

Soma, Sema, Sacred: Prolegomena to an Ethics of SufferingAbstract

The following is a *Bildungsroman*, or a memoir essay of a coming of age, which begins to unravel midway through an undergraduate student's life at Oxford University. Familiar wisdom literature themes emerge in a contemporary context of universal suffering and deprivation, yet no respite from the very opposite of existence. From this deprivation, human life and ethics emerge simply because there is no alternative, though there are important choices along the way.

Bought Wit

My sweet grandmother Zula, presently 87 years young, always tells anyone in shouting distance that “Bought wit is the best kind of wit, if you don’t have to pay too much for it.” Much of what I have learned in my life—my bought wit—has come at a high price. I have spent the finite coinage of my youth battling an incessant enemy, an enemy which one of my doctors deemed “the perfect storm of illness.” In this memoir essay, I will attempt to articulate what this *imperfect* storm teaches about and charges for life. Let me go no further without first admitting that the exorbitant premium that I pay for another day here—one more day of bought wit—far exceeds the alternative; though ultimately, all of us wage-earners-of-wit will face the alternative, and it will cost us everything.

Sartre (1987), in a defense of his version of existentialism, railed against the notion that we should ever “end up in a philosophy of contemplation” because contemplation may be construed as “a luxury” that terminates in a “bourgeois philosophy” (p. 9). On one hand, Sartre has a point: derelict and philosopher are often synonymous. On the other hand, he misses the important point that contemplation may be forced upon us. There are those of us with a philosophy born out of suffering, which isn’t the same thing as simply “lying about”—even if you are bedridden. There are times when I read certain philosophers, even our prized Plato, and imagine throwing them in a room with someone like Frederick Douglas, a man who literally fought the slave owner’s lash for his life. Douglas said the day his adolescent hands came to grip his master’s neck, he and his master came to grips with a particular philosophy. Douglas (2005) wrote, “however long I might remain a slave in form, the day had passed forever when I could be a slave in fact. I did not hesitate to let it be known of me, that the white man who expected to succeed in whipping, must also succeed in killing me” (p. 44). What a breathless passage and

inspiring epiphany; but, Douglas paid a high price for that wit! Maybe I would toss the likes of Sartre to Malcolm X, because I resonate with his jeremiad: “We didn’t land on Plymouth Rock; Plymouth Rock was landed on us. We were brought here against our will” (X & Haley, 1990, p. 201). Personally, I didn’t ask for the philosophy I have, it landed on me. Suffering brought me here against *my* will.

REELing...

To my recollection, what is left of it that is, there exists or at least existed a video tape of me leading right up to my downfall. Video tape—I know! Anitiquated. Who uses tapes anymore? This was during the infant stages of the technological revolution that has occurred in the past two decades, when the world was still warmed by the slow, fading embers of handwritten letters. In fact, the worst marks that I ever received, whilst at Oxford, were handed down to me because I turned in printed versions of my papers. Dr. Warner, or Francis as we know him, said, “The paper is fine. I will be reducing the grade though. You are not to turn in a paper like this. It must be handwritten. It will give you time to practice your penmanship. Technology is useful, but you need to be able to write without its assistance. What if you were stranded on an island without computers? A scholar must be able to write even in these circumstances.” That admonishment was handed down from the top. He knew something I didn’t. He gave prophetic utterance. It was definitely foreshadowing. I was, indeed, marooned on an island—something Plato would deem the *soma seema*. My body had become an island tomb. The year was 2003.

I can no longer find that video tape though. No voyeuristic nostalgia. I can’t look back for a second and see what I used to be. Even if I could, after all these years, looking at me back then—before the storm—would be like seeing a ghost. It’s eerily bizarre to write it down in that

way, to realize my reality by writing it down in that way. The realization that “the me” of all but these last 8 years is the ghost—now replaced by some mediocre imposter that even I think barely passes for me. I won’t tell a lie though. I would love to see it, to see me in the prime of life; my former bright-eyed self; the fit, long-haired collegiate athlete who didn’t touch so much as a Tylenol because he had—I *had* glowing health.

I try to access the built-in camera obscura of my mind but keep stumbling upon a cache of well-defined fragments of life just before the storm. These memories are so profoundly emotional that they wash over me like a tearless tsunami—paradoxical but true. When I try to make sense of my life, it’s as though I must first wage war against this great wall of fear and grief that would make the likes of Emperor Qin Shihuang proud or even the neighbor in Frost’s (1915) *Mending Wall*. In my heart of hearts, I side with Frost’s narrator, when he says:

Before I built a wall I'd ask to know/
 What I was walling in or walling out/
 And to whom I was like to give offence/
 Something there is that doesn't love a wall/
 That wants it down. (p. 12)

I have that same mischief of *Spring* in me that wants to tear down the callused partition that separates *the* self from *myself*. Socrates warned us that the unexamined life allows anhedonia to creep in and isn’t worth living. His uncommon cure: “Know thyself.” Of course, that was before Jung told us that it isn’t quite that simple; there are shadows and shadow-selves that we desperately try to avoid. We are simultaneously the divider and divided; East and West Germany to ourselves. When I muster the psychic courage to emerge from the shadowy cave of denial and stand at the Brandenburg Gate of my own making, I echo President Reagan’s words: “Tear down this wall!” How do you tear down a wall erected to protect you from an (im)perfect storm that hit you so hard it changed the landscape of the soul, the shorelines of the spirit? I

suppose you have to let the disturbing-ness of it all dance across the stage of the mind and see it for what it is.

I see a close-up of two closed eyes. I hear voices clamoring in the background: “What’s wrong with him? What’s wrong with our son? Is he going to be okay?” The eyes remain shut until two fingers begin to pry them open and shine a light into them. The voice of an unknown emergency room doctor asks, “How long’s he been like this? What’s the patient’s name? Mr. McNuwse. Mr. McNuwse can you hear me? Can you open your eyes for me and try to follow the light? He’s completely out of it. How long’s he been like this?” In a frustrated tone, the doctor says, “Okay, we need to get an IV going stat. Hang some fluids, but first let’s get a blood panel on him. Do a full workup. Oh, and get a chem-19.” The scene in my mind is mostly dark because, after all, I couldn’t really hold my eyes open. It was a bit like Plato’s analogy of the cave. These looming figures swarmed around me, dancing in and out of the light that was pounding down on me. I tried to make sense of the nameless forms, mere refractions of who they truly were.

The clamoring, so much clamoring continued. The doctor asks, “What’s this kid’s story? Hey, are you the parents of Mr. McNuwse? This kid is really sick. He’s got something bad wrong with him. How long’s he been like this?” My dad finally chimes in: “We don’t know. Maybe a week?” “Anything unusual going on in his life? Any traveling outside of the country?” My dad finally chimes in: “Yea, uh, actually yes. He’s been studying at Oxford in England and he’s been traveling to all kinds of islands and things like that. What do you think’s wrong with him?” “In his condition, judging by the way he looks right now and that cough, I’d say he probably has H.I.V.” I hear a gasp, but I can never be sure if it is me, my parents or all three of us. “We need to do some blood work on him to be sure though. Nurse, we also need a chest X-

ray on him.” “Just as soon as I get this line started, I’ll take him down for X-rays,” says the nurse in a husky voice. “Mr. McNuese, Mr. McNuese, my name is Nancy and I’m going to be taking some blood from you, then start an I.V. because you are very dehydrated. You’re going to feel a small stick, so I just wanted to warn you.” I hear what sounds like someone trying to cough up a tuberculin lung. Just my luck! The nurse is also sick and can’t stop her uncontrollable hacking.

