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THE EXAMINED ILLNESS: A PHILOSOPHICAL CONFESSION IN MICRO ESSAYS

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1. First Thoughts and Second Opinions

In late April 2016 I went to see my hematologist for a follow up appointment. I had been seeing a hematologist regularly for the past 18 years, ever since I had been diagnosed with a rare disease of the bone marrow called *essential thrombocythemia*. The primary manifestation of that disease is elevated blood platelets. In my case that had been kept under control, and I had been otherwise asymptomatic, except for anemia that had developed over the previous 8 or so years.

I've lived in a few different countries, pursuing work as a professor of Philosophy; and I've seen my share of hematologist/oncologist offices with waiting rooms often populated with visibly sick people, sometimes ashen and weak and occasionally wearing protective surgical masks. I never much enjoyed visiting the doctor, being confronted by the serious illness of others, and being reminded of my own disease. Although I taught Philosophy, I did not have what might be called a philosophical attitude towards my own mortality. But after a hundred or so visits to these offices, I had become more or less accustomed to it.

This appointment was different. It followed up on one that I had a couple weeks earlier during which my doctor, a squat man whom I often saw trotting from one examination room to the next, had administered a bone marrow biopsy on me in order to have a looksee at the state of the underlying disease. That biopsy had been the third that I had had in 18 years.

It would be an understatement to call bone marrow biopsies unpleasant. A doctor uses a needle to pierce the tissue on the back side of the hip in order to gain access to the pelvic bone. The needle is twisted one way and then the other as it is pushed toward the bone. Although the tissue can be numbed, the bone cannot. Apparently there is no way to get the biopsy needle into the

bone and to the marrow other than simply driving very hard, again with the twisting motion, until the biopsy needle pierces the bone. To speak of it as a “needle” might leave the wrong impression. It is hollow to allow for the collection of the marrow. But the stainless steel shaft has to be strong enough to pierce bone, and robust enough not to buckle under the pressure applied to jam it into the bone. The needle has a handle at a right angle to the shaft made to be grabbed by the fingers and palm. The handle facilitates the required twisting motion. The original Jamshidi™ needle boasts a knob at the top, a protuberance of blue, industrial strength polymer. Once the needle is forced in about an inch and a half, an inner core of the needle is removed and there is some 360° twisting. People sometimes talk of undergoing surgery as going under the knife. I like to think of having a bone marrow biopsy as going under the corkscrew.

Fortunately, there is little that can go wrong. So, other than anticipating the unanesthetized bone pain, the immense discomfort of the pressure needed to drive the needle into the bone, and the weirdness of the twisting, I had very little to worry about on that day. As the doctor pushed and twisted the needle into the bone, he and the nurses chatted away about a soccer game the night before. “Don’t forget about the needle sticking out of my hip,” I wanted to say. But I refrained, and braced myself for more pressure. Once the needle had been rammed to the marrow, the inner core of the needle was removed. More twisting. The marrow filled into the hollow cylinder. More soccer chat. As the needle was finally removed part of my soul seemed to be sucked away. With the game fully analyzed, they sat me up, ensured that I was steady on my feet, and dispatched me only slightly daze homeward.

When my doctor ordered the bone marrow biopsy, I assumed that he was not driven purely by curiosity. I had been informed early in the treatment of *essential thrombocythemia* that one risk

was that it might transform into *secondary myelofibrosis*, which involves bone marrow scarring that inhibits the production of blood cells. If you are accustomed to thinking of your longevity in terms of decades, with *myelofibrosis* you have to reorient to thinking in terms of years. The process can be slowed a bit by medication, but the only cure is a stem cell transplant. Given that anemia can be an indication for *myelofibrosis*, and that fibrosis can be seen from a marrow sample, I had a reasonably good hunch what my doctor was looking for.

That day in late April was sunny, the sort that lightens my spirits. The sun doesn't shine nearly often enough for me up here north of the 50th parallel north. Too many years spent in the subtropics have left me constitutionally ill-prepared for the days and days of cloudiness. I enjoyed the sunshine as I walked to my doctor's office for the follow up appointment. Once there I had my blood drawn as usual, and waited to be called into his office. In his office we did the routine survey of the results of the bloodwork. Nothing remarkable there. The platelet counts were under control and the other counts were out of whack in my usual ways. I was as anemic as ever, no more and no less than in recent history. He was advising me on when we should meet again, when I reminded him of what he seemed to forget, but I could not, the bone marrow biopsy. Duly prompted he sought the results and informed me without surprise that the indication was *myelofibrosis*. Calmly I asked him about the prognosis; he was non-committal. It seemed to depend on how quickly my counts fell, and all we could do was monitor that. In the end the scarring of the marrow that is *myelofibrosis* inhibits all blood production. The question is how long that would take. He couldn't say, really. And he gave no indication that there should be a therapeutic change. Then he made his way rapidly down the hall, a flash of a white lab coat disappearing into another office. I made an appointment for my next regular visit and left. On my

walk home the April sunshine was hard to notice for the fog of my confusion. What did I just learn?

An established principle of bioethics is that there should be no unnecessary invasive procedures. My doctor had conscientiously sought more information, doing so required more than the usual amount of discomfort, but then he did nothing with the information. Is the diagnosis not as bad I had imagined? Why the biopsy if the results would not mandate some sort of change of care?

When I got home, the internet offered confirmation that the diagnosis was as bad as I had thought and although a stem cell transplant might offer the hope of a once and for all cure, it was risky, and not an option for many patients. How long did I have? I could not even hazard a guess. More than a year, I reckoned, but perhaps not long enough to see my son graduate from high school or from college, and probably not long enough to reach retirement.

It did me no good to wonder without some better answers. So, I decided to seek a second opinion. I e-mailed the head of Hematology at the medical school of my university. He answered promptly, re-assured me, and was happy to conduct an examination and offer a second opinion. Thus began my experience of being a stem cell transplant patient.

2. Single Payer Pt. 1

At the first meeting with the head of Hematology, I was pleased that he wanted to do more testing. And I was impressed that he ordered a change of medication. But it caused me to wonder all the more that the previous doctor had altered nothing after performing a bone marrow biopsy and changing my diagnosis. Did he think there was little point of doing anything else? Or for some reason did he really think wait and see was the best approach? Did he just not know enough? But then why not send me to someone else? Or did he not know enough to know that he didn't know enough?

For at least sixteen years I had taken a medication, called anagralide, which inhibits the production of blood platelets. I started anagralide shortly after its introduction to the market. When I had the opportunity to take it, I was eager to do so because the very first medication that I had taken, hydroxyurea, was not recommended for men trying to become fathers. Anagralide seemed not to cross into the semen. That meant that BF and I could pursue our plan of having a child. Years later I had been taking anagralide since MF was just a twinkle in the eye. At 16 he is now taller than his mother, and nearly as tall as me. Innovations in medicine had made it possible for us to be a family.

The new meds go by the name Jakavi in Europe. The generic name is ruxolitinib. It has only been on the market for a few years. Here is what the European Medicines Agency says about it: "Ruxolitinib, works by blocking a group of enzymes known as Janus kinases (JAKs), which are involved in the production and growth of blood cells. In myelofibrosis and polycythaemia vera, there is too much JAK activity, leading to the abnormal production of blood cells. These blood

cells migrate to organs including the spleen, causing them to become enlarged. By blocking JAKs, Jakavi reduces the abnormal production of blood cells, thereby reducing the symptoms of the diseases.”

I took my prescription for Jakavi to the pharmacist. He typed something into a computer and then informed me that he would have to place an order for it. He looked up at me quizzically. Did I realize how much my insurance was being charged for this? No. “Over 4,200 euro,” he said. That was for a 25 day dosage. Gulp. “How much do I pay?” Ten euro, he said.

3. Patience Dear Patient

After I made the appointment for the second opinion with the head of Hematology at my university I had to wait. That, of course, gave me plenty of time to exercise my imagination. From what I had read on the internet I knew that not everyone was a candidate for a stem cell transplant. If I was not a candidate, the disease would finally take me, but that would probably not be soon. Still the end would not be pretty. “Wasting away,” it’s called.

While waiting I wrote few letters to MF for safe keeping. Years ago when my own mother died of a bone marrow disease I was 23. I had not lived at home for several years. Still I remember feeling like I never really got to know her as an adult. I had only known her through child and adolescent eyes. I still have a sense of loss about that. I expected MF would feel this all the more so, if I were to die when he was mere a teenager. So, I decided to try writing letters to an adult version of him. One of the thoughts that I had then became a source of resolve. The disease might take away our future together, but we won’t let it ruin our present. There is something perverse about letting worry about future loss render you unable to enjoy what you don’t want to lose while you still have it.

Nonetheless sometimes my imagination would outstrip what I understood to be the rational approach. I had begun strangely to experience the night sweats that I read about as possible symptoms; the fatigue from the anemia became for the first time really noticeable. I attended a conference in southern California—a place I was very happy to visit—and I was not much interested in socializing. I found myself more often resting in the hotel room, than strolling on the beach. I had begun to feel an enlarged spleen that I had read helps to produce blood as the

scarring in the bone marrow inhibits blood production there. The thought did occur to me that perhaps my imagination was getting the best of me. But I discarded that idea quickly as a failure to face up to reality. I was grimly determined not to live in denial.

When I arrived for the consultation for the second opinion, my chest was tight. Sitting was uncomfortable due to the perceived enlarged spleen, and my blood pressure was through the roof. The head of Hematology led the consultation and he was accompanied by a younger doctor, who worked in his unit. The head doctor was kind, affable and calming. He assured me that there were options and, when I asked, he expressed confidence that I would see MF graduate from high school.

“The results of the previous bone marrow biopsy indicated an advanced stage of the disease, but they were inconclusive in some respects,” he said. I gritted my teeth when he recommended a second biopsy. He also recommended an ultrasound of the spleen to determine what I was confident was its enormous size. It was clear to me that the spleen was gorging. And what was up with my kidneys? Why was my creatinine level higher than normal? More testing was called for. More waiting.

One thought leads to another. But sometimes they do not lead out of the labyrinth of worry. But still I had papers to grade, conferences to attend, writing deadlines to meet, MF’s homework to supervise, The Dog to walk, and family weekend outings to plan. John Lennon once sang “Life is what happens when you are busy making other plans.” It’s also what happens when you are busy worrying about the future. Unfortunately, I was not always as rational as the moment of clarity in the letter to MF gave me reason to be.

If one values life, it is irrational to be so consumed with anxiety about its end that one loses the joy of living. Now I am far from the first to have realized this. In 23 BCE the Latin poet Horace wrote a poem with the words *Carpe Diem*:

“Whether Jove has many winters yet to give, or this our last;
 This, that makes the Tyrrhene billows spend their strength against the shore.
 Strain your wine and prove your wisdom; life is short; should hope be more?
 In the moment of our talking, envious time has ebb’d away.
 Seize the present; trust tomorrow e’en as little as you may.”

According to Matthew 6:34, about half century later, Jesus said, “Therefore do not be anxious about tomorrow, for tomorrow will be anxious for itself. Sufficient for the day is its own trouble.” (The New Testament scholars of the Jesus Seminar doubt that the sentences can be attributed to the historical Jesus.) Another 100 or so years later the Stoic philosopher Epictetus warned of the debilitating role of the imagination. “Man is not worried by real problems so much as by his imagined anxieties about real problems.”

The ancient wisdom of Horace-Jesus-Epictetus is sound advice for patients. Most of us are accustomed to living lives directed in significant measure by our own aims. We are agents. Sure, we have to follow the laws, do what the boss says, be polite, etc. But in liberal societies adults have a great deal of scope to do as they want in the midst of these constraints. As patients, however, we may experience loss of control with regard to something that matters a lot to most of us, our health. We wait for test results. We let the doctors perform their curative attempts on us, and we wait and see what comes of it all. Typically there is little that we can do to influence the result. In these cases patience really is the best policy. Not that we can always exercise the

kind of rational control over our fears that the counsel of patience recommends, but knowing that it is the rational policy provides some leverage on our emotional responses.

Patient and *patience* have a common Latin root. Some people deny that we are ever so completely patients, without the capacity to influence outcomes significantly. They maintain that we can always affect the outcome, rather than simply wait for it to come or to be known.

