When Cancer Comes Calling

My Journey Into – and Through – Prostate Cancer

BOOK TWO: Awakening
July & August 2025

David R. Weiss

When Cancer Comes Calling – Book Two: Awakening
Well, THAT was a Premature Ejaculation …

David R. Weiss – August 15, 2025

INTRODUCTION. This is a LONG post chronicling the next chapter of my journey with prostate cancer. In it I grapple with my own dawning awareness of just how serious my particular case of cancer is—and my growing disappointment with some aspects of the care I've received thus far.

Looking back to my earlier writing about my cancer journey, I might characterize all the posts I wrote from January to June as "Book One: Innocence." Because those posts, though honest and eloquent, were written before I'd even begun to really understand the cancer I was facing. I was, as yet *innocent* of the tumult about to swallow me.

This new collection of reflections, arranged around six themes and brewing over the past seven weeks might be characterized as "Book Two: Awakening." Because now I feel as though I have a much clearer sense of what I'm up against, both in terms of disease risk and treatment options. Still so much to learn, but now I'm *awake*. It became so long because I was processing everything here *all the time*, so it never got written up bit by bit. I finally forced myself to sit down and capture it all—and this long post is what came out.

Finally, the posts coming next, as actual treatment begins, will perhaps form "Book Three: Soundings." After "sounding": the practice of regularly checking the depth of water, whether to ascertain safe passage for a boat or to map the unseen floor beneath you. In these future posts, I'll reflect on my experience in treatment in real time.

As always, I am writing *for my sake*—because writing stirs life in me. It is how I fashion meaning out of the ebb and flow of experiences that come my way. But I have learned over the years that my words often carry rich meaning for my readers as well. Frederick Buechner described vocation as the place where a person's deep joy meets the world's deep need. Writing is that vocation for me, and so, as always, I am writing also *for your sake*.

—David, August 2025

Now, on to this post …

CAUTION: *Unlike most of my writing, this piece carries occasional outbursts of profanity. Not for "shock value." I'm simply speaking the raw truth of my experience over the past few weeks. And right now, that truth is both messy and agitated. Editing out the profanity would give a false impression of calm. I'm anything but.*

The end of my last cancer blog post ("Not Even Close," June 17, 2025) concluded on a note of somber but hopeful resignation regarding my next steps in cancer treatment: PET scan, hormone therapy, and radiation:

> *So, I am in good hands. And grateful for that. The only thing about any of this that "excites" me is that it's my best path to long-term survival. It's hardly a cheap thrill. Not even close. The costs come physically, mentally, emotionally, and spiritually. But because I have high confidence in my urologist, I'll take the best options he offers me. And today, that best option is all of this.*

Several times in that post I expressed *unqualified confidence* in my medical care and *qualified-but-clear-readiness* to embark on this path.

Welp. Turns out both of those sentiments were *premature ejaculations*. My bad.

Okay, I wasn't exactly shouting in that post, so maybe "ejaculation" is overstatement. But (TMI?) following prostate surgery, the *only* ejaculations I can have anymore are verbal, so I'm claiming these ones. And I'm writing this essay to acknowledge that over the past month I have learned so much (alas, so late) that I now regard these words about "unqualified confidence" in my medical care and "qualified-but-clear-readiness" for the path ahead as naïve and embarrassingly premature.

Let me explain …

As I described in that earlier post, Margaret and I were both caught entirely off guard by the results of my initial post-surgery PSA test. (The test measures the amount of a particular protein produced *only* by prostrate cells that winds up in your blood.) Your PSA score more or less reflects the activity of those prostate cells in your body. Because my body is now without a prostate, my PSA score should theoretically be zero. Any persisting PSA level reflects prostate cells still active in my body; in my case, all of those would be *cancerous* prostate cells.

The hope was for an "undetectable" PSA: which *might* mean none, but more likely would just mean that the amount of PSA in my blood was below the sensitivity threshold of the test. Even so, "undetectable" means breathing space. A score of < 0.1 ng/ml is considered "undetectable." As the title of my last post announced, my score was "not even close" to undetectable. It was 0.48.

[NOTE: in my subsequent learning, I've come to recognize that while the "standard" definition of "undetectable" remains at < 0.1 ng/ml, newer tests can identify PSA levels down to 0.01 ng/ml, meaning that "undetectable" really begins at < 0.01 ng/ml. The most educated men with prostate cancer (and the most honest doctors) understand that a post-prostatectomy PSA of 0.1 ng/ml, far from being just the start of detectable, is a PSA *already on the rise*.]

Nothing had prepared us for that score of 0.48. My blood was drawn at 9:00 am. I sat back down in the waiting room momentarily, and then Margaret and I were taken back to a small (cramped) exam room holding just one chair. Margaret took the chair, and I sat up on the exam table while my vitals were checked by the nurse. By 9:15 my urologist joined us.

Within the first two minutes, after sharing a genuine greeting, he gave us the sobering news about my PSA. Honestly, everything after that was a blur because the "0.48" was reverberating in my head(heart) the whole time. Framed by "How?" "What? "Where?" and "Why?" Somewhere far *behind* that stream of stunned questions, phrases like "we knew," "high risk factors," "initial PSA," "seminal vesicles," "positive margin" and others were introduced. As though they were supposed to offer me an "Aha!" moment: "Oh—of course!—now I get it. All makes sense. Thanks!"

NOT.

Then, still far *behind* the ongoing echo of "0.48" and its existential weight, came mention of a PET scan, a referral to a colleague for radiation, going on Lupron, a 6-month to 2-year window of hormone therapy, some side effects, and scheduling that injection soon. *All a blur*. Somewhere in that flurry of words, the phrase "chemical castration" was uttered—with something akin to clinical indifference. The way you might tell a guy, "Now I'm going to cut off your balls, I hope you don't mind too much." WAIT—WHAT?!

In barely a dozen minutes, in a small (cramped!) room where we couldn't even sit next to each other—couldn't hold hands or even offer a reassuring touch—our world was flipped sidewise. And then my urologist, still standing near the door (there wasn't a chair for him either) wished me well, and moved on to his next patient … and left us to sort through the shards of our life.

I swear the last thing I heard as he left the room was still "0.48," now with "chemical castration" singing harmony in my head(heart).

It took me a week or more to realize what a *shitty experience* that was.

Sadly, my first impulse was to police my own feelings, to reassure myself that "calm" was called for. That following my urologist's advice was the wisest and most responsible course of action. That first impulse guided my writing "Not Even Close," where (goddammit!) I used the eloquence of my words to smooth over my own reeling unease. *I silenced my gut instincts in order to say what I felt I was supposed to say—and not what my gut-head-heart was telling me*. Damn.

Right after posting the blog, I called and scheduled the PET scan (check), the radiology consult (also check), and the Lupron injection (also, check). Then I congratulated myself for taking swift initiative to put the next steps of my treatment plan into action.

With things seemingly well in hand, I drove to Indiana to spend a week with my dad. He's still recovering from a broken neck six months ago, so "spending time" with him also means taking a turn as his caregiver. Precious time, busy time, with my dad. But it was during this trip that my *real education* around prostate cancer began.

On the drive down I listened to six-plus hours of podcasts about prostate cancer by men living with prostrate cancer. A couple themes appeared across multiple podcasts: the need to understand *your* cancer, the need to take a very active and sometimes critical role in shaping your own treatment, and the *near-universal grief-terror-desperation* with which men fighting prostate cancer speak … about Lupron. (Fuck! What have I done?!)

I sat up late back-to-back nights, reading dozens of pages of discussion threads posted on prostate cancer patient forums hosted on the Mayo Clinic website regarding Lupron and other ADT (androgen deprivation therapy) drugs. [Androgen—"man-making"—hormones are responsible for masculinizing the male body; testosterone is the primary androgen.] There are several different types of ADT drugs that use varied mechanisms in pursuit of the same goal: to suppress the testosterone that prostate cells need to multiply. ADT drugs are very effective at what they do, which is to produce "chemical castration," effectively erasing testosterone from the body. While they don't typically kill the cancer, they can significantly slow or stop its growth. *That is, until they can't.* Sooner or later the cancer becomes "castration-resistant": it figures out how to reproduce without needing for testosterone.

But the rest of a man's body—and psyche? Far from ever becoming castration-resistant, a man's body can be RAVAGED by Lupron (similarly by other ADT drugs). The near inevitable side effects are lost libido (not "low" libido, but *gone* libido), flow energy, weight gain, muscle loss, and hot flashes. Other side effects can include joint pain, debilitating fatigue, breast development, shrinkage of penis and testicles, osteoporosis, heart disease, suicidal ideation, and increased risk of dementia.

My urologist had mentioned nothing more than low libido, low energy, and hot flashes. Never mind that many of the rest of these are “less common” side effects. They become more likely the longer you’re on ADT. They’re *unpredictable*—some guys have only minor side effects after years; others experience severe side effects within months. And while the idea “in theory” is that these side effects will eventually go away (months or years) after ADT stops, the official word is always that they’ll *likely* subside … but in some cases may persist indefinitely or be permanent. This was hardly reassuring information to discover on my own.