I can see a man lying in a hospital bed. It’s so confusing because this man is me. His, my left arm has been stretched out and away from my body so that the hacking nurse can attempt to “get a vein.” She forces the needle in and can’t find anything that will hold up. She begins to dig the needle in deeper and moves it around until suddenly blood begins to spurt out. I yell, open my eyes and sit up.

A Brief Aside

If I had coherent internal dialogue at that moment, it might have sounded something like this: I don’t have long to talk. The nurse has punctured something with enough force that it has my adrenaline pumping. Look at this blood—my blood—all over me and the floor! Doesn’t she know how precious this viscous red material is? She’s spilling it, me—spilling me everywhere. I’ve heard of hack jobs, but this nurse really is hacking on the job. I’m no doctor, but I’ve got a medical tip for her. “How’s about putting a quietus on all that smoking? We might both live longer.”

On a serious note, I don’t know how to describe this exactly, but I could hear everything. I could hear every word they were saying. They were talking about me like I wasn’t even in the room, but I could still hear them. I couldn’t string a thought together of my own, but I could hear and feel voices all around me. If I were a swearing man, I’d swear that pain is the ultimate truth serum. Pain will make you tell the truth when nothing else will. But, we’ve grown callused to

pain; no longer treat it with proper respect as foe or friend; have shut our hearts and minds to pain; have anesthetized part of our soul too, lost something of our ability to feel—for ourselves and others. God help me, I know I wouldn't be here right now if it weren't for the pain. When the incompetent nurse started stabbing me with that needle over and over, I felt something in my arm pop or click. It's hard to say because the sound of it happened inside my body and not outside of it. But, it was definitely either a pop or a click and then a burning flood. I could just feel the heat leaving my body and feel something wetting my arm; could hear the cacophonous intermingling of shrieks from my parents and the nurse's tobacco-timbred hacking, and the puddling, the ebbing of my own life-blood out of my arm, off of the hospital bed and onto the floor. It was that pain though, that searing hot reality that brought me back to some level of consciousness. No one had to tell me that I was headed towards something like a coma or a more permanent sleep. I could feel it happening, coming over me, taking over me. I couldn't get myself back though. I kicked and cajoled, but it was too late. I had fallen into an abyss, the likes of which I was, I am no match for.

Dark Days

The darkness came over me in a flash and I fell into an abyss that lasted forever. One minute everything seemed fine; I was thinking and could speak, read, write. I was even a collegiate athlete, so I could run as far and fast as the day is long. At one point, I was training or practicing four hours a day, at least 5 days a week, sometimes 6. I was writing 20 page papers every week, with an additional 10 every other week. But, I fell into a shroud of darkness and chaos. Suddenly I couldn't think. I wish I could take that feeling and put it into you because it's stronger than my feeble words. I felt myself losing the ability to think and speak. The higher functions followed suite. I felt myself losing the self, losing the light of life. Escape velocity is

impossible without speed at your back. You've got to be moving, and I couldn't conjure the magic. I don't know if Hawking is right about black holes in the cosmos, but they definitely exist in the here-and-nowness of life. Not just a dark night of the soul, but a black hole of pain that's gravity pulls at the soul, splintering it into so many different pieces. We're talking about dis-integrating pain and suffering. Nothing escapes. Nothing is sacred. Nothing is spared. Everything collapses into a procession of collapses, each one leaving a little less of the self behind. But, it was that damnable, no, not damnable, needle that propelled my eyes open for one lyrical moment. Like a drowning man coming up for a last life-prolonging gasp of air, I tried to suck all of the oxygen out of that room; but my lungs weren't up to the task. I was no longer up to the task. I had always been up to every task. That was then, before the abyss, before the darkness that was an abyss that was the blackness of a hole that captured my soul. With nothing left to give, no adrenaline left to fuel my mad-grasp for the light, I collapsed back onto the bed and into the abyss.

Eros Lost

She was the love of my life. We were to be married in December. We met when we were just freshmen, but not like in that hackneyed song by the Verve Pipe. We dated all through undergrad. We were as close as two individuals could be. The lines between our borders were blurry; it was hard to tell where we started and stopped. We'd rehearsed being-together for so long that we were pros. We'd settled into "us" so deeply that we were like old chairs, bearing the outline and contours of the other person's self.

As I laid there suspended in sickness, slowly dwindling into ghost, she would come in and stand by my bed. Snap, snap. On go the rubber gloves. She wasn't allowed to touch me, for both of our sakes. It was the first time anything had come between us, and I'm not talking about

the latex. I was on that uber-natural kick: couldn't have paid me to put a drug in the well-oiled machine that was my body; didn't even really need to. I hadn't been to the doctor in years. She'd never seen me (or anyone else for that matter) struggle. She said she loved me so much. I believed her. She said she couldn't do this. "What do you mean, you can't do this? Can't do this? I can't do this, but I don't have any choice but to do this!" You see, for all of the loving and the closeness, it is inescapable that at the individual level of consciousness, you are alone. No one can take the pain for you. No one can suffer in your stead. And then, she knocked my tiny world off of its axis with 8 words: "Are you sure it's not in your head?" "Get out! I can't believe you would say that! Get out! Why would you say that?" I bleated in between puffs of the breathing machine. I felt something break in me. I couldn't hear it like I could with my arm and the needle, but I felt something cracking. "You know me. But, you know me. Don't you know me? Don't do this. Please don't do this!" She did that. Apparently, she did a lot of things while I was on my deathbed. Staying faithful wasn't one of them. How could it be possible that while I was withering there on the brink of next breath and eternity that she could find solace in someone else's arms? The idea, this reality was absurd. It marked the beginning of a period of absolute absurdity.

Absurdity!

Let me set the stage for you. I'm being evaluated by the esteemed psychiatrist Marshall Thurgood III. I remain slumped forward in my wheelchair with an I.V. attached to it.

Psychiatrist: Mr. McNuese, do you know why you're here today?

Me: That's not my name.

Psychiatrist: What's not your name?

Me: McNuese

Psychiatrist: No, my name is Dr. Marshall Thurgood III. Your name is Keel McNuese. (speaks into his digital recorder: Patient is not properly oriented. Seems to think I'm him. Probe further into identity confusion.)

Me: Wait, what? That's not what I meant. I don't think you're McNuese. McNuese doesn't exist.

Psychiatrist: Em hmmm (he nods his head in affirmation). Tell me more. (he takes out his recorder: Patient maybe experiencing an existential crisis or a psychotic break. Explore further.)

Me: You know I can hear you right?

Psychiatrist: (chuckles lightly but audibly). Standard procedure. Nothing to worry about. (he speaks into the recorder: Patient seems anxious, explore further.)

Me: Well, it isn't true.

Psychiatrist: What isn't true Mr. McNuese?

Me: STOP calling me that!

Psychiatrist: Calling you what? (speaks into recorder) Patient is definitely agitated. May need anxiolytic.

Me: McNuese

Psychiatrist: No, I'm Dr. Marshall Thurgood III. I am the psychiatrist here at Sacred Heart. You're McNuese. (he speaks into recorder: Patient is definitely experiencing an existential identity crisis. Explore further.)

