothing more than showing up. It a nice way to mark the end of this chapter. Thea asked me to come back and visit. At one point earlier she suggested I come and talk to some of the newer cancer patients, something about my attitude. I may take them up on the offer.

So now it’s a waiting game for a few weeks. Staying positive.

It was really special to spend the final round 6 with Matt, my friend (and manager).

Certificate of completion signed by all the nurses.

50.

This round has been brutal. The body and brain are not on the same page: brain wants to GO, body needs to rest. Body is winning. I can feel the cumulative effects of repeatedly poisoning myself. With a few exceptions I've been living life within a several foot radius of my bed though I have managed some coffee with friends, 'workouts' (moving my legs on a bike) and Hanukkah activities. I'm getting better about not adding a layer of psychological torment on top to make me feel bad about it. But I'm definitely not there yet. Lots of resting.

I've got what I'm calling PTS (phantom tape smell). Everything smells like sterilized medical equipment/medical tape though none is nearby and it is nauseating. At night I wake up basically every hour feeling totally dehydrated though my urine is clear colored. Not sure if this is this some mucosal issue or something else? My tongue feels like a dried out slug in a cave looking for moisture. So I get up and hit the bathroom to grab a sip of water. I stumble to the door in a mix of fatigue and severe aches. When I finish I grab some toilet paper. I blow my nose hard, one nostril at a time for maximum pressure. I examine the output on the white tissue canvas – Jackson Pollock!; red smears of dried blood mixed with yellow mucus (satisfying). I've done some variant of this routine for the past week, roughly 5 times a night. Feels like I'm broken.

Other ailments: my intestines feel like they are writhing at night, not really pain so much as discomfort (the drugs working on cancer? something else?) and I end up putting pressure by hand to relieve it; my calves and forearms cramp several times a day (again though I'm not dehydrated); the neuropathy is more severe than previous rounds – if I had to guess I'd say I have roughly 50% feeling in my fingertips; my neck and traps have also started sometimes seizing up on me as if somebody whacked me with a bat across the shoulders – makes breathing hard; everything tastes bad and bland – carbs seem to now have a filmy layer of slime that's repulsive. No pasta! Generally speaking I'm moving at half speed these days.

Today I finished the last of the zarxio injections! At least that's done. Time to dispense with my full sharps container.

Hard not to get anxious about these upcoming scans but I think I'm doing as well as possible to not think too much about it – not in my control. Looking forward to getting stronger from here.

Time to empty my sharps container. I've lost count but that's a lot of injections!

Lev: Daddy are you going to be strong now that you're done with your shots? Me: I hope so, Lev

Lua encourages me after my last shot.

51.

It’s been an eventful past few days. Here’s the latest.

Visiting my Grandma for the last time

I was feeling great early last week and was doing a lot of visits with folks, went into the office and saw my colleagues (felt normal for a few hours) and was able to catch up with others. I really thought I was over the hump. Starting Tuesday afternoon though I was back in bed feeling weak and tired. Wednesday, more of the same. By Thursday I was sure I was coming down with something. I had gotten news that my grandmother was slipping and that it was now a matter of days or weeks. I booked a last minute ticket to the east coast. But a few hours before the flight I really wasn’t feeling strong and thought it unwise to fly (to be clear it was not wise regardless but I decided the tradeoff worth it). So I delayed it a day in hopes that a good night sleep would help. I definitely came down with whatever everyone has now but I think my body is fighting it well enough (no fever).

On the way to seeing her I jotted down the memories, talking point bullets in my notebook: the warm feeling from sitting on the carpet as a kid, the smell of spaghetti and meatballs permeating the air on a random weeknight; coming over for breakfast across the driveway for Kasha; etc. I wanted to sit with her and share those memories, I knew by this point she wasn’t likely to be lucid but still, maybe she could hear/recognize my voice. And I could remember. I must say that I didn’t have that flood of memory that sometimes happens. I really had to dig to get those neurons firing – it had been a long time since they were active. I find that as time passes my ability to remember childhood events becomes harder.

On the way to Rhode Island from the Boston Airport I stopped to buy nice shoes. It was kind of a weird idea but I realized that showing up with sneakers to see her (perhaps the last time) was simply unacceptable, disrespectful even. What kind of an example had she set when her oldest grandson visits in sneakers? She was that kind of lady – elegant, dignified and poised. And she was always ready for action – feisty, decisive. As a younger lady (maybe late 60’s/70’s) she would give the RI mayor’s office a piece of her mind (in impeccable handwriting) about all the litter on the street. And when after the third attempt they didn’t clean up that grungy intersection on Allens avenue, she literally parked her car, got out, picked up the litter and put it in a trash bag herself. That’s how she operated. One day, years after my grandfather had died, she just decided to sell the house she lived in for something like 50 years because, “*why do I need all this?”*. Once she decided a thing then it was done. *“Ari, when you make a promise it’s a strike of lightning”* she told me as a kid, and that always stuck. She would also tell me things when I was a bit older, like, “you cannot *squire a lady like Michelle dressed like a THAT*“. Yeah, sneakers wasn’t going to cut it.

I arrived in her tiny Rhode Island apartment nestled in an assisted living home. She was always one of the most energetic and awake people there, light in a drab place. Several family members were there as I arrived: aunt, nephew, etc. They told me she was in her room and that I could go in and see her. As I walked into her sunny room overlooking the Seekonk river I was struck by the transformation, the delta against my last memory of her. Her skull is tiny and motionless in the large bed.

I closed the door gently behind me. I wanted to be alone with her for a few minutes unencumbered by social norms, expectations, or frankly, even words. Just to be with her and provide some comfort (if possible) to a dying woman who to me personifies quiet dignity. She is also the person who has been the most stable fixture in my life. But she is no longer the woman I’ve known.

I walk to the bed and orient myself to this reality. Here lies death. Wisps of white hair are still on her head. Her face is tilted 45 degrees left and up, as if reaching for something. Her mouth is awkwardly open. I suspect her head has been in roughly this position for some time. I sit down on a basic chair beside her medical-grade bed (the kind with adjustable settings to go up/down etc). A blanket is pulled to several inches below her chin. She is roughly facing me as I sit. I study her face. The only hint of the rest of her body is the skeletal collar bone I can see just below the blanket. Her body is so emaciated that her jawline sharply protrudes against her wrinkled neck like a fossil against striated rock. She must weigh 70 pounds. She is pale as plaster and her eyes are closed. Her body has it's own agenda to live despite the lack of movement. The mechanical workings of breath and pulse form a somewhat jarring backdrop to her stillness: the jugular vein pumps like a locomotive; her breath is steady, though labored and involuntary. It's musical. For a while I marvel at the machinery underlying my grandmother.

My eyes drift. I notice the scene outside the window. A carpet of yellow leaves below barren winter trees and branches. The river is calm and I think for a minute what old age and dying was like for the Native American tribes that were here first. The room is a mixture of sculptures, family pictures, paintings and small accumulations from the years. These things don't matter so I come back to present.

I was dumb to think I would talk about memories and good times etc. That's the last thing I want to do. Instead this is visceral. Instinctively, as with a child, I reach over to stroke her hair. I tell her that *it's me; that it's ok and that we're all here for her; that we love her; that my kids send their love to her*. I tell her it's *ok to relax*. I don't say much more. Just stroke her hair and try to be present. At one point I quietly said the שְׁמַע יִשְׂרָאֵל (Shema Yisroel, one of the most important Jewish prayers). Maybe I didn't notice it at the outset but as I looked at her face again I noticed moisture – yes, a tear – in one eye. That single, nascent tear was welled up, trapped in the folds of her eye. I was sure I'd have noticed it from the start. Perhaps it was just what happens. But I took this as a sign that she, or some part of her, was still there with me and perhaps she was more aware than her appearance would suggest.

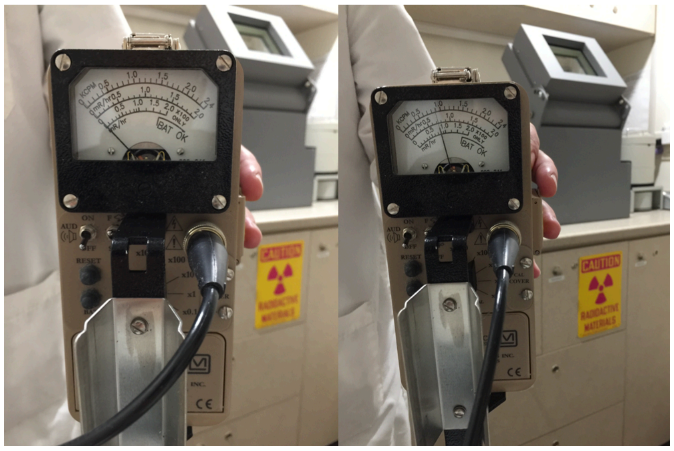
She would not want this. She would have ended it years ago if she could have. She would have taken a pill and ended it on her own terms, as she lived her life. She even told me she wished she had this option several times. That's how she did things, decisively. She decided she didn't want to live years ago. The problem is her body was too strong. All I can do in this situation is to provide comfort to the dying. I wish for her to go calmly, painlessly and peacefully. And quickly. There is nothing to hold onto.

I left the apartment with my aunt and uncle as the hospice nurse stayed behind. We got dinner. I said my goodbyes and felt like I had done what I came to do. There was nothing left. I shifted my focus on the living and what would come next for the family. This is the family matriarch and the glue holding things together. We went to dinner and discussed logistics – what the first 30 days look like after she passes, e.g., funeral prep, selling her place, etc. It was kind of cathartic to discuss all these things openly. And yet kind of strange to mix the mundane with the biological.

I spent that night with my uncle in Portsmouth RI (beautiful place if you haven't been). The next morning he told me that she passed last night. I was both sad and relieved. More relieved actually. I was pleased to have had the opportunity for a brief yet meaningful goodbye and to be there for her in some tiny way. The next morning I went to see her for the last time. Her face had changed dramatically. It was no longer positioned in an awkward way. Her lips were closed and I swear there was a slight smile on her face. Certainly there was a peacefulness about her. It was amazing to see. If my presence in any way helped then taking a two day trip when not fully recovered from my last chemo infusion, then it was completely worth it and I wouldn't trade it for a thing.

The scans

Yesterday I went in for back to back scans. These are the ones that tell me if the cancer is gone or not. The CT scan will look at the anatomical part – is there still a mass there. The combo PET/CT scan will answer if there's any activity/active cancer cells. I'm somewhat surprised at how I'm not too emotional about these tests. Perhaps it's because I don't control the outcome. Not sure but I'm not complaining. Now I wait.



Amusing myself in the PET holding area with a quick experiment. Here's the Geiger counter held up to my chest vs. the test admin's after injecting me with a radioactive tracer. Guess which is me.

I should amend that last statement. While I'm managing to stay reasonably calm about the results I am frustrated with Kaiser about the small things. In this case I showed up for the PET drinking green tea. They had to call the doc to ask if it was ok (it is). That amounted to 10 minutes of uncertainty that I didn't need – the thought of rescheduling the appointment was too much. The issue is the Kaiser appointment reminder provides no instructions for these tests – never mind the green tea – they don't even tell you to fast – and therein lies the rub. The tech told me that this kind of issue happens all the time in some variant or another. Really how hard would it be to write up a single description of do's/don'ts and put it in the calendar reminder? AARGH! More feedback is on the way. Again, the medical technology is amazing, but the practice of medicine – riddled with poor human judgment – or more likely lack of thought/diligence/attention to detail – can be infuriating.

The PET administrator was great. We had a lively discussion about the effects of radiation on the body. He was less pessimistic about the negative effects than me. He cited some studies suggesting low-dose radiation may have positive effects, on rats anyway. To which I responded that I'd be inclined to think about the problem differently. First, ionizing radiation introduces double strand breaks on DNA. Those are either repaired properly (with incredible repair proteins). Or they are improperly fixed which can introduce issues, say in the case that a gene was hit directly. Either way it's a bad thing, and to think the body gets better at it by increased exposure seems unlikely and certainly like it would require some convincing data. Second, it might make sense to study sun worshipers, astronauts, Nuclear plant workers, etc to test the claim in real-life – I don't think you'll find it's a good thing. Anyway we're not talking about low-dose exposure here. Spying the geiger counter in the corner I wanted to see just how much radiation I was getting with the radioactive tracer. He let me check – results in the pic above.

The basic way this test works is you fast overnight. As the body is starved for glucose (apparently) the active/cancer cells preferentially uptake the injection which consists of glucose and radioactive tracer (it's actually F-18 fluorodeoxyglucose, which from a metabolic standpoint acts like glucose). You wait in a dark room for 45 minutes while the cells do their work. The idea is to keep as many non-cancer cells from firing as possible. Then they put you in a large tube for 15 minutes that images the radioactivity in the body. The concern with caffeine or other activity like walking is that you could get false-positive results because other firing cell types might uptake the glucose. In case you're curious the PET/CT carries about a third of the radiation of a full CT scan. A full CT is on the order of hundreds of times that of a routine chest x-ray (about 600 from conversations I've had). For reference a dental X-ray, or TSA scan is not even on the same scale.

Perspective

I've been having this recurring dream and it's always variations on the same theme. I'm in Hawaii or some watery part of the world. I'm surrounded by the giant waves. I surf them or I swim in them. And sometimes I prefer to stand on some exposed piece of rock as I'm scared of them because a) they are big, b) there are pterodactyl-like monsters in them with triangular teeth like a 5 year old might draw on a dinosaur. The dream is both exhilarating and scary. Why? Because I'm a great swimmer, I have a surfboard and I do know how to surf. But I've only mastered smaller waves. These waves are building size, huge. And they are inconsistent – coming this way one minute and from another direction the next. The landscape is always shifting and evolving. There is no clear orientation (e.g., my house is here, west is that way). All is flux. There is nothing stable except my ability to navigate the waves. And that really seems about right. Taking it one wave, one problem at a time.

This week I've seen the full cycle of things. It's felt like months crammed into 4 days. I've got my own cancer front and center in my mind. I said goodbye to my 92 year old grandmother and experienced death up close for the first time. The next day I was snuggling with my 1, 4, 6 year old kids.

My circle of concerns has shrunk considerably. There is just so much less that I care about – my tolerance for drama, B.S. and the generally unimportant was low before but it's now virtually gone. And I care so much about those things that are within my circle on concern. All of these things are imperfect works in progress, and constantly presenting problems to solve. If you think one day there will be life without problems, or you don't enjoy solving those problems then, well, you're in for a hard time. We get to roughly choose the space of problems we can handle: if you're going to complain about winter then don't live in New England or figure out a way to make it work; if you don't like changing diapers, then don't have babies or figure out a way to make it work, etc. Other problems are handed to us as the price of doing business (cancer). But the alternative is no problems, which is less fun, because you're probably dead. So embrace life, one problem, at a time. It's all a gift. It sounds trite but it's so fragile and precious – and it can all go away quickly.

So, on with it. Test results will be in by this Friday.

Grandma 1 (Photo from by Brother Eli)

Grandma – always so well put together. Sitting outside her apartment in R.I. (Photo from by Brother Eli)

52.

Today is a big day: it’s my grandmother’s funeral, it’s the last day of school for the year for the kids, and I get my test results. If I were a superstitious person I don’t know if I would think this is a good or a bad thing. It’s a good thing I’m not superstitious. I have a call scheduled with my oncologist this morning to review the results. I want to think positive thoughts but I’m remaining pragmatic. I need to be prepared for either piece of news and remain mentally prepared. To be too positive going in would be a hard blow in the negative case – that is, if the cancer is still present. That’s all I have to say for now – trying to stay present and note all the thoughts coming and going.

53.

Not great news.

The first line treatment hasn't worked. While the cancer has shrunk significantly, based on the CT/PET results it's still there and active. It's in 2 locations – so far as I understand these are sites that were already active. That means cells are either mutated, resistant, or maybe something else. I now need to get another biopsy scheduled to see what cell types are present. Based on what I took from the conversation with the oncologist this is what next steps look like:

1. **Complete biopsy/validate resistant cell types**
    1. Biopsy – This must be done with a more invasive laproscopic biopsy (whereas before it was done with ultrasound guidance). The reason for the more invasive procedure is because of the risk of hitting nearby organs, and that the tumor is so much smaller than before, so targeting is non-trivial. The tumor was large before that they could just go in with a needle guided by ultrasound but that won't work for this context.
    2. Analysis **–** I'm really not sure exactly what analysis is done on the tissue samples: pretty sure they do some ICC staining and I think FISH. Had a conversation with a friend about potential for tumor sequencing but I'm not clear if this is a) something they do, or b) if it's even useful. But I'll inquire as I'm curious about this.
2. **Define approach**
    1. Get second/third opinions (gated by getting the biopsy done)
    2. Triangulate various opinions, pros/cons, and decide course of treatment
3. **Depending on (1, 2) but based on current thinking proceed with 2 rounds of a different chemo protocol**
    1. GDP+Rituxin (the current recommendation vs. RICE, or other second-line chemo protocols). The idea is to target cells w/different drugs to bypass possible drug resistance.
        - The Oncologist claims there's a high chance of success here (still a binary outcome)
    2. Each round will take 21 days as with RCHOP, and it will be *even more* intensive.
4. **Validate responsiveness with PET/CT to new chemo treatment**
    1. if successful then go to (5)
    2. if not successful then try other protocols (or …?)
5. **Complete autologous bone marrow transplant (that means using my own cells)**
    1. harvest my cells (this may happen before chemo above – not sure the sequencing).

The purpose of this so far as I understand it (poorly) is more about replacement of my compromised bone marrow due to all the chemo exposure vs. some type of curative procedure.

2. Do the transplant
3. Go in daily to monitor – I think this takes several months, and I'll be immunocompromised throughout. This would all happen at Stanford.

This whole thing, assuming it works etc, etc will take on the order of 6 months. I remain optimistic, as does the oncologist w/r/t the chances of success here (though his use of the word 'devastating' on the call might not have been the most prudent word choice… perhaps one day our medical AI overlords will display greater ability to induce calm regarding these types of calls).

So I'm doing all I can, taking this one step at a time and trying to stay calm/present. It's a mental adjustment. At this point I'm focusing on tactical stuff like getting the biopsy scheduled, which is proving challenging due to the holiday. I'm not comfortable tacking on an extra 1.5-2 weeks on this whole effort as the cancer is still very aggressive. I'm pushing hard to get this done asap.

So the next part of this adventure is starting soon. More to come…

54.

Scenarios:

- Car-T second line succeeds

Pros:

- If it works there’s no (autologous) bone marrow transplant needed.
- 85% success (verify!)
- This is all this lab does
- clinical trials require very close monitoring – I guess there’s a lower chance I’d get lost in the shuffle
- really cool; I would have more fun than at Kaiser.
- Also since it’s new I would be helping future people (which is partial BS because I’m doing this for me and helping others in this case isn’t a motivation)
- Paid for by kaiser. Apparently CAR-T is in the neighborhood of $0.5M, not cheap.