On the Mayo Clinic website, I read *dozens* of first-person accounts of lives undone by Lupron or other forms of hormone therapy. Granted, some of the guys ended their laments by saying, “But at least I’m still alive.” Others, however, openly wondered whether the life they’d bargained for with ADT was still worth living.

In the still of those nights in Michigan City, I realized how woefully unprepared I was to meet the demon that was stalking me. All of sudden, the calm words at the end of my “Not Even Close” blog post suddenly seemed *not even close* to true anymore.

Since then, I’ve been on a *steep* learning. Reading about prostate cancer in a big picture perspective (something I largely failed to do earlier, when I should have). Wrestling with my feelings about Lupron and ADT in general. Learning how to fine tune my body’s own readiness to fight cancer. Choosing (too late, or perhaps just in time) to be my own fiercest self-advocate. And surrounding myself with a medical team of my own choosing. I want to expand a bit on each of these.

A FAILURE TO LEARN

I can excuse myself for not commencing on a deep dive into prostate cancer (or PCa as I often see it shortened to in online forums) right after my October 2024 “red flag” PSA score. After all, the first thing my primary care physician told me—emphatically—was, “This does NOT mean you have cancer.” And that’s true: cancer is only one of several things can trigger a high PSA score. No reason to “panic” without cause. I did a little googling around “high PSA,” a little worrying, to be sure, but mostly I went on with my life until my urology consultation in mid-November. I told Margaret about the PSA right away, but we told no one else. It could’ve been nothing.

In mid-November we met with my urologist for the first time: a virtual visit because it was the first appointment available. He, too, told me it might not be cancer, although he added that the combination of a high PSA and absence of any symptoms of an enlarged prostate (like needing to pee during the night) made it “quite likely,” in his opinion, that it was cancer. He referred me for an MRI, to be followed by a biopsy, which would provide a formal diagnosis (or a big relief).

I could have—probably should have—started an intentional self-education on PCa at this point. I did ask my urologist about resources to educate myself, and he recommended the website of the Cleveland Clinic (Ohio’s version of the Mayo Clinic) because that’s where he’d done his training. They do have an extensive website, but (like most “clinic” websites) it ends up feeling both labyrinthine and piecemeal. Lots of short articles with multiple hyperlinks to further content, but after a while you feel like you wandered deep into a maze, and you aren't sure how you got to this page or where you read that one interesting thing several clicks back.

I found it easier to focus on the next immediate thing—how will the ultrasound work? what is a biopsy like?—rather than actually learn about the cancer itself. Besides, my urologist had reassured me that if it turned out to be cancer, he'd review my options for treatment at that time. He also said that if surgery was appropriate, he was a skilled, experienced surgeon and would take good care of me. As a result, with Thanksgiving coming up, followed by the full flurry of December holiday activity, I spent another six weeks *not learning* about the cancer itself … while it was no doubt busily learning about me from the cover of my prostate.

I don't quite blame myself for this either. Maybe throwing myself into cancer self-education before anything was certain would've been an overreaction. Still, looking back now, I can recognize how the implicit choice to let my urologist "take care of me" was an unwise surrender of my own agency.

Over three quick weeks, from December 29 to January 16, courtesy an MRI, a prostate biopsy, and the subsequent pathology report, my diagnosis was clear: cancer. High grade. High risk. Alas, if I can excuse myself for preferring to wait on self-education back in October … November … and even December, following this diagnosis in mid-January, it's now *inexcusable* that I didn't swiftly and fervently invest myself in fathoming what it meant (and continues to mean) to have high grade/high risk—potentially metastatic—prostate cancer cohabiting with me in my body.

Instead, I invested in my urologist's pledge that he would go in surgically (on March 5—we set that date at the January 16 consultation where we reviewed the biopsy report), remove my cancer-riddled prostrate, and do his best to return me to a cancer-free life. Who wouldn't choose that option when it's on the table? Problem is, *it was never the only option in play*, just the most attractive one. And the one that asked the least of me.

But there was another presence at the table … looking over other options. Cancer.

This is why, in retrospect, I *should* have started educating myself about the full scope of prostate cancer right after that mid-November consultation, while there was still a measure of "safe distance" between David and diagnosis. There is something to be said for meeting your adversary before the first blow is thrown. I missed my opportunity to do that.

Moreover, knowing what I know now, my urologist *should have actively encouraged me to do that*—and should have put some printed resources in my hands right away, six full weeks before telling me on January 7 that the MRI made a cancer diagnosis all but certain. I write this with profound conviction because I now know viscerally what I did not recognize then: cancer has its own dynamic and momentum. Its sudden threat of silent creeping mortality appears a form of self-betrayal: *these are after all my own cells turned against me*. And that head/heart rush of disorientation and fear is not the ideal time to start learning. Not least because by then time itself is ticking away.

In any case, I *STILL* did not start learning about the monster that is high-grade, high-risk PCa. It comprises only about 15% of all prostate cancer. It is an altogether different beast than its more genial cousins. But for the rest of January and February, I stayed focused on understanding robot-assisted radical prostatectomy, the procedure that was supposed to leave me cancer-free and worry-free (at least for a good few years). I added in "study units" on how to deal with the incontinence and impotence that go along with prostate surgery (at least most of the time). These were worthy endeavors, but in the big scheme of things (a scheme of which I was still blissfully unaware), there were far more pressing lessons to be learning.

In late-January I had one last pre-surgery procedure: a PSMA PET scan. At the January 16 biopsy review, my urologist was a bit vague regarding why he ordered it. He said something about just wanting to confirm we were "all clear" for surgery. I took him as his word. But a week later I discovered (accidently—while researching the robot-assisted prostatectomy procedure) that by "all clear," he, in fact, meant "not yet metastasized." My cancer (which I'd barely made acquaintance with yet) was so high grade, so high risk, that there was a real possibility it was already spreading throughout my body! That realization did throw me (and Margaret) for a loop the day I realized it. But even that loop didn't jog me out of my complacency. (WTF?! It should have!)

That PET scan picked up one "suspicious" spot in a pelvic lymph node. However, because these lymph nodes sit immediately adjacent to the prostate itself, even if it turned out to be cancerous, it wouldn't count as full-blown metastases. Besides, my urologist told me not to worry about it since he would remove it during surgery anyway. So, I continued to guard my innocence and focus only on my upcoming surgery.

Nine days after surgery I cheerfully relinquished my catheter and reviewed the final pathology results with my urologist. The good news: neither of the two pelvic lymph nodes removed were cancerous. So that suspicious spot on the scan could be dismissed. (Spoiler: *not so easily!* But at the time, I completely put it behind me.) The mixed news: as expected, the cancer, all located on the left side of the prostate, *had* invaded the seminal vesicle and neurovascular bundle on that side. Not metastatic per se, but an added risk factor as it reveals that my PCa is not the homebody sort. And the bad news: there was a small positive margin—a tiny but distinct place where cancer came right to edge of the prostate tissue where it was trimmed away before being removed; this meant there *might* be a wisp of cancer on the other side of that margin—still inside me. Another risk factor.

Nevertheless, in what had by now become a persistent theme, I left the clinic on March 14 assuming that since my urologist had told me the surgery went "very well," the odds were still with me to be "cancer-free" for at least 5 years. Back in mid-January, he'd shown me the nomograph (a prognosis calculator) listing my odds of "recurrence" at 5-year (83%) and 10-year (90%) marks, and my odds for reaching my 80th birthday (60%). The post-surgery pathology report was further confirmation of these long odds, but my urologist encouraged me not to worry. And so, with my catheter out, I went home that day still imagining my biggest challenges for the remainder of 2025 would be not wetting myself and figuring out how to reliably enjoy sex with an unreliable erection. *I was so wrong.*

But (at least?) I was wrong … with focus. From mid-March to mid-June, I *did* work on Kegel exercises with commitment—and success. I haven't wet myself in months. And Margaret and I *have* explored post-surgery sex with equal commitment—though admittedly with far less "success." That's not to say without tenderness and joy, but these days my entire body remains fascinated by and wholly unsure what to do with erotic touch. (That's a blog for another day.)

Finally in late June, after the 0.48 post-surgery PSA on June 16, I began (far too late!) to learn as much as I could about PCa, this nasty little monster to whom I am now married for life.

Prostate cancer has a more or less well-deserved reputation as an "indolent" (slow-spreading) cancer. There are six risk groups for persons with PCa: very low, low, intermediate favorable, intermediate unfavorable, high, and very high. Your risk group is determined by PSA score, "grade group" of cancer cell (how malformed the majority of your cancer cells are), biopsy results, and tumor stage (whether the cancer is confined to the prostate, progressed into nearby tissue, or spread into distant tissue). 85% of PCa cases fall into the low or intermediate risk groups. In these cases, especially when caught early, PCa is often managed by "active surveillance" (careful monitoring) because it grows so slowly, or when needed by surgery.

Only 15% of PCa cases are considered high risk or very high risk. That's where I am—at the upper end, in the *very high risk group*. All the data determining that was right there in my final pathology report in mid-March, but I didn't connect the dots until late June. And my urologist never explicitly connected them for me either.