Me: NURSE! Nurse, please get me out of here!

Nurse: Mr. McNuese, what seems to be the problem?

Psychiatrist: It's okay. It's just a mild decomposition. I've seen worse.

Me: (looks at nurse plaintively) You've got to get me out of here. This guy's a joke; and for the record my name is Kyle McNease. Stop calling me McNuese.

(nurse and psychiatrist both look at one another and shake their heads).

Psychiatrist: (brandishes his clipboard) It clearly says here that your name is Keel McNuese.

Me: Well someone must have made a mistake. This is all just a mistake. I need to go back to my room now.

Psychiatrist: When we're finished. But first, we need to talk about why you're here.

Me: In the hospital?

Psychiatrist: Yes

Me: The doctors say I have "the perfect storm of illness." For some reason my immune system stopped working right and I've got pneumonia and all of these immune viruses attacking me.

Psychiatrist: (pulls out recorder: Patient has possible persecutory syndrome. Explore further.)

Why do you insist on staying in that wheel chair?

Me: Maybe I missed something or don't know enough about how this works, but you do know I'm in the hospital because I'm sick, right?

Psychiatrist: Of course you are. I've been brought in to help determine the etiology, whether it is strictly organic in nature or due to something else. There's some speculation that you may be malingering.

Me: What does that mean?

Psychiatrist: If you don't mind, let me ask the questions Mr. McNuese. It really will go better that way. Now, am I to understand that you withdrew from university?

Me: Well, um, I'm not really sure about all of that, you know, like the way it went down. I got really sick and had to be picked up from school and taken to the hospital. I've just been in and out of the hospital, but I think my parents talked with my university and I've been withdrawn.

Psychiatrist: Who picked you up from university?

Me: My mom.

Psychiatrist: (writes something down on the clipboard). Em, I see. And who took care of your withdrawal?

Me: My parents.

Psychiatrist: Who cooks your meals?

Me: My parents.

Psychiatrist: Em, interesting. Who pays your bills?

Me: Um, since I'm in the hospital my parents are taking care of them.

Psychiatrist: (speaks into the recorder: Patient seems very defensive. Explore further.) What about hanging out with your friends? When's the last time you did something to get you out of the house?

Me: I just feel like we're not on the same page or something. This is my life. This is what I do now. My life is the hospital and doctors' appointments. So, I don't see anyone anymore.

Psychiatrist: (speaks into recorder: Definitely axis two activity. Schizotypal personality traits. Refuses to have anything to do with his friends. Can't maintain meaningful relationships, except with parents. Explore further.) Would you say that you are depressed, Mr. McNuese?

Me: I don't think so.

Psychiatrist: (loudly speaks into recorder: DENIES depression.) So, you're happy with your life?

Me: Of course not. Who would be happy like this? It's just that I didn't get here because of depression, you know? I mean, yes, it is depressing to be sick and to have lost everything that matters to me, but if I weren't sick, then I would be back to myself, back to being happy. I want to be myself again. I want to feel like living again.

Psychiatrist: Feel like living? Do you want to die? Are you having suicidal thoughts Mr. McNuese?

Me: That's not the way I mean that. It's just that I am so sick so much of the time and am racked by pain that keeps me awake. I have this ravenous insomnia because of the pain. Nothing can seem to make the pain stop hurting, especially in my legs. Sometimes in desperation, I feel like if I could just have them cut off I'd feel some relief. I don't want to die though, so no. No, I'm scared of dying. I just want things to go back to the way they were.

Psychiatrist: (speaks into recorder: Has issues with his legs. Possible body dysmorphic disorder. Explore further.) Mr. McNuese, I'm getting paged, which means that we're going to have to wrap up this evaluation. Based on what I've seen and heard today, you need to begin treatment for clinical depression right away.

Me: I told you my name is Kyle McNease and I'm not depressed. I'm sick.

Psychiatrist: Look, Mr. McNuese, I've been doing this for 6 weeks now, so you're not going to pull the wool over my eyes. I know clinical depression when I see it. You've got all the classical signs and symptoms. You are sick, but it's in your head. But, don't worry; I'm writing you a script for a cocktail of drugs that should help.

Me: In my head? Haven't you been listening? I'm not depressed. Nothing changed about me or my outlook on life before this illness started. So, even if I were depressed, it wouldn't be the reason I'm sick. Something's wrong with my immune system.

Psychiatrist: (speaks into recorder: Patient has expansive ego. Thinks he's a diagnostician.) Why don't you calm down and leave the doctoring to those of us trained to do so. I'd love to continue talking a while longer, but I really must go. I will be sure to get the nurse to bring you your meds stat. Thank you Mr. McNuese. That will be all. (calls for nurse). Nurse, go ahead and take

him back to his room, as he calls it. When his meds are ready, take them to him and make sure he swallows. He's extremely defiant.

And the nurse, unlike my ex-fiancée, was loyal and faithful to his charge. Those drugs were forced upon me and into me. They weren't treating a patient or an illness. They were after docility. They won, and meanwhile I became catatonic.

Over 1,278 long days and longer nights I lay shipwrecked, marooned on an island for misfit diagnoses. 3.5 years of suffering, wracked by an invisible yet insidious enemy. My head was placed between pillows to keep it from shaking uncontrollably. I was too weak to even lie down and hold my head still. My energy was dissipated by something cellular, something they couldn't find. Worse than not being able to walk or talk or read was the fact that I couldn't go to the bathroom on my own. This one memory stands out in my mind so clearly. The doctors wanted another series of tests, so I had to be run through a CAT (computerized axial tomography) scan. In order for them to get the kind of images they needed, I was pumped full of more radioactive dye. By this time, wasn't I already glowing? Then, I was rolled out of my room into the testing area. I was rolled out of my hospital bed and onto the hard table that slides into the CAT scanner. "Take deep breaths but don't move, or we'll have to start it all over," a disembodied voice rings out over the intercom. One problem: I had to urinate like a rushing race-horse. All of those fluids being jostled around by the scanner proved too much for my bladder. "I really need to go to the bathroom," I say back to the disembodied voice. "Just a few minutes more!" "Look, I don't have a few minutes more. If we don't stop this test, I'm going to wiz everywhere. I can't help it. I gotta go." A nurse reluctantly came in the room and says, "Okay, go." "I um, I can't get up. I um, I can't walk." "Oh, well, I will help you then." The nurse assists me in getting off of that ice-cold machine and over to a little potty with a built-in plastic

container designed to collect and show how much fluid you evacuate. I knew it wasn't going to be enough. Sometimes you just know when it's going to be a monsoon. As I darted my eyes back and forth, I could tell this was going to devolve into a Mel Brooks moment. "Um, this thing is um, it's filling up and I've still got to go." "Can you hold the rest of it until you get back to your room?" "No. I'm so sorry... but I mean this is bad. Can't stop it." So, the nurse comes and hugs me up to a standing position, does some kind of swim move to reposition herself. She's holding me around the waist and walking me forward in what looked like an awkward dance. She didn't know what else to do, so she just started grabbing at the nearest containers. She finally secured a vomit catchment and with one arm wrapped around my chest, she put the receptacle down to capture the streaming urine. My head was uncomfortably resting on her as she had to balance this shaking, streaming shell of a man. I know she was a trained professional, but holding some random guy's penis is probably not how she wanted to spend her day. Being that helpless and exposed was surely not how I envisioned my life. I learned that there are definitely two kinds of adult nudity in this life: one a virile, sexy-kind that arouses passion in the heart of the beholder; the other, an exposition of indignity that couldn't arouse passion in the heart of a beer-holder.