Cons:

- 1-2% chance of death (but not really a ‘con’ since apparently that risk exists either way, just different)
- This trial is still Phase I which is a safety trial and completion isn’t slated for 15 years. I’m assuming that’s because they’re tracking folks over the long term but still, seems very early. Related to this unknown future recurrence. Also the fact that CD19 and CD22 weren’t on my pathology report is somewhat concerning since those are the main targets. Cells lacking those targets could potentially still grow from what I think I understand.
- Untested vs. a known quantity with many years of data
- unknown long-term outcomes
- cytokine storm; neurotoxicity; other?

What would you do?

III

Uncertainty

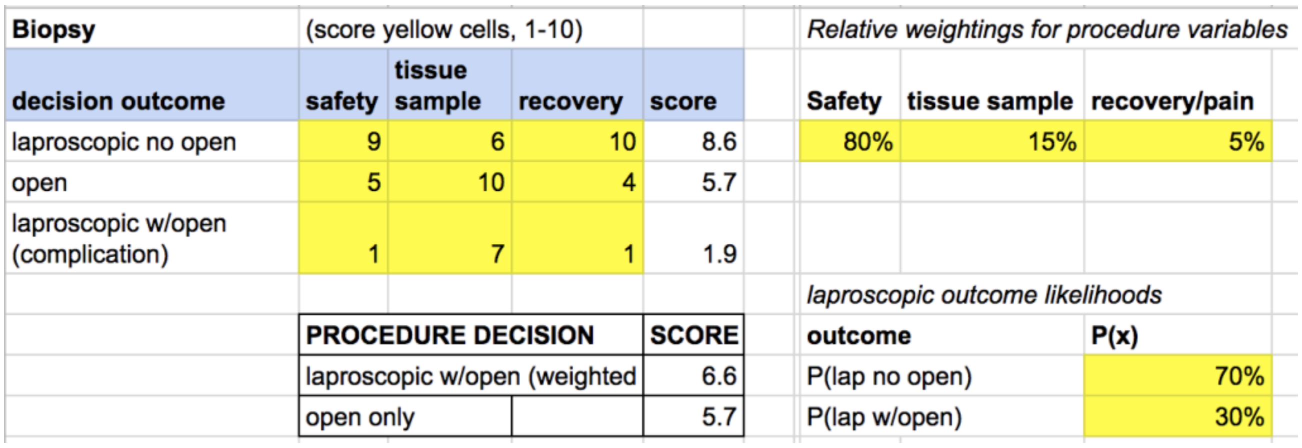
The chemo didn’t cure me.

55.

This week has been filled with surgery consultations, calls with nurses, logistics etc. I ended up skipping the trip w/family to Boston because I needed to deal with this biopsy decision, consultations and etc. I was originally scheduled to have it done yesterday (wed) but that moved to Friday (tomorrow). So I've been flying solo for a few days which is both good and bad. Good because I can tie up some loose ends and get stuff done around the house and catch up with some folks I haven't seen; bad because I'm not with family during the holidays – which is a real bummer despite facetime/technology.

The biopsy is much less straightforward than expected. Turns out the location of the tumor they are sampling is non-ideal. Specifically it's attached to the mesentery which supplies the small intestine with blood. Injuring this area would be bad. So the original plan was to needle biopsy this area laproscopically using 3 ports: 2 for navigation/cutting, one for visualization. But a needle would poke the tissue blindly too close to that area. Another surgeon available looked at the scans and suggested doing this open where he can use his hands and stem any bleeding manually. Why screw around? This would be a 6″ cut down my abdomen – WAY more invasive than originally planned, or than the original biopsy. But potentially safer despite 2-3 weeks of recovery. Ugh!! This is a balance of safety vs. recovery vs. getting the best sample possible. And of course all this is in the bigger context of time and planning. Again I want this done asap. There is no perfect in these kinds of situations.

I requested a call with the surgeon that wanted to open me up. The surgeon and I aligned yesterday on a compromise – he will first attempt to do this laproscopically. But he will not use a needle but rather some other cutting tool. If he gets into trouble or can't get a good sample he will then shift to open surgery. I put together a quick model below to ensure I wasn't missing anything glaringly obvious and that this approach makes sense.



Biopsy	(score yellow cells, 1-10)			
decision outcome	**safety**	**tissue sample**	**recovery**	**score**
laproscopic no open	9	6	10	8.6
open	5	10	4	5.7
laproscopic w/open (complication)	1	7	1	1.9

PROCEDURE DECISION	**SCORE**
laproscopic w/open (weighted	6.6
open only	5.7

Relative weightings for procedure variables

Safety	**tissue sample**	**recovery/pain**
80%	15%	5%

laproscopic outcome likelihoods

outcome	**P(x)**
P(lap no open)	70%
P(lap w/open)	30%

In the model laproscopic w/open scores close but higher than just doing open surgery. I basically combined the 2 likely outcomes of lap w/open to derive a single score for the decision to go with this approach. Note that lap w/open specifically means starting with laproscopic with an option to switch to open surgery should a) complications arise, or b) the surgeon can't get a good tissue sample. I think the decision output makes sense despite the weightings and scoring system being complete SWAGs (medical friends please chime in if I'm missing something obvious; one example might be inclusion of surgeon quality though I really haven't been able to find a way of assessing this except back-door knowledge through other surgeons which is obviously time consuming and not scalable). Based on this I don't see a strong argument to ONLY do open surgery. As I see it the main way this model could be off is if I'm grossly underestimating the risk profile of the laproscopic procedure, e.g., regarding intestinal damage (which would require a resection) or bleeding, but based on conversations with 2 Kaiser surgeons and one friend who does this kind of thing (thanks Charleen!) I don't think this is the case.

Meantime the whole family is in Boston. They'll return on Friday evening. My brother is flying in tonight to support me while Michelle is out and to help with all the things that need to happen (e.g., transition to/from hospital) – whenever that is. This is supposedly outpatient but if they move to open surgery I'll likely be staying overnight, possibly more. So there's a very real possibility I'll be spending new years in the hospital. And for sure in lots of pain.

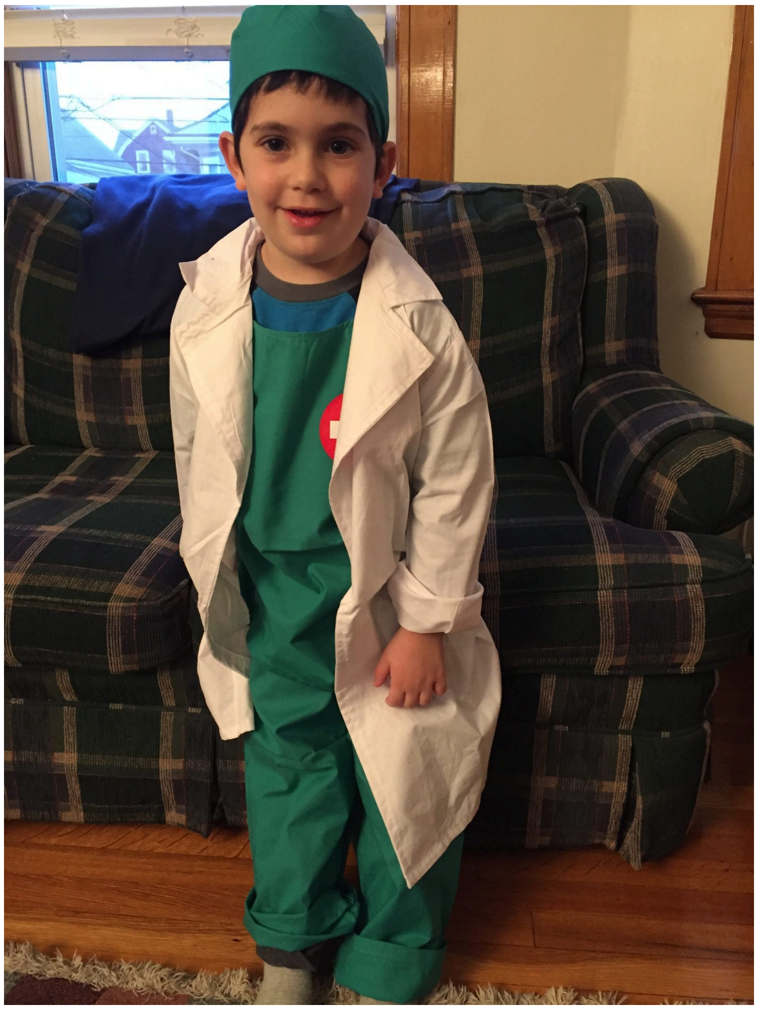
The other day I treated myself to a movie – first in I can't remember how long. I saw free solo on Christmas. This was the perfect movie for me to see given my situation. I cannot recommend it highly enough, whatever you think about the 'sport' of free climbing (lots of people plummet to their deaths). The one sentence summary is Alex Hannold climbs El Capitan in Yosemite without ropes becoming the first person ever to do it. But this really doesn't do the film – or the staggering accomplishment – justice. The stakes are perfection or death. The cinematography is phenomenal. But what's most interesting is the mindset and psychology of such a feat. And the training and strategy to prepare himself. He essentially breaks up the wall into 6 main sections. He works each one with ropes until his comfort level is so high that it totally eclipses his fear (a quite fascinating way to think about fear). There is a fundamental and raw element of the human spirit on display. This is worth watching if only to check your own values against someone who likely differs from you in significant ways. For example he is non-materialistic (lives in a van), abhors comfort (obviously), and is willing to risk his life for what he loves (would you?). I found myself relating to him despite our significant differences. Going through cancer one realizes how precarious life is. This type of rock climbing heightens that sense and I suppose that's a large part of the appeal; living on the edge quite literally. Anyway as a metaphor for life it's perfect. At one point he says his main value is performance and the warrior spirit, while his girlfriend values comfort. It's interesting to see how this psychological oil and water mix.

56.

Today is the day – heading into the hospital shortly for the biopsy. Eli is here helping support me – he flew in from Boulder last night and it's amazing to have his company. I'm still anxious to get this done. Getting this scheduled during the holidays has not been easy. I'm also nervous in part because I've seen this kind of routine surgery go wrong. My father was injured and had to retire early because of a surgical slip-up on a fairly routine procedure. My head goes there – it's probably why I'm ~~such a pain the butt~~ so meticulous when it comes to this stuff. But that line of thinking isn't helpful now that the decision is made. Now is the time to let go, have some faith in the surgical staff and stand on the confidence/ knowledge that I've done what I can within reason. I might do better in considering surgeons as the professionals they are and equivalent to pilots (high rate of taking off and landing well!). Optimizing is hard, time consuming and stressful and it's hard not to second guess ones-self in a situation like this. Questions swirling: *have I done enough to ensure an optimal outcome on this specific procedure? Am I being hasty? Should I have waited until after the holidays and done a more exhaustive surgeon search to get the very best one? How much signal does one need before trusting something like this? Do I have enough signal? …etc.*

While I don't want to look past this particular piece of the journey I'm also being practical and biased towards getting this done quickly; key decisions about the next line of treatment hinge on this information. Getting second opinions scheduled is also non-trivial – in some cases it'll take 4 weeks to get setup so already I'm feeling pressed against the clock. I felt comfortable on my call with the surgeon the other day (good phone/bedside manner!). I've seen no strong reason to NOT proceed at this point.

Trying to put my nerves to the aside and focus on keeping things calm. Below is Lev in his surgical outfit sending me good vibes – I think it's helping. Maybe this ordeal will serve as inspiration for this little one.



Lev in his surgeon costume. "I'll make you better, daddy" is a common refrain in our home.

57.

I'll get results as soon as tomorrow or early next week.

Meantime I've been getting second opinions setup. It's time consuming. So far I've got a meeting setup with Dana-Farber in Boston. After some back-and-forth we agreed to do this by phone (it was originally supposed to be in-person). This will happen once the results are in. I'm also working on Stanford but this requires a referral from Kaiser that is not likely to happen (even if I'm paying out of pocket!). I've got low odds on this one happening in any reasonable timeframe as appointments are booked a month out. I'm hoping to be well into second-line treatment by then. Finally I'm also setting up an appointment with UCSF. Yesterday I had to drop off cd's of my PET/CT results at the UCSF hematology center (yes, like by hand – it still works that way). I was struck by the contrast of gorgeous SF bay area views from the Parnassus campus against the cold reality that most folks in the waiting room were getting bone marrow transplants (masks required just to enter the waiting room). I appreciate these views – don't get me wrong – they are stunning. But it almost feels like this sort of activity should all be happening somewhere else. Somewhere subterranean. That would better reflect my levels of comfort with the whole thing. It's like view magnificence is inversely related to the gravity of the situation, to how mentally trying it is. It feels like a balm or numbing agent, much as I appreciate it. There's a fighter's mentality that can easily get lost in too much beauty, certainty and comfort. That mentality is required in situations like this.

Imagine something that stressed you out: those envelopes for college admissions that came in the mail (fat or skinny), waiting for exam results, 360 performance reviews, or getting on the scale each morning if you're trying to lose weight. Or choose your favorite form of suffering. Then raise that feeling literally to the level of life and death; like poor test results equals "you live" or "you die". It requires some adjusting. I could never get comfortable with fate coming to me in an envelope or a phone call. Usually one has an indicator of how they did, or at least how well they prepared for that exam. Here though, preparation is not related (or at best is least loosely connected) to outcome.

But our fate isn't sealed! It rarely is. I find it helpful to think that the plinko chips of circumstance sometimes get nudged (sometimes hard) in a certain direction. How one deals with the circumstance is of equal or greater importance than the circumstance itself. We play the hand we're dealt. I'm bracing my mind for bad news (good news takes care of itself!). No point in wishful thinking here. I'm nervous. But it's not as bad as I might have thought. I've had some time to acclimate to this new normal. I've already absorbed some hard blows so I know what it feels like. That doesn't make it easy. But maybe it'll sting less.

58.

Pick a good dream.

The anesthesiologist tells me this is her only requirement. This task was not as easy as it sounds. I found myself getting slightly anxious about not having catalogued my dreams. What if I don't wake up? What's the last thing I want to be thinking about? How could I not have a ready playlist of good dreams? I had never really indexed them in any proper way!! fool! I ended up thinking about Michelle, the kids, wedding day, births, hikes in nature… then my mind drifted to something physical, kinesthetic, visceral – sailing on the Narragansett bay on a small craft (a sunfish). I could feel my bodyweight dance with the wind and water. My right hand clenches the cold, rough wet rope as my left hand holds steers the boat holding the wooden tiller. I was "hiking out" leaning back against the top of the boat to keep the forces of wind on sail in balance as the boat hummed along (when you do it right the hull literally does make a humming sound). I liked the contrast of physical/sensory embodiment and finger tip feeling (Fingerspitzengefühl) against my current state of immobility in bed. But I wasn't yet ready for dreamland so I came back to reality.

I was still in the pre-op area. My brother Eli was with me having flown out from Boulder the day before. He brought a book by Jesse Itzler who goes to live with Christian monks. He was reading aloud to me to help calm my nerves. I couldn't stop laughing at certain parts. For example his account of biting into a crispy apple in a room of quietly eating monks (as if they were in a silent movie). We were both howling in laughter when the guy next to me, behind a curtain, starts wailing in pain (couldn't tell if it was mental or physical but it sounded like he was quite literally dying). I kept shooting glances over to the nurse like – *you want to give this guy something*? I felt simultaneously excited to be getting on with this (now that I we had a solid strategy after a week of stressful planning), as well as hyper anxious that I was going to be permanently injured in some surgical error. Anyway the decision was made and I always feel relief when shifting from strategy to execution mode. Now we can focus on the fight. So now it was a waiting game and all I could do was keep calm.

Eli keeps my spirits up!

I jotted down some notes in my black notebook (that never leaves my side – I'm naked without it).

> *Live each day as the last (cheesy but true); light against the dark of nothingness. Let the day emerge as pure joy, you need only allow it to happen for it is existence. And while the arc of life may be suffering, the moment is joy. Polish the mirror and seize the gifts as they are abundant. Dwell less on earthly stressors (you do that too much). Safety/security is found in goodness & love, not the social contract. Continue your seriousness & purposeful conduct – it matters. But the key is to anneal purpose with lightness. Remember this feeling of impending nothingness, of the looming knife cut, as you conduct your affairs. No time to overthink – Act! You will emerge from this successfully.*

Just before going in. Feeling anxious.

The Surgeon Dr. A came in dressed in civilian clothes. He looked like a regular guy that I would have met for a coffee. We spoke for a few minutes. His manner was soothing. I felt again comfortable with him, as I did on the call a few days prior in which we discussed attempting the procedure laproscopically. I asked if he would mind speaking with my friend to which he readily agreed. I called Charleen (my surgeon friend) and they spoke for a few minutes. He walked her through the concerns and details (very candidly, which was actually awesome as he wasn't hiding anything). He handed me the phone after and she gave me her vote of confidence and wished me luck. I thanked them both. He then left and said he'd see me in a bit in the OR.

The nurse then placed an IV in my arm. I'd have skipped this piece of the account as routine except that after about 3 seconds it was obvious she did a poor job with the placement. She then struggled to push it in while I started heavy breathing to deal with the searing pain of her snaking that IV into my vein. 30 seconds later Eli tells her she should give it up and try again in a different spot. As readers by now know I have little patience for this kind of thing, so I said: *"Listen, I've had 6 rounds of chemo and countless blood draws and not once has an IV hurt this much. Can we please get someone over that's more skilled in this department?"*. To her credit she calls over another guy, her manager. He places it in about 10 seconds with no pain – done. Thank you! Eli jumps right back into more reading and laughing – exactly what I needed.

Ok – we're ready. The nurse anesthetist then loosely placed the molded plastic mask over my face. *It's just oxygen*. They wheel me from the pre-op area to the OR. Large automatic doors spring open as I move deeper into the operating theater. White light everywhere. Each room gets progressively colder. We get to the final room. I'm comfortably laying on the bed. They placed warm blankets over me to offset the cold temperature. I'm certain the temperature doesn't fluctuate more than a degree or two and think for a moment how I'd design a study to optimize OR temperature for maximum performance. I quickly turn my attention to the surroundings and instruments in the room. Lots to take in; all this for me. Maybe it was the propofol (had they injected me?) but I was feeling quite relaxed. I fixated on the large light that looked like a circular array of nubbly crystal things. In my peripheral vision I take note of the personnel. The team goes around in a circle discussing their checklist items. In my last post I mentioned that I wanted to think of surgery more like a pilot flying a plane. And here they were implementing the best practices from flying (as referenced in the excellent book, the checklist manifesto)! Once they completed their round (basically the equivalent of a standup in the tech world) I removed my mask and told the team that witnessing this was very confidence inspiring. Then I wished them all good luck, placed the mask back over my face and inhaled deeply of the sevoflurane.

That was it.

There's a moment when you wake up from surgery when your world is suspended between various possibilities. *Was it successful? Did something go horribly wrong? Am I in one piece? ….*

Me: Opening my eyes I see a faint outline of blond nurse. I soaked up that moment of uncertainty. No pain. Good. I knew I lagged behind reality. *How did it go?*

Nurse: *Dr. A. was able to get the needed tissue sample. And he was able to do it all laproscopically! No residual damage – it was clean. You have 3 small cuts in your abdomen. It was a great success. We'll keep you overnight. You're very lucky.*

I let the news sink in for a very long moment. I'm so used to getting horrible news these days that it took a few extra beats to process the magical feeling that something went well! I floated on a cloud of joy. I'm still floating as I write this days later. This was the second surgery I've had in my life but certainly the most involved (first was a hernia repair which is routine). And it was the scariest. The nurse and I then spoke for probably 15 minutes. I talked about how satisfying it was to have put together a quick model that suggested pushing for this direction; how amazed I was with Dr. A., and how now all I wanted was to see Michelle and the kids (they'll be landing soon!).