Patience, they claim, is the counsel of defeatism. Instead, maintaining the right attitude towards the outcome helps to promote it. This is supposed to be the deep power of positive thinking.

There is a new-age movie called *The Secret* that proclaims that maintaining a positive attitude causes health and riches. But if you are a friend or family member of a patient think carefully about this before you utter such a view to the patient.

It's not just that the view is wishful thinking, although it is that. It's much worse. Consider the logic. If good fortune reliably comes to those with good attitudes, then those suffering ill fortune have at least in part brought it upon themselves. In some way or other they must have failed to be sufficiently positive. The secret of *The Secret* is vicious victim blaming.

Having a good attitude is without a doubt crucially important. It's the *Carpe in Carpe Diem*. The Horace-Jesus-Epictetus counsel is to let go of our worries about the future, whatever it might bring, because doing so let's us enjoy the present. The value of a good attitude is not in its service to a better tomorrow, rather it's constitutive of enjoying the present.

The ultrasound showed that my spleen was slightly enlarged, but not all that much really, and not any more than it had been for the last several years. That's when a miracle of modern medicine

occurred. Strangely I stopped being able to feel my spleen! What I was telling myself was grim determination not to live in denial turned out to be the anxious workings of my own imagination.

I steeled myself for the second bone marrow biopsy. A doctor that I had not seen before, who seemed hardly old enough to even be in medical school introduced herself. She escorted me into a room and to a gleaming stainless steel table and asked me to take off my shirt and pull down my pants to the point at which enough of my hip was exposed for her to get to work. She was all business. There would be no soccer chat this time. I lay there bracing myself. First the cool spray of the topical disinfectant. Then the needle anaesthetizing the tissue. She was very short so she had to lower the table to get the kind of leverage on the biopsy needle that she would need to pierce the bone. She drove the needle in. Grimace. She twisted it. And then it seemed as if she had decided to go on an exploratory mission. Was she heading off horizontally? More grimacing. The corner of my eyes were moist. She twisted the needle. She was working hard, and she was not satisfied. She was not finding what she was after. Finally, she asked, “Did they get blood last time?” How the hell should I know, I wanted to say. But instead I mustered a curt. “I don’t know.” Hmm. I wondered what it all meant. Could it be that my marrow was producing no blood at all? Finally, seemingly satisfied, she withdrew the needle and packed up. I pulled up my trousers and put on my shirt, and then I was invited to leave.

But I got up too soon. The ground below me had had transformed into a wave, and my legs were not surfing it well. As I headed to the waiting room, I resisted the strong temptation to sit down. I was not going to show any vulnerability, not there. I swerved to absorb the waves and headed down the hall. Where to? What next? I found a side corridor; in it was a vending machine. I leaned against it. Sugar...chocolate would help. I fumbled for the money, bought the candy, and

ate it, as I weaved, but a bit more steadily, down the hall and out to my car where I could sit alone for a few minutes.

Another week or two of waiting went by, during which I had time to entertain magical thoughts of spontaneous healing. But when I went in for the results, there was no magic. No miraculous recovery. Medical books would not be re-written in light of the case of the philosopher whose disease inexplicably disappeared. The diagnosis from the previous bone marrow biopsy was confirmed. The *myelofibrosis* was in an advanced stage. I was in the upper section of the intermediate risk group. The median survival rate without a transplant was 3 years. The transplant had about a 70 percent success rate. The choice seemed clear. I could wait for a while on the transplant, but the longer I waited the more I would deteriorate and the success rate of the transplant would fall.

Myelofibrosis is an incredibly rare disease. There are only 18,000 diagnosed cases in the US. I don't know a single person who has had it. Never met another patient. I have two colleagues who each knew people who had it. Both died. But neither had access to a transplant.

Was I a candidate for a transplant? Was I healthy enough? What about my kidneys? What about that creatinine level? A transplant is tough on the kidneys. They have to process all the chemo that is sent to destroy the bone marrow. Then if there is any trouble later with infections, the kidneys have to process the diagnostic fluid consumed to help identify where the infection is. I could perhaps end up dependent on dialysis. A nephrologist had to be consulted. I would need an ultrasound performed on my kidneys. I would have to wait and see if I were a candidate for transplant. And then even if I were a candidate, could a donor be found?

In time this all worked out. The kidneys are slightly weakened but stable, probably damaged from some unknown past infection. There is some risk of becoming dialysis dependent, but the benefits of the transplant certainly outweigh those risks. And although my two siblings were not matched donors, it turns out that in the donor bank there were many. Two anonymous donors were very quickly identified and secured.

I don't claim to have been a model Stoic during this final period uncertainty, but I also wasn't a complete wreck. Life is what continued to happen. BF and I went to a Bruce Springsteen concert. We had tickets for the standing section near the stage. The concert was like huge tent revival, but for the faithful of many creeds and even of none. Over 20 years ago I read an article by Michael Eric Dyson in which he described a Michael Jackson concert as a modern day secular religious experiences. The call and response, the fellowship, the ecstasy. Dyson nailed it. When Springsteen played "My Hometown," a song about a town with a troubled racial past now suffering the ravages of de-industrialization, the audience of 10,000 people or more, took over the refrain, "My home town, my hometown." It was haunting and beautiful.

I stood with my Rayban Wayfarers on. The guy next to me, at least two decades my junior stood in his Misfits baseball cap and Aviator sunglasses. Ragtag communicants at the altar of rock 'n roll, we sang along to every song. Often nearly shouting, but our voices didn't stand out. The entire audience was the choir. Then Springsteen hit the chorus of "No Surrender."

"Once we made a promise we swore we'd always remember

No retreat, baby, no surrender

Blood brothers in a stormy night

With a vow to defend

No retreat, baby, no surrender

No retreat, baby, no surrender.”

Something warm was streaming under my sunglasses. I looked over at my brother in song, and I saw tears appear from under the bottom edge his Aviators. Moved by the spirit, we sang on as the band played.

4. Father to Son and Back

I have dim memories of sitting in front of a TV with a rounded screen inside a blonde cabinet and rabbit ear antennae positioned on top. *Art Linkletter's House Party* is playing in black and white. The show regularly contained a segment in which children were interviewed. Invariably they would say something cute and funny, which gave the segment its title, "Kids Say the Darndest Things." Later Bill Cosby had television show based on the same idea using the identical name. What made these shows especially entertaining was the unexpected nature of some of the responses. Sometimes a kid would say something disarmingly honest that made Art stop in his tracks. Pause. Then the audience would explode into laughter.

When I was first diagnosed, the only person I told for several weeks was BF. The ruse was up, however, when after attending several doctor's appointments during the work week, my secretary found an appoint slip for a Hematologist. She didn't pry. But I knew that I was going to need her able help in juggling my schedule since the doctor's appointments were multiplying. Going to the doctor had become a part-time job. So, I told her. I then adopted the policy of telling people on a need-to-know basis, the first group consisted of close colleagues, siblings, and good friends. I was generally hesitant to tell people before I knew that a transplant was going to be available. How would I tell someone that there is no cure? I couldn't imagine, and I preferred to await the approval for the transplant and the identification of a donor.

I dreaded telling people about my diagnosis. In large part this was because of the unpredictability of the responses. Sometimes I was thrust into the role of the therapist setting the grief stricken person at ease. I was struggling enough with coming to terms with the diagnosis myself.

Therapeutic distance was not something I had attained. Other times the message was easily and calmly absorbed. The person listened thoughtfully, expressed concern, asked good questions, and then we moved on. But in not a few cases it was much more difficult. Shock and anxiety would pour into the person's face. I could imagine them wanting to fumble to reach for their Xanax. My own precarious equilibrium could become unsettled. Their fear was, of course, some cocktail of care for me and the appreciation of their own vulnerability. The proportions would vary with each person.

I knew that I had to tell MF once it was relatively certain that I was a candidate for a stem cell transplant. The familiar dread returned. I steeled myself. BF was away. After serving him one of his favorite dinners of fresh pasta and panna cucina sauce, I began, "Remember how we sometimes talk about my anemia." Between forkfuls I conveyed a few of the details of the treatment, induced immune system death via chemo-therapy, hospitalization, surgical masks, good prospects of a cure, the whole business. With his mouth full, he paused, reflected, and said, "Oh, it's like AIDs caused by chemo-therapy." He swallowed and shoveled in another bite. I gulped. "Uh, yeah...I guess you could say that." I hadn't really thought of it that way, and I was not particularly eager to do so. But, given my limited knowledge of the course that AIDS runs, I had to admit that it seemed about right.

I was anxious about the next move of the dialectic. He was processing. "When is this going to happen?" "Well, maybe not for another 6 months, maybe even a bit longer. We don't yet know exactly. I need a donor, and there's no big hurry." He chewed and reflected again. "Good, then I can procrastinate worrying."

Done. The line was much longer than the ride. The conversation moved onto other topics.

I would have welcomed something stronger, but I was glad to have at least a glass of wine to drink as I reflected on his equanimity. I'd like to credit his parenting. But whatever the source, it had made things easy. And I was grateful. Procrastinate worrying. He made it sound so simple.

5. Give it Up for Lent!

The Lenten period is when Christians are encouraged to reflect on their own limitations. In the midst of the hustle and bustle of life, the pain and inconvenience caused by giving up a pleasure or a minor indulgence brings the attention of the faithful back to their own finitude, embodiment, and mortality.

I don't think that I will have any trouble reflecting on my mortality; I'm giving up my immune system.

This coming Thursday—the day after Ash Wednesday—I check into the hospital, at which point I surrender myself to modern medical knowledge, the competence of my doctors and nurses, and the vagaries of complex biochemical processes. Surrender is just another part of being a patient.

Here's the plan. The treatment protocol assigns the days numerals that revolve around the transplant day. The days before the transplant have negative numerals, the days after have positive ones. I arrive on day -7, and I am given an anticonvulsant. The chemo, it seems, can cause convulsions. I am also fitted with a port through which the chemo and stem cells will flow, the first to destroy and the second to rebuild. On days -6 through -3, I continue to receive the anticonvulsant supplemented by two different forms of chemotherapy, busulfan and fludarabine. These attack the immune system and immature blood cells. Three days of the regimen is sometimes used, but for the strong a fourth day is preferred. The additional day better serves the purpose of killing the marrow, making the likelihood of a successful transplant greater.

According to the Wikipedia entry on fludarabine, “Common side effects include nausea, diarrhea, fever, rash, shortness of breath, numbness, vision changes, and feeling tired. Severe side effects include brain dysfunction, low blood cell counts, and lung inflammation.” The doctors have assigned me a fourth day of chemo. I’m glad; I guess. But I don’t expect to have the leisure of ignoring my embodiment.

The point of the whole drill is to destroy my body’s erstwhile best friend, my immune system. The mutinous forces of my bone marrow must be crushed and replaced with more benevolent ones.

Day -2 looks to be something of a respite. I receive only the anticonvulsant. On day -1 I receive an immunosuppressant called *Tacrolimus*, which targets T cells in my muscles. Produced by soil bacterium, Tacrolimus helps to reduce the incidence of organ rejection.

Meanwhile my anonymous donor will be receiving daily injections of filgrastim, which causes the bone marrow to make and then release a whole bunch of stem cells into the blood. After several days of injections, the stem cells are harvested by a process called *apheresis*. Blood is removed and run through a machine; the stem cells separated out; and the remaining blood is returned, all over the course of 2 to 4 hours. It could take a day or two to harvest enough stem cells from the donor. The result is the greatest gift that I could be given at this point in my life. I am filled with gratitude beyond measure for the generosity of that donor.

Day 0 is the transplant day. Almost anti-climatically the stem cells are introduced into my body by means of an IV. By a mechanism of biochemical causation that I can’t really fathom, the cells are propelled to my bones—I want to say that they seek my bones—where they squat in the

residence that used to house my marrow. During days +1-+6 I receive an additional immunosuppressant called *Mycophenolate* to prevent rejection of the new bone marrow.