My groundhog day of suffering was to lay there, shaking, sweating, and gripped with pain—while I watched my mom feed me, spoonful by spoonful. Reminds me of Prufrock's words:

For I have known them all already, known them all:
 Have known the evenings, mornings, afternoons,
 I have measured out my life with coffee spoons;
 I know the voices dying with a dying fall
 Beneath the music from a farther room. (Eliot, 1998, p. 2-3).

It was as if I was looking in on this cruel and backwards scene that had become my life. To see that kind of pain on my loved ones' faces and know that I was somehow the cause of it; and that there was nothing I could do to help...was and is brutal.

I'm a firm believer in this theory I made up and tested. It runs something like this: When you're toying with the idea of your own mortality, trying to reason through your own impending demise, it remains an intellectual endeavor. You know you're sick and dying, but it is not until you see that confirmed on the face of someone else that you feel it to be true, undeniable. You can always tell how sick you are by looking at the face of someone who loves you. If there are tears, it's bad. If they have to steel themselves before speaking to you, it's worse. And, let me take back that comment about not being able to help; I could help by subjecting myself to every test or treatment that stood even a remote chance of improving my condition. So, my father would gently carry me in his arms, like the wounded animal I was, and lay me in the back of the van—which had become my hospital chariot.

I certainly developed a new respect for all of the wagon-travelers of the past. If I was jostled that much in a comfortable automobile with suspension, I can't imagine what their elderly, pregnant and sick went through and the will they had to possess to make it. Now, we call that ethos rugged, but they called it necessity. And, I have this deep, nagging suspicion that if one of those pioneers had my life, she'd make more of it than I have. Even in my suffering moments, I got to do it in a controlled environment; I always had a roof over my head. Even though I was sick, I still had central heating and air. Even though I couldn't get up and run around, I could stay still in a hospital bed. It makes me look back over history with a new appreciation for our ancestors. Everything they did, they did in what would be considered impossible situations by us today. If one of them got an infected tooth, they died in excruciating

pain. For many, something as simple as a fever or cough spelled the end. An insect or snake bite and you were done. As for me, I was taken to see the best immunologists, infectious disease specialists, endocrinologists, and cardiologists around. Sometimes it was just my blood that made the trip for me.

Philia Lost I

Jarret, a friend of mine and my family, was at MD Anderson in Houston, Texas—that beautiful monstrosity, where classical piano music is being played by someone on one floor, while on other floors dozens of patients are either dying of cancer or are guinea pigs for cancer research. Don't get me wrong. This is where some of the best care is given by the leading experts. There's a lot of money invested in this kind of structure, and hopefully it won't get in the way of finding a cure. My friend Jarret was there being treated for brain cancer. They were doing some new experimental therapies on him, using stem cells that promise so much. Incredible guy that he is, he told his oncologist about me, which provoked his clinical curiosity. He wanted to know everything, go through everything with a fine tooth comb. If there was something that had been missed, he'd find it. "There's something wrong with him, something going on in his blood, but I don't know what it is," says the expert on diseases of the blood. My case began to take on a life of its own, like you see in those ridiculous hour-long shows where they figure out exactly what's ailing the patient and cure him. One of the lowest points in my life was the day the Mayo Clinic called to tell my parents that they couldn't take me on as a patient because there was *too much* wrong with me. Mayo didn't know what floor to put me on? That's when you know you're done. The gig's up. Time to channel the inner-frontiersman—grin and bear it.

For all of my groaning about the illness and how it hurt, I seem too often to gloss over the practical impacts. I went from traveling around the world to being cloistered in a room. I mentioned how the pain acted as a black hole, which maybe you find too dramatic. It is dramatic. This thing took me down in such a way that it made a ghost out of me. My name was still spoken of by friends and family, though in hushed tones. My brother came home one day and said that while he was out grocery shopping, a relative stopped him and asked if it was true that I was in a coma from having ingested something contaminated during my travels. He said, “No! Patently false, but if you thought he was in a coma, why haven’t you been to see him?” It was like having a 3.5 year-long funeral that no one came to.

I fully accept the fact that my life held so much promise. When I was getting glad-handed at Oxford and it looked like I was on a scholastic fast-track...when my hair was long, thick and curly...when I was a ripped-up athlete...there were lots of people who wanted in. When I fell, I fell into silence and obscurity. Even I didn’t want in on this austere existence. That was the point Dr. Marshall Thurgood III, the psychiatrist, missed. I would’ve loved to have been out with friends, enjoying parties and the triviality of youth and beauty. Instead, I was considering whether or not the Greeks were right to consider this *soma* (body) a *seema* (prison). People I knew got engaged and married. I couldn’t attend, and they couldn’t understand why; so they no longer spoke to me.

The first half-year of my illness, I couldn’t even stand to watch moving images on the television screen. It was too much information for my brain to process. No music either. How many people want to go and sit in utter silence beside a once-upon-a-time-friend? Would you? What if I told you that due to the medications, this terrible stench emanated from my sallow skin? How about when I started losing my hair and excessive amounts of weight? Let me

interject that I fear something very important is becoming almost cliché. When a person battling illness decides to shave her head, know that a transaction of fundamental importance is occurring. You can't control anything—not the illness, the medication, your body, not your body's response to the medication. You have this limited sense of efficacy and an unlimited sense of powerlessness. Everyone is different, but when I saw the hair falling out on my pillow, it was too much for me. I thought, "Now, I may not be able to control whether or not this happens, but I can control the rate at which it happens." So, I asked my oldest brother to shave it off for me. He did a fantastic job. I am forever in his debt. When my mom got home and saw me though, she said, "Oh honey you look so sick." I had to burst the bubble of denial: "I don't look sick. I am sick." My dad pleaded with me not to do it again. "Keep those locks as long as you can." He didn't realize this was as long as I could.

One day, out of seemingly nowhere, I started crying. Not just crocodile tears, more like a crocodile's predecessor. I'm talking deep guttural sounds like you think a T-Rex would make, if it were crying. I was nearly inconsolable. It's hard to put into words, but I felt something I had never felt before. I had this ominous feeling, and I don't mean premonition, that someone was dying. It was as if I could feel him or her passing over the threshold of suffering out into something far more expansive, beautiful even. Jarret hadn't made it. The doctors thought he was cured, but it came back with a ferocity that they couldn't control or treat. Just like that, he was gone. I couldn't attend his funeral or pay my respects to his family. No, I know that letters, cards and emails are better than nothing, but there are some things in life that you should be there for, if you can. I was miserable with grief because I drew so much hope from his life. I felt like we were yolk-fellows fighting our battles together. A comrade had fallen, and I was left standing—not standing but lying. How could this be? A man with a happy young family—someone much

more thoughtful than me, much kinder, and with much better medical support had lost, while I lingered on? It seemed like a twisted joke, one that I was unprepared for.