That evening as I recovered in a private room I was totally high. Eli was exhausted and I kept talking and talking. He must have told me to shut up (nicely. *But how are you not tired! what's wrong with you?*) about 8 times but no matter. On and on…I was so happy to be alive and functional. Had we gone with the open surgery approach I'd have been in the hospital 5 days to recover. Then It would be 3-4 weeks of further recovery at home (no lifting etc). Instead because this was done laproscopically it was just an overnight stay and ~10 days no lifting. And I would go home to celebrate Lua's 2 year birthday! Meantime my friend Abe grabbed the car and went to the airport to pickup Michelle and the kids (thanks Abe!). What a team effort!

The next morning the surgeon came in and we de-briefed. He was very pleased about how it went. He paid me a complement for being diligent and pushing for laproscopic.

3 stab wounds. And it feels like it. But the alternative would have been WAY harder.

He said that MOST of the time this kind of procedure ends up going open surgery (called laparotomy) but it worked out very well. I thanked him again for his incredible bedside manner, his flexibility in approach, his willingness to take a few extra moments to talk to my friend, and his skillfulness in getting the job done. I then asked him why the procedure took so long (>100 minutes vs. estimated 60) given that he didn't have to cut me open. He said that most of the time was actually spent on the phone with both the oncologist and pathologist. He wanted to ensure he got exactly the right tissue from the right spot and that he got enough for them to do their jobs. I was blown away. This guy is a 10/10 and to me reflects what a professional doing a job right looks like. Sometimes my faith in people gets restored. This was just what I needed. Talk about good fortune!

So this is a terrific win and I will celebrate it for all it's worth. I got home the next day and was already walking around (painfully, but still). We celebrated Lua's birthday with cake – the big payoff!

This was just a step with many more to go. The tissue will now be interrogated with flow cytometry (to sort/assess various cell populations), and various cell staining techniques. I should get those results end of this week or a bit after.

On the way back from Boston – wishing me well (they were in the air as I went into the operation)

Mission accomplished. Happy birthday Lua!

59.

Friday morning I got a call from a 617 number. My phone was across the apartment and I nearly missed it. Out of breath I pick up the phone. *Hello*? *Hi Ari it's Caron*… It was the Dr. from Dana Farber for my second opinion. She got the results through the automated 'EPIC' system. *Wow I haven't even connected with my own doctor about it yet.* We talked for 30 minutes. Here's the current situation:

First off she had some questions about the pathology report as there were some conflicting pieces or at least open questions. She recommended getting a second pathology report at Stanford (she reached out to a colleague there so we'll see). Also they classified the resistant cells as '3a' (called follicular) vs. the original '3b'. Essentially these are slower growing cells with a different profile, don't ask me specifically how they differ as I'm not there yet. I'm still wrapping my head around what it means, exactly how many populations exist, etc. This likely won't have implications for second line treatment but it would impact next steps if second line fails.

She mentioned that whenever first line treatment fails she gets concerned. I asked what percent of the time it fails, she said somewhere around 20-35%. But she also left the call emphasizing that I should feel like there is still hope and that I should remain optimistic. Even if it is follicular there have been lots of innovations in the past 3 years on this front. Specifically there is a new treatment called CAR-T which basically removes a patient's T-cells and engineers them (by adding new genes that code for specific proteins) to recognize and attack the cancer. Of course this depends on what targets are available and whether the T-cells can be engineered against those, but I'm getting WAY ahead of things here. Anyway if this is follicular it seems there is no CAR-T option (at least not yet). So confirming the pathology report seems important assuming there is sufficient tissue to do that, another question.

The 'good part' about where things stand based on this opinion is that second line treatment is mostly standard and aligns with what I mentioned in a previous post: 2 rounds of another type of chemo; assuming that works it's followed by high dose chemo (wiping out the stem cells) and finally an autologous stem cell transplant to repopulate the stem cells. This is still a 'curative' path with a decent chance of success. What's decent? The second line treatment success rates seem to be somewhere in the neighborhood of 50%, maybe better (I've heard 50% to 80%) based on what the docs have told me thus far. By the way that means 20% to 50% failure rate. For folks aware of prospect theory (see the chart p.279) the latter framing is WAY more scary because we are loss averse creatures. Doctors are smart in focusing on the treatment success rates.

But regardless my anxiety level spiked after the call despite that it reinforced the likely path forward…or maybe because it confirmed it?….or maybe it's reality sinking in that I'm signed up for at least 6 more months of treatment…or maybe it's that having more details brings more mental overhead and uncertainty? Or perhaps the real issue stems from the overall trend that when I dig in on these conversations it not only confirms my own ignorance (that would be fine!), but our collective ignorance in treating this disease. We're smart but still groping in the dark. For all the stats that get thrown around when it comes to making decisions we don't get to average results over multiple treatments. We each have only one body.

I'll discuss these results with my oncologist this evening. More to come…

60.

Last night I had a call with my primary oncologist to review the results. Not much has changed regarding the treatment path he outlined earlier. I'll apologize in advance as there's a bunch of jargon below that may not be easy to parse. This post is as much to clarify my own thinking as anything:). With that said here's the current status:

Next steps:

1. We're still waiting on a FISH study to verify genetics (specifically expression, translocations etc for myc, bcl2, bcl6). Not sure if there's anything else they look at. Report should come back later this week/early next. This could change treatment path if it's different from original 'double express' designation. Note, it could only thicken the plot but no point speculating until we get the report. Generally it looks like the same tumor with some minor anatomical differences.
2. Kaiser will re-review pathology report internally (was nudging hard). He thinks it's more like follicular 3b, not 3a per the anatomic histological characterization (the staining), but it's a subjective call and likely somewhere in the middle. I'm still a bit unclear how to think about this terminology as it's always been 'follicular' 3b and called DLBCL. Apparently grades 1,2 follicular are managed paths (not curable), whereas 3+ is still curable, and I definitely am a '3'. From his standpoint it seems the designation wouldn't change 2nd line therapy. He mentioned that CAR-T (where they engineer one's own immunity) is only an option if 2nd line fails, so that's another open question.
3. If 2nd line fails then I would likely move to CAR-T therapy at Stanford. That would still be a curative path. When I asked about cd19 not being on the report (that's the main CAR-T target) he said it's not part of normal panel and there are complicated questions of sensitivity etc. that he didn't think worth getting into. I guess they'd test for it down the line? Again, not sure how the 3b vs 3a designation bears on the situation. But Stanford would run their own pathology report in that eventuality.
4. We will plan to start chemo within next 2 weeks. He doesn't want to wait 3 weeks.
5. R-gdp is his preference on second line chemo protocol. R-ice is the other one, favored at Dana-farber. He suggested choosing the one with lowest side-effects (apparently there's no test to predict responsiveness). We'll need to discuss this in greater detail before starting. Likely we'll do it once the FISH results come back.

Other notes/open questions:

- It's good that the cd20 receptor is highly present as Rituxin theoretically should work. He put 2nd line odds at 70% success. Proliferation rate is moderately high, not as high as before – also a promising sign.
- If this goes CAR-T and it works there is no autologous stem cell transplant needed.
- I asked about supplementing with bcl2 inhibitors (since that protein is also present on the

report as a potential target) and some friends suggested it. He said he wasn't convinced about clinical efficacy, relevance to this particular situation.

- All tissue was paraffin embedded vs. fresh frozen. Hopefully this wouldn't be a blocker on getting any key information that might be needed for say a second pathology report.
- Is CAR-T avail as second line treatment if 3b or only if second line fails? Worth pursuing?
- Other paths/options to consider e.g., in-vitro tests etc. before jumping into treatment?

Next up I'm trying to get UCSF and more importantly Stanford opinions scheduled. Wouldn't it be great to setup a conference call with the various docs so I'm not the one in the middle – is that even an option? *Is there some service to coordinate conference calls with busy doctors so patients can make more informed choices?*
I'm also thinking about integrative medicine options going into this second line treatment. I haven't really done much on this front thus far. I'm particularly interested in diet/fasting if only because it's controllable. The key here seems to be mitigating potential negative impact vs. possible upside since the data isn't especially convincing when it comes to these areas. No doubt this is a separate post but I currently have 3 areas of interest here:

1. How's the **insulin response,** sugar/glycogen metabolism impact cancer progression? I've eliminated any processed carbs, and generally eat low-glycemic carbs but haven't gone extreme, e.g., ketogenic diets. My understanding is the basic theory is that cancer cells preferentially metabolize glucose (seems that's at least partially true as that's the mechanism via which the radioisotope is selectively up-taken by cancer cells in PET/CT scans), whereas healthy cells can use ketones which are basically broken down fatty acids as fuel.
2. What's the Impact of **animal proteins**, especially on lymphomas? I'm no longer eating meat or dairy anyway (I'll make exceptions if my body craves it). I do eat fish – especially sardines and salmon. Should I eliminate eggs too? Some data I've seen suggests meat consumption is correlated with cancer in genera and in particular with lymphomas. Easy to go crazy here. There's certainly a venn diagram with small overlap between ethical eating
3. What's the deal with (intermittent) **fasting**? I've reduced my eating window to about 10 hours per day or 14 hours fasting per day. All that means is that I stop eating early in the evening and start around lunch most days. Seems a good 80/20 solution to this from what I've read. I haven't gone beyond 24 hour water fasting but there's apparently lots of interesting info around this that I'm not up to speed on. I'm doing that while not trying to lose weight but I've lost 3-4 precious pounds in the past two weeks. Surgery involving moving my intestines around probably didn't help there. Also this has been easier than usual because my appetite is complete crap, so I may need to rethink this. Again the key in all of this is remaining pragmatic and not over complicating it. All the above are fairly simple to implement, relatively non-controversial, and with little downside (Keto is the only one that fails this criteria but still seems interesting). Anyway I may find a specialist that focuses on this.

The oncologist wanted me to leave the call still feeling encouraged at the chances and that there are many options still available. So of course, one decision at a time. Meantime I'm doubling down on efforts to stabilize my perspective with meditation. Things are getting harder and I can tell my anxiety levels are increasing (at least I'm aware of it!). It can sometimes feel like each new piece of information is pulling reality out from under me. The key it seems is to achieve a much higher degree of comfort with uncertainty (or impermanence, if you prefer), which is especially hard with a family.

Finally, amidst all this I'm going to try damned hard to enjoy the next week+ to whatever degree possible before I jump back into treatment. Seems the best case is I'm on the other side of this just as the kids' school year is ending. That said I'll know around March if second line has been successful; that's my Q1 objective. I'll try to stay encouraged that the treatments are all curative and that two opinions mostly align in terms of second line next steps.

61.

First off I was finally able to get another opinion at UCSF setup for early next week (thanks for greasing the wheels, Mel!).

Then yesterday I got a call from the Stanford doctor that my Dana-farber connection had recommended I connect with (the one she emailed). If yesterday's post hurt your head you would not have enjoyed this call. But I did. After about 20 minutes of listening to his perspective he's strongly recommending I go for a clinical trial specific to CAR-T therapy as second-line treatment. Not sure how to think about bias here – are our incentives aligned? As next steps he will connect with my oncologist (who he already knows) and they'll see if Kaiser would make the referral. Stanford would still need to run an independent pathology report and validate some of the cellular targets (CD19, CD22) and that I'm actually a candidate.

He called into question the stats I'd been given, citing less than 50% odds of second line working when taken along with the autologous transplant. Also it seems the outcome of second line isn't always as clear as yes/no, often it's percent response. So it's somewhat more complicated than has been presented thus far. I must say that despite some sobering information I liked this guy instantly if only because he strikes me as a straight shooter that's willing to go into details.

I might have been a bit dismissive based on just the information that he's recruiting for a study. But something interesting here is that he and I seem to be on a collision course via 3 possible futures: (1) if second-line treatment through Kaiser succeeds, I would see him for the autologous stem cell transplant as that's also his area, (2) if second-line treatment through Kaiser fails then I would likely move onto CAR-T, which is FDA approved as third-line therapy (and my understanding is it would also go through him), or (3) I do this clinical trial mentioned above as the second-line treatment.

What to think? At this point I'm triangulating opinions and taking whatever any single person tells me with giant doses of skepticism. What's especially challenging from a patient perspective is thinking independently about these decisions, they often hinge on asking just the right question of the right person; the issue of unknown unknowns looms large. Therefore trusting one's doctor is important. But it's also important to not trust them too much as they have their own biases & blind spots.

The nuts and bolts here are that if I were to go down this road (and I'm not signing up for anything yet), there's a 50/50 chance I'd get standard treatment vs. the CAR-T therapy. By standard treatment I mean I would get identical treatment as what I'd get through Kaiser – including that I could still choose the specific cocktail. All this would happen at Stanford.

I'm still trying to understand the pros/cons of the various approaches. From what I gather thus far the potential benefits to CAR-T include that the success rate seems quite a lot higher (more than double, according to him), is faster, has equal complication rates (different issues, but equal rates), avoids chemo and all the side effects, and no need for the stem cell transplant if it's successful. While on paper it's intuitively appealing to bypass chemo entirely and have my innate immunity kill the cancer, there are so many pieces I still need to understand before bring in any position to decide on a path.

My head is spinning and the whole thing is emotionally taxing. At this point I'm seeing this as little more than one more (possible) option to weight against standard of care second line chemo. More to come as things progress…

62.

I **WILL** get through this.

But I'd be lying if I didn't confess to the fact that I've been having some serious anxiety the past week. I'd have thought that with time things would smooth out and I'd get more comfortable with this situation. But the truth is that as I've been recovering my energy and strength (slowly but steadily) I've been feeling more anxious. I'm not stressed because I'm feeling bad; I'm stressed because I'm feeling good. Not that I'd want this but paradoxically I think my situation might be easier if I felt worse physically. The differential between how I feel and what I intellectually know about my condition is widening (feeling good, but complicated cancer).

The other piece is that the conversations I have seem to present an ever increasingly bleak outlook – or my mind is spinning it that way. For example yesterday I called the lymphoma & leukemia society (LLS). I spoke to them briefly before starting first line chemo but didn't get much out of it. Now that I'm further down the treatment rabbit hole I figured I'd give it another try. I can tell there are knowledgeable folks to help guide decisions and talk through situations. I spoke with a very knowledgeable person for 15 minutes to explain my status and talk things through. I'd have thought the path I'm going down is somewhat well understood – one would think that first line treatment has to fail fairly often… and it's not like NHL is a rare disease (though it is highly variable with something like 60 subtypes). But I was thinking there are more options than may actually be the case, e.g.,

Me: *so pre car-t therapy (which was only FDA approved for third line treatment of my disease in Q4 2018) what was the standard course of treatment if second line failed?*

LLS: *various clinical trials*

Me: *Really? That's it? There was no real third line treatment?*

LLS: Well *that's why everyone is so excited about car-t therapy. Of course we have no long term data. And there are extremely long wait lists to get the treatment so doing this as second line treatment might be worth looking into if that's an option…*

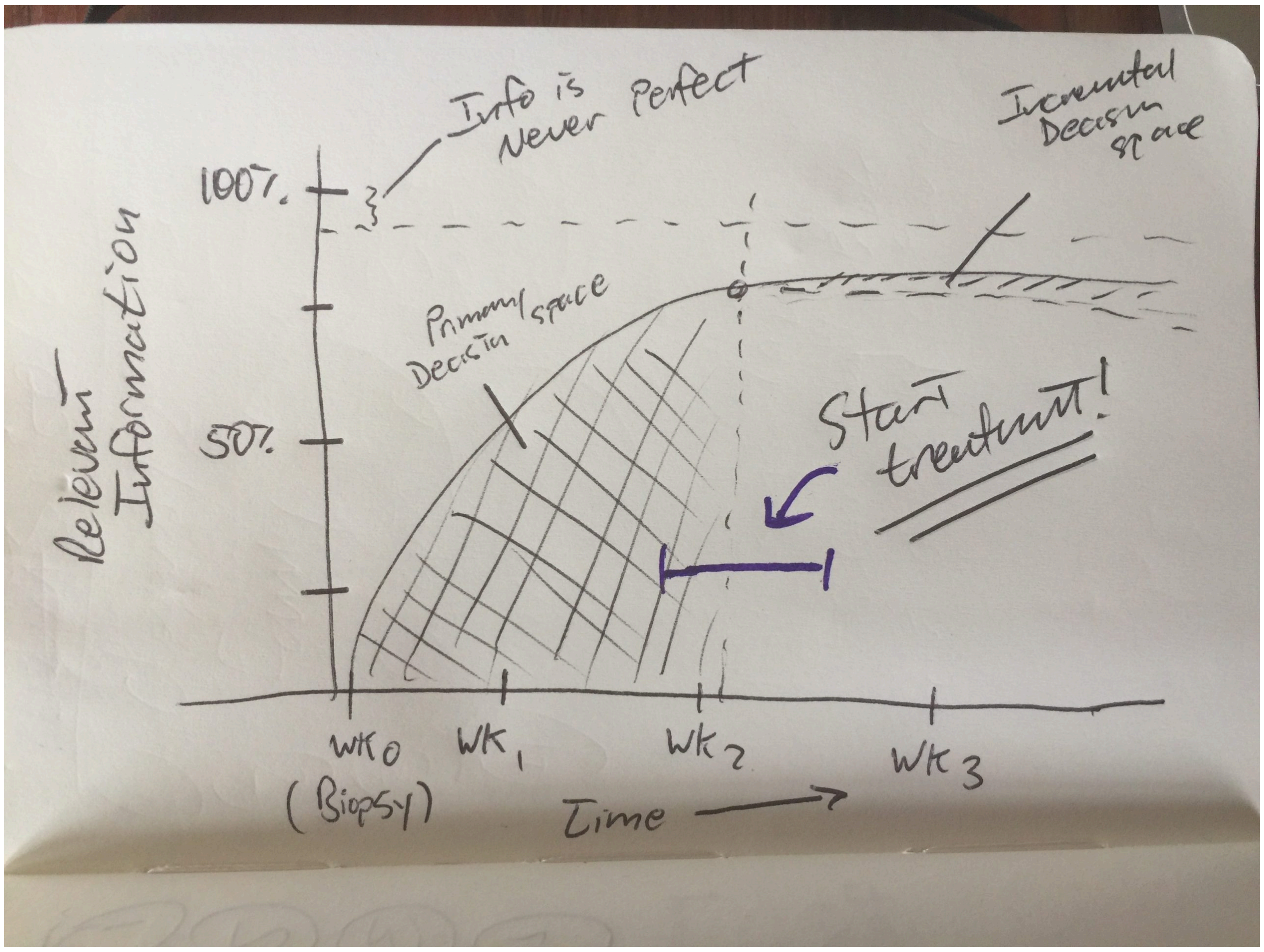
As a next step LLS is going to support me by connecting me with a clinical trial coordinator. My understanding is they help navigate this world, which includes looking through which ones might be relevant to my specific circumstances. One more arrow in the quiver. The fact that I'm even here writing about this, considering trials is frightening, one of my worst fears. Like in the past when I would think about horrible scenarios this is definitely up there, along with various wartime situations not worth discussing. Frankly keeping this blog has been a lifesaver for me to vent this stuff in a hopefully productive path rather than spinning my brain like some tether-ball around a pole of fear.