The first week or two after the transplant is critical. I will be in a condition known as *aplasia*. Absent any well-functioning bone marrow, my immune system will be in shambles. I will be dependent on blood transfusions. My job is simply to wait. The doctors look for signs that the stem cells are grafting and starting to make new bone marrow—this occurs 90 percent of the time. And I hope to avoid serious infection. My blood counts are continually monitored. When the new bone marrow produces enough blood for me to be safely released, I go home.

From start to finish I can expect a five to six week stay at the transplant unit. I start on the day after Ash Wednesday, and I hope to be on my feet after Good Friday.

6. Day -7: The Countdown Begins

When the day began it was still dark. I went downstairs to wake up MF for school. When I walked into the room The Dog greeted me like I had been gone for weeks. I was taken aback. He never does that in the morning. Uncanny. How did he know that I was leaving today? The Dog will be all right. He has lots of humans who will take him for walks in woods. He makes friends easily. He's already forgotten about me. I will miss him much more than I will be missed. The inequality between species is not always to our advantage.

At the transplant unit BF and I were greeted by a remarkably friendly staff. A doctor and a nurse sat us down and explained various rules. I was given the first of several anticonvulsants, and I was put on warning that the day would be full of information. But that's not all. They planned to perform a third bone marrow biopsy right away in order to get a baseline before the transplant. You could have heard my good cheer crash to the floor in whimpers. I tried to appear to take the news in stride, but I was not fooling anyone. The doctor said it was absolutely necessary. I was also to have a catheter inserted into me so that they could run all of the many fluids into me without re-poking me every time.

Then the nurse took us to my room. We entered an ante-chamber where she inspected everything that I brought along: A laptop, a tablet, two ten pound dumbbells, a yoga matt, several books, DVDs, eight pairs of sweat pants, eight long sleeve v neck t-shirts—hospital chic—eight pairs of socks, and eight pairs of underwear—all previously washed per instructions at 60°C /140°F. Most of the DVDs were not allowed because the album that they were in would be too hard to

disinfect. The same with an old book. Only new books are allowed. The computer, tablet, cell phone, cables, and weights were all swished with some kind of alcohol wipe.

I had an opportunity to peer into the room, my place of residence for the next five weeks. It is probably 12 feet by 15 feet, with a single bed, exercise cycle, TV, two monitors, a couple of stands that you might confuse for coat stands but in reality are IV stands, various devices that seem to read out measurements. All sorts of one-time use devices, wrapped in plastic, and a couple valves to which hoses apply. One seems to be for oxygen, but something tells me that nitrous oxide is not part of the deal.

It was a bit harrowing to look in. It is most certainly a hospital room. And it is where I will live. BF had to wear a gown and face mask to enter. Once in the room the nurse took my blood pressure and temperature —the latter I will have to do several times a day. I was weighed, again my job twice a day. Then the nurse explained that they are vigilant against hospital bacteria. Every orifice except my ears—I mean every one—was to be swabbed and examined in the lab. Fortunately there were two places that she left me to do in the privacy of the bathroom. I like her. She has a fine sense of humor about it all.

My instructions were then to shower, leaving the anti-bacterial soap on for at least two minutes before rinsing, and then put on my sweat pants and long sleeved shirt. I was beginning to look the part of a patient. More rules: Close the toilet top before flushing. Always wash hands with soap and then with disinfectant. If I drop something on the floor—where all the nasty germs live—I must call a nurse to pick it up.

Then lunch came, but it deserves no further mention. As the doctor came into preform the bone marrow biopsy and the catheter insertion, BF conveniently used the opportunity to go buy some shower shoes for me, which we had forgotten. Bone marrow biopsies are almost routine affairs to me now. This doctor was good. But I felt the deep, deep pain in the bone, nearly too much to take. She knew and backed off. She was also having trouble finding blood. She explained that it was due to the fibrosis, the scarring of the bone marrow. That might have gotten worse since May. The doctor got enough of what she wanted and withdrew the needle.

I was left to rest for little while; then she came back with a tranquilizer, which I took before she inserted the catheter. By the time she started that I was a bit light-headed and certainly compliant. A hole in my neck was made first. Then 20 centimeters of tube were run into a vein almost as far the heart. So the stuff they hook up to the catheter and drain into me will be taken directly to the heart and dispatched throughout my body right away. I now have a master tube sticking out of my neck. It divides into four littler tubes. As I write I'm hooked up to two bags of saline solution. I push the stand around like a dancing partner.

With the tube, the stand, and the bags, there is no denying now that I am a patient. After all of these months of waiting, of worrying, of working at not worrying it is really happening. I am a stem cell transplant patient. I have the tubes to prove it to myself and everyone else. I texted a picture of me and my tubes to my sister. She replied, "Just think of it as your cure starting." I like that.

It's a long ways from being over. One day at a time, I tell myself. Epictetus. Night has fallen. Tomorrow morning I will awaken to a doctor who will start my chemotherapy regimen. It is really happening.

7. Day -6: Carpe Diem

From all I've heard, I'm on the downhill slide now, in terms of how I will feel and the risk level assumed, so I'll look forward to many more loving comments in the coming days/weeks.

Last night I didn't sleep especially well. I had some discomfort from the tube and the biopsy site. But mostly I think it was simply the unfamiliar room. That it was a hospital room probably made it worse, but even when I travel for work and sleep in much nicer hotels I usually have disrupted sleep.

Shortly after 6AM, having given up the battle with sleep, I hopped on the exercise cycle and rode it for 30 mins while listening to Mudhoney's self-titled album. Nothing like a little 60s inspired grunge first thing in the morning! As I was moving over to the dumbbells the nurse came in with the first of my two daily bags of chemo. He had to start early because there must be 3 hours between the administration of each kind of chemo. They don't mix well immediately. I wasn't in the mood for a chemistry experiment; so we got started. My first time was a non-event, just like being hooked up to any ordinary bag of liquid.

The nurse then weighed me and took my temperature and blood pressure. The latter was high at 180, but that was due partially to riding. I saw no reason to let a little chemotherapy interrupt my work out. So, I spent about 20 mins pushing and pulling the dumbbells around.

Breakfast came. But the food leaves me too little of interest to describe; so I won't dwell on it.

After breakfast I began to feel a bit dizzy. The nurse took my blood pressure again, but nothing was found that could have caused the dizziness. It was down to 160. Still too high. Later he came

in with the results of yesterday's blood test. The sodium and creatinine levels were also high. This has been a recurring theme throughout my treatment. It all points to the kidneys. But a couple of ultra sounds revealed nothing. And the creatinine, at least, has been high but stable for nearly 10 years. But the kidneys are important for processing chemo out of the body. In my circumstances any dysfunction of them is a concern. There is the risk that dialysis might be needed.

They hooked me up to a couple of bags of water over the course of the day, the better to flush the system with. And I have been drinking liquids almost continually, and...well needing to visit the toilet every 15 mins or so. So I push Ginger Rogers, who carries the fluid bags, over to the bathroom and do the required deed. Once I forgot to close the toilet top before flushing. I broke the rules! I was paralyzed. Do I call someone, as if something had dropped to the floor. Then I reasoned that urine is sterile in any case, and once the flush starts there's not a damn thing anyone can do any way. So, I took a deep breath, stepped back, and went about washing and disinfecting my hands. Up till now, no one even knew!

My link to outside world today has been through the nurses. They are all terrific. The morning guy wanted to talk politics, and as long as there is a fair amount of agreement, I never mind doing that. He also knew one of the two people whom I know who went through this here (8 years ago) and was pleased to hear that I had been in contact. The midday woman has a hugely sympathetic heart. For a while yesterday she just stood by me, smiling behind the mask. It made me a little uncomfortable at first till I realized she was just being with me. It didn't matter if we spoke. After that I was completely won over. Today she told me the dizziness is caused by the anticonvulsant. A little dizziness beats a seizure any time. And it would pass.

She also knows the two people whom I know who had treatment here and are now thriving. We talked about how people react so differently to very similar treatments. These two both had *Leukemia*, not *Myelofibrosis*, and at least one had had chemo before the transplant and was severely weakened. One was in and out in only 3 weeks! The other had a really rough time of it and the prospects were not so clear for a while. I'd be happy for something in between! The night nurse I see less often. But she also has been warm, attentive, and caring. And she gave me sleeping pill for tonight.

The transplant doctor checked in. She expressed concern about my kidneys in relation to the optional fourth day of chemo. She wants to see what my readings look like on Monday before deciding whether to give me the fourth day. This is an example of one of those unwelcome decisions that patients and their doctors often have to make. A fourth day could possibly really foul up my kidneys, rendering me temporarily or permanently dialysis dependent. However, it would improve the prospects for the success of the transplant. But she stressed that she has done it successfully with just three days.

The biochemical processes are not in my control. The kidneys will either be functioning better or not. Realistically I can do nothing but wait, and, from the perspective of *Carpe Diem*, not worry. I am all right with that; at least I have been so far.

From what I hear from my outside sources and the second nurse, on Monday after three days of chemotherapy when the weekly nursing staff returns, I can expect to be feeling at least weaker—maybe worse still. I need to get all my partying in this weekend! Those who live and work near me know that I did not feel very bad entering the hospital. Except for about four days in the last 10 months when I could not drag myself off the couch I was so fatigued, I have been running at

about 95 percent of my full energy level. Full enough for no one, who didn't already know, to notice. How weird! That is probably all about to come crashing down.

Beginning of the cure. One day at a time. Carpe Diem!

8. Day -5: Would a Vegetarian Do This?

Today the doctors introduced a new medicine called anti-thymocyte globulin (ATG). It's an infusion harvested from rabbits that have been pumped up to produce antibodies that can destroy human T cells. The ATG will serve as a prophylactic against the rejection of the new stem cells.

I have no idea how the rabbits are treated. I imagine that they are at least encaged. I don't know what the over-production of anti-bodies does to them. I'm not a principled vegetarian although I know that it is better for the environment not to eat factory-farmed cattle. That's an argument for reduction, I think, not cutting meat completely out of the diet. Animal suffering in factory farms is real, and I think we should try to eat animals that are raised humanely. But once again, that's not an argument for principled rejection.

The issue of causation in the suffering is complicated. The rabbits have already suffered. I have not caused that suffering (if there was any) by using the medicine harvested from them. Some people who call themselves *road kill vegetarians* accept that argument across the board—they eat what is already dead. That seems awfully lenient. Nothing at my grocery store is ruled out. If by using this medicine I'm responsible for rabbit suffering it is either symbolically so, which I can't really make sense of, or it's in virtue of the market demand that is created by my usage. That demand might be real, but it's very small. It's far from clear that there would be *any* market effect if I did not use the medication. Markets are complicated and I don't understand them very well, but I know that they tend to adjust. So, my usage might simply be "corrected for" by someone else's. But maybe the usage matters simply in virtue of being *mine* rather than making matters any worse. Would a principled vegetarian reject this medicine? Would she have good

reason to do so? The benefit to me is potentially enormous. But how many rabbits will suffer or be killed in the future by the demand created?

The infusion of ATG runs over the course of three days, with today being the longest at 13 hours. So, in addition to the bags of water and the two kinds of chemo, Ginger Rogers is especially loaded down today. Hope she can still dance! The truth is that I'm feeling a little tired today and may not be dancing that much myself.

I woke up early and did my exercises, 30 mins on the bike and 15 mins with the dumbbells. I took a little nap after breakfast and have been light headed and tired ever since. Perhaps that explains my logic above! Otherwise, I am doing fine. I'm looking forward to seeing BF and (possibly) MF later today. But I will be spending lots of time in bed, the place my care givers prefer me to be when receiving the ATG. I have a bit of an anti-authoritarian streak in my personality, but I try to be a very good patient. When you comply that way, you don't have many things left to decide. I decide to write the blog (while I have the energy), to exercise (again while I have the energy), what to read, which music to listen to, what to watch, and when to nap. In different circumstances it would a nice vacation. The range of choices available to me is pretty limited. But it is, after all, by choice. I'm not frustrated by it.

I really like the Epictetus quotation that LT sent: "There are things in your control, and things not in your control, and if you keep your will confined to what is in your control, you can be happy." Stoicism seems the perfect philosophy for patients. But maybe for that reason it's not well-suited for citizens and activists.