WHAT I KNOW NOW

My cancer shows all the characteristics of being an apex predator of PCa. The type that isn't content to just get under your skin; it wants to get into your bones. That's the end game. When prostate cancer spreads beyond the immediate area of the prostate, 90% of the time it takes up residency (metastasizes) in your bones. And the 5-year survival rate after that is just 33%. The median life expectancy once it's in your bones is two years. Not to be too grim—because not every case of very high risk PCa ends up as metastatic PCa in the bones—but this does mean *my PCa is a forest overfull with dry kindling, just waiting for a lightning strike (or worse, a stray spark from a careless hiker) to become a full-blown wildfire*.

Again, fuck.

I've learned that for all the talk about "curing" my cancer, when it comes to high-grade, high-risk cancer, that's rarely if ever a live option. In fact, "cure" is defined as going 5 years with *undetectable* cancer. (More honestly put: 5 years with *cancer-in-hiding*.) In my case, the odds are *overwhelmingly high* that there will *still* be PCa cells percolating in my body on the day I die, whether it's the cancer that takes me out or something else (even old age). Percolating in my body; hopefully not in my bones.

Yes, it is *possible*, even with high-grade, very high-risk PCa, to battle it to a draw. To keep its presence sufficiently at bay that your PSA remains undetectable (which mine is not even close to right now), but even that really only means that its numbers are too few to make a blip on the PSA radar. If they do blip (shit, in my case they *already* blipped on June 16) that's called "biochemical recurrence." Biochemical, because it's picked up in my blood chemistry, though not yet visually on a scan. Once it can be picked up on a scan that's called *clinical* recurrence. And mine *also* appeared on a PET scan just eleven days after my PSA test, so I got to move swiftly on to clinical recurrence as well. And "recurrence," because that means the cancer came back.

EXCEPT IT DIDN'T. IT NEVER LEFT. IT NEVER DOES. Recurrence is a term intended(?) to make doctors and patients (I'm guessing) feel good for a while. But ultimately "recurrence" just describes the far side of cancer that was never fully removed; it was just temporarily pushed below the threshold of our best technology to measure it. Not to get all religious on you, but cancer like mine—high-grade, very-high-risk—may not kill me, but *it will never go away and then come back*. Like Jesus, though with nothing close to his calm assurance, my cancer leers at me and says, *"Lo, David, I am with you always—even to the end of your age."*

Well, fuck you, cancer.

But also, fuck cheap talk about cure and recurrence. Genuine cure (more than just the 5-year "cancer-in-hiding" cure) does sometimes happen, but not often with the hand I've been dealt. And when cure isn't an option, "recurrence" is just sleight-of-hand medical magic talk that deliberately stops shy of speaking the truth.

I know now that there *are* good, printed resources that could have given me a clear lay of this land before I actually set foot on it. Booklets by the Prostate Cancer Foundation (www.pcf.org) and the National Comprehensive Cancer Network (www.nccn.org)—and I know that are plenty of others—are written precisely for patients and others new to the prospect of prostate cancer. And even if I'd just read them at a glance back in December, while holding out hope for a clean MRI, they would've provided me with at least a beginning place of language, categories, possibilities. All in the abstract, all at a safe emotional/existential distance, but also *all in-the-waiting* when needed.

Had I gone looking for them before late June, I would've easily found them. Had my urologist even given me a printed list of resources back in January upon my diagnosis, I would've tracked one down sooner. My lack of self-education is *not* his fault, but this being my first cancer rodeo as a patient (but far from his first as a doctor), I pretty sure he understood the stakes of my case long before I did. And rather than offering me persistent words of reassurance, I wish he'd invited me far more directly to equip myself with the knowledge necessary to be a full partner in not only understanding but also shaping the direction of my care. Now I find myself making up for lost time, while time itself keeps ticking away.

I don't doubt that my urologist believes in "a patient-centered approach to health care." (His profile says as much, and I'm sure the words are genuine.) But within the juggernaut of Western medicine—the power differentials, the complex subject matter, the generations of bias that has privileged some knowledge and some voices while discounting others—even genuine words are no match for centuries of reductionist and paternalistic habits.

Our conversations from last November to this July have been concerned primarily with my cancer and how to treat it (if possible, how to "cure" it). While he's always been pleasant and polite to me, the patient, *my personhood*—the specifics of my life and my values, and how they would intersect with a cancer diagnosis-treatment-prognosis—*never really entered the conversation*. Yes, *I'm* being treated for cancer. But that "me" is a thin wisp of a person—not much more than a "prostate-bearing individual" and a husband; this latter by simple virtue of Margaret's presence at several of my appointments.

But ME, as father, grandfather, writer-theologian: all absent from the conversation. Me, as someone profoundly aware of impending eco-social collapse and deeply driven to use what relatively little time I have left before things fall apart to organize and articulate my thoughts on this existential crisis facing all of humanity (this, the very North Star of my existence!): entirely absent from the conversation.

My patient profile is now thick with data about the renegade cells that threaten to disrupt or even abbreviate the work and the love that are my reason for being. But the work and the love—the very things that make me, ME: altogether missing. This is a fundamental shortcoming of most Western medicine. It dwells on the things it can quantify—vitals and diseases, demographic descriptors and such—while politely but persistently eliding from view (and from discussion) the intangible—indelible, irreducible—thickness of the person at center.

So, now, besides working overtime to educate myself, I'm also working against inertia to insert myself—not as patient but as whole human being—into the conversation about my cancer, my treatment, my prognosis. Honestly, there are days—too many!—that it feels as though the goal of medicine is just to beat the cancer, without regard to the toll that beating cancer takes on the person. I don't say "patient," because patient is too easily generalizable into an abstract category. And, yes, medicine does make an effort to consider side effects and quality of life—"in general." But to insist on centering the "person" is to insist that each patient *in their full unique individuality* be at the center of conversations about cancer. That hasn't been my experience. And I'm determined to change that as my treatment goes forward.

FINDING MY TRIBE

Besides the 60-page booklets by the Prostate Cancer Foundation (www.pcf.org) and the National Comprehensive Cancer Network (www.nccn.org), the other more powerful and empowering learning has come from fellow travelers—others living with prostate cancer, whose voices I encountered on 12+ hours of podcasts driving down and back from Indiana, and whose words I've read in online forums and support groups.

Whether I like it or not, these voices represent *my tribe* now. And whether grateful or disgruntled, these voices carry learning that's been hard-won through their own embodied experience with prostate cancer. Many of them have become ardent students of PCa, often under circumstances not unlike my own, feeling frustrated by what they weren't told and or by options they were never given. Their understanding of the disease is impressive—as is their generosity with others in the tribe.

But even more than their knowledge, what *really* struck me was their determination (at least among some of them) to claim proactive and critical agency in their own care. Why I hadn't fully claimed that for myself, I don't know. True, I've been committed to understand each procedure and each set of test results as best possible, but I have not been as committed as I should have been to understand the big picture of prostate cancer, where my case fits in that larger frame, and—most especially—what it means *for me* to be proactively and critically engaged in shaping my own care.

In these podcasts and forums, I'm discovering what it truly means to insist on a patient-(person!)-centered approach. It is to insist that our capacity for understanding be respected, that our experience be weighed in the balance, and that our unique values and desires be heard and honored. Ultimately, it is to insist that *the competency of our agency* (not the conquest of the disease) be recognized as the final measure of treatment success.

While I was blessed to receive kind words of solidarity from an unexpected number of friends who identified themselves as prostate cancer survivors, most of them were fortunate enough to have met my cancer's kinder cousin (PCa with low or intermediate risk factors).

However, one friend from my congregation, Roger, is also battling high-risk PCa. He's much further in his journey, now battling metastatic PCa, but he has been a true mentor, connecting me to literature that has deepened my understanding of PCa—and perhaps more so by modeling what it means to be a patient (person!) critically engaged in their own care.

What Roger offered me in person is what the podcasts and forums have offered across a much wider range of voices and experiences. I need to give a particular shout out to Murray (Keith) Wadsworth, host of the podcast "Prostate Cancer Lessons" (and author of *Prostate Cancer: Sheep or Wolf*, a memoir of his PCa experience). His podcast is framed around the idea that those of us living with PCa need to become *patient-scientists* and *patient-detectives* in order to effectively self-advocate for our care.

I've found several PCa podcasts very informative, but "Prostate Cancer Lessons" has been a game-changer for me. So much so that it's fair to say the dividing line between my blogs written from January to June and this new set IS "Prostate Cancer Lessons." Keith and his guests have educated me, provided me with a felt sense of solidarity, and helped me hone my own posture as patient scientist-investigator-advocate.

LUPRON—A BEAST ALL ITS OWN

There are a growing number of drugs used in hormone treatment (also called ADT: androgen deprivation treatment). Their mechanisms vary, but in one way or another they all suppress the testosterone that is essential for prostate cells to reproduce. In doing so, these various drugs slow and even arrest the growth of prostate cancer. By "starving" these cells of testosterone, they weaken them, making them more susceptible to being killed by radiation.