Then yesterday I lost my cool on the phone with Kaiser. Turns out I won't get genetic tests until next Monday, the 21st. That's over 3 weeks post surgery! While it takes 2 weeks to run this (FISH) study I do not understand why it would take a week to send – or at least start processing – this. I could certainly understand if there was there some backlog due to holidays or some other reasonable explanation, but I have yet to hear it despite my inquiries. I feel like I'm in the dark about what they may (or may not) be working on. It's incredibly frustrating as a patient trying to quickly sort out treatment options.

Meantime I'm focused on keeping calm amidst this 2 front war: body on one side, medical systems/decisions on the other. For the past week or so I've been feeling quite strong (now that I can move mostly without pain in my mid-section from surgery) so I've been starting to exercise again. That's always been my standby solution to challenging times. So I workout and visualize cancer as the enemy. I've been doing hard intervals on the bike and some strength training. Sometimes I'll close my eyes and grind out a hard interval while I visualize defeating the cancer. It's odd, I'll admit but it definitely helps address the anxiety. And it's a great mechanism to help me to assert a feeling of control over this situation; fine, I'm not into judging myself much these days. Of greater importance I've noticed that over the course of chemo I gradually drew down my strength reserves. I'm doing what I can to build up those reserves before jumping back in.

63.

How much uncertainty is tolerable when making a life and death decision? And what are the forcing-functions on that decision? I really like what Jeff Bezos says in one of his annual letters about one-way versus two way doors: 2-way doors ought to be made with a bias towards speed over perfection (you can always go back or iterate the decision). One-way doors in contrast are non-reversible and ought to be made with great care and deliberation. This second-line decision is clearly a one-way door…and I'm getting kicked through it from behind!

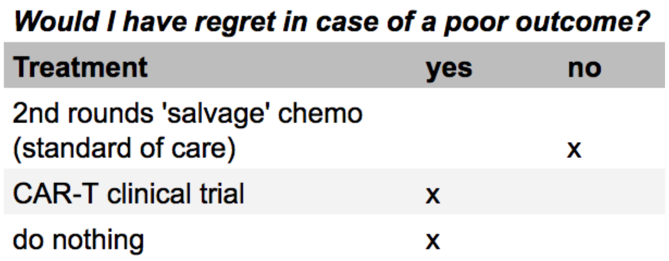


Schematic of decisioning second line treatment (pardon my quick scrawling). Y-axis is relevant decision info vs. time. There is no perfect information and much that will never be known. The majority of the relevant information must be gathered within 2 weeks (big shaded area), with incremental utility coming after that (small shaded area). Not shown: there is risk to dragging a decision out further than week 2 as risk of cancer progression.

As with any decision there is a key distinction to be made between the decision itself and the outcome: sound decisions can turn out badly, poor decisions sometimes result in success. But lucky outcomes over time tend to favor the better decisioning process, while any single decision may not. So the mental framework I've adopted here is to saturate my information gathering space such that I'm in the best possible place to make an informed decision under a hard constraint of time (see schematic). In this case that’s roughly 3 weeks from the biopsy (affording for context-specifics like exploring any clinical trial options).

Thus an important question I’m asking myself is which option minimizes regret in the case of a poor outcome. For example, if I did a trial for CAR-T and it failed (though on paper the odds might look better) I would likely have regret for not having tried a standard of care treatment with a reasonably decent chance of success first (see table below). That’s a strong argument against CAR-T as a 2nd line option. I’m about 85%+ convinced that going the standard 2nd line treatment is the way to go. I could see reversing this viewpoint if either I get new information from my conversation with Stanford specific to 2nd line outcomes, AND/OR if there’s some ‘gotcha’ about 3rd line CAR-T options that changes the landscape (say unavailability of the drug which I’ve heard can happen, payment issues, outcome changes given that 2nd line failed, etc). Before I start treatment I want to ensure I fully understand how exactly CAR-T would be an option (see questions below, e.g., *where would it happen, which manufacturer, etc.*) for me, should I need to move onto 3rd line treatment.

For all the talk about valuing independent thinking in our society – and especially in silicon valley – it’s a challenge, and perhaps of questionable merit when it comes to making complex medical decisions. Going against standard treatment options or recommendations is a form of mild heresy.



Would I have regret in case of a poor outcome?

Treatment	yes	no
2nd rounds 'salvage' chemo (standard of care)		x
CAR-T clinical trial	x	
do nothing	x	

But as situations become increasingly desperate and odds of success dwindle there is probably some threshold whereby it becomes sensible to start thinking more laterally, more independently. I’m not saying this applies to me at this point but it is something I think about as a person that likes to reason for himself. It’s worth asking questions and ruling them out for ones-self versus not considering them in the first place. For example, I’ve been pushing to start treatment IMMEDIATELY. But if I think more holistically I can ask the question: what if I sit on my hands and do nothing for 3-6 months here? Part of the motivation might be to see if yet more treatments come online as there’s much in the current FDA pipeline. No medical professional would recommend it. It’s like the bioinformatics joke my friend Mike tells about protein folding problems… *Protein folding problems are hard under any circumstance. The PhD students in his group would sometimes ask whether they would solve the problem more quickly by hitting their head against the wall NOW, versus putting the problem aside, playing hookie for 6 months, then coming back to it then. Counter to intuition, and assuming Moore’s law holds (computational power improves markedly over that period), the latter approach might sometimes yield a faster result.* It’s not meant to be laugh out loud funny but it illustrates the point well.

You might be this very moment thinking that the chemo has compromised my ability to think straight for even going there. But there are documented cases – at least one – of spontaneous regression/ remission in aggressive B-cell NHL; life is certainly weird. And a quick skim of the literature suggests these rates (>=10%, at least in the more indolent types) warrants further investigation. Which means we don’t know enough about it to make any kind of substantive claims one way or another…which means it’s not a topic of conversation and hence, for practical purposes doesn’t exist in the possibility space of options. Don’t worry – that’s not what I’m going to do. While it may take a bit longer my bias is to consider it and explicitly rule it out versus not thinking at all about it all. I really take this seriously and want to consider every reasonable possibility, if only for peace of mind.

I’ll do my best to summarize where things stand after taking in a LOT of information. You’ll have to bear with me if this is dense as I’m trying to synthesize a ton of information and not sugar coat anything.

To paraphrase (French mathematician) Blaise Pascale *"I'd have written you a shorter letter if I had more time"*.

UCSF second opinion:

Tuesday I met with a UCSF oncologist. I wasn't expecting to get much from this apart from validation about what (I think) I understand. I'm paying out of pocket for all these other opinions. And it's money well spent. The goal here is to maximize the useful information I get toward making a decision within a very contracted timeframe. This was supposed to be a one hour conversation, which seemed like more than long enough. We ended up meeting for nearly 2.5 hours. We didn't start until around 4:45pm and ended at 7:15. I first met with one of the fellows. "*I've read a lot about your case*" she said. "*I can't believe you exercised through R-CHOP. I haven't seen anybody do that!*". She then inventoried the questions I had for the doctor before bringing him in. I rattled off some of the questions I've been pondering. "So *how did you get so medically literate?*" she asked. "*I probably just take more of an interest than most patients*".

First off we went through my information on EPIC. Because I took the time to read through the pathology report, have been studying this quite a lot lately, and have been having many conversations with knowledgeable folks, we were able to go VERY deep on various issues. Not only was I incredibly impressed with the level of answers (at one point we were sketching outcomes on paper), but his willingness to go there WAY beyond anything I've seen thus far; I expected him to kick me out after an hour but we kept on going until he was sure I was satisfied. Extremely impressive. I walked away feeling like I took a step-function jump in my understanding and comfort level in terms of proceeding with standard line therapy. I've now got nearly sufficient information to press ahead. After the meeting the fellow actually came in and thanked me, "Thank you for going so deep and probing so hard, I learned a TON in this conversation". I thanked her but said that of course I was the one now better informed. UCSF must understand the placebo effect and must be banking on those non-trivial effects by boosting patient egos:). I'll take it! Here's a summary of the discussion and where things currently stand.

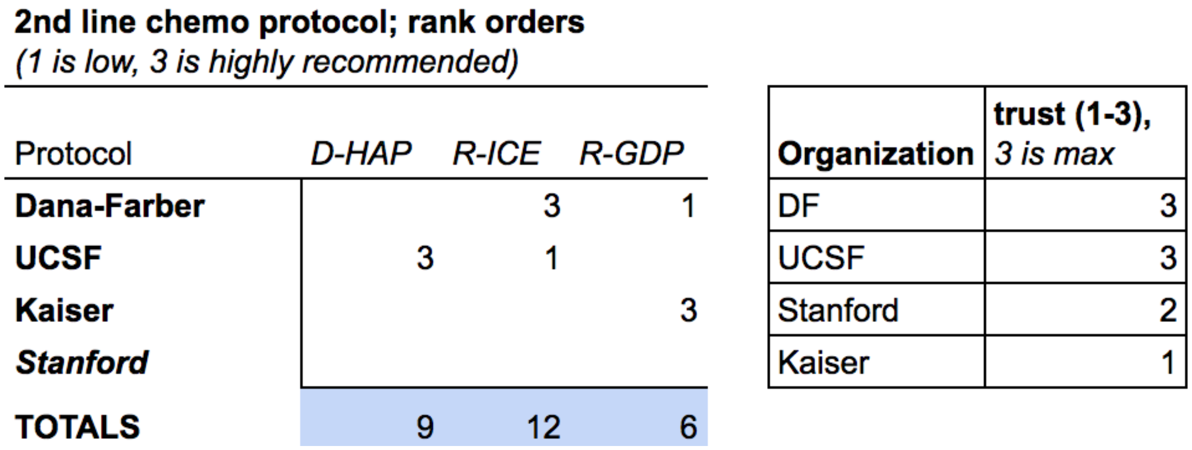
Diagnostics:

Kaiser told me the genetic study wouldn't come back until Monday (per my last post, when you'll recall I lost my cool). Turns out the FISH study was in the system after all! So I got my results from UCSF before I got it from Kaiser. That's the second time in as many weeks. Ugh Kaiser! Anyway the news is good there that I don't have any genetic mutations, all negative, which is great. That information could really only have complicated an already complex situation but I'll take the small win where I can get it!

For Non-Hodgkin's lymphoma, at least my type, there's a continuum from follicular to large b-cell lymphoma (DLBCL), with the former being slower growing/less aggressive and the latter being more aggressive. Follicular is manageable whereas DLBCL is curable. I'm somewhere in the middle. For that reason I always thought that, given a choice, DLBCL is better assuming you catch it. But turns out the odds of curing it if first line fails are not so high and therefore options get limited with each subsequent treatment – basically Russian roulette. The doctor basically rebutted the argument saying effectively: *would you prefer to live a normal life managing cancer (if follicular), or roll the dice on curing it and possibly not succeeding (DLBCL)?* This was a VERY hard conversation.

Standard treatment

There is still some disagreement about which protocol to use (see table below). Specifically, the recommendation from Kaiser is to use R-GDP as the chemo protocol. UCSF explicitly recommended not doing that one, opting instead for D-HAP or R-ICE due to my 'ABC' subtype. Note these are 3-day inpatient treatments, not outpatient which reflects that they are ratcheting up the toxicity. The second line chemo has a 50% response rate.



2nd line chemo protocol; rank orders
(1 is low, 3 is highly recommended)

Protocol	*D-HAP*	*R-ICE*	*R-GDP*
Dana-Farber		3	1
UCSF	3	1	
Kaiser			3
Stanford			
TOTALS	9	12	6

Organization	**trust (1-3),** *3 is max*
DF	3
UCSF	3
Stanford	2
Kaiser	1

Triangulating various professional opinions on second-line chemo regimen. I'm considering 2 dimensions: trust vs. strength of recommendation. R-ICE scores highest across 3 opinions, though I'm still waiting on Stanford recommendations.

It's important to understand that this is only part 1 of a 2-part success story. If it's successful I then move to high-dose chemo and autologous transplant. The success rate of that (combined) procedure is 60%, meaning there is no recurrence (I think this is measured on a 5 year timeframe but not totally clear on that piece). Anyway, taken together this gives a 30-35% overall success rate for second-line chemo + high dose chemo and transplant. That's really the number that I think matters. I ensure everyone is clear in their descriptions because numbers are thrown around without definitions, which is maddening. There's a bunch of fuzzy parts to those rates (age, attitude, strength, my specific mix of cells; 3b, 3a, not sure about gender, etc), that I've not been able to segment out. But triangulating all these opinions the overall rate is likely somewhere in the 30-40% range, maybe 50% if I put on rose-colored goggles. Turns out that a mere 3 years ago second line treatment was the last standard care option and if you fail that (at least with a DLBCL diagnosis) the outcomes are poor. Only recently has Car-t therapy started to offer a (very expensive, $500K) third-line option. I've been told that should be encouraging news and take some of the pressure off. Easier to say than to actually feel.

I want to get to a place where the autogenic stem cell transplant is an option as that provides a curative outcome with long term data (30+ years). Again, it's not the transplant that's curative but rather the high dose chemo that precedes it (think: rebooting your computer hard drive). The transplant is a means to repopulate my stem cells after they've been destroyed by chemo. By the way the reason they don't jump right into the high-dose chemo (I asked) is that it's not likely to succeed if the second line didn't show response. Also, they wouldn't use radiation to zap the tumor here either (I asked), as that would be a local solution to what's a systemic issue. Makes sense. In case you're curious this will be assessed with CT/PET imaging and then a system called Deauville score.

Car-T & side effects:

It seems there is not much data on follicular grade '3b' for CAR-T therapy, the current somewhat questionable diagnosis based on first pathology report. The response rates for DLBCL 3rd line are about 35% (I'm hearing different numbers here so I'll verify with Stanford). Also it turns out there are 3 drug makers of CAR-T treatment that all differ in terms of how they are engineered and the side effect profiles. A Gilead/Kite version, called Yescarta is used by Stanford and apparently hits the cancer hard and fast, with a high initial toxicity profile. On the other hand the Novartis and Juno versions are used by UCSF and are slower acting, over 6 months I think, with lower initial toxicity (there's something called cytokine storm which doesn't sound pleasant that seems the main issue, along with some neural toxicity). Essentially the t-cells get infused and stick around longer. I gather both are equally effective and all hit the same target (CD19).

Side effects of chemo:

Me: *So what other long term effects might I expect from the high-dose chemo and stem cell transplant, assuming I get there?*

UCSF Doctor: *"Are you done having kids"?*

Turns out there's a high risk of sterility from the high dose chemo. I haven't thought deeply about this piece but something to consider. If there's anything I'm thankful for on a daily basis it's that I've already had 3 beautiful kids. While we do talk about a 4th – at least we have before this (we want 6 more Lua's!) – I'm happy. This would be even more agonizing if I didn't feel satisfied with that part and was contemplating treatments that result in effective castration. Of course the normal stuff you would expect is also going to be an issue: weakness, possible nausea, neutropenia, etc., but more severe than first line chemo. Sounds fun.

Nutrition/Integrative medicine:

I asked about this topic. There's really not that the medical establishment will say about it. No strong opinions on any of it. He told me to see folks at Osher center for more detailed stuff.

Next Steps/summary:

- I spoke with Stanford coordinator and finally things are moving w/r/t getting that tissue from kaiser and processing the pathology report. I'll hear from them end of this week or early next week to setup an appointment to come in and review with the doctor.
- I finally got that referral and am now getting updates from Kaiser after my mini tirade on the phone the other day. For all my complaints they do seem responsive to (very strong) patient feedback. Let's see if it lasts…
- As discussed above I'm close to convinced that standard second line chemo is my best next move. I think the only remaining piece is if I get some new information from Stanford regarding the possibility of a CAR-T option. Hoping this happens my early next week.
- Validate pathology report w/stanford/Kaiser — align on diagnosis specifics and assess if that changes anything.
- Finalize CAR-T options for 3rd line treatment. Before proceeding I want to know what this looks like in the pessimistic scenario that second line fails. I need to understand several key pieces (outlined below).
- Decide on which specific 2nd line chemo treatment to go with.
- Once I speak with stanford I may circle back with UCSF/Dana-Farber to validate everything, assuming any open questions.
- Align with my oncologist at Kaiser about open questions and fill him in on the information from various other opinions. This will happen this evening.

Here's a list of open questions I've been mulling meantime:

–diagnosis validation–

a) second pathology report @kaiser & what's the status? Is it 3b vs. 3a?

b) Second pathology report @stanford: (1) what's it say? (2) does anything change w/r/t 2nd line? 3rd line?

c) FISH results are negative – does that change anything regarding odds?

–Referrals & financials–

a) Is referral to UCSF an option for CAR-T (different drug specs: Novartis vs. Gilead/Kite) should we need to go that path?

b) Does Kaiser pay for CAR-T as 3rd line as standard of care or is it only supported in the context of studies ($0.5M)? Reason for asking is based on conversation with UCSF where they suggested Kaiser only would support in research context.

–2nd Line: standard treatment–

a) Is referral to UCSF an option for the autologous transplant? All else equal (are they?) this would be logistically easier.

b) Is referral to UCSF an option for CAR-T, or just Stanford?

c) which chemo? D-HAP vs. R-ICE vs. R-GDP? UCSF says R-GDP is not good for ‘ABC’ subtype as second line…

d) odds of sterility post high-dose chemo? How long to recover if it does?

e) Risks/other things to think about here?

–2nd Line option: CAR-T–

a) odds analysis

b) Scenarios:

– are outcomes worse if chemo fails THEN Car-T? What’s the benefit of CAR-T? pros/cons. Seems it’s mostly about the quality of life during treatment itself (and long term effects, e.g., sterility) more than about the outcomes?

– If go straight to CAR-T are we simply missing a ‘shot on goal’ with chemo? Supposing CAR-T failed would chemo be an option at all or is that option simply bypassed?

c) Is there any concern about actually GETTING CAR-T if 2nd line fails/as 3rd line (waiting list etc)?

d) Are there other trials that I should consider or is the one at Stanford the most relevant (follow up LLS on this piece)?

e) What do we know about my specific pathology (follicular 3b) and CAR-T?

–3rd Line Treatment–

CAR-T:

a) where I would get this? Is a trial necessary?

b) would Kaiser refer/pay for this?

c) is there a waitlist or other ‘gotcha!’ to be aware of?,

d) which specific product would I get (kite vs. novartis),

e) validate my eligibility given the specifics of the pathology report.