Let's all extend a prayer or a silent expression of gratitude for the bunnies.

9. Day -4: Sweatin' and Shakin'

The guy who cleans my room is always good for a riddle. So far I have not solved a single one. I blame it on the drugs circulating through my brain. Last night the rabbit anti-bodies disagreed with me. Around 6pm I started to shiver; then it turned to the sweats. The fever burned and the elevated blood pressure pounded most of the night. Apparently there's nothing much unusual in my experience. But knowledge of that didn't make it feel any better.

The evening nurse scolded me for letting several cables drop to the floor when I got up to use the toilet. I couldn't tell if she was serious or somehow playing. But I consoled myself with the thought that perhaps every hospital needs a Nurse Ratchet. The night-time nurse was attentive and comforting, but clearly also a force to be reckoned with. These two are veterans of the transplant ward. They've seen it all. They know how to make sure what needs to be done—medicine taken, rest taken—gets done, but they also have sympathy for the patients. One part drill-sergeant, another part camp counselor. The evening shift nurse tends towards the drill sergeant.

It was a fitful night. The fever and sweats lasted nearly throughout. I awoke feeling better, but distinctly worse than yesterday morning and the day before. The baseline is dropping along with my blood counts. The chemo seems to be effective in killing off blood production. My hemoglobin is down, which results in fatigue. I didn't exercise this morning. It was just too damn hard after the night I'd had. I didn't take the decision lightly. I know it's important to do. If tonight goes better, I'll do it tomorrow.

My mouth is as dry as a desert. This brings no joy to eating. The bread and cheese for breakfast felt like wadded up paper in my mouth. It was all I could to swallow it. That's also the chemo.

I'm getting more rabbit anti-bodies today (and tomorrow). The nurses tell me it should not be as bad as yesterday. In any, case my big plans for the day are to spend it mostly in bed, dozing and waiting for it to pass.

10. Day -3: Making Decisions when You Can't Think

“Draw a square with three straight lines,” the janitor said to me. I looked up from the paper at him and thought to myself, I’m not sure I have the energy to do this. “Don’t overthink it!” You’re talking to the wrong guy, buddy! “And no, you can’t use the side of the sheet of paper as an extra line.” My head felt packed with cotton wool. I wasn’t really enjoying the challenge. In reality, I could barely even under-think the problem. When he wrote answer, □ |||, all I felt was tired. Next puzzle: “Suppose you got a wolf, a sheep, and a lettuce on one the side of the river, and you need to transport them across to the other side. You can only take one at a time, boat’s not big enough for more. But you can’t leave the wolf alone with the sheep; the sheep will be eaten. And you can’t leave the sheep alone with the lettuce, or the lettuce be eaten. How do you get them across?” I couldn’t get any farther than taking the sheep across first. I was mad about that because, unlike the first puzzle, this one was no trick. I blamed the cotton wool in my head.

BF is a breast cancer survivor. During treatment she received chemotherapy once every three weeks for four or five months. She used to speak of “chemo brain,” a generalized lack of sharpness. I think it’s descending on me, and I think the janitor knows. Don’t let me make any bets with him!

Yesterday when MF came to visit, I presented both puzzles to him. He also gave up on the square and three lines one, and he was not happy about the right answer. But he cranked out the answer the river crossing. It goes like this: First, take the sheep across. Next, go back with an empty boat; grab the wolf and deposit it on the other side. But before crossing back, grab the sheep; cross back with it; leave the sheep; but grab the lettuce. Go back across with the lettuce;

leave it over there with the wolf. Finally, go to the original side with an empty boat; pick up the sheep; and bring him to the other side. MF may have a career in logistics, or maybe directing.

Yesterday evening and last night were thankfully considerably better than the night before. Even though I slept reasonably well, I noticed this morning that it takes me a long time to get going in the morning. I did finally get to my exercise routine, and take my shower, just before the nurse came in to put a bag fludarabin on Ginger Rogers and hook me up.

The question of what to do about my kidneys and chemotherapy was solved by compromise. You might recall that the doctor spoke of a trade-off between the possibility of the fourth day of chemo damaging my weakened kidneys, rendering me dialysis dependent, and receiving only three days of chemo, as typically people over 60 do, which would make the transplant itself a bit more risky. She recommended splitting the difference. So, on this day, the fourth day of chemotherapy, I received only the fludarabin and not the bulsavin. She has done it this way before with success and she seemed confident. Who am I to know better? As patients we put ourselves in the trust of doctors. We make ourselves vulnerable to their judgments. It's not that we have no role to play at all. For how we want to live is at stake. But we can't pretend to have better grasp of the empirics than the doctors.

I'm fuzzy in the head, dizzy when I stand up, and tired most of the time. I'm hardly a model decision-maker right now. Two things stand out about that short discussion and decision. First, insofar as she is recommending a slight reduction of chemo on behalf of my kidneys, she must be confident that the reduction does not change the likelihood of success all that much. Why do something on behalf of my kidneys, if I'll be dead? Second, when I first spoke to her early last summer, she seemed eager to point out the risks of a transplant and unwilling to recommend any

decision at all. She adopted the position of informing, not advising. Just now, her stance was firm. She must feel strongly about it.

Being a patient is not only about being patient. There's a boat load of trust involved too.

11. Day -2: Nausea and Fatigue

Yesterday afternoon and evening were comparatively good stretches. The last bag of chemo went empty with little fanfare. No marching bands were to be seen on the transplant ward. But I felt almost ready to join one. I had plenty of energy and even felt about 80% of my normal self all evening. I slept a very long time last night, but come this morning I experienced the familiar feeling of not being able to get started. The nurses woke me at 7am to hook me up to an IV of antibiotics. After the IV, I was requested to shower while my bed was changed. It was in a heavy morning fog that I went into the shower. I know people for whom that is usual, but it never has been for me, and I found it disconcerting. Breakfast was delivered and I could hardly face it. I forced down the yogurt, juice, and kiwi, but wasted the rolls, cheese, and ham. What I get at mealtime seems to overlap about 75% with what I order. There's always an element of surprise involved!

After breakfast the nurse always cleans the valves on my tubes. Today that meant I could lie back down, which was welcome. Nausea seemed to be visiting me, really for the first time. And it was a pretty dispiriting feeling. Because the IV tube goes in at my neck, the four tubes that it divides into hang high on my shoulders. I can't see very well what she does, but she seems to be attending a bit to the dressing, whipping things down, and checking for blockages. She's talkative, and I like her. Recently she moved to this transplant clinic from another one so that she could move in with her boyfriend. They are remodeling his grandma's old house together. I started to drift a bit through the story. When finished, she declared that I had about 20 mins before she would hook me up to a bag full of rabbit anti-bodies.

So, with a huge heave and a tremendous act of will I mounted the stationary bicycle. It was the last thing I felt like doing really. But I have been scared by nurses' stories—they are so devious—of people who nearly waste away in here after 5 to 6 weeks of doing nothing. A sport consultant also came by yesterday and stressed the importance of keeping active. I got 16 mins of riding in before the nurse came back with bag to connect me to. I was managing to ride, but not having any fun. I had dropped my Ipod to the floor, and lest I get deadly germs, I left it there, riding in silence against the tremendous headwind of chemo and to little voices in my head calling me back to bed. I was glad to quit when the nurse came back in. I hadn't lost, but I also hadn't won. I resolved that I'd finish up the riding and hit the dumbbells later on today.

After she hooked me up to the rabbit anti-bodies, I laid back down again. I drifted in bed until lunch. The meal consisted of was some sort of white fish and boiled potatoes with white sauce and a side of zucchini brought delicately to the consistency of jarred baby food. I ate it with surprising enthusiasm. And my energy has subsequently come back as well.

The energy ebbs and flows are frustrating. I've learned to act when I can, and simply to wait it out when I can't do much of anything else. Will it be like this after the transplant on Thursday, or am I in for something completely different? I suspect the latter. The nurses tell me that everyone reacts differently. With the mission of destruction over, it will be the beginning of the critical rebuilding mission. I don't know how long the chemo and rabbit anti-bodies linger, but I imagine my travails will be very different, waiting and hoping for the successful re-building an immune system that will protect me—waiting for my cure.

12. Day -1: Courage

It's Wednesday. Last Thursday, feeling reasonably healthy I checked into this stem cell transplant unit. I did that completely voluntarily in the hopes of curing a disease that would otherwise kill me in the coming few years. A week ago I could easily run several miles, lift weights for a good half an hour, do work related tasks, and make meals for my family. I've had good care here. I'm in excellent hands. Yet, when I got up out of bed to shower this morning, I was so weakened that thought I might black out in the shower stall. The doctor was not surprised to hear this. He recommended using the shower stool they provide. That's why it's there. He explained that as a result of the chemotherapy my hemoglobin has dropped so low that I am very weak, when I stand up and go into warm shower I have a low blood pressure moment, and black out is a possibility. I guess it's all routine. I had no idea what the routine was when I checked in last week. I still really don't. And I guess it varies a fair bit from person to person. But I've become astonishingly weak, very quickly. I've never read any first person accounts of stem cell transplants. I could find nothing on the internet to prepare myself. Now I wonder if there is a secret confederacy of patients, dedicated to not telling others how crappy it gets, in order not to scare people away from having the life-saving procedures.

Tomorrow is transplant day, soon after which I hope the pendulum swings from destruction to re-building. If I were to walk out of this hospital today, I would not get far. Before long I'd succumb to fatigue, and without much of a working immune system, I would probably catch a severe infection. The bodily processes that make up this living organism that I am would go into deep crisis. I have no choice but to move forward with the transplant. It's the only option now,

but it was also the best option, I'm confident, when I chose it. I do have a choice, however, regarding how I face the travails and risks that are ahead.

Aristotle thought that courage was the virtue that is particularly called upon when facing fear, and the fear of death in particular. Courage is not only a martial virtue, but it does have particular application in battle. Like all virtues of character Aristotle thought it was concerned with feeling and acting, neither too much nor too little but the right amount, in the right way, and at right time—a mean between extremes. The courageous person is neither fearless, nor a coward, but feels the fear that is appropriate and acts accordingly in the face of it. As with all virtues of character, Aristotle claimed that we come to be virtuous by imitation. If at first we have to quell an excessive level of fear in order to act in a way a courageous person would, over time so acting may produce results. We may become the courageous person we were imitating.

Curiously, Aristotle thought that courage had no role to play when facing the dangers that manifest as the result of ill health. This might have been true given the health practices of his time, but it's not true anymore. Aristotle thought that the virtues were only applicable where one has the capacity for choice. No one chooses to be sick. And once sick, in his time, there were few choices regarding care, or how best to live with illness. In the surgeon Atul Gawande's important book, *Being Mortal: Death and What Matters in the End*, he writes that "For all but our most recent history, death was a companion, an ever present possibility. It didn't matter whether you were five or fifty. Every day was a roll of the dice...Life and health would putter along nicely, not a problem in the world, then illness would hit and the bottom would drop out like a trapdoor..." People did not linger in death, and they did not live for long periods of time with serious chronic illness. How to live in the face of a chronic disease, how face the risks of medical

treatments, how to prepare for one's steady decline are not questions that people have long asked. But confronting such questions oneself certainly raises the matter of how to proceed in the face of the fear of death.

Patience seems particularly appropriate in regards to waiting, for a diagnosis, for the test results, for a therapy to show some effect, or for some counts to improve. Patience counsels the continued enjoyment of the value that life offers, the value that anxiety about the future eats away. Courage is appropriate once the risks are known, the diagnosis and prognosis are in, or the risky course of care lies before us. Patience is needed in the face imagined risks, courage in the face of real ones. But they have a similar importance, both direct us to the continued pursuit of the value that remains in life in the face of fears that could overwhelm us and could prevent us from the full appreciation of that value.

13. Day 0: Communion

Transplant day started earlier than usual. The night nurse came in at 5am to draw blood and to give me a preparatory infusion. I was too groggy at the time remember now if it was an anti-biotic or an immune system suppressant or something else. I was awoken again shortly after 7am with more preparations. I was hooked up to a big bag of immune-suppressants and to a smaller one of water. I sat at my desk for a while and then the transplant doctor came in. She told me the plan. The transplant would happen in the morning. Enough stem cells had been harvested yesterday to do the transplant before noon. There were not enough to freeze extras should they be needed, but the donor would be available for more in that event.