What's not to like about that? Nothing. Except that testosterone isn't simply necessary for prostate cells to reproduce, it's essential—in a host of ways—for a man … *to be a man*. Suppressing it—cutting it off at the source, as "chemical castration" suggests—amounts not simply to starving the cancer, it amounts to starving the man of his "manhood."

The list of observed side effects is sobering: lost libido, fatigue (sometimes debilitating), weight gain, muscle loss, hot flashes, joint pain (sometimes extreme), brain fog and word-loss, concentration and memory issues, breast development, shrinkage of penis and testicles, osteoporosis, heart disease, suicidal ideation, and increased risk of dementia. In short, these are *the bodily manifestations of an entire system, the very infrastructure of selfhood, under a full-scale assault*. As I noted above, some are more common than others, but their occurrence and severity in any individual person is entirely unpredictable.

And while in theory the side effects are reversible after hormone treatment stops, that "after" can mean a time period equal to or longer than treatment itself. If you're on Lupron for 6 months, you can *hope* that 6-9 months *after* you stop taking it, your particular set of side effects will subside. But there's always the fine print that says, "in some cases, side effects may persist indefinitely or be permanent." Oh, for fuck's sake.

So, as handy as it is that we've discovered (back in 1946) a nifty way to turn off a person's testosterone with therapeutic effects for prostate cancer, it's really only as "handy" as you are comfortable having the whole of your manhood potentially jettisoned as well. Indeed, several persons—including my wife, Margaret—have offered well-meaning consolation around things like “hot flashes.” You know, “welcome to my world.” Well-meaning though that might be, *it entirely misses the point*. And I need you to pause long enough to hear this.

Lupron plays an important role in gender-affirming care. For transgender girls and women, Lupron is a life-saving drug because it prevents their bodies from masculinizing them against the truth of their deeply known selves. Our bodies are inescapably interwoven with our psyches. Thus, it is no overstatement to call it “life-saving” because we know, tragically, that to find one’s bodily self out of alignment with one’s psychic self can pose a life-threatening tumult of inner awareness. Transpersons, particularly youth, have borne fateful witness through isolation, depression, suicide attempts, and suicides to the DAMNING PERIL posed by such a stark conflict between body and soul.

So, listen as I say this. It is equally true for cisgender persons like me. (“Cisgender” is to have a body whose sex aligns with your inner sense of gendered self.) For cisgender persons, smack in the midst of their “therapeutic effects” on PCa, hormone-blocking drugs like Lupron begin to FORCE a gender-transition upon our bodies *against our wishes, without our consent, and beyond our power*. This, too, is nothing less than a DAMNING PERIL. Telling myself “It’s all to cure the cancer,” doesn’t lessen the peril.

And if you only take time to listen to the witness of countless men whose PCa journey has included ADT hormone therapy, you’d hear this loud and clear. But those voices are *made* hard to hear because they’re racketed outside the medical discussion which sets cancer, not the person, at the center of treatment.

I have to assume this is why my urologist, *without any conversation with me at all about the impact of potential side effects on my personhood*, proposed to schedule me for a (fucking!) six-month injection of Lupron. This despite there being four-month, three-month, or even one-month options as well. I get it. A six-month shot is more convenient, but it offers no “off ramp” to a guy who can’t tolerate the side effects. It presumes Lupron’s ability to arrest cancer eclipses any possible costs it might bear—that the supreme value is beating the cancer, regardless of cost to the person. Simply stated: I reject this.

I am not interested in beating cancer, if the only terms on which I can do so involve trading away my energy, my passion, my gifts as a writer and theologian. *That’s David.* “Cure” my cancer at the cost of erasing those and you’ve done so … *at the cost of David*. There is no light-hearted joke to be made about hormone therapy. There is no well-meaning consolation to be offered. There are actual persons’ bodies, hearts, souls, lives at stake here.

Now, it may be, on account of my very high-risk PCa, that I will *need* to entertain some high-risk treatment options. Perhaps, after carefully weighing the pros and cons of ADT for me, I will *choose* to add it to a treatment regimen to increase the efficacy of radiation. I *may* decide to do that. At least to see if I find the side effects relatively tolerable. There is a version of ADT that is a daily oral medication; if I’m a suitable candidate for that, it would have the quickest off ramp. And that matters to me—*as me.*

But I must state these two things very clearly. First, I will only submit to hormone therapy after carefully considering all my options —and preserving *fully* my agency to opt out at the earliest possible moment should I find that I need to. My urologist did not offer ADT on those terms. *Not even close*. And I’m holding out until those terms are met. Second, even if I agree to it, it will be with *unapologetic and strident reservations*. As a necessary evil, in which neither word—necessary, nor evil—gets to eclipse the other.

REMEMBERING, "MY BODY IS CAPABLE"

That phrase is a "call out" to the Stanford University Mind & Body Lab EMBRACE study I'm in right now for cancer patients. The study explores how to best support cancer patients' mental-emotional wellbeing as they fight cancer. One facet of the study reminds us that our bodies are designed to endure many challenges and are capable of much healing—both on their own and in partnership with medical procedures.

In the weeks immediately following my 0.48 PSA, my gut sense was the panicked feeling that *I had become a bystander in my own care*. Caught off guard and unprepared for such a sudden shift in diagnosis and escalation in treatment, I found both my urologist and radiologist eager to move forward—and with a clear sense of direction—while I was still spinning and trying to make sense of what I'd just been told. I felt like my agency—my ability to direct my own life choices—had gone "missing in action" amid the strong current of medical advice about what to do next. It was a suffocating experience.

One way I came out of it was to learn everything I could as a layperson about my prostrate cancer. Hence, all the reading and the podcasts. The other thing I did was to learn what I could do on my own *for myself*: to strengthen and leverage my body's own intrinsic cancer-fighting capabilities. A special shout out here to my friend, Roger, who shared with me some of the literature and plant-based supplements he was using to support his body in his struggle with metastatic PCa. Although I was initially guarded toward his passionate enthusiasm for plant-based medicinal strategies, as I read the literature for myself, I found it exciting and compelling.

This is part of my argument with Western medicine's happy reliance on hormone therapy. It strikes me as a move quite parallel to the Western embrace of chemically-facilitated agriculture. Our industrialized model of agriculture uses chemical fertilizers and pesticides to *force* the ground and the flora to do what they've long been *willing to do in partnership*. Rather than learn from the eons of wisdom held by Nature itself, we've chosen to raise food (and then process it) with reckless indifference to the long-term health of the soil, the ecosystem, or even the bodies for which the food is destined. I fear Western medicine has followed a similar path, privileging the brute force of chemicals and technology harnessed by human intellect, while undervaluing the softer, slower wisdom held in bodies, plants, and practices.

Permaculture is the name we give to the practice of agriculture that seeks to learn from and partner with the natural world. Its medical counterpart(s) might be considered Indigenous, traditional, natural, and (in some forms) integrative medicine. These traditions of medical knowledge, some ancient, others contemporary, are less scientifically "vetted" largely because they arose prior to and/or outside the Western paradigm. But also, because their methods and medicinal substances are less easily folded into the profit-driven model of medicine that decides where to invest research funding. Nonetheless, they often hold generations of wisdom gleaned from reverent attentiveness to the natural world and disciplined observation of human response. Moreover, in recent years clinical studies have demonstrated the medical efficacy of practices like fasting, acupuncture, mediation, mindfulness, and movement, as well as the medicinal power of certain plants and plant-derived supplements in fighting cancer.

Ralph Moss, in The Moss Method (among other books he's written), reviews the scientific evidence for enhancing our bodies' own cancer-fighting capabilities through natural medicine. Without denying the insights gained by Western medicine, Moss argues that we ought not overlook these other most primary partnerships available to us: leveraging our choices in lifestyle and diet and making alliances with the powerful medicines of plant world.

As a result of his book, I've adopted Time Restricted Eating and added a handful of vitamin and plant-derived supplements to my diet. I'll only briefly review these choices as it is *not my aim to recommend them to anyone else*. I've read several hundred pages—a couple books, a number of articles, and a couple dozen of the medical studies Moss cites—to make my choices. (And, as I note below, I'm now in consultation with an integrative oncologist about them.) Any choices you make should come from a similar investment of time and medical advice.

Time Restricted Eating (TRE) is a form of Intermittent Fasting. It involves expanding the length of time between your last meal one day and your first meal the next day. The idea in my case (very basically) is that cancer cells are hungry for glucose all the time. It's the easiest sort of "fast food" available to any of our cells, but cancer cells are rather *fixated* on it. Sometime around twelve hours after your last meal, the glucose in your bloodstream is exhausted. Beyond that point, normal healthy cells begin to utilize other sources of energy—often cellular debris. In effect, they "clean house" making themselves leaner and more efficient while waiting for the next meal to send another round of glucose through your blood. But cancer cells lack this ability, so they're left weakened by this persistent (daily) fast, making them more vulnerable to your body's own immune system—which is, in turn, stimulated into action by these intermittent fasts.