–Other thoughts/peripheral questions–

a) China studies? I’ve heard they may actually be farther along than US for this?

b) Thinking about last resorts and allogeneic transplant if 3rd line fails…do siblings need to see if they’re a match? Should I start checking databases/if so when to do that?

c) What if I adopt a wait-and-see approach and sit on my hands for 3-6 months? Let’s talk about specific issues with this:

*Is it that the tumor grows quickly and the tumor burden is higher when I do treat?

*That it spreads (will this type spread too?) and does nasty things?

*might the cancer morph, say from less favorable to more favorable type?

*something else?

64.

Bruised

Every morning for the past month I've gotten out of bed feeling like I was beaten. My back takes a very long time to feel close to normal. I'm constantly stretching and twisting it waiting, hoping for some vertebrae to pop into position. Regardless what the cancer is doing (something, nothing) there is still a tumor behind my intestines the size of a tangerine. I have to assume that is the root cause. I did a week of yoga to test the theory that perhaps it's muscular, but there's really no change since then. Yoga is great but only if I'm in the right head space for it (like listening to Pink Floyd), I basically spend the entire time wishing that Shavasana (or, "corpse pose" in English, typically the last pose in a class).

Also as of a few days ago I've noticed some fluttering in my intestines on the right side. It's not painful but perceptible. Impossible to say if it's related but I'm on high alert for anything untoward.

Finally, I went to the doctor for my toe the other day. She said I could cut half the big toenail which would be about 5-7 days recovery, or I could just wait it out. I wasn't going to do it. Nope, going to Hawaii without a big bandage on. I agreed to bring antibiotics in case it got infected on the trip.

It's a marathon, that never ends

I've run the Boston marathon 3 times. I've been reflecting on those races lately. Specifically about how I approached them, untrained as I was. This is not a complement by the way, but a critical observation. In 67% of them (2/3) I put my head down and just did it. I ran smart races but there was nothing to savor in them. If I'm really honest with myself they were hardly memorable.

2009 Boston marathon (bib: 2502). Running with my buddy Abe.

I attached to the goal and a time outcome and that was it. I'm too good at suffering through whatever it is I sign up for. In that regard being overly disciplined is a character flaw. The only time I remember much of that race was the one I ran poorly. I had shifted strategy midway, from a time goal to an experience goal. The reason was that I started the race too fast and blew all my energy, bonking hard around the 22 mile mark. I walked for several minutes (unheard of!) to see if I could regain my composure. It was that or quit and I was desperate. So, with the time goal out of reach I focused on enjoying the race and noticing things around me. There was a smiling kid on the sideline cheering me on. He was enjoying the race. I figured I was actually running the race so I should do the same!. And I did. One question planted in my mind then is how to move performance and pleasure to the same side of the ledger. I'm specifically talking about the times where things are pushed to the edge of one's ability (note: pleasure and performance co-exist just fine within one's comfort zone). Here, how can I battle cancer while enjoying the process? It's like a koan.

The solution? Love is the bridge. If you must do it then you must love it. The approach I've taken is to find a way to love the process, hard as it is. I've decided that for now writing is the best tool available so I've been using it to explore this terrain and share the experience. It's been working reasonably well thus far.

And there is no real finish line. Yes, we have milestones but then there's another one after that. The end becomes the beginning and the end – looping through an infinite yin/yang symbol – until it stops. So I've been trying to stay aware that while the upcoming scan is a milestone I shouldn't fixate on it. While the outcome here matters (understatement) – it's the difference between going back to work I love, or back into treatment – I'm trying to remain equanimous about it. I don't control the damned outcome so energy going outside that perimeter of control is wasted. When my attention drifts outside that perimeter I pull it back in. I've gotten so many reps in that it's almost becoming automatic; drift and yank.

What's the value of more?

The other night I met a prominent CEO/founder friend for a drink. His company is running out of runway quickly and he was working 18 hour days trying to get funding. We remarked on how our situations felt stressful, stemming from uncertainty – NO!, stemming from uncertain outcomes with known timelines. By necessity our ego has built up various biases that provide a balm of certainty. The big difference is not so much that we're actually living in more uncertainty than others (though we may be), rather it's our heightened *awareness* of the uncertainty – it's right in our faces. It's a key distinction.

So I suggested an odd question we both found interesting. In fact, we both thought that if we had a single question to ask this would be the one. *What's the value of more?*

Isn't it implicitly obvious? More days, years of life, or of business runway is obviously better than fewer. Ok, why? If you pull on the thread it's hard to come up with a logical answer. Just because. Why life? Just because. Ok then. More is better and thus we should be sad that our lives (or business lifetimes) are not infinite. Indeed we should prioritize longevity above all else. QED, right?

Maybe. But a better argument hinges on the idea of compounding. Why is living longer better? Because you can do more good in the world. Actions and decisions filled with goodness can compound the good in the world and reduce suffering. And conversely evil can amplify, Hitler lived too long.

So, do more good. How? Here's a non-exhaustive set of possibilities:

- Have kids. Those kids will perhaps go on to have kids of their own and so on. I often look look at pedigree charts or family trees to convince myself of this power.
- Spread kindness. Kindness compounds – kindness begets more kindness, rendering the world less scary.
- Be better, do more. If one is a parent it could mean being more present and aware to raise kids more likely to to do more good of their own. If one is a manager it's being a damned good one. If one is a friend/aunt/cousin/son-in-law – then do more. You are a mighty lever impacting the lives of your loved ones or subordinates.

Doing good compounds our existence, providing a clear answer to the question of "*why more*". Being awake, aware and intentional matters as it helps us be positive models for others and reinforce the idea that the world is good. Call it the case for the Mitzvah (מִצְוָה, good deeds).

Don't skimp


10 days in Kauai!

I booked these tickets to Kauai on learning I have cancer last year. It was my gift to myself and my family for completing 6 rounds of chemo. I didn't say for beating cancer. The key point is the celebration was de-coupled from the outcome. I can tell I've matured because the younger me would think such an idea misguided. The younger me would have been ferociously planning and saving money etc. if the outcome was poor. He would be willing to trade his own experience and suffer through whatever it took for an outcome.

Screw it! It feels indulgent, but if ever there was a time for that now would be a good one. So I splurged. Did I need to book the presidential suite? Yes I did! There's a time to scrimp and save. Now now. It's about memory making. If you're going to commit then do it right.

Mold grows everywhere. Nothing is perfect. Experiences don't exist in isolation, for us to plug into like modules. There is no party that's objectively good or bad but what we bring to it makes it so. We don't just show up places to have ourselves magically transformed. It's our intention and mindset that matters.

The plane ride to Kauai was pretty stressful. Lua was like a little animal out of her cage the whole trip. Kids were acting up, acting spoiled which boils my blood more than anything – I will not tolerate raising spoiled kids! I was getting stressed. Once we arrived the kids were hungry and generally intolerable. Not sure if I mentioned that I got my phone glass fixed about a week ago after having dropped it (in a moment of clumsy non-awareness) on getting the news that I still had cancer. As I was getting the kids into the rental car, multitasking while holding the phone I dropped it – literally onto a bed of sharp rocks – smashing it yet again.

But in a way it was great, seriously! I looked down utterly bewildered at my stupidity. I was reminded about my tendency to focus on doing over being. That outcome was a function of pure inattentiveness. Every time I now pickup the phone, covered in packing tape to keep the shards intact, I'm reminded to be present. Yank!

65.

Back in SF!

So was 10 days in Hawaii relaxing?

Kind of. If you think it was sleeping in and pina coladas on the beach all day you've got the wrong idea. We definitely had lots of quality downtime with the kids, which really was the main point. Still, 10 days with 3 kids and no babysitter or school does not produce a beautiful tan (the chemo is likely still lingering in my body so I was vigilant about limiting my photon exposure anyway… I was the guy with long pants and running jacket on most of the time). But it was a necessary pattern interruption on the 'big C' and we did it the right way – no regrets. I think the kids really enjoyed themselves. I know I did.

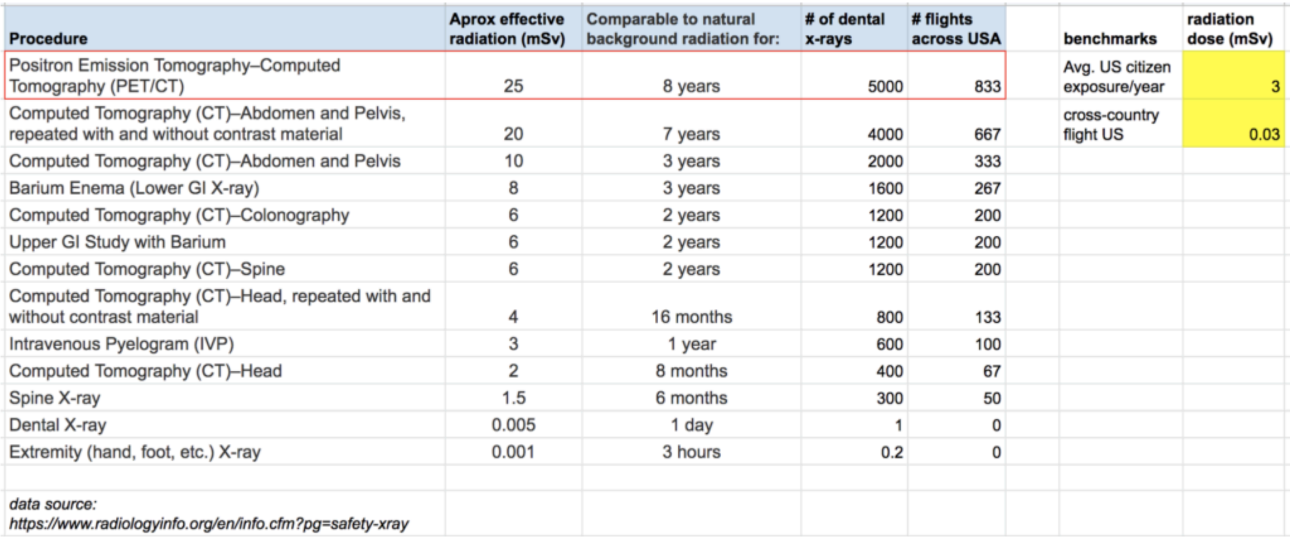
PET/CT scan

It's done. I had the scan yesterday afternoon. I expedited the schedule by a few weeks to coincide with my return. The outcome will determine whether I'm headed back to treatment right away or not. I'll find out results today or tomorrow.

If the tumor is not progressing that will be a strong signal that indeed we're looking at Follicular lymphoma and that (I think) it's somewhat stabilized. It's a bit odd to think that's what I'm hoping for, but given a choice I'll take an immediate future of 'watching and waiting' over some of the treatments I've lately been contemplating. Regardless I'll circle back with my panel of docs to ensure alignment, especially if the scans are anything but super clean.

When I arrived I pushed for an answer as to why this time we were doing a 'whole body' scan (as the order indicated) versus what I had last time which was 'eyes to thighs'. It's not a big difference from a radiation exposure standpoint but more a question of principal. Why the difference? Anyway I was able to get a hold of the oncology nurse before going in. Her explanation was that because I'm now post-treatment they order whole-body. Good enough – at least it wasn't an oversight.

While pushing back for an answer I got to talking with the tech that was running the equipment. I was asking more details about radiation exposure. The last tech I spoke with indicated the radiation exposure from a PET wasn't especially high. When I mentioned this the tech laughed that this was ridiculous. So I asked if he had any way of putting these various scan types all together as I haven't seen a clean comparison across all procedure modalities? He did a few minutes of searching and showed me exactly what I wanted to see in a handwritten table on his phone. I copied the values and cross-checked them. Here's a table breaking it down. I normalized against some common benchmarks: the number of dental x-rays, flights across the US to put it in perspective. You can see the top row shows PET/CT as the equivalent of living 8 years in the US, taking 5k dental x-rays, or 800+ flights across the country.



Procedure	Aprox effective radiation (mSv)	Comparable to natural background radiation for:	# of dental x-rays	# flights across USA		benchmarks	radiation dose (mSv)
Positron Emission Tomography–Computed Tomography (PET/CT)	25	8 years	5000	833		Avg. US citizen exposure/year	3
Computed Tomography (CT)–Abdomen and Pelvis, repeated with and without contrast material	20	7 years	4000	667		cross-country flight US	0.03
Computed Tomography (CT)–Abdomen and Pelvis	10	3 years	2000	333			
Barium Enema (Lower GI X-ray)	8	3 years	1600	267			
Computed Tomography (CT)–Colonography	6	2 years	1200	200			
Upper GI Study with Barium	6	2 years	1200	200			
Computed Tomography (CT)–Spine	6	2 years	1200	200			
Computed Tomography (CT)–Head, repeated with and without contrast material	4	16 months	800	133			
Intravenous Pyelogram (IVP)	3	1 year	600	100			
Computed Tomography (CT)–Head	2	8 months	400	67			
Spine X-ray	1.5	6 months	300	50			
Dental X-ray	0.005	1 day	1	0			
Extremity (hand, foot, etc.) X-ray	0.001	3 hours	0.2	0			
data source: *https://www.radiologyinfo.org/en/info.cfm?pg=safety-xray*							

For those interested in radiation exposure for various medical procedures this table shows the equivalent amount of background radiation a person would get living in the US (not at altitude which adds 1.5 mSv/yr) by procedure type. The last 2 blue columns normalize procedures to other contexts.

As we got talking further I was horrified about a story he told me. To summarize there was a PET/CT center in southern California in which the amount of isotope injected into patients was consistently 30% too high – and this happened for several years. Concerning as the radiation exposure would be, the real issue was that tumors might show as more active than they were, which could be interpreted as showing more progression than actually existed! Sometimes you just don't want to know how the sausage is made.

With that he left. I sat in dark silence for an hour as the radioactive isotopes penetrated my cells.

How do I feel?

Truth is I'm less worked up about it than I would have thought – despite that I can almost already hear my oncologist on the phone delivering yet more bad news. And I've still been having nightmares – different forms each night since before leaving for Hawaii. I won't bother going into details but to say that in some I emerge victorious, others end inconclusively. These are clearly the subconscious processing of a mind grappling with high uncertainty.

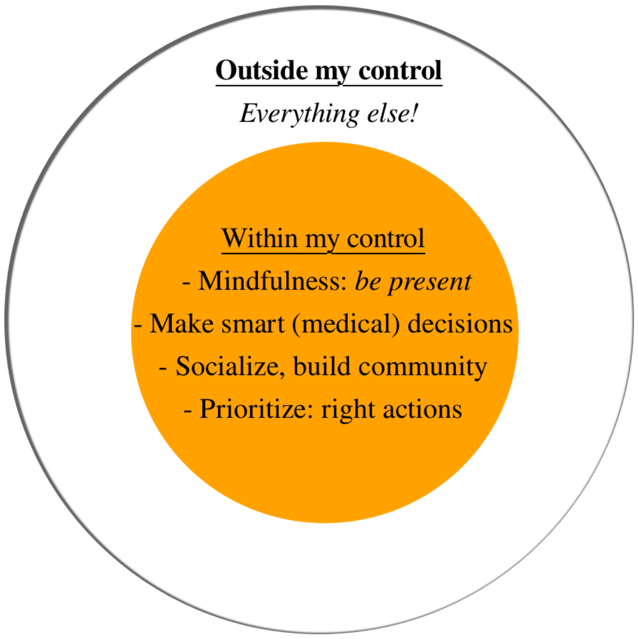
Still, for some reason I've been feeling optimistic about things lately – regardless how the scan goes. Not sure I'd call it faith but I certainly don't feel like a helpless victim. I believe that focusing within my circle of competence has been helping allay many of these fears/anxieties (sketch). I'm getting better at explicitly identifying where energy expenditures are helpful vs. useless.

Re-patterning

One goal of mine is to break in new patterns of being and commit them to habit. I've started to think about my immune system as a child I need to care for (and what's one more kid at this point!). I'm trying to be intentional about coddling it because it's fragile and I've perhaps been unkind to it. Hawaii was the tip of the spear on this path.

If anxiety has a negative effect on immunity – and I think there's sufficient quantitative/qualitative data suggesting this is so – then it's worth asking the question of what causes anxiety. When I put this question to myself it was clear that *thoughts cause stress*. That seems so obvious when in black and white; it's not the event itself but the thoughts surrounding it that cause stress. Thomas Jefferson said almost 200 years ago:

> *How much pain have cost us the evils which have never happened?*



So which thoughts specifically? For me it’s *future-oriented* thoughts, e.g., *What might happen, will the scan be good or bad, how bad is this diagnosis*? etc. Anxiety for me is about getting caught up in *scenarios*, “*what if’s*” and ‘*should’s*‘. I have this tendency to observe scenes in the third person, objectively as a bystander. If nothing else it’s a pleasure blocker. So what’s the solution?

Be present. Here. Now!

To be present is to circuit-break anxiety. I don’t think that being *truly* present can co-exist with anxiety, in the same way that you can’t simultaneously hold multiple conversations at once. If I’m grounded in the here and now then none of that matters. When I feel the sinking feeling of waiting for this test I try to bring it back to the present moment. I’ve heard this so many times, to focus on the breath etc., but only on this trip did it actually sink into my bones.

There was a moment on the last day. I decided to get out of the house before anyone was up while still dark. I went for a jog beneath a crescent moon peaking out from behind silver pre-dawn clouds. I was running alongside the ocean along Kauai’s perimeter, an ant edging a jar lid. I stopped and looked out, taking in the magnificence. Truly paradise. I looked out over the black rocks with the type of deep stare I get when totally immersed in a thing. I would do it as a kid all the time. When your eyes find a focal point it becomes clear how energetically expensive eye saccades are. The focus was slow, deep and constant. I stared for a long time and felt one with the scenery; nature looking on herself. I was simply the observer to that exchange. Peripheral events didn’t matter – a truck in the distance, morning roosters, etc. Another word to describe it: *absorption*. Nothing really happened in that time but to say it was obvious this is an optimal state of being and one worth actively cultivating.

That kind of awareness is like focusing the sun’s rays to a single point to light a fire. In this way being present seeds a positive feedback loop that leads to seeing -> to knowing -> to loving -> to calmness; and back again to being present. It’s taken me this many years to really get it. I’m still working on doing this more and infusing it into my daily life to the highest degree. I see cultivating an ability to turn it on like a switch as a worthy, life changing challenge. It’s been really interesting to play with this, like a new brain gear.

One good gut-check I’ve been doing each day to find out if I’m actually present is with washing the dishes (or whatever chores). When I’m present it’s meditative. My future-oriented/anxious/distracted self tends to dislike chores like the dishes because (I think) I should be doing so many better things. But not really. The best thing to be doing, is the thing right in front of you. Right now. Fully and with love.

Not trying to be a Jewish 80's rapper so much as protect myself from the sun. With Michelle – I think this is one of the only pictures with both of us together.

Lua at the pool!

Same activities, different location.

66.