Sometimes death catches us by surprise, though I suppose it shouldn't. The history of humankind would suggest that we aren't getting out of this thing alive. We are beings-towards-death, so said Freud but not as well as Heidegger. That is our unique ontological framing. But, I guess there is a difference between the knowledge that a general event will take place (that we're all going to die) and experiencing a particular happening (my friend just died).

In order to live a somewhat sane life, though, I think we exist in a state of perpetual denial about death. We are shocked because we would rather be shocked than cynical. All things considered, that seems like a fairly decent philosophy. The only problem is that this philosophy is subject to fractures, as we're interrupted by the thing we most wish to deny. I tend to approach life as if it were a strict, intuitive-linear mode of being; something it isn't. I expect tomorrow to go something like today and the day before it. I rarely examine that assumption. My illness speaks to this oversight. I never saw it coming. I had plans. Didn't life know I had plans? I was going to marry the model I was engaged to, move back to Oxford and do my graduate work. I was going to say important things and know important people. I wanted to help cure cancer or end world poverty, possibly both. And, yes, I've read Bormann's (1972) thoughts on fantasy themes and how we're sold a load of crap that we easily buy into. That's not what I'm talking about though. In the words of Eddie Morra, the protagonist in the film *Limitless*, I didn't have delusions of grandeur; I had a recipe (Burger, 2011). However, this recipe (no pun prefigured) did not consist of a life of peeing in a plastic container. I hadn't read the forecast that called for nights where the pain was so excruciating that all I could do was slam my head against the wall while howling "F-ck me!" as if this counted as a prayer.

In some way, “F-ck me” was a prayer. It was the most honest thing I’d ever said in my life. It was raw and unfiltered. Stripped of all pomp and circumstance. It was an admixture of humility and humiliation. Up to that point in my life, I didn’t know there was an inner-truth that deep and complex that could be stated so succinctly. As I think back on the suffering and try to allow a hint of how it felt to roll back over me, the times that I pulled at whatever hair was on my head and desperately pleaded “F-ck me,” what I was really saying was: If there’s a God anywhere out there...if there’s anything higher than me in this universe...please have mercy on me. Either kill me or release me from this, but don’t leave me in purgatory. There’s not much of me left, much less of me left to refine.

In order to understand how cathartic it was for me to come to terms with this exigency-induced “Fuck me!” prayer, you’d need to know that I came from a community where you never said a thing like that, even if you meant it. I was put out in the hall one time because my friend and I had gotten into a verbal sparring match. Someone let a curse word slip, and we were ‘busted’. My seventh grade teacher, a woman widely respected for her intellect and feared for her willingness to get in your face, scolded us in a way that just stuck with me. I tried not to ever say something that banal again and was successful until my fiancée started cheating on me while I was too sick to get revenge. Of course I wanted revenge. Yes, I had to take it all lying down, but that didn’t mean I had to take it all lying down. There was a part of my soul that stood up and said: “Be as positive as you can. Take whatever medicine you have to. Do what the doctors say. Try to get revenge by getting better and living an extraordinary life.” So, you can see how a prayer like “F-ck me!” violated both of those principles. On a deeper and more paradoxical level, it was exactly the kind of violation I needed. In order for me to ever say something as vulnerable as “F-ck me!” and mean it, that meant I was getting very creative indeed. I had condensed all of

my hopes and fears into two words. “F-ck me!” that’s not bad. On a deeper and more serious level though, it helped me to break with this notion that patients have to be perfectly positive if they hope to recover.

I had put so much pressure on myself to be the perfect patient, as if illness and disability itself were exams that I could master in the same way as course material. In my mind there was this equation: Saying all the right things and thinking all happy thoughts will improve your overall illness score by 50%. Add to that my pharisaic regime of medication compliance (drink this, eat that, swallow all 36 pills, breathe this in) and the grade should come up another 30%. If I could get an 80 on this test that was disability, maybe I could get my life back? Sure, it wasn’t the perfect score I was used to pursuing. I figured the other 20% was up to chance though, random chaos in the system. I was terribly wrong. I say that as if it were news. Of course it was magical thinking. Magic was about all I had left, and I needed to pull a cure out of a hat that didn’t exist. Bellowing “F-ck me!” helped me to break with the magical thinking, the strict perfectionism that had become embedded in my quest for recovery. The problem with telling the truth like this is that most people don’t really want to hear it. They want you to keep up this façade of perfectionism and act like there is a formula. *Caveat emptor*: I bought that lie, and it isn’t worth the anguish. Instead of needing to be perfect, I instituted ‘Rat-bastard Mondays’.

‘Rat-bastard Mondays’ were a treat, for me. My poor family, not so much. On these special Mondays, I would gripe and complain until my heart was (dis)content. I would say anything that I had been holding in or holding back. I took Emerson’s (1890) advice and spoke words like “cannon balls” and never cared if I contradicted myself (p. 54). After all, “foolish consistency is the hobgoblins of little minds,” and I wasn’t interested in that kind of consistency or that kind of mind (p. 54). What that one day afforded me was total release, total denial if I

needed that kind of distance from my lived-reality. At first, I was very fastidious about assigning all complaints to the ‘Rat-bastard Monday’ file. I could revel in the most negative way possible about the smallest thing that angered me. Eventually, I decided there were no rules, no proper way to be a Rat-bastard. This is how the process looked, had you turned me inside out.

“So your seventh cranial nerve is swollen? The right side of your face is paralyzed and you can’t smile or taste your food? How much can you ruminate on that? Can you extrapolate upon your fears until they no longer make sense, if they ever did? Go ahead and think it. You know you want to. Okay, fine. No one is ever going to love you like this. You look like a holocaust survivor—barely. But, there’s still time for that to change too. There’s still plenty of time for you to kick the proverbial bucket; buy the farm. Oh, and you smell like sulfur, onions, and cat urine. Dave was right, you do look like a homeless man. P.S. One of these trips to the hospital is going to be your last.”

By virtue of having a day where I could lose my cool, I began to feel a little lighter, a little less uncool. It didn’t move the needle on the pain or the physical anguish. After all, I was still on my deathbed. But, it gave me some space so I could exhale. As time stretched out like a long desert horizon, this special Monday became a kind of meditation for me. I knew if I was taken by surprise, say my heart rate spiked or my blood pressure dropped, I could work out that frustration. This meditation seemed to reduce the uncertainty and lessen the anxiety that I felt. I knew Monday was there waiting for me, if I could just make it. By virtue of having that Monday on reserve, it turns out that I stopped needing it. That is, until November 10th, a day that will live in infamy.

Philia Lost II

I've already admitted that I'm bad about expecting things to go on perpetually unchanged. Even though my life had been turned upside down by a mysterious illness that confounded just about everyone and left me fending for myself against those who always equate difficult diagnoses as mental aberrations better confined to asylums, I was learning to cope. My youngest my brother once told me, in a flash of wisdom belying his age, that even if I never got better, I'd get better at dealing with not getting better. I was managing; some might say learning to cope with being an extension of a hospital bed. Talk about strange bedfellows.