My blood counts suggest that the chemo had achieved the intended effect. I have entered into aplasia. My white counts have hit nearly the bottom. The platelets counts are the lowest ever. And I have anemia like never before. I used the stool this morning when showering. I'll remain transfusion dependent now for at least two weeks.

The anonymous donor travelled several hours yesterday to be here to donate. He's 32 years old, and from a large city in the east. He is a perfect match. He even has the same blood type. I don't know any more about him. I wonder what conviction led him to help. Why was he so generous with his time and body? Perhaps he's a member of helping profession, and donating is part of the professional culture. Maybe a fireman. Or maybe it's done out of religious faith. Maybe there is a family history of similar illness. I've never known anyone to donate stem cells. Plenty of people donate blood, especially at colleges and universities. Even I have done that. But donating stem cells is less common. Maybe with stem cell donation there is a deeper sense of satisfaction.

The donor is *the* person making the life-savings effort possible; the stem cell donor is not just one of many donors contributing to the cause.

Whatever his reason to help, it was with a deep sense of gratitude that I accepted his communion gift this morning at about 10:50am. I was connected to a bag of his stem cells; some 5.4 million, I'm told. The tube flowed red for about an hour. But I was also hooked up to some kind anti-allergen infusion, which made me drowsy. So, I drifted in and out on a sleep as sweet as frankincense.

Now we wait, once again. The stem cells need to graft, and then begin the formation of the new marrow. We hope to find evidence of the pump being primed, in the form of rising blood counts, in two weeks. Risk of infection will be the main threat during that time. After that we hope that the new immune system takes its guard dog duty seriously and attacks only hostile outsiders.

I know the process is not over yet. But I feel a little lighter today. Whatever else, that disease is past. So, say a toast tonight for the demise of a disease, and for further health! I'd like nothing more than to join in, but on this ward tonight I get nothing stronger than the words of T.S. Eliot: "[T]o make an end is to make a beginning. The end is where we start from."

14. Day +1: Confinement

There's little to report on the first day with the new stem cells floating around inside. The transfusion raised my counts above the scarily low level. Gone is the vague bad taste in my mouth and the fuzzy head of chemo. Fatigue and mild nausea unfortunately remain powerful forces pulling me to the bed today. I did get my exercise routine in, but I may have over done it. I feel like I've run a marathon. Well, I don't actually know what that feels like. But I am exhausted. My appetite is not very strong, but maybe the food here has something do with that.

I have developed strong aversions. After the chemo I haven't been able to face the two bags of potato chips that BF brought me. So much so that I had put them away in the closet. I can't drink sparkling water anymore. And worse yet, one of the two mouth washes I am required to use four times a day is disgusting to me.

I also for the first time felt confined today. After only a week in this room, I feel like busting out. Don't worry lack of energy keeps from doing anything stupid. The janitor told me that when patients' counts are high enough for them to walk in the halls, they are allowed to go to a little window and breathe the fresh air through their masks. I dream of that window.

15. Day +2: Waiting and Anxiety

I'm doing as well as could be hoped for physically. No serious side-effects of the transplant have arisen yet. And so far there are no indications of serious infections. And I had more energy and less nausea today than yesterday. Currently the only issue is that I still have little appetite and eating feels like a chore.

Waiting the next two to three weeks to see if the stem cells graft and begin producing blood is going to be much harder for me than waiting for the transplant itself. Pre-transplant I was happily at home with MF and BF playing an enthusiastic role in the family, running in the woods with The Dog, and working. Surrounded by those whom I love most and engaged in meaningful work, my life was full of valuable roles and activities. The Horace-Jesus-Epictetus attitude (that I spoke about in the Patience entry) was easier to attain and maintain pre-transplant because it encouraged my attention on those activities. And it fed on itself; the more I enjoyed them, the easier it was not to be distracted by worry. But now I am isolated from all that. I am not living with the ones I love. Everyday life is far less rewarding. It's lonelier. It's boring. And it's anti-septic. When BF visited we sat and held hands, hers in a plastic glove, while watching *Ghostbusters*. To make matters worse, the repeated measurements of my temperature, weight, and blood pressure, the daily blood drawing, and the may IVs are constant reminders that my circumstance is still precarious and uncertain.

I see no magic fix for the precariousness of the Carpe Diem attitude in these circumstances. Debilitating worry is still irrational in the sense that it only undermines whatever good could come out of the present circumstances. That provides some leverage on the worry. But alone it's

not enough. I'll need as much contact as I can get with my family either physically or virtually. Light diversions help too, especially when I'm too tired for anything else. A little work seems like it might even help in connecting me with activities that are important to me. And after last night, I've embraced the utility of a sleeping pill.

These next few weeks, I think, are not going to be easy. But they'll be easier if I continue to feel relatively good physically, if the side-effects and infections remain minimal. If all goes as is likely, we will be able to celebrate the blood production beginning before too long.

Writing helps. It gives me something to work on.

16. Day +3: Gratitude

I had great and supportive comments to my blog yesterday, images clocks dripping. Reflections on beginnings, and even a reading suggestions (which had always been my intention until my powers of concentrations seemed compromised). I'm filled with gratitude. I will follow BF and LT's suggestion and continue to say a few words.

Whereas the first two days after the transplant were a difficult period of re-adjustment to further waiting, today was a good day. Lovely and sunny outside. I awoke feeling fine. My energy was slightly less than the day before, and that proved to be due to lower hemoglobin levels. The doctor decided it was time for another transfusion. Now with two new bags of blood, I'm gassed and ready to roll for a couple of days.

The doctor's visit was very encouraging. It's far too early to tell if anything is going on in the re-building department, but he was happy with how stable things are and with the lack of complications thus far. That, he thought, bode well.

I did a slightly lighter than usual exercise routine and then committed myself fully to being in recovery mode. This was the first day since entering the hospital that I felt so completely relaxed. It was a treat! In the afternoon BF and MF came for a visit and we watched most of *The Blues Brothers* together. The two of them sitting with gowns and masks on and me lounging in between. It would have been a nice family picture!

17. Day +4: Toiling and Spinning

A friend reminded me of the passage in Matthew that precedes the one that I quoted in “Patience.” Matthew 6:28-29 (King James Version): “Consider the lilies of the field, how they grow; they toil not, neither do they spin: and yet I say unto you, that even Solomon in all his glory was not arrayed like one of these.” I have long loved that passage as an expression of wonder regarding nature and natural processes. BC suggested that I consider the stem cells growing, neither toiling nor spinning, in their new home inside my bones. It is a wondrous thought! I marvel at how these things must work—not that I really understand them. In any case, I don’t think that scientifically understanding how seed germination works, when it works, makes it any less wondrous that it works. The disenchantment of nature should not lead to indifference regarding it. In many cases, as often is the case with art, understanding can foster even greater appreciation. If all natural processes were one day well understood, we still have reason to sit back and marvel over their workings, over the comprehensibility of the whole, and, of course, over the sheer fact that something exists rather than nothing. There is something wondrous about those stem cells growing deep inside my bones.

Two events from the day: This afternoon I was visited by a pair of 3rd year medical students, making the rounds for their studies. These were two young women who until then had never examined a living human body! Their job was to knock around on my belly, listen with a stethoscope, and examine my lymph nodes. They were nervous, hesitant, and self-conscious. It was all very sweet. I did what I could to put them at ease. After all, I am happy to further the cause of advancing medical studies!

The oncological psychotherapist also paid me a visit today. We talked at some length about the experience of being a patient. One thing she said that really stood out for me was the nearly complete loss of autonomy that one experiences when entering a hospital. One deals with the disease alongside everything else outside the hospital. But in the hospital treatment of the disease rules, and one's life is governed by that. So, when one is thrown into the waiting mode, without an everyday life to participate in, it is a much more foundation-shaking experience. Without our usual everyday projects, we may be at a loss. And the realization that one is sick, indeed very sick, can produce a profound loss of orientation, a vertigo. That's normal under the circumstances. Now, one is not consigned to the bottom should one land there. Rebuilding a routine of valuable activities, while waiting, is possible. And the resultant structure might be all the more secure as a result the fall taken.

I remarked to her that I was less bothered at night after taking the pill the doctors prescribed several days ago. She informed me that it had nothing to do with the pills. Those take a couple of weeks to begin working. The rebuilding had already begun. I'd like to think the same is true of the stem cells, neither toiling nor spinning.

It was another beautiful day here, and a good one for me.

18. Day +5: Single Payer Pt. 2

I am sitting in my hospital room in a bone marrow transplant unit in a Frankfurt, Germany. I am a patient who has recently received a stem cell transplant. I am U.S. citizen, but I am a resident of a country with a single payer health system. The insurance system here covers 85 percent of the population. And participation is mandatory, although high earners can opt out by purchasing private insurance. Citizens and working residents pay a tax of about 15 percent of their earnings for their government financed health care coverage. The insurance is administered by one of several non-profit organization that differ very little in coverage benefits because of the mandatory high level of minimum coverage. Doctors and pharmacists in private practice are reimbursed by these insurance administrators.

I am not a permanent resident of this country. I live here legally on a temporary work visa. Nonetheless I am full participant in the insurance plan. The costs of stem cell transplants vary considerably, but in the United States they average about \$800,000. Here they average a bit more than \$250,000. In my case, that is about what the insurance plan will end up paying for my transplant. When I walk out the hospital, my bill will be a \$10 per day charge. Let me emphasize that is not because I have a Platinum plan at a cost affordable only the jet-setting global elite. On the contrary, I am getting the same coverage for the same excellent treatment that anyone else living here would receive. That's what single payer means to me and my family.

Today the doctor paid me a visit and handed me a letter that I need to submit to the insurance administrator. The letter states that when I am released, I will need to make frequent follow up visits at a time when my immune system will be weak. By doctors' orders I may not to take

public transportation. In this case, the insurance administrator is required to reimburse my taxi fare. Once again, a standard benefit of this single payer scheme.

When Paul Ryan seeks to defend the new Republican healthcare plan, which according an independent analysis of the Congressional Budget Office would render 14 million people uninsured next year alone, he tends to lean on the rhetoric of liberty. Naturally this is because he can't plausibly claim that it is good for health outcomes. He says, "If the government says, 'Thou shall buy our health insurance,' the government estimate are going to say people will comply. And when you replace that with, 'We're going to have a free market and you buy what you want to buy,' they're going to say not nearly as many people are going to do that."

It's time to for Americans to face up to the costs of the kind of liberty that Ryan and his followers advocate. The basic principle of insurance is risk-pooling. If people participate voluntarily on the basis of their beliefs about their own risks, participation will be limited mostly to those who see themselves as vulnerable (the poor, the sick, and the elderly) and the premiums will be expensive. Mandatory participation not only broadens coverage, but it reduces premiums.

Americans already pay more for health care than their counterparts in other wealthy countries. In 2013 the Commonwealth Fund conducted a study of health and healthcare in the wealthiest countries in world, the OCED countries. It found that "In 2013, the U.S. spent far more on health care than these other countries...Despite spending more on health care, Americans had poor health outcomes, including shorter life expectancy and greater prevalence of chronic conditions." Spending as a percent of GDP in the USA is just over 17 percent. In continental Europe it tends to be just over 11 percent. For the UK it is just under 9 percent. More spending in the US did not result in more doctors to serve the population. There are 2.6 physicians for every 1000 people in

the USA, and 4.1 per 1000 in Germany. More spending in the US does not increase life expectancy. Life expectancy at birth in the USA is 78.8 years, and in Germany it's 80.9. Nor does more spending yield a healthier population. The percentage of the population over 65 with two or more chronic conditions in the USA is 68, in Germany only 49. And the number of infant deaths per 1000 live births in the USA is 6.1; in Germany it's nearly half that 3.3. In general, the coverage is far wider in Europe; the costs of care are less; and health outcomes are better.