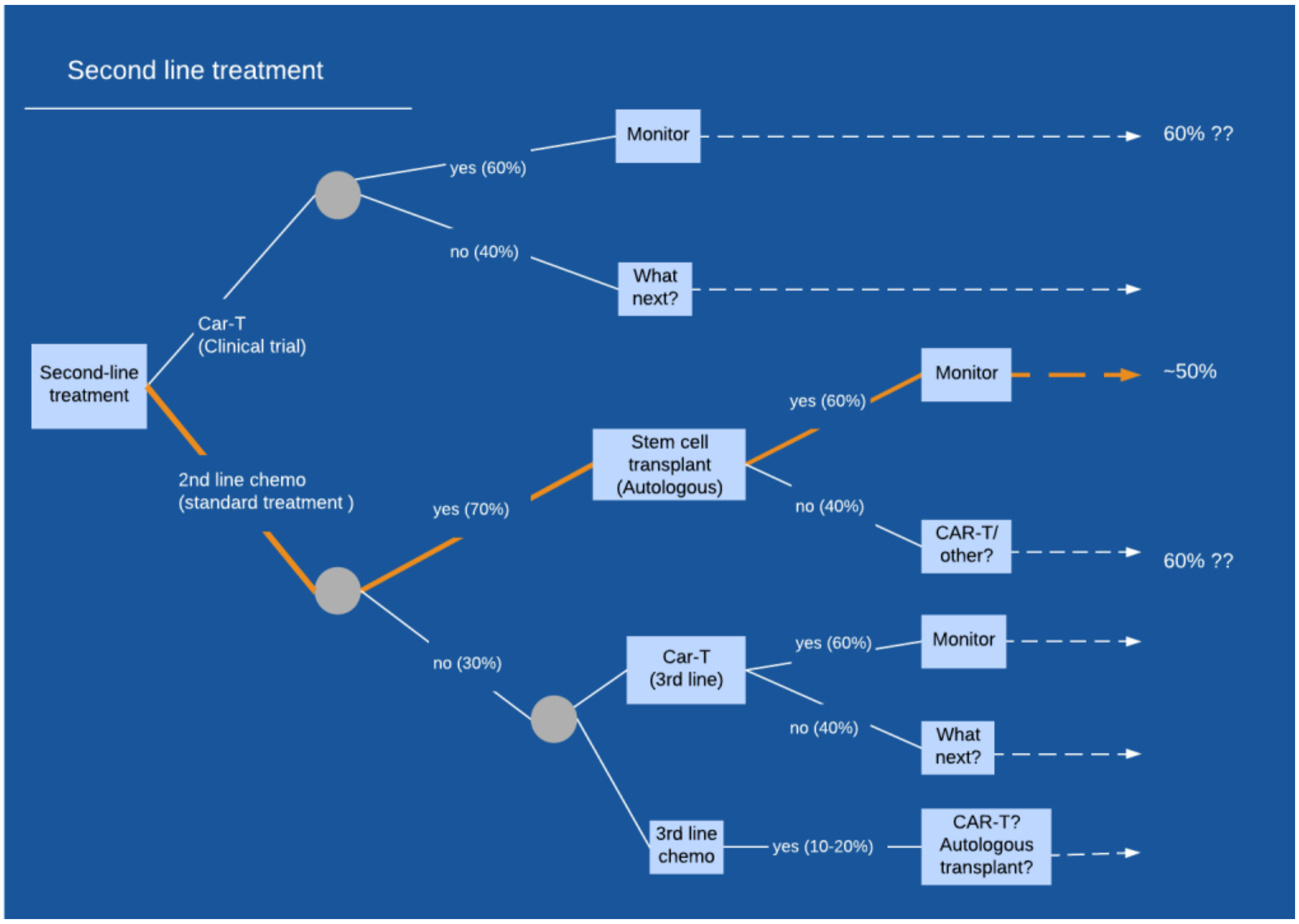
Last night I met with my Kaiser oncologist. He seemed encouraged by the genetics studies coming back negative for everything saying that's predictive of a better prognosis. I asked what 'better' looks like to him. He said he thought second line treatment would be in the 70-80% range. I mentioned that others I'd spoken to put that number quite a bit lower, closer to 50%. "*Right, those are global averages they've been giving you, and you're young and strong*". Fine, I like higher.

Then I told him that we were looking at an incomplete picture, that we should be looking at this situation "end to end" and taking the second line odds along with stem cell success rates. "*Yes, that's right*" he said. I told him that if I do this it looks fairly pessimistic, more like 35% overall. He said he thought my chances going through this were higher than 50%. None of this whole conversation about odds really changes much but what's frustrating is how much digging and prodding I feel like I need to do in order to get a clear picture of what's going on. These are VERY important decisions and I would expect my doctor to level with me about not only the immediate step ahead (what I currently get) but looking a step or 2 further out and presenting a clear picture of what success looks like, not just an intermediate step. Not sure if the motivation is to not get ahead of ourselves, or to not freak me out or something else? I also inquired about CAR-T therapy as second line treatment. He thought it didn't make sense to go that route given the odds are still decent for standard lines of treatment. That aligns with the UCSF conversation. I'll have a better idea after the Stanford meeting.

Turns out that in terms of referring for CAR-T treatment should second line fail, Kaiser only refers to clinical trials. This was yet another somewhat frustrating part of the conversation. This was all framed as being in the patient's best interest because the drugs are 2nd or 3rd generation versions whereas the commercial products are, say, first generation. To which I offered that clinical trials are by definition not FDA approved and hence risky. So then we got to the real issue which is that Kaiser doesn't want to pay for it. If it's cost then fine – that's a legitimate consideration. That's different than framing it as something in the patient's best interest. But again, I keep feeling like I need to peel back the onion 2, 3, sometimes 4 layers to get a satisfactory answer to basic questions. My head is swirling with a LOT of information and high emotion and I don't want to be on guard to discern what a doctor is *really* saying to me.

And I didn't get a straight answer to the pathology opinion either. I asked, "*So did you get more eyes on the pathology report internally*"? "*Yes we did but I don't think they wrote it up*". I said, "*so why not*"? He then bypassed the conversation saying that the Stanford pathology report is what matters here and that piece is happening. "*Maybe I'm mistaken but I thought the diagnosis matters, if only for setting ourselves up for 3rd line treatment*". He then said he thought I was going too deep on a pessimistic scenario – that there was no need to go there yet. I agree to a certain point but in the end these are VERY real and somewhat imminent possibilities. All I'm looking for is satisfactory answers about next steps. That doesn't seem unreasonable. I walked away shaking my head and thinking that my levels of comfort with Kaiser are sinking.

In attempts to simplify a complex situation below is a decision tree illustrating the various scenarios and rough odds to the degree I think I understand them (in some cases not at all). This is evolving and there are quite a few unknowns w/r/t various paths but I don't think I need a complete picture of every possibility here, just the main ones. For example it's unclear to me if there's some sort of a 'penalty' associated with failing second line treatment then moving onto CAR-T therapy; are those CAR-T odds reduced in such a case? Also, what happens if CAR-T therapy is not successful, what then (e.g., in the case of doing this as second line treatment it seems there's not much to fallback to)? Finally, these percentages are best guesses and could in several cases be wrong; for example I have no idea the CAR-T odds for my situation so I'm going with 60% (I've heard ranges from 35% to 85%). Anyway if it's not better than that it wouldn't be worth discussing now. I've marked in orange the most likely path I see myself going down for second line – that one seems about right.



Orange path is the likeliest one at this point

67.

I got a call yesterday from the Stanford new patient coordinator. The second pathology report is in and I do qualify for the study. She set me up for a meeting Tuesday. This must mean they think this is DLBCL, not follicular lymphoma.

The pessimist (realist?) in me considers the following ***totally hypothetical & unsubstantiated*** scenario: What if Stanford 'finagled' the pathology report such that I'll qualify for their study…the diagnosis was nebulous anyway and this is a fairly rare diagnosis especially in my age bracket (see below). So recruitment for this study is likely hard; I know they've only successfully recruited 10 patients in over a year. I also I know that Stanford and my Kaiser doctor discussed my case other day. In their discussion perhaps they disagreed on the diagnosis, second pathology report findings. That might be seen as reflecting poorly on Kaiser, if only given how questionable the first pathology report was. If you're Kaiser then perhaps better to say nothing, hence the cagey answers to my questions the other day. Not trying to hatch any conspiracies but am I nuts for thinking about such a possibility? I'm sure stranger things have happened.

That got me thinking about the size of my age-bracket cohort for this disease so I dug up some stats. From my napkin math based on Cancer.gov and rates I've heard elsewhere, I'm estimating that I'm one of fewer than 300:

New cases, U.S., 2018: 74,680
Cases 35-44 yrs old: 3,958 (5.3%)
% DLBCL: 1,187 (30%, assuming it's equally distributed across all ages)
% DLBCL that fail 1st line treatment: ***297*** *(~25% fail rate)*

Then at about 6pm I got a call from the study coordinator. She asked me what questions I had about the study. We discussed what happens in the scenario when CAR-T fails as 2nd line (assuming I got that arm, it's 50/50 and not blinded). Turns out **I would in fact switch back to the standard treatment and do the second round chemo with a goal of getting to the stem cell transplant if CAR-T failed!** That was the key piece of information that had been missing. It's not clear how passing through CAR-T before the chemo treatment would change the odds, if at all. That will be a follow up for the doctor. I also asked about the CAR-T odds vs. standard treatment – here's what the document they sent me says, verbatim:

> The Stanford Cancer Cellular Therapy Program is offering a clinical trial for patients who are affected by Diffuse Large B Cell Lymphoma (DLBCL) that is relapsed or refractory to first line chemotherapy. The sponsor of this study, Kite Pharma, Inc, conducted ZUMA1, a Phase 1/2 clinical trial using the same CAR-T cells, now called axicabtagene ciloleucel (Axi-cel). ZUMA 1 investigated the safety and efficacy of Axi-cel in subjects with refractory aggressive NHL, and axicabtagene ciloleucel significantly improved ORR (P < 0.0001). **The ORR was 82% with a complete response (CR) rate of 54%. At the primary analysis, 44% of subjects had ongoing responses (39% in CR) and 42% were disease free more than one year following Axi-cel therapy.** Axi-cel received FDA approval to treat relapsed/refractory DLBCL after two or more lines of systemic therapy in October 2017 and is marketed as Yescarta. Axi-cel may have an improved efficacy and tolerability in patients with less chemo-refractory disease and lower disease burden treated earlier in their DLBCL disease course. In this randomized control trial, axicabtagene ciloleucel will be compared to standard of care (SOC) therapy.

I’m just getting up to speed on the trial outcomes lingo: ORR (objective response rate) vs. CR (complete response) etc. I’m going to need to ensure I understand the various measures for BOTH the traditional vs. the CAR-T arms of the trial. My schematic the other day didn’t look at these nuances, it was simple yes/no outcomes that track to CR (which is defined as no detectable evidence of tumor).

This study is 50/50 randomization which means that there’s a 50% chance I’d get CAR-T therapy and 50% chance I get standard chemo; same as if I did it at Kaiser except that infusions are done on a 3-day inpatient basis. Also I’d be the youngest participant by about 10 years (at least at the Stanford site, there are others around the country). Most participants are in their 60’s, 70’s which probably makes sense given the disease rates. This is the specific study for those interested. I left the conversation feeling much more comfortable with the situation despite my wild speculations noted above.

I’ll head down to Palo Alto and meet with them Tuesday to get more information…

68.

I'm heading down shortly to meet the team at Stanford about the trial. I'm both excited and anxious. I have a list of questions (below) I feel like I need answered to make a more informed decision here. I'm getting tired of the analysis piece and excited to move onto a decision already. I'm close. The more I pull on this thread the more interesting/scary this whole thing gets. For example I was talking about cytokine storm (basically your immune system releases cytokines) yesterday with my friend Geoff. He reminded me that the great influenza pandemic (1918) also inflicted cytokine storm but disproportionately impacted the otherwise young and strong. Great point. Where might my age possibly work against me in all this?

There are two domains I'm considering here. The first is around making the soundest medical decision possible. That's the main focus. The second one is navigating the labyrinthine world of medical insurance. On that piece the key issue is verifying what Kaiser will/will not pay and refer for around the various potential scenarios. Since Stanford is a partner I'm hoping they may be able to shed light from the other side.

So the next steps here are to hear out Stanford and get a feel for my levels of comfort, ask: *would I go to war with these people*? Michelle and Lua will be there to help! From there if I still have questions or feel like there's bias at play I'll follow up with UCSF, Dana-Farber to finalize my decision.

Access

While this whole situation is obviously emotional and hard for me, I've been thinking a lot lately about the idea of medical access. I'm deliberating questions that are really hard. And there may or may not be a great answer. But I need to explore it fully, if only to ensure I'm not stepping into potholes (trusting one doctor is probably not the best way to do that)! But I have access to great institutions to seek out the top opinions. I have the Chutzpah to stand up to doctors and enough curiosity to find answers. I have very smart friends that can help me think it through. Most people in our country don't have this. And it's so easy to misstep. So I'm trying to put my situation into perspective, reminding myself that both options are pretty good given my situation. I'm lucky to even be making an informed decision here.

Here's my working list of questions.

- can you switch arms from car-t to SOC without 'penalty' if not successful? Is it really a simple swapping of events?
- are the odds for auto transplant really 60%? Can that be segmented by age?
- What other trials are around the corner for CAR-T? (e.g., targeting cd22+cd19?) what if it comes back? Would it be harder to enter into other (CAR-T) trials?
- How close are checkpoint inhibitors in addressing NHL? Lots of excitement and from the looks of at least one (phase 1b) trial there are virtually no side effects. Interesting
- longer term issues with T-cells? How long do the chimeric versions last in body?
- What if CAR-T is only partially successful? Assuming outcome is binary else move to SOC (standard of care)

- suppose I do SOC and it’s successful! Then cancer comes back several years down the line. I’d assume CAR-T tech is further along. Am I in a better place then? Conversely would I have limited my options because of doing this trial?
- What’s the penalty for waiting 3 months w/r/t treatment?
- How much tumor burden can CAR-T handle? Better off trying to reduce it with SOC first (meaning better chance of CAR-T working?)? Is that a benefit of doing it 3rd line?
- Cytokine storm – does it hit young/strong harder than old? Remember the influenza pandemic of 1918 (I think young were disproportionately affected); any data on this re: CAR-T?
- review odds of various arms
- have kaiser patients gone through this? Has kaiser paid for 3rd line treatment assuming I get SOC and it doesn’t work?
- run through scenario if cancer progresses on SOC, on CAR-T? What would then happen?
- Meet the lymphoma doc if possible
- what does the autologous transplant process look like?
- Opinion on which chemo regimen for SOC
- Review benefits of timing on both arms. Getting to a yes/no happens faster with CAR-T (by 50 days we will know). That suggests that within say a 6 month timeline the cancer could get hit with 2 separate approaches vs. just one. How to think about that…

More to come after the meeting…

69.

> ‘*I’m sorry, you don’t qualify for the CAR-T study. Sorry you had to come all the way down here to hear that news…*’

That was the the ‘Fellow’ I met with. He continued, ‘…our *pathology report says this is ‘follicular lymphoma, grade 3a’, which means there is no CAR-T option available at this point’*. I was stunned. This was not the conversation I was planning to have.

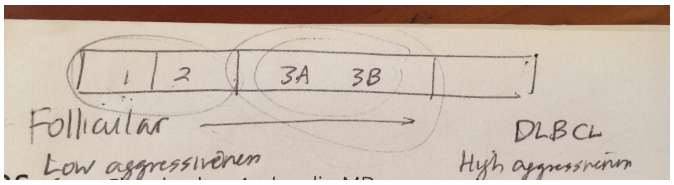
So the pathology report conflicted with Kaiser’s. For some reason on the call Friday the nurse told me I qualified for the CAR-T study and that’s why I should come in Tuesday. Based on my read of the clinical trial I took that to mean I had a DLBCL, or at least existence of 3b cells. Then the study coordinator called me and we discussed the trial details under that assumption. There’s a saying I am finding increasingly helpful: *do not attribute to malice that which can be explained by incompetence*.

Then I met with the primary doctor. VERY sharp guy. He opened up the fire hose, speed talking immunology like we (Michelle and Lua were there) were PhD’s in it. I didn’t follow every mechanistic detail but I got most of it. And I appreciated that as I took it to mean he was leveling with us. This stands in stark contrast to what can often feel like party-line medical answers from other doctors.

The issue, in part, is that the programmed cell suicide pathway is disrupted on these B-cells; when a signal is sent that it’s time for a cell to die (called apoptosis), they don’t listen. As a result these cells will accumulate in the body. At what rate they accumulate remains unknown. In contrast DLBCL/3b cells actually divide more rapidly. Aggressive Follicular it seems is kind of a grey zone – scarier than follicular 1 or 2, but less of a Russian roulette treatment path than DLBCL.

Tracing this back to the original diagnosis, the current thinking/most plausible explanation for the current diagnosis is that the original tumor (before any chemo) was a mix of 3a follicular and DLBCL. Stanford actually re-classified the original Kaiser pathology report as 3a + DLBCL (it was originally 3b+DLBCL). Regardless my treatment was the correct one though we’ve been saying it ‘wasn’t successful’. That might be a bit unfair given what we’re seeing now. What we think the latest biopsy shows is the first-line treatment *was successful* in killing the nasty DLBCL, but left the slower growing 3a follicular cells which aren’t responsive to that treatment. Apparently this is not an uncommon situation.

Your eyes may be glazing over at this terminology but it’s a clinically important distinction to understand. To remind you, ‘follicular’ lymphoma is the slower growing, somewhat less aggressive version as compared to DLBCL (see the sketch). The ‘3’ means it’s more aggressive than 1 or 2, so it’s on the high end of the indolent/slow growing type. And Follicular lymphoma is not curable – not now.



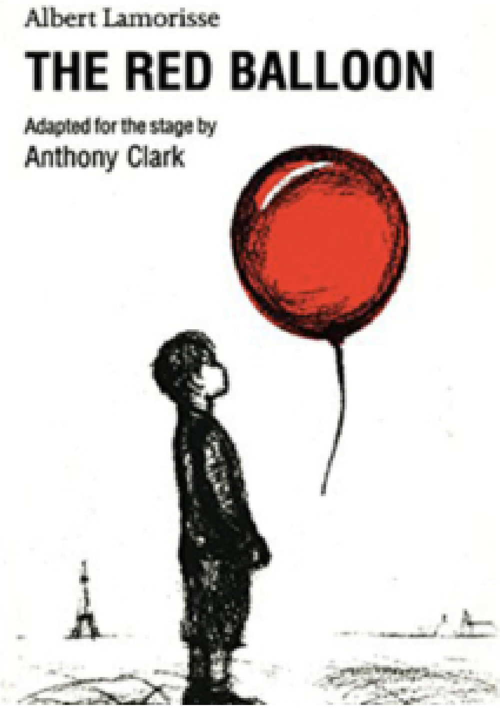
Quick sketch of aggressiveness: dlbcl vs. follicular lymphoma. The original diagnosis from Kaiser showed a mix of 3a+3b cells (circled here). Stanford in contrast says there's no 3b present.

His recommendation, incredibly, is to watch and wait. He doesn't think I should undergo treatment this very minute. He said I should do a scan in 3 months (that's 3 months from the last scan date) – which is a few weeks from now. In his view the risk/benefit of undergoing increasingly toxic chemotherapy and stem cell transplantation doesn't make sense given this report. He then went on to describe the side effects and long-term issues with those treatments. As just one example, when I asked about CAR-T cytokine storm disproportionately impacting young more than old – turns out that's true. Scary. He said *"you're 41 years old. You have a beautiful daughter. I want to hold off putting you through this if we can."*

Or, translated to Yiddishkeit*: Mazeltov! You have an incurable form of cancer.*

How am I holding up emotionally?