I began my practice of TRE around the first of July. As a longtime habitual bedtime snacker, I was initially intimidated at the prospect of surrendering my late-night cheese and crackers, chips and dip, and occasional bowl of ice cream. But I've actually found it a very easy transition into TRE. Whenever supper is over, I'm calorie-free until the next day. Water and unsweetened tea are fine, but zero calories. Over the past 40 days, I've allowed myself three evening glasses of wine and one small bowl of ice cream, but on 36 other days no calories at all. I average just over fifteen hours between last meal and first meal, ranging from 14 to 19 hours of daily fasting.

My biggest surprise has been the absence of any real hunger. But I would also say my energy level has been extraordinarily steady; I've done two hours of yard work 14 hours into a fast and felt no weakness at all. I'm guessing my healthy cells have "learned" to seamlessly switch over to other energy sources, so that my body is functioning more efficiently. And I hope the cancer cells are being regularly stressed and more easily held at bay or even taken out bit by bit by my own immune system.

A wide variety of foods with cancer-fighting properties have been identified (extra virgin olive oil, broccoli, garlic, carrots, beets, ginger, tomatoes, various berries and red grapes, green tea, turmeric, to name just a few of the "stars"), although it might be difficult to achieve a *medicinal level* of their active components in your diet alone. While Margaret and I already eat quite healthy, I've now also added two vitamin supplements and five plant-derived supplements to my daily diet.

I take extra Vitamin C and Vitamin D3 (the latter in a formulation that includes Vitamin K2 to increase absorption). I take supplements containing berberine, curcumin (from turmeric), a mushroom extract, DIM (Diindolylmethane, the active component in broccoli and its relatives), and melatonin. Oh, and besides incorporating extra virgin olive oil (EVOO) into all manner of food prep, I'm also "enjoying" 3 Tablespoons of it "straight" by shot glass each day (and this is "top shelf" EVOO—in order to ensure it has the high polyphenol count that is EVOO's superpower).

Without going through all the research, suffice to say that each of these foods, vitamins, or supplements has the power to assist our body in fighting cancer in a variety of ways. They help regulate blood sugar levels; improve our gut biome (the infrastructure of bodily health); reduce inflammation (lowering our body's baseline stress level thereby freeing up resources to fight cancer); enhance our immune system; support healthy cell cycles while also inhibiting cancer cell growth; and directly attacking cancer cells.

Some of them have even demonstrated the ability to selectively target *cancer stem cells* (CSCs)—the subset of cancer cells that appear to be the driving force in cancer spread. Unlike most of the cells in a cancerous tumor, CSCs (like healthy stem cells) can replicate themselves as well as produce differentiated cells that make up the bulk of cancerous tumors. Additionally, they're adept at repairing their own DNA, and they can enter a phase that allows them to move with covert freedom throughout the body, thereby seeding metastatic tumors. These CSCs are *the* cells that need to be taken out to truly defeat cancer. And there are studies that show certain plant-derived supplements that can do just this.

There are a much larger number of supplements that I could take. I've made judicious choices based on those supplements with strong evidence-based studies behind them—and, realistically, what I can afford (about $50/month).

I'll be the first to admit, *I am unlikely to beat my cancer using only these methods*, but I am persuaded these choices will help my body to do its part in fighting cancer. A sort of "permaculture"-informed strategy, they seek to learn from and partner with natural allies (with no or very limited side effects) in this fight. Moreover, they're one fundamental way that I can assert my agency—taking charge of choices within my reach.

I can't think of a better way to honor the maxim, "my body is capable." These efforts have already had a tremendous positive impact on me physically, mentally, and emotionally. And, in no small measure thanks to having strengthened my own agency, I've been able to participate more actively, both critically and creatively, in directing my care.

BUILDING A TEAM THAT IS MINE

THE UROLOGIST

As with most medical crises, we begin with the medical professionals "on hand." Since I wasn't expecting prostate cancer and had no prior history of prostate issues, I didn't have an established relationship with a urologist. When I needed one to address this cancer scare, I viewed the online bios for multiple urologists in my healthcare provider's network and selected one who seemed young enough to be "up" on the latest knowledge and old enough to be reasonably experienced. I had nothing else to go on. Seemingly by default as the initial treating physician for my cancer, he has been the anchor of my care team. He's certainly been competent, but as implied above, I've been disappointed with him in several significant ways.

I believe he knew, at least since my biopsy in January, that my cancer was high-risk, but he never directly communicated that to me, nor did he help me comprehend where my cancer fell within the larger picture of PCa. He could have done far more to educate me, especially as he was well aware of my desire to understand my treatment.

Additionally, several times I asked questions about my sexual "rehabilitation" post-surgery. His response was always that I should "manage my expectations." I can only surmise this reflects a lack of comfort or competence on his part, and I don't begrudge him for that. But (on my own) I've discovered a vibrant conversation around sexual health post prostate surgery—including urologists who assert emphatically that the best outcomes begin with "pre-habilitation" practices even before surgery and post-surgery guidance almost immediately. Plus, I recently found out that M Health Fairview (the health care system that I go to and in which he practices) has a *dedicated Cancer Support Services program* that specifically includes sexual health! My urologist's responses not only minimized my hopes, they also failed to connect me to persons right in the M Health Fairview system who could address them more effectively.

Most recently, I felt rushed into Lupron therapy on WAY too little information. Ultimately, I cancelled the start of that therapy and asked for a follow-up consultation to discuss it further. In that conversation he tried to calm my apprehension by providing more information, but he seemed less able to hear my very specific concerns than to repeat medical data that wasn't particularly reassuring *to me*. Bottom line: I didn't feel heard as a person. Never a good feeling.

Maybe I'm unique in weighing the quality of my doctor-patient relationship as much as the quality of my care, *but this is who I am*. And when the doctor leading my team doesn't seem to fully appreciate me as patient-person, it puts me persistently on guard. Which is not an enviable position from which to pursue medical care.

THE RADIATION ONCOLOGIST

Following my 0.48 PSA test, my urologist referred me to a radiation oncologist for "salvage therapy"—perhaps a clinically accurate but hardly inspiring term. Nonetheless, my initial (and thus far, only) encounter with the radiation oncologist was itself actually pretty inspiring.

He explained clearly how radiation would work—communicating alongside that basic info his *sheer enthusiasm* for the way radiation treatment has improved and the joy he takes in using his skill to maximize the benefits to me. We had an extended and very respectful conversation around my anxiety about hormone therapy. Even though he explained why he believed it would be to my benefit, he also confirmed that he would do the radiation treatments even if I declined to use hormone therapy alongside them. He also provided a very helpful handbook that explains the whole process of radiation treatment in plain language. It was the sort of handbook I *needed* (about PCa) from my urologist back in January.

Both the oncologist and his assistant were generous with their time and gracious with their words. Margaret and I left that appointment feeling heard. And feeling confident that when the day comes for radiation treatments to begin (likely early this fall), we'd be happy to trust this person and this place with these treatments.

THE PRIMARY CARE CONNECTION

I forget how I first connected with my current primary care provider, but he's been a steady source of both medical knowledge and genuine care over the past decade—including some very challenging times while battling depression. He's not a "frontline player" in my cancer care team, but he was the first person I reached out to following my June 16 urologist consult—the 0.48 episode. I told him I felt overwhelmed by the decisions facing me and ill-prepared to make them, adding in a MyChart message, in all caps: *IT IS ALL HAPPENING **TOO FAST**, AND I FEEL LIKE I AM A BYSTANDER IN MY OWN CARE.*

He found time to meet with me in-person within a week. I relayed my apprehension over Lupron to him and his first response, "I won't kid you, *Lupron is tough*," at least affirmed my feelings. He went on to say he believed it would be useful to my treatment but also made a point to remind me that at the end of the day, the decision about whether to use Lupron or not is up to me.

I left his office struck by how his "advice" was objectively almost the same as my urologist's but that it landed quite differently because it was framed by empathy. The exchange persuaded me that it might be possible to consider some form of ADT—if I had sufficient trust in the person managing it. I'll see him again in a few months for my general physical, but he also told me to reach out at any point if I need support.

THE INTEGRATIVE ONCOLOGIST

I didn't know anything about integrative oncology before doing my own research about ways to address cancer outside the mainstream paradigm of Western medicine without running after every internet claim of a miracle cure. Integrative medicine is a field with growing recognition as it weaves solid evidence-based care alongside and often in complement with Western medicine.

In fact, integrative oncology is a field that straddles three domains or expressions. First, the "bedrock" of integrative medicine overall is promoting *functional or whole-body health.* It draws on rich personal narrative to create a portrait of the patient as a whole person facing challenging and holding hopes. Then it uses labs to assess how optimally well body systems are functioning—and then proposes dietary, lifestyle, and vitamin/supplement adjustments with the aim of enabling the body to be its best self as it meets challenges and pursues hopes. Every integrative oncologist presumes this as their baseline.

Second, some integrative oncologists are board-certified medical doctors who employ more wholistic and natural methods of *direct cancer treatment*, usually alongside Western medicine (although often to the chagrin of their Western medicine colleagues who view them as straying beyond the boundaries of "accepted" medicine).