I had been having an extraordinarily bad day, all around. I didn't know how it was possible to feel worse than I did and still be alive. It felt like I had a compilation of the worse flus you have ever imagined, all reimagined and recombined in novel ways, just to increase the intensity. I had been having this strange feeling too, something that I couldn't put my finger on was troubling me. What was it that was troubling my waters? My oldest brother showed up at my parents' house rather unexpectedly. In my wild imagination, I thought he must have come to sleep on the couch or something. Maybe he and my sister-in-law were having a fight? Very uncharacteristic, but what else would bring him out during the night? I jokingly said as much: "Hey bro, you hoping to sleep on the couch tonight? You and the misses not getting along?" His faced changed suddenly. It wasn't like him to wear a frown. He's one of the most positive individuals I've ever had the pleasure of meeting. He started to tear up and then looked at my mom. She looked at me and her face—God, the horror of it—was distorted. She had to reach out and balance herself before she could speak.

"Kyle, I'm so sorry to have to tell you this," she said. "Tell me what? What is it?" I asked. She began to sob. "Kyle, Dan was kill—" Before she could even get the word all the way out, I cut her off. "NO! No. No. No. Oh God, no. What? What do you mean? What does this

mean? No, no, no.” Still crying she replied, “We don’t have all of the details yet but we’re being told that he was killed in action.” Trying to make sense of it all I said, “It’s got to be a mistake. He just called. He was fine. It’s probably a mistake. This kind of unfortunate thing must happen all of the time.”

As long as I live, I will never shake that moment; the feeling of it; the look of it; the weight of it. Whoever came up with that nonsense about “Words can never harm me” was a damnable liar. My mom didn’t speak the words as cannon balls, but they were that heavy and deadly. In *A Passage to India*, E.M Forester (1924) says that when a person tells you about the death of someone that you know, it is as if the deceased were killed by the messenger. Message and messenger are forever linked. Her words, just a precious few, divested me of all of my favorite delusions. There never would be a better-together in my future. Whatever else might happen, we wouldn’t all be together.

I don’t have the space here to talk about Dan in the meaningful way that he deserves. Even if I did have the space, I don’t know if I have the words. Dan Thomas Malcom, Jr. was the smartest person I’ve ever known. Keen intellect mixed with a rare grace. We first met as kids on the big yellow school bus. He lived just over a mile from my house, which for those of us living in the sticks, made him a neighbor. We played chess on the way to school every morning (he never lost once) and got into some form of trouble on the way home in the afternoons. Then, when we got off of the bus, we played basketball, football, and baseball with my brothers. He was a permanent fixture in our home. We all considered him family.

Dan’s father was a decorated military man. Mr. Malcom had all of these pictures of himself and his company in other countries. From the look of him in those pictures, he appeared happy. He had a beautiful wife, one daughter and one son on the way. About three months before

Dan was born, his father was killed in a freak accident. All he knew of Mr. Malcom was from those photographs, medals, and stories his mom shared.

While we were still youngsters, Mrs. Malcom would come and pick us up from school, especially if we had some kind of practice. She was a very sweet, intelligent, loving, soft-spoken woman with deep, gray-blue eyes. She and I got along famously, which meant that she gave the okay for me to come over any time I felt like it. It also meant that Dan could come over to our house any time he wanted. So we did.

Around the 10th grade, something began to change in Mrs. Malcom. She no longer came to pick us up from school. She wasn't able to talk with my mom on the phone for very long either. She had developed advanced MS and was quickly deteriorating. It was hard for her, such a tall, elegant, pianist, not to be able to use her hands or voice for extending periods of time. When the 11th grade came calling, she could no longer take care of herself without help. Dan started driving before I did, so we would take Mrs. Malcom's car and pick up the things that she needed each week. Unless it was a sports function or an academic trip that required traveling, Dan stayed close to home—just in case. Eventually the time came when Mrs. Malcom needed full-time care and was forced to move to a nursing home. That meant Dan came to live with us, at least for a time. My parents treated him just like me and my brothers, in fact showed a little deference to him. Upon moving in, he was awarded my room, but I didn't care because we were happy to have him.

There are moments that you somehow know stand for something much more important, even though you don't have any proof. When Dan was about seven, he went up to one of the kiosks in the mall that sold G.I. Joe's. For a couple of bucks, you could answer a few questions at the kiosk and you would receive a printout of what kind of profession might best fit with your

interests. His, of course, came out to be a marine. Fast forwarding 11 years, Dan had been meeting with recruiters from the Marines and was doing ROTC. He decided that he wanted to follow in his father's footsteps and serve in the military. Based on his father's legacy of service, I know that is something that Dan wanted to emulate. The Marines also provided him with a \$48,000 a year scholarship to attend the Citadel and earn a degree in finance. But, I fought him on that decision tooth and nail. I was with him the moment he signed his life over to the U.S. government. Right up to the last second, I begged him not to do. I have a large family with many veterans, so it's not that I think it an unworthy vocation. Dan was like my soul's twin though. I told him there were so many other things we could do if he chose not to join up. We had so many plans. Didn't life know we had so many plans?

Unsurprisingly, he joined and quickly became a standout at the Citadel. I received this large envelope in the mail one day and inside it was the front page of the newspaper. On the front page was a large picture of him running the steps of the stadium. In officer training school, he distinguished himself once again. This was a guy who destroyed the SAT, back in the day when only a handful of students in the nation made 1600. He was a highly ranked chess player and would, no doubt, have become a Grand Master. He was well on his way. Instead, Uncle Sam called upon his incisive leadership and asked him to control the Iraqi airport. He refused to learn Arabic in America because he didn't want to pick up any bad habits. He began learning it on the ground there. Before long, the locals knew him as Malcom and asked to deal with him exclusively. He became so popular that he also became a target.

Before he was shipped out the next time, I had this surreal few days of respite, as if my body and illness called a temporary armistice. Sure, I was still only able to lay-about, but at least I was physically able to talk and laugh some. I was lucid enough to carry on a conversation. I

still hold those moments close to my heart. That was the last time I would see him. He called from Iraq whenever possible, and we chatted about everything: women, video games, politics, and the ultimate purpose of life. About three weeks before he was killed, he called very early one morning. I asked him to give me a rundown of the good news from his neck of the woods—er, desert. “Well, we were just on a convoy and we started taking heat. I was getting shot at but was able to take cover behind the tank tracks and follow it in. So, I guess the good news is that I didn’t die.” Of course that was unbelievably good news. But, what he really wanted to talk about was the love of his life. How was she? Did I think she would marry him when he got back? We talked about everything but the increasing volatility there in Fallujah. Bukowski (1990) said it best: “The most important thing is the obvious thing that no one is saying” (p. 271). Maybe we both knew how dangerous it was and that, as an officer, he was at the front of the front line. Since we knew, maybe we didn’t need to address the camel in the room.

Rather than draw attention to his work in Al-Anbar, Dan was so unassuming about his position there that he didn’t mention the fact that the BBC had an embedded reporter following him around. They slept right across from one another and developed a pretty good rapport. The embed was impressed with the fact that these “Jar Heads” were young, intelligent guys who were quite content to sit around playing chess tournaments. I share what I share here, certainly not to celebrate war, but to give you an idea of why it is I miss him so much and why I cry when I consider the fact that my wife will never meet him.

The Al-Anbar province was quickly destabilizing and required a surge of our forces. It was incredibly dangerous, probably the most deadly period of the decade-long war. That specific area was euphemistically deemed “tha shit.” This particular variant of “tha shit” is not to be confused with mindless drivel that often oozes out of the mouths of derelict hipsters (damnable

sophists) when they exclaim: “Hey, this bowl of weed is “tha shit.” No, the kind of shit Dan and his mates were thrust into meant that hell was raining down on them. Asses were literally on the line, and Dan was not immune to this reality.