The country that I live in can hardly be described as a tyranny. Freedom of religion, speech, and movement are all secure. Elections are free and far less corrupted by money than in the U.S. Better health outcomes at lower costs have not been purchased at the cost of basic liberty. Yes, people must pay into the scheme. But being secure in their healthcare coverage they are also freer to take chances in employment moves and entrepreneurial initiatives. And perhaps the biggest difference is in the attitude of solidarity. It is simply unthinkable for most people here that a person should be left to suffer ill-health or even death due to the lack of insurance. Ask not for whom the bell tolls.

When I am healthy enough to leave the hospital and go home, I will count myself as fortunate to be living here where coverage and excellent care was made available by tax payers. More than that, it *is* unthinkable to me that someone with my disease in the U.S. might fail to get the life-savings transplant she needs because she is either uninsured or without the insurance that would cover the procedure. That outrage will cast a long shadow on my feeling of good fortune.

19. Day +6: Patience *and* Hope?

I am happy to share an important life lesson that I have learned over the course my stay at the transplant unit: If you have to rinse your mouth several times a day with two different medicated mouth washes, one of which you find foul, repulsive, and dreadful, rinse with the bad one first. It would be too embarrassing to tell you how long it took me to figure out that doing it in that order helps to mitigate the lingering wretched taste.

The medication regimen imposed on me is impressive. Orally I take 14 different kinds of medications, most of these more than once a day. Additionally, through the IV there flows various immuno-suppressants, antibiotics, and hydration infusions. The medications tend to proliferate as some are aimed at facilitating the success of transplant and others deal with the side-effects of the first kind of meds. For example, I take an immuno-suppressant, which dials down the immune system so as to reduce the severity and incidence of battles between the emerging immune system and my organs. But the one that I take has the side-effect of increasing blood pressure, which in my case was already slightly elevated. As a consequence I had a couple mornings this week when my systolic pressure (the top one of the two) was through the roof. Dealing with that requires taking another kind of medication. And all of this, of course, has a certain learn-by-doing character; every organism is different and differently complex. So, doses need to be adjusted to achieve the desired effect. But, of course, sometimes you can't just tweak one dosage because it has side-effects that have to be managed.

My homework every evening is to lay out all my pills in a tray with four compartments for the different times during the following day that I am supposed to take them. Not a day has gone by

when the plan that I have followed has been the same as the previous day. In some cases the milligrams of the actual medication differ from the milligrams on the plan, in which case I have to do the calculation and either halve or double the dosage. When I was in chemo this was really taxing work. It took all my powers of concentration, and it was exhausting! It could be that the nursing staff just doesn't want this job. But I have a hunch it is some kind of competency test because when I was receiving chemo the night nurse would check my work. And once or twice she playfully scolded me for screwing up.

In an effort to reincorporate aspects of normal life into my life here, I'm meeting this evening with my internet book group. There are three core members of this group, and we have met off and on for over ten years, first in person when we all taught at the same university after that virtually when two of us moved. We cover the fields of classics, political science, and philosophy. We pick a hard piece of philosophy that we are all at least somewhat interested in and we work through it over the course of many months. We've read lots of different things, including Plato's *Statesman*, St. Augustine's *City of God*, Nietzsche's *The Gay Science*, and Adorno's *Minima Moralia*. For some time now we've been reading volume one of Ernst Bloch's *The Principle of Hope*. I cherish this group and my friendship with the other members. It's wonderful to get back to meeting with them.

The section of Bloch that we are discussing tonight is relevant to my earlier invocation of Epictetus in the "Patience" post. Epictetus's attitude of focusing on what is in one's control is a tonic against anxiety, but perhaps it also rules out more positive future-oriented attitudes about things that are uncertain, attitudes like hope. Rightly or wrongly Bloch interprets ancient thought as skeptical about the value hope due to the unhappiness that unfounded hope may cause. His

major purpose in the book is to vindicate the really fundamental importance of hope. In his conclusion of a discussion of ancient skepticism about hope, he says the following: “And founded hope especially, that is, hope mediated with the real Possible, is so far removed from evil...that it in fact represents the at least half-open door appearing to open on to pleasant objects, in a world which has not become a prison, which is not a prison.”

20. Day +7: A Letter Arrives

Today marks two weeks that I have been in the hospital and one week since the transplant. I am feeling better than I expected to feel at this point. A bit tired today and I will probably need another couple of bags of red blood tomorrow or the next day. But that should keep me going for a while.

I am entering a phase in which my white counts are in the cellar. The name of the phase is *aplasia*, the lack of a regenerating immune system. With respect to infection it's an especially risky time. But various stores of antibiotics stand ready to be tapped. I'm already taking some antibiotics, both prophylactically and in response to a gastro-intestinal bug. Still there could be need of more. There is no re-building the new immune system without the counts bottoming out. So, this phase must be gone through. For patients who have had leukemia the average waiting time after transplant before the first signs of rebuilding are measured is fourteen days. Leukemia is not my disease; so the average might be slightly different. But not very much, I think. Maybe in a week there will be some signs.

I received a letter today from my donor, written the day after he donated the cells. It was strange and wonderful to receive. There is this person out there, whom I don't know; he has just rescued me; and now he is writing to me. He told me of his thoughts for my family and friends, how happy he was to help, and that I will never be alone. A gracious and beautiful gesture of compassion and support. I am speechless.

21. Day +8: Anemia

Today has been low energy. All the counts are falling. That includes the hemoglobin; so I am very anemic, leaving me with a lack of gumption. I did get in a very easy bike riding session. By doctor's orders I can't break a sweat because my platelets are so low that bleeding in the head could result. That would mess up my plans. The nurses are very strict, even scolding, about this. When I got out of the shower I dried myself with one of the coarse towels they provide—I've come to like the coarseness due to a side effect that makes my skin itch. After that when I put the industrial strength moisturizer on my skin I notice that I was bleeding in two spots. Low platelets once again.

The day consisted mostly of resting, watching *The Office* (American version), and reading *Anna Karenina*. By the end of the day my doctor decided to give me a platelet transfusion. So they hoisted a bag of pale yellow-orange liquid that looked a bit like watered down dahl and connected me to it via an IV. The doctor explained that this would allow more exercise tomorrow. But unless they also feed me a couple of bags of red, I might not feel much up to it. That, I suspect, will happen tomorrow.

22. Day +9: Writing

Strangely I've had little more energy today than yesterday, even though my hemoglobin is even lower. The platelet transfusion yesterday increased my counts enough for a slightly more vigorous work out today. In addition to riding the bike at a very easy pace, I lifted the dumbbells a bit. We'll hold off with red blood transfusion for another day or two.

My tongue is swollen in my mouth and it rubs against my teeth on the side, and that is making the tongue sensitive. As result of the chemo slime production all throughout the gastro-intestinal track is way down, including the saliva my mouth. The dryness of my mouth diminished the pleasure of my first room delivered pizza last night. Still it was great to get it. I suppose the biggest issue right now is dealing with my stressed out kidneys. The chemo, as expected, has been hard on them. My potassium and creatinine levels are high, the former is a bigger concern than the latter. So, I am on diuretic that ensures that I get plenty of exercise standing up and walking to the toilet. I am also taking a substance that it supposed to capture the sodium in my gut before it metabolizes. The doctors expect the kidneys to bounce back to a better suboptimal level, and they don't seem terribly concerned yet.

When I return home, the house will need to be very clean because my immune system will still be weak. So, BF hosted a house cleaning party today, promising pizza to everyone who showed up. Amazing, she tells me, over 20 people showed up! This is another example of the wonderful generosity that people are bestowing on us. The transplant itself, all of the words of support that I receive from friends, the friends who have come to stay with BF to help around the house, the

neighbors who walk The Dog, and now the house cleaners. It's all deeply moving. I am very grateful for it.

Why do I write? A dear friend wrote to me today asking if I sent upbeat messages so as not to worry people, and if that is the case urging me to be willing to show the hardship more. I started out writing with the purpose of informing family and friends. But the writing has taken on another kind of meaning for me. It has become a way in which I can make something out of the experience. It's not an experience that anyone would choose to have. As a patient I may be hostage to the disease, the biochemistry, and the medical treatment. I may not control the outcome, and I may have to suffer the experience. But if I have to suffer it, perhaps I can have something to show for it. This record itself is what I made of the experience, and I hope what I made is good. So, I work to convey the experience. The writing is not a therapy journal written only for myself. I would like it to be good in the sense that it touches others, but also in the sense that it is honest.

Honesty and comprehensiveness are not the same thing. I don't have to write about everything, but if I write about it I aim to convey it honestly. If I'm not fully comprehensive, it's not because I am consciously choosing to avoid the bad stuff to spare the worry of my readers. I have talked a lot about the physical suffering. But so far that has not been as bad as I expected. Regarding the psychological suffering, I think I've explored some dark places. Day +2 goes there, as does to a lesser extent +4 and the earlier "Patience" post. I admit that it is harder for me to write about the psychological suffering. I think it's harder because it feels more exposing. Still, I hope that I haven't been avoiding writing about it and that when I write about it I capture it.

Not only the friend who wrote today but others, have remarked that from what I write I seem to be doing very well. I wasn't doing great on Days +1 and +2, but mostly it's true that I have been optimistic and given the circumstances energetic. All of the support that I have received has played a role in that. I didn't realize how much support the blog would generate. Sometimes when I wake up in the middle of the night I read the comments. Or, I start the following day by reading them. The support has been very important to me. I also write for the support.

Lack of great physical suffering thus far and receiving great support have allowed me to stay fairly upbeat. But I have come to realize that by disposition I am also generally positive. I'm just lucky that way. It's probably due to good parenting and good genes, both of which were simply gifts, not in any way accomplishments of mine.

If I am upbeat, it's been a matter of good fortune: lack of severe physical suffering, the loving support of others, and the gift of a positive disposition. All of them also reasons to be grateful.

23. Day +10: Why I Dyed My Hair Blue

I woke to a canker sore that had exploded just below the inner lip at the front right-side of my mouth and to a tongue that felt like it had been rubbed with sand paper on the sides. And the top of my throat had also joined in the chorus of pain. Once I was finally awake I also realized just how tired I was. That's more or less been my condition for the day.

I tried to ride the bike, but after 15 minutes I started to feel dizzy and weak, so I stopped. I received a red blood cell transfusion today, so my energy should improve tomorrow.

The doctor tells me that the mouth pain is just part of the process. It often gets bad enough that patients go on a 24 hour morphine drip. I guess that's one way to relax, but I hope it doesn't come to that, as I imagine that it makes reading and writing more challenging. The mouth pain will remain, I'm told, until the immune system becomes strong enough to fight back. And I learned that the first evidence of white blood cell production for patients with myelofibrosis is typically about a week later than for patients with leukemia. So, I shouldn't really expect signs of success until about day +21. Sadly that's still a full 10 days away.

Dear friends C and K arrived today all the way from Long Beach, CA! They are here to play my normal role of house-elf. They are following two other friends; the first to come was I and then D. All of them have come a long distance at considerable expense to help out. How very big-hearted and sweet!

I used to say that when men a half a generation older than me would retire, they would often grow pony tails as an expression of their freedom from professional norms, but that when I retire

I intend to dye my hair blue. Shortly before entering the hospital I decided to go blue before I lost it all. So, for several days before I entered the hospital I walked about town with neon blue hair. MF found this pretty embarrassing, but he tried to be tolerant of my eccentricities. The night before I was admitted to the hospital I cut my hair very short. Two weeks of washing it with high octane germ-killing soap in here turned the color to marine green, and then finally mostly to the underlying bleached blonde. Now, however, the shedding has begun in earnest. This morning my nurse informed me that tomorrow would probably be shearing day.

24. Day +11: Shorn

The shape of my day here seems pretty well-established. At 5am a nurse comes in and draws blood. They like to have the counts early so that they can adjust my medicine dosage for the day in response to the lab report. I then fall back to sleep and am roused at 7am. At which point the first of many daily measures is taken. Blood pressure, temperature, pulse, and weight. I've been having trouble retaining weight due to diarrhea caused by a gastro-intestinal bug. The day before yesterday I was down over 7 pounds from my weight at entry. But we may be winning the battle against bug, and I'm now only two pounds away from my entry weight.