Third, some integrative oncologists use their expertise in functional health to suggest very specific dietary, lifestyle, and vitamin/supplement adjustments (as well as a range of other practices from acupuncture and massage to mindfulness and Tai Chi) that can minimize or mitigate the physical-emotional-psychological toll of cancer itself and the side effects of its treatment (by Western medicine techniques). Some of these are board-certified medical doctors who've chosen to adopt the principles of integrative medicine and apply them to oncology *in a supportive role*. Others are direct practitioners (for instance, someone who specializes in acupuncture and acupressure to alleviate the side effects of radiation or chemotherapy).

Once I understood what it was, I knew I wanted a board-certified integrative oncologist on my team—if I could find one. It's still a rather marginalized specialty and outside of leading cancer centers (Mayo has a small roster of integrative oncologists), most persons who identify as integrative oncologists are practitioners in one subfield of supportive care (like acupuncture) rather than a broader generalist. I found *just one* board-certified medical doctor specializing in integrative oncology in the Twin Cities. One. But based on her profile, she was a gem: deeply committed to centering her patients' wellbeing and driven by *love*—seriously who puts "love" on a doctor's profile? She did. And I was all in.

Still, when I had earlier broached my interest in natural medicine and integrative oncology with my urologist, he was quick to explain that these things don't have the level of research behind them that guide the better proven standard of care treatments he was familiar with. When I explained that the integrative oncologist I'd found used integrative medicine in a *supportive* role, to support my health and mitigate disease symptoms and treatment side effects his response softened, "Well, I suppose that can't hurt." Ouch.

But I had suspected he would be cool to the idea, so I had already asked my primary care doctor to give me a referral. He was happy to do this, and my first meeting with this integrative oncologist proved to be of great value. She was familiar with and supportive of my new practice of Time Restricted Eating—and with every one of the vitamins and supplements I've added. (Proving that I'd done my homework well). She made some initial recommendations: upping my intake of extra virgin olive oil, adding green tea to my routine, and an assortment of other foods to include in our meal planning. She's ordered some labs to review and will offer further adjustments to my vitamins and supplements after she's reviewed the labs. And she's provided me with a full slate of options for "Mind and Spirit" care. We meet again in 4-6 weeks to review my labs and go from there.

When I begin radiation, *if* I begin hormone therapy, *if* my cancer progresses to a more serious state, and *because* overall I simply want assistance in living a well-grounded life with cancer in the constant background, I expect her expertise will be priceless.

THE MEDICAL ONCOLOGIST

My urologist, though cool to the idea of integrative oncology, was happy to provide me with a referral to meet with a medical oncologist. Because medical oncologists specialize in all the various medical therapies used to treat cancer: such as chemotherapy, immunotherapy, and hormone therapy. He felt a medical urologist might be able to further address my concerns about Lupron and (unspoken, but what I clearly heard) *get me on board*.

He gave me the name of a colleague in his building with whom he shares several patients. Forgive me, but that was reason enough for me to look *elsewhere*. I didn't want a second perspective from someone whose views my urologist already anticipated. I wanted a fresh perspective. After reviewing twenty-plus profiles of medical oncologists whose expertise includes prostate cancer. I found one that really intrigued me: research-engaged, patient-centered, interested in alternative medicine, and steadfast in respecting her patients' values and beliefs.

When Margaret and I met with her she listened intently as I explained my hesitancy to go on Lupron—*and she heard me*. This is not to say she said it would be wise or right to decline hormone treatment. She didn't. But she heard my anxiety so completely that she could mirror it back to me, at one point saying, “It sounds like your livelihood as a writer—and your very sense of self—could be at risk. And that’s really important to bear in mind.”

Ironically, within the first 10 minutes of our appointment it became clear she could not treat me, because she only treats men with advanced, metastatic PCa. But we discussed my case at length for an entire hour, and at the end she recommended that I meet with a urologist practicing out of the University of Minnesota clinic. She explained that because of my drive to understand my disease, to carefully weigh my options, and to be fully involved in the potentially tough decisions around my care, she believed a university-based urologist would be most willing to offer the empathetic intellectual engagement I desired. She gave me the name of a urologist there that she knew—and provided a referral for me to see him.

This medical oncologist will not be “joining” my team—unless (and let’s hope not!) my cancer goes metastatic at some point. Nevertheless, although my consultation with her was “accidental” (had I known she didn’t treat *localized* PCa I never would’ve made an appointment to see), her listening ears and her willingness to discuss my concerns at length were a substantial gift. And her referral was spot on …

THE “NEW” UROLOGIST!

Earlier this week Margaret and I had a virtual consultation with the university-based urologist I’d been given a referral to. We wound up waiting for what seemed like an eternity in the virtual waiting room, but when he finally joined us, we got his full attention for 55 minutes. He listened to my concerns, shared his views, and summarized the relevant research about using hormone therapy alongside radiation. It turns out I’m in one of two small sub-groups for whom ADT appears to make a significant difference in “survival advantage”: a post-surgery PSA of >1.5 (mine is currently 0.48; or a Gleason score of 8-10 (that’s ME—mine is 9).

He was very clear: I’d “absolutely” benefit from radiation therapy, with or without ADT. But he’d encourage me to add ADT to the mix because it would significantly increase the odds of radiation being “curative.” Remember, curative for me, “just” means buying at least five years of life during which the cancer remains undetectable. Not a full cure. I’m not likely to ever know the relief of a full cure. (Hence the value of a long-term integrative oncology strategy to live well *with* cancer.) But at 65, with very-high-risk PCa, AND with a wife, kids, grandkids, and a full plate of writing in front of me, that “just” looms pretty damn large. No guarantees. In fact, he was at pains to clarify “probabilities describe odds within groups, not odds for individuals.” But since I’m already in the “very-high-risk” group, I’ll do what I can to access that “survival advantage.”

That means doing some form of hormone therapy, probably for at least 6 months—and hopefully not much longer. This urologist was also transparent in admitting there’s no definitive research evidence on whether 6, 12, 18, or 24 months is optimal. If I can manage side effects for 6-12 months, I’ll probably call that good enough.

As for the exact form of ADT, my preference will be Orgovyx, a daily oral ADT drug. It uses a different mechanism than Lupron but is just as effective (by some accounts more effective) in suppressing testosterone. Because it is an ADT drug, it has the same basic set of side effects as Lupron, though at least some men say they find it more tolerable—perhaps because as a daily medication its level in your system is steadier. In any case, it has (in my mind) two clear advantages: if it becomes unbearable, you can stop it the very next day. And it clears out of your body faster, so theoretically the side effects fade and your testosterone can rebound that much sooner.

I may still face some challenges here. Lupron seems to still be the ADT drug of choice for most prescribing doctors—at least at my stage, which is still localized. And Orgovyx doesn't yet have a generic equivalent, so it's pricier. Though not by much. Brand name Lupron runs about $6600/month; the generic is down to $2200/month; and Orgovyx comes in at $3000/month. My out-of-pocket cost would be a fraction of that (I think just $50/month), but I'll need a doctor to request prior approval to prescribe it. And I'll no doubt have to self-advocate zealously for this. But I'm learning how to do that (at last!).

I'm choosing this new urologist as my lead physician moving forward. I have *no reason* to think my original urologist was anything less than competent. He followed the standard of care at every point. But, as I've described, I wanted much more transparent communication and in-depth engagement than I was getting. My first consultation with this new urologist left me feeling more informed and more empowered to take charge of my own care. Margaret agreed. So, from now he'll be the point person in my care, and I feel *good* about that.

My last remaining decision is about a radiation oncologist. Margaret and I both felt good about the guy we met with at the end of June, but my new urologist encouraged me to get a second opinion (they're free, after all) from a university-based radiation oncologist. He thought it would be a valuable experience just to listen to a second radiation person review my case and tell me what their treatment plan would be. But it would also give me the option of selecting someone who is a colleague of my new urologist as my radiation oncologist. This might make some aspects of my treatment more seamless. And it might make advocating for Orgovyx a bit easier.

I have *that* consultation next week. With a radiation oncologist whose practice is in the east suburbs, but who teaches alongside my new urologist in the medical school. I'm hoping she feels like a good match for me. After that consultation it will be decision time.

THE LULL BEFORE THE STORM

So that's where I am right now. Profoundly aware that some of my own cells have turned against me—and with the vengeance of an apex predator. Unsettled that the first attempt to remove them, although successful in extracting my prostate and (most of) the other involved tissue, left behind a thriving remnant, as signaled by the 0.48 PSA. And anxious to move forward with treatment.

I'm determined to make the tough decisions I face with as much medical understanding as I can manage—while also balancing the values held by my vocation and my sense of self. Even as I've been trying to avoid ADT or at least find a form of it I feel okay about, I know it won't be a decision I'm good on every level. But it will be my decision, and I can live with that.

Two other bits of information fill out the present.

First, I had a *second* PSA test on July 16, exactly one month after the first one. It came back at 0.47—statically identical to the 0.48. That's welcome news because it tells us that right now the cancer isn't doing anything. That's no cause for complacency. It remains very-high-risk and potentially lethal cancer—no doubt contemplating its next move even as I type. But it isn't moving right now. So, I at least have the time (perhaps a week, not more than a month) to be thoughtful in deciding on my next move.