During the hottest part of the insurgence, Dan’s grandmother died; and, since he was the only living male in his family, he was given leave. He could’ve returned to the states but refused. He had trained these men, picked them, and felt responsible for their lives. On November 10th, a group of Marines were trapped on a roof in Al-Anbar. They were taking on serious fire and weren’t going to make it out. Dan volunteered for the rescue mission and succeeded in shepparding all of them safely off of the roof. Based on the accounts of the fellow Marines and from the BBC embed, Dan was actually headed down the stairwell when a sniper caught him right under the arm—a vulnerable spot in the flat jacket. The bullet entered his heart and he died shortly after. The thing that haunts me about it though is the fact that everyone says he had this “Oh shit look on his face. Like he thought he was home free. Like he couldn’t believe he had gotten shot.” The BBC embed said that in one of Dan’s runs to save a guy’s life, a sniper shot hit his helmet and glanced off. Call it poetic injustice because Dan always had a big heart. How could that have been the target when his heart was so bent on doing good in the world?

I was inconsolable for months. Adding insult to injury, I was still too sick to attend his memorial service. I had to lay there and listen to the news talk about him; had to listen to my mom talk to reporters about him. It kept throwing me for a loop. “How can you all just talk about him like he’s gone, like he’s dead and never coming back? How dare you talk about him like an artifact of history!” I often murmured. I think it’s safe to say that I entered a very dark period. Physically, emotionally, spiritually, psychically—and whatever “ly” words you can think up—I was spent. I had lost another yolk-fellow and my best friend. What in heaven’s name did it

mean? How would I get over this when I didn't even get a chance to be there and mourn with everyone? Those were some of the quietest days and nights of my existence. My body was so weak that even crying could cause me to go back in the hospital. I know for some that may seem impossible, but it is true. My neuro-immune system was so wrecked that getting my heart-rate up would further compromise my condition. The damnable catch 22 was that I would get worse and feel worse but likely survive with medication and I.V. infusions. So, I had to consciously choose not to cry because my body couldn't handle it. That part did start to feel like torture. I had to at least consider whether or not this was just the universe or God's way of punishing me for something. My best friend gets killed and you're honestly telling me that I can't cry about it? That would be a resounding yes.

My mom came in one day during her lunch break and sat on my bed. She looked at me and said, "You've got to get better! You have to. Do it for Dan. Who else will tell his story if you don't?" I'll always appreciate those words because she knew they would motivate me. Everywhere I go and everything I do, I carry with me the memory Lt. Dan Thomas Malcom, Jr. Not a day goes by that I don't miss him. When holidays roll around, we all expect to see him walk through the door. Alas, not again. But, I would be remiss if I didn't mention something very important.

The last time we talked, at the end of the conversation I mentioned above, for some reason I just felt this overwhelming tug to tell Dan that I loved him. It certainly wasn't due to any belief or fear that he wouldn't return. That thought, I would not allow that thought room in my life. As guys, we never said things like that to one another. It was just understood. But, I remember something like lightning running down my spine: "Tell him you love him." Okay? "Dan, I hope you know how proud we are of you and how much we love you...and...I love

you.” Those were the last words I spoke to my brother from another mother. No one can ever take that moment from me. Had I not been sick, I would’ve been working and not gotten his call. Dan, if you’re reading this, I wouldn’t trade the years of suffering because it meant I got once last opportunity to tell you how much we love and miss you. We still love and miss you!

Remorseful Survivor

Talk about survivor’s remorse. To this day, I still can’t come to terms with a world in which Jarret and Dan are cut down in their prime, while I continue on. That will never make sense to me. Not now. Not ever. It’s not worth concealing either. I feel guilt that I’m here and they’re not. It just doesn’t seem fair. But, as I’ve been so often reminded, this life isn’t fair. The fact that we believe there is something called fairness or justice and that we recognize this isn’t that thing we call fair or just, I think that bodes well for humanity. We shall keep at it, hopefully getting closer with each infinitesimal act of goodness and mercy. Al-Anbar Sniper, if you’re reading this, I forgive you for killing my best friend. Your life probably hasn’t been that fair either.

My body finally started giving way to the unrelenting nature of the illness. It had proven exceptionally resilient for the first 2.5 years. That was one of the things that led most clinicians to pass me off as a “head case.” But, there came a point in time that I looked almost as sick as I truly was. I had lost 50-60 pounds. It is hard for me to know for sure just how much because the last time I was weighed, it was so devastating that I didn’t ever want to look again. No matter what I did, I kept losing weight. My muscles started tearing from simple things, necessary things like sitting down on the commode. We all knew that at this rate, I didn’t have too much longer to go. The answer for what ails you is always more tests.

I was loaded back into the chariot like a wounded animal and carried to a research hospital where they could prod at me a bit. They wanted to do a biopsy on my stomach while I was there, so they began prepping me. My blood pressure wasn't high enough for them to use anesthesia, so they asked me to try and cooperate. "Do you think you can do that, Mr. McNease?" Hey, they got my name right, so the least I can do is assist them in this procedure. As they were wheeling me into the exam room, I could hear one of the doctors saying, "His BP (blood pressure) is low. His O₂ (oxygen) is low." "Well, can we give him more oxygen?" asked the physician responsible for the procedure. "Well, we're really not supposed to, but what's a few more liters amongst friends?" Then, someone puts a clipboard on my chest and says, "Mr. McNease, please sign this form." "What does it say?" I questioned aloud. Mind you, I had wires coming out of me, lines going in me, and was wearing a mask. "It says that if we puncture something in the procedure, we can try to correct it." "What? What can you do if you puncture something—not in the procedure but in me?" I asked with increased anxiety. "Well, we could operate on you." With this bunch, I wasn't feeling very confident about the outcome. What choice did I have though? If I would have been able to run or walk or even wheel myself around, I would have tried to escape from that place. Before the procedure began, they took me to the restroom and left me in there by myself for a few minutes. It felt like an episode of *Prison Break* but for the disabled. I desperately wanted to tunnel out of that room. I wanted to get out of this nightmare. I actually reached over and pulled at the mirror. It was attached to the back of the exit door but wasn't part of it. So, even with an amazing feat of strength, even if I had torn that mirror off of the door, I would've had to chisel my way out. I was missing both crucial elements for an escape of that nature: I had neither the time nor the chisel. They took me in and rolled me onto the operating table. "Mr. McNease, please open your mouth as wide as you can. Whatever

you do, don't swallow!" I did as I was instructed. Then the doctor says, "Mr. McNease, I'm just going to have to do this with you awake. I will try to be as quick as I can, but if you're not going to be under, we need you to help us. Prop on your left elbow." He began shoving this big black hose down my throat. Of course I was gagging on the thing and they told me, "just relax and breathe through your nose." Lucky for me, my idea of relaxation happens to be choking on a huge hose while people cut pieces of my stomach and duodenum out. As if it weren't uncomfortable enough, out of the corner of my eye, I could also see my insides on a monitor. I can empirically say that I am not one of the folks you hear about that are beautiful on the inside! It was too much for my feeble brain to take in. Just in case you were keeping score, I got way worse in the weeks following that debacle. My stomach burned so much that even the thought of food made me sick. I existed off of bouillon and a few scattered sips of Diet IBC Root Beer.