I've got whiplash. I entered that meeting considering poison A vs. poison B. Instead I got an entirely different recommendation to sit tight a few weeks, to wait for that next PET/CT to tell us what the disease is doing. So, again, I have conflicting data points. If I allowed my mood to reflect the circumstances I would be a disaster. I love the idea of awareness as reflecting the space one has created between stimulus and response. I've been trying to pry that space wide open lately and not get perturbed by information: good or bad. Here's an exercise I do sometimes: I imagine these bits of information as an object, like a storm cloud or a blob floating in the air above my head. And it's charged – it has energy.



Boy contemplating an information blob: am I going towards or away from this?

Energy itself is neither good nor bad on its own, it's what it gets used for. I look up, like a boy to a balloon and consider how that energy is affecting me. I try to keep it simple: am I going towards that energy, or away from it? Then I peel it back another level, why? And then another, why? Until I feel like I'm at the root of what's causing that feeling. What's in it? It's not perfect but I find it a helpful practice to get perspective. Left unchecked, thoughts can be pernicious things, can de-rail a mind. In particular I find that non-helpful narratives spring like weeds. I need to be a vigilant gardener, lest they take over. For example, as a father, it's hard not to envision what life might look like for my kids if I weren't around, if this thing got me. It's horrifying to consider and it's so easy to get enamored with those kind of ideas, to let them take you down. I try to root that stuff out without mercy. The trick is to be aware of them in the first place which is not so easy.

Swinging on branches

After the appointment we met a friend for lunch. As we sat outside on the quad at the nearby Google campus on a beautiful day I was overcome with the idea that I was at that moment living on a highly improbable branch of possible futures. If for a moment we assume Stanford is right then here's the most likely alternative reality that I'd be living had I not sought all these other opinions…I'd right now be undergoing 6-8 weeks standard of care second-line treatment focused on targeting the wrong cells (DLBCL). That would probably not work because, as I understand it, follicular 3a type aren't responsive to that treatment. Then I would do a PET/CT to see if it was successful in curing my (incurable) cancer. Another week of waiting. Then, when the results returned negative my hopes on moving to the autogenic transplant would be dashed – no passing through the second gate toward curing this. Cue feelings despair, devastation, hopelessness. If the disease showed progression I might need to get another biopsy to see if there was any mutation – it's not uncommon for follicular lymphoma to mutate into DLBCL (that's likely what happened at the outset). Now suppose for a moment that a few weeks/months/years down the line that happens again. What then? Well, then I'd be in a position whereby I've exhausted two of 3 (currently) available bullets to treat this (First line – done; standard of care – done; CAR-T – still available). All because of the wrong diagnosis. I'd be in a position of yet more stress inflicted on me and my family, reduced optionality, and with elevated toxicity inflicted on my body.

Next Steps

Who do I believe? What's my next move? There are, broadly, two pieces to consider. The first is aligning on the diagnosis, then, what to do about it. These seemingly minor differences in diagnosis suggest wildly different approaches and it's frightening how different the recommendations are given that it feels like we're splitting hairs on terminology.

I need to know that Kaiser is aligned with Stanford. And I need to cross check all this with UCSF and Dana-Farber for additional confidence. The original recommendation to press ahead with second-line standard of care still lingers. Taking news at face value hasn't been my approach so far no matter who is delivering it – good or bad. So even if the Stanford pathology report is to be believed (and I want to), ***there's still a very real possibility that I travel down the standard of care path in the immediate future. It might still be the right move***. Here are the most obvious scenarios by which I could see this happening:

1. **Stanford reverses their recommendation.** Stanford hadn't yet received my PET/CT results from Kaiser. They need to review that information and follow up with me.
2. **Second opinion disagreement.** I'll validate this second pathology report with my 'panel' of expert doctors. There could of course be sufficient doubt about this diagnosis and a recommendation to bias towards supreme vigilance. I'm considering getting a third pathology report if there's sufficient tissue to do so to bump my confidence in the Stanford report. Or perhaps a 3rd pathology report would agree with the original? I can't help but still feel uncomfortable that this may be a sampling issue whereby they sampled a part of the tumor, and then are staining a sample of that sample. This may be overkill but seems a reasonable step to take at this point.
3. **Next PET/CT scan shows progression.** If I do wait and watch this thing, my next scan could show disease progression. Might that suggest the pathology is wrong and that aggressive cells are still present? Not sure yet how to think about that piece, without doing another biopsy (ugh!). Either way the assumption this is 3a/slow growing would seem debunked at that point and would I think suggest the standard of care route.
4. **Transformation**. As noted above it's not uncommon for follicular lymphoma to transform into DLBCL. This could be happening now, could start weeks/months/years, or might never occur. From a quick read of the literature that likelihood

> increases 2-3% per year, not sure if it's age or grade dependent.

So, immediate next steps:

- Ensure Stanford views the PET scans from Kaiser and sticks with this recommendation. That seems critical to rounding out the picture.
- Ensure Kaiser aligns with Stanford on this diagnosis and treatment path. The doctors hadn't spoken last I checked but both agreed to connect and discuss.
- Align with UCSF, Dana-Farber on second pathology report and treatment options/risks to various strategies. The conversations I had previously assumed a different diagnosis.
- Run a 3rd pathology report? Schedule next PET/CT in a few weeks?
- Finalize answers to open questions, concerns and decide on the path forward.

Lua is skeptical. She tries to log into EPIC to review the pathology report for herself!

The best drawn plans tend to be done on mini etch-a-sketches at the kitchen table. I’m going to need a bigger etch-a-sketch!

70.

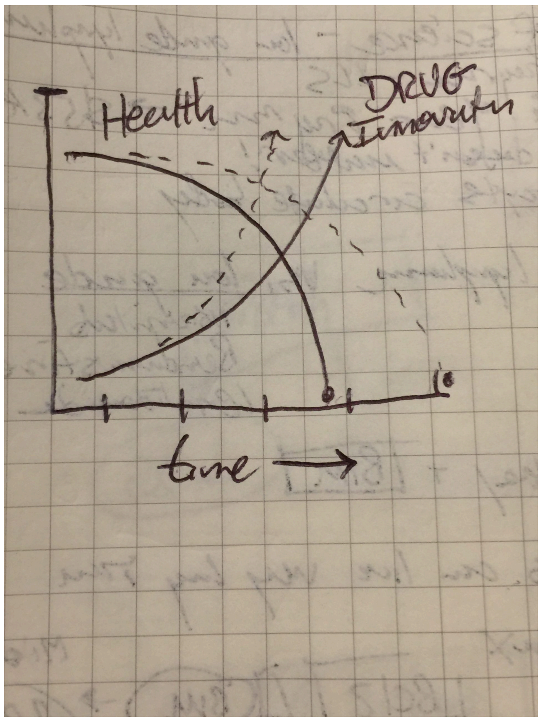
Over the weekend I attended a conference hosted by the Lymphoma & Leukemia Society. Turns out my UCSF doctor was one of the speakers. So not only was I only able to learn a fair deal about Follicular Lymphoma but I was able to ~~accost~~ find him afterwards and speak about the updated diagnosis.

His perspective seems level-headed. He agrees with the watchful waiting strategy in the immediate term; 3 months from the last scan is reasonable. He would call the strategy *aggressive* watch and wait. In his view this disease is likely not obviously the VERY aggressive DLBCL, but it's also likely not a Follicular grade 1 or 2, where you have the luxury of treating it as more a chronic condition. He also doesn't quite buy into the dual-population theory that Stanford offered, instead suggesting to forget the grading for now and call it 'Follicular X' which he still thinks of as a high risk follicular. The high risk is of transforming to the aggressive type. In his estimation running a third biopsy won't help clarify the picture. We'll know more with the next PET/CT – that'll be a more definitive data point. That scan will present one of the following 3 pictures:

1. **it doesn't progress** – which would strengthen the 3a grading and further support confidence in the strategy to 'watch and wait'
2. **it progresses in a predictable fashion** – which (I think) means we treat as follicular with some chemo but I don't understand enough about this.
3. **it progresses in a new pattern**, e.g., new disease. This would require another biopsy to understand the cellular composition. From there we would discuss options – likely a similar set of decisions to what I've been contemplating regarding standard of care vs. some form of clinical trial. We're not there yet.

The other piece of ambiguity (as if there wasn't enough) is that '3a' follicular tends not to get included in most studies as it's somewhere in the middle: not clearly aggressive like '3b'/DLBCL, nor is it clearly indolent like Follicular grades 1 or 2. So the treatment paths aren't clearly defined.

I still have a few pieces that need shoring up – specifically follow on conversations with other doctors. Assuming no major new information comes to light I'm bought onto the strategy to wait a few weeks for a scan and not jump into treatment right away. Part of the reason I think this is I'm for the moment asymptomatic, I think. I'm trying to be as attuned to my physiology as possible so that I get the earliest possible scan should something feel different. I remember what it felt like (fatigue, back pain) before my original diagnosis. What's unnerving over the past couple of weeks is I've been feeling some of that same back pain and fatigue. How much of this is psycho-somatic or remnants of the surgery I couldn't say. I'll remain vigilant on that piece.



The benefit of waiting: All else equal it's better to wait and intersect my treatment plans with the drug innovation curve. This will largely depend on the disease aggressiveness (x-axis ticks purposefully left ambiguous).

The other part is that I'm bullish on the medical/drug innovations on the horizon. I think of it something like the sketch (left). Specific to CAR-T innovations I suspect toxicities will come under better control; targeting effects will improve by getting more specific and yet more varied (think e.g., targeting 2 cellular domains instead of just one); and the longer-term effects will be better described. In terms of the drivers toward innovation there are at least 3 drug companies engineering CAR-T cells somewhat differently and vying for a foothold on a massive oncology market. That, combined with fierce competition and the desperate patient need will drive this forward.

I also learned in this conference Follicular lymphoma is starting to get worked on, though is still in very early days. The reason it hasn't been the initial focus is that it can be managed with other strategies whereas DLBCL options are much more limited. Fair enough.

So based on the conversations I've had thus far with my 'panel' my likeliest strategy for now is to sit tight a few weeks to find out more from the next scan, to let the disease tell us what it's doing. I feel like I've taken ONE small step away from the ledge. And very soon I'll step back up to it. As you can imagine this is all quite stressful (an understatement). But for whatever issues may be lingering in my genome, I can be grateful that a tendency toward despair isn't one of them.

71.

Instructions from somewhere

The other night I looked at my kids as I put them to bed. I really ***saw*** them. It was one of those moments, all too rare, where the din of thought quiets just enough for truth to present. As if cleaning a dirty window. I looked on Lua, tucked into her “cornucopia” (wrapped in a large blanket, tapered to a triangle at her feet, the opening a bouquet with all her stuffies arranged around her head). We are small but critical parts of an infinite chain. Our actions ripple into the future.

How much did Michelle and I have to do with this girl’s creation? Everything – after all we are her parents. But also nothing. It feels hard to take credit. I did not design the alveoli to support oxygenation; nor did I invent the action potential that enables neural functions like thought and movement; I did not decide that 5 fingers is optimal for a hand design; and never-mind the immune system, too hard. No, I’m merely the executor of instructions.

Not only did I not invent the parts, but even if I did, to claim true ownership would be misguided. Universe is not static. Yet our minds long for unbending certainty. Ownership suggests permanence. That’s not how things are; the linguistic sloppiness reflects inaccuracy of thought. No, we are stewards, maybe guardians, but not owners. This may sound like mere semantics but it’s not. Why does it matter? Because the relationship we have with *things* matters. To me this small re-frame matters: it makes the prospect of loss easier to process as it (whatever *it* is) was never ours to own; and appreciation becomes more accessible.

The point? That rational understanding (strict materialism, all is the sum of the parts) without a sense of awe is severely limited. It’s easy to get swept in the rushing waters of reality. Sometimes it’s worth stepping to the side and watching it from the riverbank. To get perspective. It’s humbling to consider myself the steward of these creations. It helps to come to terms with the fact that I do not control the full picture, outcome. That said it’s inspiring to know the degree to which things are controllable. It’s not all a hot chaotic soup of bits and atoms and no rules. Outcomes can be measured, rationally designed, predicted. Think of the complexity involved in a surgical procedure. Or in an endeavor like the Manhattan project. It clearly is possible to understand, to predict and to ship things that work well. Control is possible. But let’s not forget we are all taking the materials we’re handed: whether genes, molecules, atoms, words. We do not create entirely new parts; we remix.

Upside down is also true

Looking upside down at the world, between my legs like a downward dog or headstand, is a pastime that I don’t get to do enough of. Cars pass by, impossibly attached to the road. People walk on the ceiling like strange mostly ungainly creatures. It’s thrilling to have one’s notions of gravity disrupted at each moment. In doing this (admittedly) odd practice one gains an appreciation for the simple idea that we are upside down as much as we are right side up. Coming to grips with that fact is not something we’re in the habit of cultivating. On occasion I’ll do the same thing in the gym where I’ll monitor people’s posture and lifting technique, though upside down. It’s amazing how obvious the issues become if you do this – there’s no end of stooping, knee buckling and forward neck lean to be witnessed.

And it’s strangely addictive. That perspective helps see where things are flawed. This is not a new trick. The old master painters used to do something similar – they would look at the painting in a mirror, to render it backwards, and the mirror would point out exactly where the rendering is broken. This is especially helpful with portraits where a nostril being off just a millimeter is the difference between a smiling Mona lisa and a syphilitic.

Seeing things with fresh perspective has been helpful as I deal with this ambiguity.

Here's a video from earlier last year doing rocket experiments with the kids. This was really fun teaching the kids about scientific methods (I'm at the table recording our proportions of various ingredients to see what produces the greatest lift – of course they lost interest in that part quickly). Our actions ripple into the future. We do the best we can with what's in our control. Then we let it go. Rockets!

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://pressbooks.pub/chemolog2/?p=259#oembed-1

72.

I've now got 4 doctors aligned on the '*watchful waiting*' strategy. I'm considering that a mini triumph given that 3 doctors were in agreement to jump immediately into intense chemo just a few weeks ago before the second biopsy results came in. I should right now be in the midst of treatment.

So that leaves me in an interesting place. I'm feeling good and regaining my strength. But storm clouds loom on the horizon. There's a feeling among the doctors that this more aggressive form of follicular lymphoma will progress, it's just unclear when. One of the keynote talks at the lymphoma society conference last weekend was about stress and cancer. There's a name for it, it's called the fear of (cancer) recurrence (or fear of progression, basically it's the same thing the difference being if one is in remission or not) – that's a good name. The speaker talked about how much anxiety these kinds of scans can elicit and how that can impact immunity, caregivers, quality of life and etc.The stuff we all know already but worth a periodic reminder. Reading through some literature on the topic it's not clear that stress can cause cancer; the relationship seems clearer in terms of managing cancer once you have it. For example the National Cancer Institute (NCI) says explicitly,

> *Evidence from experimental studies does suggest that psychological stress can affect a tumor's ability to grow and spread.*

Imagine how stressed you might have gotten over something like a job interview, big exam or the SATs. You might have even gotten sick around that time (exam time always seemed to bring that on in school). The immune system is complicated (understatement) and anyone pretending to understand the relationship between one's mentality and immunity is probably lying, except to say that positive beats negative. My friend Geoff sent me over Stephen Jay Gould's excellent essay, the median isn't the message on just this topic. The essay is Here's a particularly germane excerpt:

> *Attitude clearly matters in fighting cancer. We don't know why (from my old-style materialistic perspective, I suspect that mental states feed back upon the immune system). But match people with the same cancer for age, class, health, socioeconomic status, and, in general, those with positive attitudes, with a strong will and purpose for living, with commitment to struggle, with an active response to aiding their own treatment and not just a passive acceptance of anything doctors say, tend to live longer. A few months later I asked Sir Peter Medawar, my personal scientific guru and a Nobelist in immunology, what the best prescription for success against cancer might be. "A sanguine personality," he replied. Fortunately (since one can't reconstruct oneself at short notice and for a definite purpose), I am, if anything, even-tempered and confident in just this manner.*

I'm feeling optimistic despite all this ambiguity. I'm making it a priority to maintain this attitude as best I can. This optimism is less about blind hope, that an impending hurricane will magically shift course. No, instead it's rooted in confidence about the house I've built being able to withstand the storm. I've been challenged with hard things in the past (I don't have time to go into them – maybe another time). And I've survived. In fact I can honestly say that after just about each major challenge things in my life have improved materially. That belief is now hardwired in me. Were any of those challenges *this* hard? No. Not even close. But at the time some of them did feel cataclysmic (despite being mere blips on the cosmic radar).

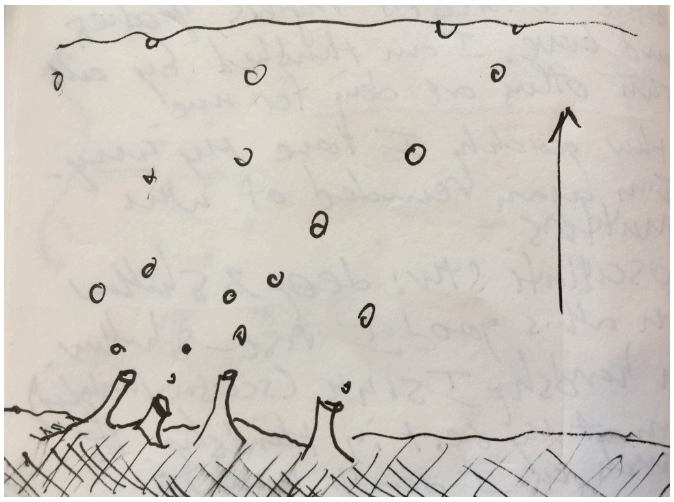
I consider those warmups, or simulations, preparing my mind to handle all this. In this respect I'm grateful for all the challenges I’ve experienced until now. It seems to me there’s a compounding effect to handling hard situations appropriately such that each experience carries over to inform the next one. Over time this sums to strong judgment, perhaps wisdom (not that I’m there yet). But these hard experiences are serving me well. I shudder to think what getting this kind of diagnosis might have looked like for me 20 years ago.

In fact these experiences are so important that I’ve started making it a practice to explicitly run through them again to remind me that I’ve experienced hardship before. I need constant reminding that I can do this. Data points.

73.

The fear and anxiety come in waves. Most of the time I'll feel fine. Them BAM!, that cold rush of reality overcomes me… I have cancer! And I can tell my mind wants to go in that direction, to charge with that energy. It's like a strong-willed child pulling a feeble adult towards the shiny thing. A moment later it's like I have a backpack filled with rocks reminding me about gravity. Then, the complexity of all that I MUST do, should have done, should be doing NOW rushes in. I'm nearly overwhelmed.