Second, much to my chagrin, today I met with a surgeon who confirmed that what I have been assuming was a stubborn bit of scar tissue above my largest incision (right above my belly button) is, in fact, *an incisional hernia*. Crap! We discussed a number of scenarios and decided it made the most sense to do radiation first, then repair the hernia. So, sometime between September and November, I'll spend eight weeks getting radiation (likely starting ADT about one month prior to radiation and continuing it for 3-6 months after radiation. And before Christmas (on December 12), I'll have another robot-encounter in the OR, this one to repair the hernia that resulted from my last close encounter with a robot. Sigh.

As you can imagine if you've made it to the end of this long chapter, there isn't a day that goes by that Margaret and I aren't keenly aware of what we're up against here now. But there also isn't a day that goes by that we aren't deeply grateful to be up against it … *together*. And, of course, grateful to have each of you supporting us in your own unique ways. Simply and deeply grateful.

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When Cancer Comes Calling – Book Two: Awakening
Final Tumblers Before Treatment

David R. Weiss – August 28, 2025

This is a last (and much shorter) post to conclude my "Awakening" around prostate cancer (PCa). As indicated in the Introduction to my last post, when my formal treatment begins this fall, I intend to post a series of "Soundings," short reflections on my lived experience in cancer treatment itself.

My "awakening" began in mid-June with the prospect of hormone therapy as part of the next phase of cancer treatment. I describe this in greater detail in my previous post. In short, although I had prepared myself (at least in the abstract) for the possibility of needing radiation after surgery, I had not really even considered the possibility of hormone therapy.

Thankfully(!) there was a week delay between the recommendation and my scheduled injection of a first six-month dose of testosterone suppression medication. I shudder to think where I might be today if my urologist had prepped the injection in advance and suggested I simply take the shot that day. I probably would've accepted it—likely to my immense regret.

During the intervening week I read up on hormone therapy, more specifically, ADT (Androgen Deprivation Therapy). ADT, which can be done using a variety of drugs, basically suppresses testosterone. Bluntly, *it chemically castrates a person*. Because prostate cancer cells depend on testosterone to drive their growth, ADT very effectively slows the spread of PCa, often weakening the cancer cells and making it easier for radiation to kill them. But testosterone suppression comes with a host of potential side effects damn near as unnerving as the cancer itself. After a frantic deep dive into ADT, I had learned enough to be legitimately alarmed about it—and legitimately reluctant to agree to it.

I cancelled the injection and ultimately changed urologists. While likely within the range of "standard practice" for cancer care, the way this treatment had been presented to me felt like a betrayal of my interests and a breach of trust. Since then, I've spent the rest of my summer learning about PCa, asking questions of my doctors (occasionally pushing back on their answers), and assembling a medical care team that fits my twin desires: to understand treatment as deeply as possible and to feel centered *as a person* during that treatment. I want to ensure that DAVID—and not just the cancer—is being treated.

And yet, here I am now, in the waning days of summer, preparing to *start ADT* in the next couple of weeks. Well, what's shifted to bring me to a place of grim, resolute calm about this perilous chemistry project about to play out in my own body? (Equally in my mind. And just as truly in my marriage.)

I titled this post "Final Tumblers" (thinking about the tumblers inside a lock) because one way to consider my reluctant resolve toward ADT is to identify the various tumblers that have all aligned to allow me to move forward. I'm not "excited" about this phase of treatment. Even if it drives my cancer into remission for years (that's the goal) it *will* come at a cost I cannot gauge in advance, and a cost I cannot be assured will be worth it at the end. Even if it adds years to my life. This is risky business, with existential stakes. So, let me tell you about the tumblers that have aligned to make it a bearable risk.

1. The first tumbler was the recognition that *my cancer is the killing kind*. 85% of prostate cancers are low or intermediate risk. Even those are nothing to smirk at, but (caught early) they can almost always be successfully managed or treated. The other 15% is the killing kind. Aggressive, mean-spirited, and bent on building a nest in my bones. In fact, my particular PCa is in the *upper range* of that 15%. I wish I had understood that sooner. But as I've come to terms with it, I've come to realize that, in the face of such extreme risk, I may need to embrace equal risk in my treatment. Not happily, but with resolve. I think, humbly, of Warsan Shire's poem about refugees, in which she writes with heart-rending poignancy, "No one puts their children in a boat unless the water is safer than the land." ADT may be my boat.

2. The second tumbler is having a medical team I trust. I should emphasize: *nobody gave me poor care*. But as a person driven by intellectual understanding, I needed every single person on my team to be forthcoming and transparent with me about my diagnosis and treatment options. Moreover, as someone deeply grounded in personal values and a sense of vocation, I needed a team able to recognize and honor those facets of me in the midst of shared decision-making—especially if we ever need to face even more harrowing choices. (Which, with high risk PCa is a distinct possibility.) It took some effort to make that happen; such a team doesn't assemble itself by chance. But now, from my primary care physician to my urologist, radiation oncologist, and integrative oncologist, that team is in place.

3. The third tumbler is claiming agency in my day-to-day health. Guided by my own reading, I've adopted a whole set of dietary choices and plant-based supplements aimed to position my body to fight cancer alongside medical treatments. Ensuring that I am no mere bystander in my own care is critical to being able to "lean into" the storm. I'm confident the choices I've made thus far can support my health, but I'm especially glad to have the guidance of a trained

integrative oncologist to help me further refine them. And I'll be adding a variety of practices, ranging from active exercise to gentle movement and mindfulness in order to ensure I'm as active a participant as possible in my own care.

4. The fourth tumbler is having extra medical support ready and waiting in the background. Although I've not yet tapped into them, I recently found out that my health care system (M Health Fairview) has a whole suite of Oncology Supportive Care Services. Through them I can access guidance for nutrition, exercise, and mental wellbeing, all specific to a cancer patient's journey. I can access counseling, expertise for sexual health during cancer, and, if necessary, palliative care and a social worker. I may not need all of these services at the moment, but just knowing they're available provides a level of added security. It's like discovering my care team has a "deep bench" that I can draw on as the needs arise.

5. The fifth tumbler is having medical insurance that, while imperfect, is pretty expansive and pretty generous. While it stung earlier this year to pay out my *entire* deductible and out-of-pocket max for co-insurance over just the first 65 days of the year, since then my medical expenses have been 100% covered—and have *far outstripped* what we had to pay early on. Every procedure and medication recommended by my doctors has been approved for coverage (except for one medication, which wasn't a big deal). That's not true for everyone. Cancer is expensive, and financial anxiety—or worse, medical bankruptcy—can be a devastating side effect. Thankfully, I'll be able to focus on the side effects going on in my body and psyche without worrying (too much) about what going on in my wallet.

6. The sixth tumbler is my (still) growing awareness of the multitude of support groups and other resources that offer insight, guidance, and solidarity on this path. Through online forums, social media, and in-person encounters, I've engaged with other men dealing with situations similar to mine. One of PCa's most insidious "symptoms" is its capacity to isolate you. There is so much untapped energy and empowerment in sensing the solidarity of others alongside you. Solidarity may not be curative of the cancer, but it is *healing* of the isolation. I expect I'll be deepening my connections with support groups, because having good roots here will help anchor me—and because it's a good feeling to know that I can help anchor others.

One specific resource I've just acquired is *Androgen Deprivation Therapy: An essential guide for prostate cancer patients and their loved ones* (Wassersug, Walker, and Robinson, Demos Health-Springer Publishing, 2023, Third Edition). There are countless online discussion threads about ADT and plenty of stand-alone articles and videos about managing the side effects, but this book is the only comprehensive guide written collaboratively by PCa survivors and medical professionals and *focused exclusively on the side effects of ADT*. It addresses how to anticipate, understand, and (as best possible) manage the side effects, personally, socially, and in one's intimate relationships. Arranged as a workbook (ideally read and discussed with a partner or close friend), it just arrived two days ago, and it already feels like I've received a compass *designed* to help me navigate this unknown land—with Margaret at my side.

7. Last, but far from least, the seventh and final tumbler to slide into place has been the understanding of family and friends. Over the past two months, I've been able to bring family and friends up to speed on what this fraught path means for me. While I politely accept the well-wishes that say, "I'm sure everything will work out. I know you've got this," the truth is *I'm not at all sure 'everything will work out,'* and I've read far more about my PCa than anyone who tells me that. *I'm not at all sure that 'I've got this.'* And words of encouragement that strike

me as naïve don't actually deliver encouragement at all. What actually *does* feel good is the much humbler pledge of simple solidarity: "Wherever this leads, David, we'll be there with you and for you. And with and for Margaret, too." *That's gold.*

If my writing has been stark over these past two posts, it's been so to make sure that the support I have, meets me *where I am.* I *need* the support of family and friends—Margaret does, too. But I can't afford for that support to be rooted elsewhere than in the stark reality that I/we are facing. I'm glad to say my family and friends have taken the time to read my words carefully and do their best to hear me. I am *not* giving up, but neither am I interested in pretending that the odds are on my side. They're not. Which is why it matters all the more to know that the people who love me *are on my side*—and that they're not pretending about the odds either.