After the measurements, the first of three morning infusions starts. I try to fit in 20-30 minutes of cycling and 15 minutes of dumb bell work next just before breakfast. The infusions are usually over by breakfast or by the end of breakfast. Then I am untethered from Ginger Rogers for a while. I chat with the janitor while he cleans the room. And then while the nurse or orderly makes my bed, I take shower. Today the nurse shaved my head first. With my earring I now look like [Mr. Clean](#). Or maybe with the glasses it's more like [Michel Foucault](#). Come to think of it, I have to wonder if Michel Foucault modeled himself after Mr. Clean?

After the shower I lie on the bed while the nurse changes the dressing around my catheter. That's a process that lasts 15 to 20 minutes. When that's all done it's nearly 10:30 or 11am. At which point I either respond to e-mail, read, or nap. The last few days napping has prevailed. Lying on the bed while the dressing is changed tends to induce a nap. The doctor visits once a day, and it's often during this time.

Lunch comes at noon. And there is more measuring of temperature, blood pressure, and pulse. In the afternoons I'm untethered, and I do some combination of the reading, watching TV, and blog writing. This is usually the high point of my energy for the day. Once a week the sports trainer or the oncological psychotherapist pops in and we talk. After dinner, temperature, blood pressure pulse and weight measurements are taken again, and there are more infusions for an hour or so. In the evening I have to organize my medication for the following day, after doing that it's some combination of the reading, watching TV, listening to music, and blog writing. Before going to bed I get one or two more short infusions and sometimes a shot in the stomach. Lights go out at some point between 9 and 10pm. The night nurse checks on me periodically throughout the night. And then the drill starts again at 5am.

25. Day +12: Tired, Itchy, and Hiccupping

Hemoglobin is one of the components of red blood. It has the important role of transporting oxygen, which is why people who are anemic experience fatigue. In adult men the normal range for hemoglobin is 13.5-17.5 g/dl; in women it's 12-16 g/dl. For several years I have lived with hemoglobin counts in the 10s, which is classified as mild anemia. I used to say that I simply lived at a higher altitude than everyone else. The fall in my counts had been gradual over several years—an early indication of myelofibrosis—and it didn't affect my life in any significant way. Exercise and a busy lifestyle were still possible. More than that, I had the benefit of a ready excuse to offer BF and MF should I fall asleep while watching a movie! Before being admitted to the hospital my hemoglobin count was in the 8-9 g/dl range, which is moderate anemia. On Sunday my count had fallen to 6.8 g/dl, severe anemia. The transfusion later that day resulted in a count yesterday of 7.8 g/dl, still severe but much easier to handle. That gave me enough energy to both ride the bike and lift weights. Today the count had fallen to 7.2 g/dl. And all I could muster was 15 minutes on the bike. I will probably have another red transfusion tomorrow.

One symptom occasionally experienced by people with anemia is pica, the urge to eat unusual things, like ice, clay, cardboard, crunchy foods, or raw starch. Fortunately I have never had that! But I find that when my counts fall into the 8s, I am more easily cold. So, I've been chilly and fatigued today. It's just the afternoon and I've already taken two naps under the covers of nearly an hour each.

The fatigue is augmented, I think, by an antihistamine that I took to deal with itchiness. It's not clear whether I'm itchy as a side-effect of one of the many medications I take or as a result of the

chemo induced dry skin. But the sensation has gotten progressively worse. Strangely, there is no rash just the itchy feeling on my forearms, shoulders, back, chest, and ankles. I think that I have fairly high pain threshold, but my itchy threshold is low! I can't hold out long without scratching. And as amazingly satisfying as a good scratch can be to a persistent itch, it typically does not have a lasting effect. As soon as the scratching stops the itch is back, sometimes even stronger. The cycle can be vicious. The scratching itself becomes a problem; the skin gets red and then raw. In the *Gorgias* (494c) Socrates asks Callicles whether a man who has an itch and wants to scratch it, can pass his life happily in continual scratching. I'm here to testify that he most certainly cannot.

During the day it's easier to get distracted by the other things and not notice the pin pricking itchiness. But at night in bed it's much harder. I woke up this morning with red patches on my right arm, presumably due to nighttime scratching. So, today the nurse prescribed an antihistamine, which has conspired with my anemia to leave me especially fatigued.

The last three or so days I have been suffering from another odd and unexplained side-effect. The hiccups. I hate the hiccups almost as much as I hate being itchy! These are severe enough to incapacitate me when they are especially intense. They come in waves, and it feels like the release of gastric pressure in my lower throat and upper gut. Sometimes they are strong enough to hurt mildly. And every now and then they also trigger additional pain in my sore throat. But on the whole they are much more a nuisance than a cause of pain. The doctor tells me that they are not uncommon in patients in the transplant ward, but that they do not know what causes them. There is some medication that I can take that should help. I plan on doing that. I have no intention of being a hiccup hero.

It could be worse. The pain is not bad. I don't have a fever. And I don't have nausea or diarrhea any longer. I'm not miserable, just somewhat uncomfortable.

The oncological psychotherapist just stopped by with two ice cream bars. This is going to be a good evening!

26. Day +13: Waiting

I was chilly and tired again today. Chilly not due to a fever, thankfully, but like the fatigue due to the anemia. I got in a record three naps. Everyone who has been urging me take it easy should be very pleased! I don't take-it-easy very well. But the fatigue has been slamming me hard enough that I haven't really had a choice.

The doctor, a very tall young man, with glasses, and a brown beard under his surgical mask, paid me a visit. He said that everything looks to be on track. All that we can do presently is wait for the stem cells to graft and fight back the side effects that arise. My throat is very sore, which makes eating difficult. The itching is bearable with the antihistamine. And the fatigue just requires me to rest. I did do some reading for my Bloch reading group tonight. I also rode the bicycle for a mere 15 minutes and had a nice visit with BF at lunch time.

27. Day +14: Signs of Progress

It's been three weeks since I entered the hospital and two weeks since the transplant. Almost as if in recognition of the milestone, the doctors and nurses delivered some fabulous news today.

Neither spinning nor toiling, those stem cells seem to have set up residence and are growing blood cells! The doctor is not the type who would dance the jig with me, but that's what I felt like doing when she delivered the news. Instead, we both just smiled heartfelt smiles at each other.

The doctors watch two counts in particular, leukocytes and neutrophils absolute. Leukocytes make up the class of all white blood cells; and neutrophils are a particular kind of white blood cell that goes after bacteria and fungus. If you look at the Wikipedia page for white blood cells, you can see a cool picture of a neutrophil engulfing Anthrax bacteria. Neutrophils constitute 60 - 70 percent of all leukocytes. When your finger gets infected and pus forms, the pus is dead neutrophils. The leukocytes started climbing yesterday and the neutrophils today. I've received transfusions of red cells and platelets, but not of white cells. So, the best explanation seems to be that the immune system is re-growing. The doctor expects this to be a trend. And even mentioned that I might be out of the hospital some time week!

Fear of the graph not taking hold was my biggest anxiety after the transplant, even though the odds were good that it would. So, this comes as a huge relief. I'm not quite ready to celebrate though because I suppose it could be a measurement error, or the process might halt. But there was no mention of either of those possibilities. So, they must be remote.

In expectation that my immune system will be stronger by next week, I was also moved today to a double room, which I have to myself now, but will share next Monday and perhaps beyond. It

was strange leaving the other room. I won't say that I had become attached to it. But it was all that I knew for three weeks, and significant events had occurred there. Still, even walking down the hall with my gown and face mask on to the new room felt like a taste of freedom. Next stop, I hope, will be that window where I can smell the fresh air.

28. Day +15: I Shall be Released

I awoke in my spacious double room today. But I felt vaguely nauseous, chilly, and completely exhausted all day. I argued with myself about riding the bike, but finally dragged myself up on the saddle and rode for an easy 15 minutes. I lay down for an hour or so after morning routine was finished and then again after lunch, which I could barely eat. I spent most of the day in bed. Nobody is worried about this. The doctor has ordered a red blood transfusion, which I thought for days I'd be getting. I should feel a bit better tomorrow.

The nurse who manages the stem cell transplant and also the release of patients from the unit came by. She's been kind and sympathetic throughout. When I checked into the unit she said to me "I'll see you three weeks." Three weeks and a day later she came by to talk to me about my release! She wasn't sure when—we'll follow the counts—but she mentioned that she was away the first three days of next week; so she needed to come by today in case I'm not here by the time she returns! During the conversation I sat there marveling that we were having a discussion about my release.

How will it be after I've been home for about 6 month when life will be getting back to normal? I've lived with the first disease for 18 years until it morphed into the more serious one last year. Will I walk more lightly free of the shadow of disease? Will the future seem more open ended? I don't know, but I'm looking forward to finding out.

29. Day +16: Fresh Air

As I expected I felt a great deal better today after yesterday's transfusion. All this vampire needs to keep running is a little blood.

I made it to that window today. Although it wasn't quite like the characters busting out *Cuckoo's Nest*, it felt pretty damn good. The window is in a large kitchenette. The sky was blue, and up on the 11th floor the wind comes pouring in. It allows for a view in the opposite direction from the windows of my two rooms. I looked down over the brown-green river and out to the radiant sky scrapers on the other side. Light reflections shimmered busily off the buildings and were captured in the dull river. It's still early spring here, and trees have for the most part not yet budded. That permitted gazing far into the distance. Some ways away I could see the town where I live. I wondered what friends and family were doing at that moment. On the river there was plenty of commercial boat traffic, and along the river people were strolling with and without dogs. A work day for some and day rest for others. I walked up and down the hall several times, but I kept coming back to that window, the cool, fresh air, and the warm, bright sunlight.

Tomorrow I might be allowed to go downstairs and out the doors.

Things are moving quickly for a possible release next week. Today the doctor spoke of releasing me "on vacation" on Monday afternoon to go home for the night and then to return for the day on Tuesday and then home again finally that evening. This is all contingent on further growth in the counts, but all of sudden it seems upon us. It may all be too quick for BF. She is concerned that the house is not yet sufficiently clean, and she is hobbled by a head cold that she doesn't want to transmit to me. So, I'll see tomorrow what the doctors recommend.

30. Day +17: Postponement

Another good day. The leukocyte and neutrophil absolute counts continue to rise steadily. Unfortunately the latter was not quite high enough to allow me to go outside today. Maybe tomorrow. But there was dispiriting news today with respect to getting out tomorrow. BF has a doctor's appointment in the morning, but the docs here will not release me if she is contagious. So, it looks like I'm going to be spending my remaining days here routing for BF's immune system, not mine. What bitter irony! I confess, this was a huge disappointment for me. But there is nothing else to be done.

BF had another house cleaning party today. And again, the turnout was great! We are incredibly fortunate to have caring and helpful friends.

C and K came all the way from Long Beach, CA to help BF around the house last week and this week. Our relationship with C goes a long ways back to before MF was even two years old and she was a hall director in the campus dorm that we lived in as Faculty in Residence. Then later after a bad break up she lived with us for a year, sharing a room with MF in our then postage stamp of house. Thanks to another friend who drove them to the hospital while BF continued to clean, I was able to visit with them. It was wonderful to see them. We had a long and happy chat; and they brought lasagna! Their coming all this way to help was a magnificent act of generosity and love.

A friend sent me a copy Havi Carel's *Illness* just before I entered the hospital, and I've finally started reading it. She's a philosopher who was diagnosed with a super rare, degenerative, and incurable lung disease. Her story is far more harrowing than mine. But her account is presented

with admirable insight and sensitivity. She argues for the importance of phenomenology in understanding illness. I can't say that I agree with all of it, but I find it an important and remarkable piece of writing. I'll, no doubt, have more to say about it as I digest it, but let me leave you with an insightful quotation that is relevant to the Horace-Jesus-Epictetus attitude that I've discussed.

“Ironically, by really having something to worry about my mind was cleansed from many sources of anxiety. So many things didn't matter. Only one thing really mattered. And that one thing was beyond my control. I learned to respect two things; that the laws of cause and effect governing the universe may generate suffering over which we have no control and that everything, including myself, was ephemeral.”