But I know how to meet this feeling. We're well acquainted. I meet it with a deep inhalation; a circuit-breaker. What else can I do? I'm getting a lot of practice at making that space, creating a pause. And I'm grateful for the practice since it helps push these unhelpful feelings away. This is definitely not an innate ability. No, this is forged from experience. And I'm getting lots of reps.



Sometimes I feel like a bubble floating through the great ocean, inevitably upward to the surface (sketch). Perhaps we're all bubbles. And once we reach the surface we deposit our contents (soul? consciousness? nothing?) into the great unknown atmosphere. When I'm feeling overwhelmed I try to remind myself that being a bubble is rare and special. And that it's a privilege to feel anything at all, even if it's hard. It's better than popping.

74.

I'm slated to get these scans done early march. That is, unless I 'feel symptoms'. Simple, right?

There were three symptoms specifically that I noted just before my diagnosis last year: blockage (constipation, due to the tumor's location in bowel area), a specific kind of dull back pain due to the tumor pressing on nerves (not unlike pregnancy I suppose), and fatigue. Put me down for 2 of 3 in the past couple weeks. I've been on edge as I monitor. For example in the past week I've slept 12 hours at least three times – unheard of for me except if I'm sick. The most troubling piece is that every time I stand up I feel this dull pain in my lower back/pelvis area. The only time I've felt this type of pain was last year just before my diagnosis. And I'm constantly feeling my abdomen for evidence of tumor. The other day I realized that this might be for naught. It occurred to me that since the tumor is now placed somewhat differently that perhaps it could be growing in different locations – perhaps more towards the back than the front.

These are not encouraging developments. But they're also not quite enough to get me over the edge to expedite the upcoming scans. There are rational explanations. Lua (2 years old) has been having sleep regressions since moving her in with the boys (yes we did that a few weeks ago and it's been mostly amazing, dumb luck I think). Anyway that might have something to do with the sleep/fatigue. For example last night I was up for two long stretches from 2am to 3:30. Also I've caught whatever has been going around recently from the kids – mild, but still. I've been exercising more to build up my strength and I want to believe that's the cause of the back issues but I really don't think so. I'm going to try doing more active stretching and light walking etc. to verify it's not just a muscular thing.

Regardless of these explanations there's also trepidation (I don't want to say fear since that doesn't quite resonate as I'm not deluding myself). I can tell that monitoring this is definitely eating up some mental cycles. I want to enjoy a few weeks of relative normalcy and minimal stress before very possibly jumping into more intense chemo/treatment. The thought of doing another biopsy in case of a poor scan is not palatable right now. Also, and it sounds trite to say, but we've had tickets to Hawaii since last year (I booked them just after getting my diagnosis) coming up end of April on Saul's school break. We haven't had a family vacation together in quite some time and it feels necessary. Recall our December family holiday was interrupted by my surgery.

I've emailed my doctor about this to see how he would think about it, the obvious question is what's the downside to just doing it now? I haven't heard back yet but to answer my own question: 3 months is not a long time as far as these things go, hence expediting would increase the likelihood of a false negative result (meaning that the scan doesn't show meaningful progression because we didn't wait long enough). That would not be good.

I'm trying to be honest about what I'm feeling, if only to convince myself not to be willfully blind about this. Obviously if this is aggressive then I'll deal with it immediately. My trigger event at this point is that if these 'symptoms' persist or worsen for another week I'll likely press the issue and move to expedite the scans.

75.

The scans

Sorry, I left you all in a cliff hanger! My primary oncologist replied that I should sit tight and wait on the scans and not expedite things, that I would get all the radiation exposure without meaningful information if we did this earlier. So I'm waiting. The symptoms have basically stayed the same: still feeling consistent back pain but at least it's not worsening. And I'm still sleeping too much, 9-11 hours/night. I've been unable to wake up before 7am which is very out of character. I've heard the effects of chemo can stick around for 6 months, so some lingering poison might be part of it. Also I've had mild underlying sickness from the kids. So I'm going to lay low and trust in the 4 aligned opinions for now. I'm picking my battles and laying low for now.

Additionally, about 4 days ago I got an ingrown toenail on my big toe. It's been pretty painful but not a big deal. I emailed my oncologist, asking what I should do. I finally got a reply today. Though I'm not neutropenic I still need to deal with this. The main issue is that lymphoma is a problem with the immune system. As such infections need to be taken seriously, even if I'm not currently neutropenic (which I'm not). So today I'm headed into urgent care to see what they can do.

And I got the upcoming scan setup. I was able to finagle a bit and it's scheduled for 3/5, right when I get back. It's like something out of a bad movie. I can see it cinematically: lush Hawaiian landscape fades out as the camera pans across the shimmering ocean, gently waving palms at dusk. Cut to clinical scene with harsh fluorescent lights glaring on me, as I'm dressed in an ugly medical gown.

Bad movies

Glued to awful movies

Over the weekend the kids had friends over and they watched 'Ninjago' (it's awful on so many levels – I don't have the patience to discuss here). I can't believe I'm a parent that allows this stuff in my house. I cozied up with them, eating my homemade popcorn if only to snuggle a bit. One of the subplots revolves around a tense father and his son relationship, akin to the one in Star Wars. When it was over the other kids went to the room but Lev stayed back, lying on the sofa. He was obviously holding back tears, his tiny body has no room to hide large feelings. I sat with him for a few minutes rubbing his back. He put his arms around me, squeezing hard, his smooth cheeks on my neck. Then he started wailing. We probably stayed for 10 minutes like that. He didn't tell me what it was about, but I know it pertains to my health; these feelings and concerns have to come out somewhere.

After that episode it occurred to me there hasn't been much crying or discussion around my condition lately. We've focused on nuts and bolts (e.g., daddy goes to the hospital today, daddy will be tired for the next few days) after the initial conversation. I've tried to keep things smooth around the house to whatever degree possible and to avoid putting unnecessary anxiety on them. Now I wonder if that was the right move, or if it's just percolating inside them. Maybe we should talk about it more? The last thing I'd want is some unhealthy long term response because we smoothed things over in the short-term. Monitoring this vigilantly.

And to be clear, sadness is a very appropriate response to life. Even if things are great. That doesn't mean one should mope! But in my opinion reflecting on it helps bring gratitude for what is, and a sense of urgency make things happen. We should strive to be well-calibrated to reality. I appreciated Lev's openness with his feelings as he struggles to understand them. It seemed really healthy.

Helping others

And it's been nice to continue getting some feedback on the blog (it's emotional rocket fuel for me to keep it going). Seems to be causing some nice ripple effects and I'm pleased that this crazy journey can in some way be helpful to others. Here's my favorite piece of recent feedback. Randi – thank you for sharing this and thinking of you as you get deeper into treatment (and hope this gives you a small boost for whenever you catch up!).

> *I was connected to your blog through my massage therapist in Rhode Island who is friends with your sis, Ilana. *Thank you* for your blog and for your intimate thoughts and feelings. It has been so comforting and validating for me. Must admit that I haven't gotten too far in the reading. I am at September, 2018… Oftentimes I will read, reread and read again because the words resonate so much with me. So because I am not at February, 2019, I am not sure where you are in your journey, and I don't want to "cheat" and read ahead. I hope you are doing OK. You are helping fellow cancer patients, like myself, to *push* ourselves on a spiritual, emotional and physical level. On days when I just don't feel like pushing, I think of you.*

Meantime I've joined a few Lymphoma Facebook pages to both get some questions answered, as well as to support others going through this. All the info I've been learning seems to be coming in handy to that end. Knowledge should never go to waste.

76.

Visiting colleagues & getting back to physical health

I biked to SOMA the other day for the second time since diagnosis. It felt great to do my work commute, if only to convince myself for a few minutes that things are back to normal. Also it was good to see I could still do it!

Visiting the team. I'm privileged to work with such wonderful, talented (and good looking!) people. They've been amazing through this journey.

I visited with my very impressive colleagues at Tophatter (think eBay, but *much* faster). It was invigorating to spend a little time catching up on all the projects I've been missing. Many of us congregated in the communal kitchen area for several hours – I definitely dragged worker productivity down a good 50%! But it was worth it. I was reminded of the a privilege it is to work in one of the epicenters of technological innovation on the planet. More fuel!

In other news I've had my mom in town for a few days which has been great for the kids. They love their '*damas*'. As a quick aside she is the one that actually kicked off the whole conversation that I should get that mystery mass checked out last year which, very foolishly, I ignored for weeks. She also secured my Dana-Farber connection. Recall it was this connection that recommended the second pathology report. So in a real way I wouldn't be in the favorable position I'm in right now without her help. Love you mom, I know it doesn't always come through but you've been essential to the good fight I've been waging. And all this has enabled my to try and spend more healthy time with the kids.

Spending quality time with the kiddos. Saul's chess game is getting strong!

Anyway, I bought a 7 day package at a yoga studio the other day at Michelle's suggestion to see if that helps with my back issues. Since my mom is here, she watched the kids while Michelle and I did a yoga class together. We hadn't done something like that since before kids and it was physically helpful, emotionally invigorating and a great way to connect with each other. My back felt ever so slightly better this morning. I'll be taking advantage of this and getting my yoga in as I prep for Hawaii next week.

It's just what the doctor didn't order, though I wish he did.

Still, nightmares

I used to reserve the word nightmare for something terrifying that lasted a while. The line between nightmare and non-nightmare was obvious. But I don't know where to draw that line anymore, it's so blurred.

For example, take last night. In it there was a scene in which I was flagged by those around me as Jewish ('vermin', to be executed) by the Nazi-like society in which I somehow lived. To cut a very long and winding story short I watched the executions happen to others, not me – yet. But they were catching on to me and closing in. Instead of gas chambers (so 20th century) the destructions were personalized. Folks were put into scuba-like apparatus and would inhale the vapors while staring directly, unblinkingly at me. I remember the staring directly at me part since it was so vivid and peculiar. Folks would count the breaths and they would lose consciousness after 8 breaths, plus/minus two, while scientists stood by with clipboards. I remember deciding that I'd prefer to swim to my death if it came to that. Better to have the illusion of freedom than certain confinement if the outcome was to be the same.

In another dream (or scene, hard to say if they were connected) I was actually swimming in the expansive ocean. Then suddenly the surface breaks and it caves in a giant waterfall with the destructive power of a hydrogen bomb. I'm instantly sucked into the great ocean depths, falling for seconds (another peculiarity, remembering that). But it didn't kill me. The deafening roar of massive waters rushing past fills my head. But I was still, miraculously, in the world of air. I was inexplicably living in this hostile and environment thousands of feet beneath the ocean. How else to describe this but that I was in a state of complete surrender. And I was just waiting – at any moment the tides could shift and consume me – was it a matter of seconds? Enough to hatch an escape plan? Or should I just savor my last moments?

These kinds of nightmares used to affect me deeply. But now I look on as an observer, mostly amazed at the stuff my subconscious comes up with in attempts to make meaning. The underlying content is of course a reflection of my current position and is so thinly veiled as to barely require interpretation. No, what's frightening to me is the lack of impact such stark dreams elicit; I don't think I'm numb but sometimes I do wonder.

These upcoming scans are clearly causing some anxiety. That extra energy seeks manifestation. I suspect dreams are the lowest energy solution for such expression to occur given that (it seems to me) the ego shuts down in that state. That anxiety can bypass whatever defenses my ego has devised – cortical Maginot lines. The fear of cancer progression is real. Still processing.

77.

Oncologist*: Are you ok? Where are you?*

Ari*: (panting) Sorry. I'm out of breath. I just ran up a hill. You're calling 20 minutes late and I was getting really anxious – had to burn some energy…*

Oncologist: *Well I have your PET results. Excellent news. The scan shows there's* ***no metabolic activity*** *at this point. Keep running up those hills.*

Ari: (*dumbfounded, stunned) …What?*

Oncologist: *Yeah! Congratulations. You should be very happy.*

Ari: (*dumbfounded, stunned) …how can this be*?

Oncologist: *Well I don't know. It could be that we didn't wait long enough on the last scans and the drugs were still working. They must have still been in your body and there was activity still happening. There's still tissue there but it's not active. It's an amazing result.*

Ari: (dumbfounded, stunned) …So…you're saying this is ***complete remission****?*

Oncologist: Yeah, right! That's what I would call this.

I collapsed onto the sidewalk. People on their phones were stepping around me. I took in the news – disbelieving. I told him I had so many questions but didn't want to ask them right now. I wanted to let it sink in.

As I'm writing this post I still don't believe it. I called Michelle. She started crying: a pause, then "*come home now*". I lay there for probably 10 minutes, staring at the naked branches of a tree above against the grey sky. I melted into the sidewalk, hands on my head. Just staring.

Counterfactual histories

Let's consider for a moment how things would have likely played out had I gone through the original recommendation to push ahead with standard second-line treatment. Recall that I had 3 oncologists aligned on this path just weeks ago.

Well, I'd have started in January with 2 rounds of harsh, platinum-based chemotherapy. Roughly 9 weeks later I'd be doing the scan (that's about now). And assuming the chemo didn't worsen anything, that scan would have shown complete remission. And we would of course have attributed success to the second line chemo! And since remission is the signal to proceed to the second part of treatment – the autologous stem cell transplant – that's exactly what I'd be prepping for now. That's another 3+ months treatment, assuming it worked. I'd be commuting to Stanford most days, or staying in-patient. I'd definitely be neutropenic, likely experiencing complications (as seems almost inevitable with that procedure), and probably not seeing much of my family with all the logistics. I'd have inflicted an incredible amount of damage on my body.

Only to be right where I am now.

Not just that. I'd be another data point thrown into the pool suggesting second line treatment is effective, nudging the broader treatment decision space just a bit in the wrong direction for the next person.

I'm forcing myself to contemplate this and it's hitting me hard.

Stay vigilant

I still have this nagging thought that something in my psyche set the foundation for the cancer to take root – toxic soil of the immune system? A positive scan should not be a signal that it's ok to let my guard down. In fact it's the opposite – I feel compelled to double down on whatever I'm doing, to remain vigilant in guarding against slippage to old habits and routines.

In terms of how this could possibly have happened all I can say is, who knows. My primary oncologist thinks the chemo was still working after the scans. Maybe – I think that's a convenient narrative. I spoke to another doc on my panel a few minutes ago and she mentioned that spontaneous remission is rare but it does happen. It's not something she would ever offer to patients as an expected outcome (she said she'd want to study me from a medical perspective out of her own curiosity), but there's no reason not to believe the PET scan. False positives can happen but false negatives aren't a real issue with these tests. Most likely is that it's spontaneous remission of Follicular 3a cells. Mechanisms for that remain unknown.

My view is it's a confluence of factors that led to the cessation of activity. I also think it's probable that it was a combination of factors (not just genetics) that led to the initial growth. No, I'm not exactly blaming myself for getting cancer. I am suggesting that perhaps my system wasn't properly tuned to handle a genetic predisposition. I don't find this narrative dis-empowering, that my psyche may have had something to do with, say, activating some genes that would have otherwise stayed quiescent. Quite the opposite.

The illusion of control can help in these kinds of situations. And conversely a perceived lack of control hurts. Indeed, if it feels like all control resides outside of oneself, that's just a quick hop to learned helplessness, a liability when battling cancer (those rats fare worse than control). The immune system is like another brain that we aren't close to understanding yet. So that requires picking up weapons we may not fully understand how to wield!

Since it tends to come up a lot in conversations I'll thumbnail sketch some of what I've been doing (with little to no detail as I don't have the time here). Maybe I'll discuss in more detail in a later post if there's interest. What I can say is I was pretty methodical about making specific changes since chemo ended, some prior. I can only speak to what I've been doing and make no claims about efficacy of anything specific. Those changes in combination may have had no effect, or they may have been essential. It's clear that they didn't hurt. Take this for what it's worth, n of 1. With that:

Mental

- Focus on mindfulness, meditation, being present. Still a work in progress but a big area of growth for me.
- Be positive. It's a bit like that trick of biting the pencil to force a smile. It actually is shown to elevate mood though you're getting there from the outside-in, mechanically so to speak. At no point did I feel despair. I worked hard to make this so.

Nutrition. I should say at the outset that when it comes to nutrition, that nobody really knows. There's so many competing theories, and such a scarcity of compelling data to support most of it. Also, few folks ever bring up the obvious point that all nutritional advice may not be right for everyone. Taken together it seems likely that (at minimum) our divergent genetic, epigenetic and gut bacteria profiles play a significant role on our individual metabolic output. This is a separate post for sure. It's worth bearing in mind that the placebo effect is strong and real. So nutrition may fall into that bucket. But the beauty is that it may not matter! Even if you knowingly take a sugar pill to help some ailment it still can work. I wouldn't rule that out. Anyway, I've implemented some practices into my lifestyle that have at least a modicum of data supporting them (and that literally, pass the smell test), specifically:

- Intermittent/fasting until noon, and no eating after 8pm. The idea is to reduce the feeding window to 8 hours/day to limit supplies to the 'cancer army'. Some rat models suggest this has an anti-tumor effect. A less fancy way to say this is that I skip breakfast. I've fasted a few days for 24 hours but haven't gotten carried away.

- Sip green tea (all day) – 5 cups minimum. Steep it 'til it's bitter (8-10 min) to release all the catecheins, especially the most potent one called EGCG. Note that other teas, (e.g., black) are less helpful due to effects of oxidiation.
- Lots of turmeric in food (sautee in olive oil, black pepper activates).
- Eat more vegetables. Lots of stir fry including cabbage, carrots, garlic, tomato. Lots of shredded cabbage-based salads.
- Eat less protein than usual. I think I require less than I did before. Following my body's lead here. I mostly skip protein at meals if I don't crave it. Used to think I should always have it in meals. Nonsense.
- Pescatarian diet and minimal dairy (if so, high quality cheese). Some studies positively link dairy consumption, meat with lymphoma. I've eaten a bit of meat if my body felt like it needed it, once a week if at all and mostly Friday night for Shabbat. No harm done.
- Consume minimal white/refined carbs and close to zero sugar. This one hardly seems controversial. I will buckle for butter croissants though.
- Overall I've been eating less. I don't feel worse for it. In fact I feel better.

Physical

- Workout every day – whatever modality. It's just hygiene, like brushing teeth. Not worth over complicating it with various fads.

Community

- I haven't spoken enough about this. I've gotten so much positivity from all sides that it's hard to believe all that energy didn't help. If I had to pick one element only and point to that as the cause of this outcome this would be the one. It's all about the people and the love. That's what matters in the end. It's unfortunate that it sometimes takes an event as horrible as cancer to deepen bonds between us. But it's better than not having it happen at all. I feel blessed.

What's next, how am I feeling?

I've been very clear to de-couple my emotions from outcomes towards maintaining emotional stability. That's been essential to my well-being. But it works both ways, buffering the highs as well as the lows. I kind of wish I felt elated. I don't feel all that much just yet. For peace of mind I've already left messages for the remaining members of my panel of oncologists to ensure we're all aligned.

For now I'm letting this soak in and taking some time to process. It doesn't feel real. For all the thought and considerations about battling this thing, I haven't allowed myself to go to the other side, to a place of being healed (or whatever you'd call remission). It seemed too out of reach.

That work starts now.

The rainbow outside my door after getting the news. How appropriate – yes I’ll read into it!

This is where you can add appendices or other back matter.