With those seven tumblers in place—a dire diagnosis, a medical team I trust, agency in my own health, supportive services from my care provider, solid insurance, resources from the PCa community, and the love and solidarity of family and friends—I am at last ready to move forward with ADT and radiation. With something akin to grim, resolute calm.

An extra word about the final tumbler in my medical team

Last week Margaret and I met with and confirmed the last member of my team, a radiation oncologist. During that consultation (and then reflecting on that appointment with each other over supper afterwards) I could feel the final tumbler falling into place. What made me so sure she was the right person to complete my team? In a word, "kindness."

Actually, it was a lot more than just that. She's an excellent teacher; she thoroughly explained her plans for my cancer treatment, pulling up the two PET scans (January and June) that showed my one lymph node glowing brightly with its "cancer signature." It was very evident that she'd carefully reviewed my medical records, including the notes from other physicians. She entered the room ready to discuss my ADT reservations with care. She'd even reached out in advance to a medical oncologist colleague of hers about getting me a hurry-up appointment for a final consultation regarding one other medication I might want to consider adding to my treatment.

She was honest and forthright; this is a big deal in my book! I asked if she considered my cancer "curable," and she minced no words. "Most doctors agree, once the cancer has reached the lymph nodes—and if we can see cancer in one of your lymph nodes, the odds are that it's microscopically present in others—*a full cure is no longer possible.* What I can tell you, is that I'll be treating you with *curative intent*, meaning the goal of my treatment is to push the cancer far enough back that you have at least five years before it shows itself again."

As we discussed my apprehension about ADT, she reviewed the possible side effects and identified some basic ways to mitigate them. She also made two commitments that earned my trust. First, she was quick to support my desire to use relugolix (brand name, Orgovyx) as my preferred ADT drug. It's a newer drug that seems to have fewer side effects. Plus, it's a daily oral pill while every other ADT drug comes as a time-release injection lasting one to six months. Thus, Orgovyx offers the quickest "emergency off-ramp" should the side effects ever become intolerable—and the quickest return to normal (fingers crossed) afterwards.

However, because Orgovyx is still relatively new, there's no generic version on the market yet. So, it's not covered by most insurance plans (including mine) without prior authorization based on a doctor's clear recommendation. I needed her *explicit support* for it to be affordable. Based on my concerns, she submitted a prescription request that won approval from my insurance. Orgovyx is a $3500 *per month* medication (most cancer drugs are pricey), but it's now fully covered by my insurance. Honoring my peace of mind in using my "drug of choice" and getting it cleared for insurance—that's trust-worthy right there.

Second, and just as importantly, knowing that Standard of Care (Western medicine "best practices") guidelines recommend 24 months of ADT for high-risk cancer, *she nevertheless pledged to support me if I chose to stop at any point before that*. She heard my concerns regarding the toll that ADT can take on a man—physically, psychologically, emotionally, relationally, and (in my case) *vocationally* by potentially disrupting or even diminishing my ability to write. She recognized that, for me, *beating cancer could not be the singular goal*. And she promised to work with me to honor my other "quality of life" goals, even if that meant easing up on my cancer treatment.

Further, when I shared my interest in using integrative medicine to support my body's own capacity to fight against cancer, she explained that, in fact, (and in ways not yet fully understood) the combination of ADT and radiation seems *also* to fight cancer in part by creating openings for the immune system to act with its own lethal force against cancer cells alongside these other treatments. And she affirmed her willingness to respect the guidance of my integrative oncologist on how to adjust my plant-supplement regime to work well with the rest of my treatment. Because the effects of radiation on my cancer will continue unfold for several months after my active treatment ends, acknowledging this partnership between ADT, radiation, and my own strengthened immune response can make a big difference.

This value of trust in this doctor-patient relationship is amplified by one of the quirks of using ADT in combination with radiation. The surest way to track my cancer's progress—and to know the success (or failure) of our treatment efforts—is by monitoring my PSA score. The rising or (hopefully!) receding presence of PSA (prostate specific antigen) in my blood will tell us whether we've beaten the cancer back. Except—ADT by its very nature as a testosterone suppressor—renders a PSA score meaningless for as long as I'm on hormone therapy. Actually for a few months longer, since we'll only get an accurate PSA when my testosterone bounces back several months after ADT ends.

In other words, for at least the next year, as we hit this cancer as much force as I can bear, *we will have no way of knowing whether we're doing any good or not*. I'll need to trust her care, care that may take a toll on me in multiple ways, because the entire time I'm in treatment, we'll be flying through dense fog, with no way to get our bearings until we come out on the far side—a year or more later. That's some trust. And she earned it.

In all these ways, my radiation oncologist proved herself the right person to complete my team. But let me come back to that word, "kindness." There were several radiation oncologists I could've met with. Each with impeccable credentials. But this radiation oncologist highlighted the value of *kindness* in her brief online statement about her understanding of medical care. That's a rare word to appear in any doctor's description of their approach to medicine. Everything about her ended up impressing me. But it was the mention of *kindness* that first got me through the door. I'm so glad it did. And I told her so.

My cancer calendar

With all the tumblers in place, it's time for this phase of treatment to begin. Here's how.

Just this morning I had blood drawn for some labs. This will let my integrative oncologist adjust my supplements as she thinks best to support me during treatment.

On September 5 I have a consultation with a medical oncologist about whether to add abiraterone to my ADT regime. Recent evidence suggests that in high risk PCa, combining abiraterone with traditional ADT offers a dramatic increase in effectiveness. Still, while ADT is sometimes called chemical castration, using abiraterone is sometimes called androgen *annihilation*. It doubles down on the absolute erasure of androgens in the body, but it also doubles down on potential side effects. (And requires the addition of another medication, prednisone, just to offset its side effects.)

I'll say more about this after the consultation. For now, my radiation oncologist believes the research makes it worth my thoughtful consideration, but she is emphatic that only I can make this decision. Trust. We'll see what the medical oncologist can tell me.

Sometime soon after the September 5 consultation I'll start taking relugolix/Orgovyx, with or without abiraterone. The "loading dose" is three pills; after that it's one pill per day. In less than a week my testosterone will be gone. Part of the purpose of beginning ADT now is to wear down the cancer cells for a month before radiation begins.

On September 9 I'll meet with my integrative oncologist to review labs results, go over any adjustments to my supplements, and discuss any other integrative supports she can offer now that the rest of my treatment is scheduled.

On September 12, I'll have surgery to repair my incisional hernia. This was an unfortunate souvenir from my prostate surgery, an unexpected complication that appeared over the summer. I think it was present even sooner, but I initially misinterpreted it as a "slab" of scar tissue that would eventually soften and disappear. Nope. It grew and bulged. Oops. In any case, the repair, like the prostatectomy, will be done robotically—though this time as an outpatient procedure. My overflowing innards will be tucked back in place and stitched up, now with a piece of tissue-friendly mesh for reinforcement. As I heal, my body tissue will wed itself to the mesh, hopefully creating a much stronger incision site than the last one.

That repair might seem like a minor footnote in my treatment, but it's actually critical because one of the best ways—one of the *only* ways—to stave off the loss of muscle (and the gain belly fat) when testosterone is shut down, is through persistent weight training. Not to become a body builder; just to hold onto as much of my "masculine" body structure as possible without testosterone. Some of this is psychological self-care; some of it is also preventative medical care because absent testosterone, the male body is prone to bone weakness and heart problems. I'll want to commence weight training with caution post-hernia repair, but also in earnest.

On September 24 I'll have my radiation "mapping" procedure. I'll climb up on the table and the radiation oncologist records all manner of bodily reference points to make sure that each time the machine is fired up, its beams are aimed *exactly* where we want them to be—and *nowhere* that we don't want them to go. At each actual treatment, they'll use this set of reference points to ensure that the machine and I are in sync.

On or around October 6 (it takes about ten days to do the computer modeling so all the beams are coordinated), I'll begin 33 sessions of radiation. Five days on; then the weekend off to rest and heal. Then again, and again, for seven-and-a-half weeks. Around November 19 those treatments will conclude, although the "echo" of the damage done to the cancer should reverberate into March 2026. ADT will continue in the background at least that long as well. If I can tolerate it, it may run through next summer. And, of course, my own immune system will be busy the whole time, too.

So many tumblers. All lining up. Just now. Just so. Hopefully to make this treatment both successful and endurable. Each of you reading is one of those tumblers, too. Falling graciously into place to help unlock the path forward. As I've come to realize how precarious this journey will be—both the diagnosis and the treatment—I've become equally aware of how precious every companion on this path is. Including you.

Thanks for reading—for keeping me company along the way.

David Weiss is a theologian, writer, poet and hymnist, "writing into the whirlwind" of contemporary challenges, joys, and sorrows around climate crisis, sexuality, justice, peace, and family. Reach him at drw59mn@gmail.com. Read more at www.davidrweiss.com where he blogs under the theme, "Full Frontal Faith: Erring on the Edge of Honest." Support him in Writing into the Whirlwind at www.patreon.com/fullfrontalfaith.