It all felt like it was winding to a close. The clock was counting down for me, counting down on me. My family was so good at trying to keep me encouraged. They had all these awards hanging in my room. One day, a plaque came in the mail stating that I was voted the top undergraduate student in my discipline. I wasn't even a student. I had been withdrawn from the university, indefinitely. I scowled when I saw the thing. I had been so foolish for thinking that accolades or money or power or prestige matter. They don't. At best, they are distractions or illusions. How did I not know that most of the things I had been living for were a sham? Why hadn't anyone told me that when I looked back over my life, the only things that would matter were the relationships, the people I loved so much and what happens next. The ultimate epistemic question was staring me in the face, and I didn't have an answer. Heck, I didn't even understand the terms of the question. What does forever mean? What does extinction mean? What is not existing like? Please don't insult me by saying it's like going to sleep because it

isn't. Dying is not like going to sleep because if it were, none of us would ever go to sleep! And, if we did go to sleep, we wouldn't wake up. The whole idea with sleep is that you enter into its cycles and reemerge with a rejuvenated body. No, when you don't have a lot of time, you can't endure childish answers. Death is serious, while naps are not.

You can quote me on this: dying feels epic. Should've given you a spoiler alert, I know. It is difficult to maintain agnosticism during that period of life, or at least it was for me. So much is riding on it. "All's well that ends well." I wanted to end well, but couldn't wrap my head or heart around nihilism. I know many detractors say that belief in an afterlife is tantamount to wishful thinking. Perhaps that is true. But, I don't see how that is truly a problem? I mean I wished that my wife would say yes when I proposed to her. She did. Wishing something to be true doesn't automatically disqualify it from being true. This life reads too much like a Dostoevsky novel. For good or ill, I think there is a mind behind it. Whoever you are, if you're reading this, please help me write a few great chapters before I leave this place.

Fortunately for me, I was granted a stay, something like clemency during my waning hours. This one hard-headed doctor out in Colorado said, "I think I know what's wrong with you." Of course he did. "All the king's horses and all the king's men" hadn't been able to put me back together again, but some toxicologist out in Colorado could? He ordered more tests, but when they came back, he interpreted them differently than most. He saw something that no one else had. He ordered more tests to confirm his suspicion. When I received the results, I was dumbfounded. His office informed me that I was suffering from heavy metal poisoning. A guy once asked me, in all sincerity, if that was from listening to "too much rock music." Not quite. Not even close. Some of my numbers were through the roof, no (future) pun intended.

A few weeks before I got sick, I had been doing exterior work on an old farmhouse that my brother and his wife purchased. I was on Christmas break and thought I'd enjoy doing the work and spending time out in the crisp winter air. We did not know that the siding was made of asbestos and the paint was laced with heavy metals. I breathed in those particulates, and my body stored them in my tissues so that I wouldn't die. The heavy metals bind to human hormones, bind to immune cells, damage the brain, and cause unbelievable pain. The heavy metals that I ingested were responsible for breaking down all of my defenses, which is why I got that poignantly named "perfect storm of illness."

Heavy metal poisoning answered a vital question: How'd this all happen so suddenly? Also, a diagnosis like heavy metal poisoning offered at least modest forms of treatment. I was successfully treated with a chelating agent that binds to the metals and allows them to be excreted from the body. What no one bothered to tell us when I first began treatment was that detoxification equals re-intoxication. When the heavy metals were leached from my tissues, they re-entered my blood. There are about two weeks of my life that are a blur of semi-consciousness. I would wake, look around, maybe drink or eat something, then pass back out. I slept for nearly 24 hours a day. My parents and I thought I was getting worse, but we were assured that the sleeping was a good thing. It meant my body was trying to heal. Heal I did. In a few weeks, I actually felt like trying to live again. It goes without saying that I had to rehabilitate my body. You never realize how strong gravity is until you feel it pressing down on you. For 3.5 years, I had existed in a state of almost zero gravity. Now I had to learn how to do everything over again.

My body had fought unbelievable odds to give me the chance to start back at the beginning. Even Derrida wouldn't recommend this kind of deconstruction. At some point the question does become: How do you reconstruct a life that wasn't supposed to be? Keep in mind,

right up until the heavy metal diagnosis, it looked like curtains. I remember looking up at my primary physician and just fishing for hope: “What is your best prognosis for me doctor?” He thought for a minute and said, “I hope that one day you will be well enough to drive yourself to your doctors’ appointments.” That wasn’t the kind of news I was looking for, but it was light years beyond where I was at the time. I guess what I’m learning is that rebuilding my life is tedious work—brick by brick, line upon line, precept upon precept. It can also be extremely frustrating. There are parts of myself that I will never get back, and I know it but still strive to recover those fragments—more casualties of war. There is this world inside of me that I can’t seem to tap back into. Every morning is a searching. I know in those first 30 seconds what kind of day it will be and what version of me will show up.

The problem for me now is not something I was aware of back in the early days. Sure, we treated the heavy metal poisoning, and I continue to take medication for that. But, the damage that was done to my immune system and brain, maybe they’re irremediable. For years, viruses and bacteria attacked my body like marauding bandits. Unchecked, they stole and wreaked havoc. Today, I try to compensate for the lasting effects. I have to wear special red lenses in my eyes to reduce my sensitivity to minute pulses of light that go unnoticed by most people. I go and get I.V. infusions to boost my immunity, but I still stay sick. It’s an ongoing struggle to see who will win each day: the good cells or the invaders?

Recently, I was lying in the hospital—an all-too-familiar scene—and my wife brought my school books to me, per my request of course. The doctor walked in and said, “You can’t live like this. You’ve got to find a way to rest.” Can’t live like *this*? *This* is the best I can do! You should’ve seen me before. To keep the body going, I take supplements innumerable. I have a cocktail of drugs that try to manipulate my body into some form of homeostasis. I have shots that

must be plunged into my thighs; gels that have to be rubbed into my skin. Even with this maintenance, it's all so unsure. I do all of my work in bursts of binging because I never know if I will be able to continue it the next day. I exist in this invisible energy envelope that can't be violated but often is, because it is contingent upon a shifting matrix of variables.

Reading is one of the most challenging tasks that I do each day. I used to be able to read entire books in one sitting, but no longer. It takes a great deal of mental concentration and uses a substantial amount of my energy. I know, I know...picked the wrong profession then. Well, I said it was challenging. All of it is. Existing is. Add to reading the effort of actually going to class, trying to pass as a self "like everyone else" and being around contagious students (who think nothing of their temperature in the same way that I didn't when I was an undergraduate), and it gets more complicated. So, what are my options? Sit around and stew in this neuro-immune disease that was instigated by heavy metal poisoning? Sit around and struggle to read and maybe enlighten myself to the point that I can share some of it with others? Sure, I'd rather not suffer at all, but that doesn't seem like it's in the cards, at least not yet. So, if I am going to suffer anyway, why not try to do a little good with the little time I have here. It is precious. It is fleeting, that much I know. Sometimes I just want to break the silence and ask people why they aren't living with more urgency. Whatever you're going to do, you had better do it now while you have the light of life. It won't always be with you. You won't always be with us.

Beauty in youth
 Youth in beauty
 Then all fades...

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