Those are incredibly tough lessons. Many of us want to deny the first with magical thinking, which, I've argued, can all too easily have victim blaming implications. And the latter we may know intellectually for a very long time before we feel it in our bones. But recall that the Horace-Jesus-Epictetus message of Carpe Diem is good news. It's the counsel of prudence to the anxious. A message of the happiness that can be attained once we accept those lessons.

Still, somewhere in the back of my head I hear the melodious voice of Ernst Bloch asking where the place is for hope if we so narrow our focus on only what seems to be under our control in the here and now.

31. Home Sweet Home

In the words of the great [Jackie Gleason](#), “How sweet it is!”

There’s a lot that I want to write, but tonight is for hanging out at home with BF, MF, C, K, and The Dog. Check again tomorrow or the next day.

The short the story is that the docs decided the benefits of going home outweigh the risks. And apparently those stem cells made surprisingly short work of it all. I’m home for the next 40 hours. If all goes well, I’ll be officially discharged Wednesday morning. The next 6 months will still be risky, however.

I can’t drink. Have one for me!

32. Home Update

After visiting the doctors today they continued my “vacation” till Friday, which is now my official check-out day. My counts continue to improve. My leukocytes are already in the normal range. Hemoglobin continues to rise. I’m only moderately anemic. And the platelets lag behind but also are on the rise. None of this could have been predicted a week ago. It seems that I have some super-charged stem cells!

There’s a lot I still would like to write, but honestly I’ve just been too tired these last two days. Ordinary life, even in resting mode, is exhausting! How do you all do it? BF and I went for a 2 km walk along the river today while waiting for my blood results and afterwards I needed to take a 2 hour nap! Even though I was exercising a bit in the hospital, walking during the day in there consisted of getting up and going to the bathroom and back. I didn’t cover much distance over those 25 days.

BF is keeping me on the straight narrow with regard to all the rules. She even tattled to my doctor today that I mistakenly ate blueberries with my granola yesterday! (Thou shalt not eat fresh fruit that hasn’t been peeled.) Imagine my humiliation.

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33. The Social Determinants of My Survival

I've been thinking about the various circumstances that have worked in my favor.

Let's start with the global. I have benefited from living in a high-income country. According to the World Health Organization, residents of high-income countries get a life expectancy bonus of 23 years in comparison to residents of low income countries. The average life expectancy in low-income countries is just 57 years, while in high-income countries it is 80 years. No doubt many factors are at work there. Generally, early childhood health is much better in high-income countries and that has long term effects. Even still, expensive and technologically complicated treatments, requiring a high degree of advance training, such as stem cell transplants, are likely to be more readily available and more successful in high income countries. A person living in, say, Malawi would be less likely to survive.

I also live in a country in which it is considered a matter of justice that everyone is covered by medical insurance that provides for very high quality treatment. A person living in the United States might be excluded from the life-saving treatment due to insurance that does not cover it, too high a co-payment, or lack of insurance altogether. Poor people covered by Medicaid and seniors covered by Medicare who suffer from myelofibrosis only became covered for a transplant in in January of 2016. A person's access to life-saving treatment is far less secure in the US.

I've benefited by being of European descent. It turns out that race matters in finding a matched unrelated donor. Whether a potential donor is a match depends upon genetics. People who share a common ancestry are more likely to be a match. There are over 20 million people registered

around the world as possible donors, around a half of them in the US. Campaigns to register people in African and Asian countries have not taken off to a similar degree. And in the US the history of unjust medical “experimentation” on African Americans is an obstacle to people’s willingness to participate in registry efforts. Additionally, people of African descent are by far the most genetically diverse group because of the long history of human movement out of Africa and into all the regions of the world. So, not only are there fewer donors of African descent, the genetic profile of a donor is less likely to match the person in need. I can only imagine the heartache of being denied access to a transplant because no donor can be found. I had a perfectly matched unrelated donor. Had I been of African descent that would have been far less likely.

I’ve emphasized on several occasions how little success is a matter of a patient’s own efforts and how much of it depends on the vagaries of complex biochemical processes, in particular the disease’s response to therapy, as well as the skill and experience of the doctors and care staff. That’s is one reason to reject the attitude that an individual has “beaten” cancer. Survival is in large part a matter of good biochemical fortune. It’s more like a gift than an accomplishment. But the language of “gift” might suggest that it’s just a matter of charity. The social determinants of survival are matters of policy. We survivors have had the good fortune not only of biochemistry, but of favorable social circumstances. That’s an issue of justice. Better science can improve biochemical fortune across the board. Better politics can reduce health disparities.

34. Letting the Days Go By

I've been impressed with myself. With my abilities. In particular my ability to sit around and do almost nothing at all. I didn't think I had it in me, really. I have always been busy, very busy.

The Protestant Work Ethic has featured prominently as part of my adult personality. (Mind you, my 16 year old self was blissfully free of that.) But I have spent vast swaths of time these last few days sitting in one of those standard issue Ikea chairs with a bent wood frame that runs along the floor, curves up for legs, then bends horizontally again for arms, and finally arcs upward for the back. It reclines back a bit and has a matching foot stool. Due to the curvature it even rocks gently. I have a premium model with leather cushions that I bought from a neighbor when she was moving. I sit in front of a big patio window that magnifies the sunshine and...well...just relax. I tell myself, not falsely I think, that this is what recovery looks like. Sometimes I read or listen to music, but sometimes not. When not, I'm known to drift in and out of a gentle sleep. Spending so much time doing next to nothing isn't activity (if you can call it that) that I thought I would ever enjoy, at least not for another 30 years. I certainly hope that it's not corrupting.

The Dog and I also take walks in the woods. Sometimes BF and (rarely) MF come along. My only risk of excessive ambition these days is when taking these walks. There is an old Jewish cemetery about 5 km through the woods from our place. They stopped interring the bodies of the departed there at the end of the nineteenth century. Being a couple hundred years old or more, it feels ancient to an American. It lies at the edge of the woods in fields of fruit trees. I sometimes walk there and add stone of remembrance to a collection on the roughhewn stone pillars of the gate. We have had steady succession of glorious early spring days, which have encouraged me to walk. The Dog and I set out for the graveyard on Saturday. He enjoys it because leash laws don't

apply to the last stretch and to the area outside the cemetery. Our walk there was delightful. But on the way back I began to feel the exhaustion, my pace slowed considerably, and I looked for benches to rest on. I wondered if I were going to have to send him home like Lassie with a message that I needed rescue. In time we did make it home, and I was chastened to think of every walk in terms of the round trip involved.

My appetite still suffers a bit and I am distressed that the food that I love does not taste as it should. I suppose lots of taste buds were the collateral damage of the chemotherapy. My eyelashes were as well. My eyes lids itch and the corner of my eyes burn. I have my first post-release follow up doctor's appointment tomorrow, and I am hoping that my doc can provide me with some kind of relief.

35. A Thread of Good Fortune

Today I had my second follow appointment with my doctor after leaving the hospital. He was happy with how things were going. The blood counts continue to improve and the side-effects, limited so far mainly to fatigue, and the occasional nausea and diarrhea, are typical.

I learned a few things. For example, the transplant nurse explained to me that the sources of fatigue are not particularly well understood, but that I could expect it to vary from day to day and that it could last six months, possibly even a year. I also learned that the fibrosis that was scarring my bone marrow and inhibiting blood production does not simply disappear when the old bone marrow is killed and the new develops. Rather, it disappears only slowly over time, and probably never fully. But it will be very significantly diminished and will not degenerate further. So, it will not pose any health threats.

The continued presence of the fibrosis explains why, when they performed another bone marrow biopsy today—my fourth in a year, but hey who's counting?—they had such difficulty finding blood in my marrow. It was the familiar process of anaesthetizing the muscle tissue outside the hip bone, and then with great force puncturing the bone, causing a sharp pain from deep within that made me want to squeal, and finally turning the big firm needle this way and that way to extract a core of the marrow for laboratory study. The problem was that they didn't only want marrow, they also wanted a sample of blood from inside the marrow. Sadly that was not to be found on the first *four* attempts at ramming the biopsy needle into my hip. So, they made one last courageous attempt and came up in the end with a very small sample, which they hoped would be enough. I hoped so too.

Apparently I will have to endure this a couple more time in the next year as they study the retreat of the fibrosis.

This afternoon I succumbed to the fatigue and rested on the couch. But I found myself strangely bothered. I couldn't help but think about how contingent my good fortune and the success of the transplant has been up this point had been, how much harder it might have been, how it might not have worked at all. A thread of fortune had supported me, kept me from falling into dire circumstances. Some day that thread breaks for all of us. I couldn't chase away these thoughts and was sufficiently exercised by them that I didn't really sleep, or even rest all that much. So, it goes. Those were, I think, episodic thoughts. So far nothing like that has kept me up at night. And I don't expect tonight to be different.

36. The Merchants of Magical Thinking

I don't know what it's like to get a stage four cancer diagnosis. I wouldn't want to pretend to speak with authority about what an emotional punch in solar plexus that must be. Still, I get angry when I read stories on the internet of people having cured themselves of metastatic cancer by doing nothing more than drinking carrot juice. The same goes for people claiming that our thoughts can cause and cure cancer. Just as I have no patience for the Christian Scientist teaching that the sick should be cared for exclusively through prayer. I have no truck with consuming carrots, positive thinking, or prayer. My objection is to the medical claims, the causal efficacy, if you will, of these activities for curing illness.

I do know a little about having a life threatening illness; and I know something about the anxiety a rotten diagnosis produces. And I can imagine why some people would prefer almost anything to chemotherapy, especially if they have already experienced how crappy it makes them feel. I can conceive of why someone might seek alternatives to conventional medical care, especially if their prognosis is poor. Still, I think that the pursuit of these alternatives is a big mistake and that to encourage people to engage in them is irresponsible.

The thought that reliance on alternatives to conventional medicine, such as drinking carrot juice, thinking positively, or praying, can cure terrible illness is an example of what I call "magical thinking." The fundamental feature of magical thinking is the rejection of the scientific picture of how the world works. This is a picture that includes the idea that biological conditions, such as wellness and illness in organisms, are caused by other biological processes and other physical influences, such as trauma.

The scientific picture of the world bases confidence in any claim about a causal relationship between a biological condition, such as illness, and some possible influence on the existence of repeated experimentation. Biology and biochemistry are exceeding complex and much is not very well understood, so it's possible that what looks like a relation of causation is instead some sort of statistical fluke. We can't be certain without being able to repeat the sequence of apparent cause and effect, preferably on a large scale. Evidence-based medicine is supported through such processes of repetition and large scale study.

Magical thinking involves affirming and disseminating views that are not supported by the evidence in that way and that generally do not seem to fit very well with our current evidence of the way the world works. This makes the claims of magical thinking highly suspect.

There are two problems with encouraging magical thinking in medical care. First, it encourages false hope. It encourages someone to put their aspirations and emotional resources in the service of an effort that is so unlikely to succeed that relying on conventional medicine, even when it offers much less than one wants, would be better. And second, as I have stressed in other posts, it often involves claims about the control that individuals have over their wellness that are implicitly victim blaming.

Our world is through and through full of the results of scientific enquiry and experiment applied to the development of infrastructure, technology, medicines, and medical procedures. Most of us don't think much about the physics involved in the engineering of bridges as we drive over them. We simply trust that the bridge will hold us. The contrary happens so rarely that is perfectly sensible not to worry about it. We trust fundamentally in the sciences and engineering to live the

way we do. Just think of how different our lives would have been without the discovery of Penicillin and the subsequent development of antibiotics.

The trust we have in science and engineering should give us reason to pause when we are encouraged to forgo it by the offer of a cure that is at odds with the conventional scientific understanding of how causes work in the physical world. And magical thinking is precisely that.

Our basic trust in science is one reason to believe that magical thinking offers false hope.

Another is based on economics. Think about how much cheaper it would be to treat cancer by means of carrots than chemotherapy. Prayer would be cheaper still. If these worked reliably, insurers—whether private or public—would have a very strong incentive to nudge, even shove, us all in that direction. It would be a terrible waste of their money for us to receive chemotherapy. Insurers make it their business to figure out ways to cut the costs of the services they cover. Unless you think insurers are not particularly costs conscious, the fact they do not push us to consume carrots or to pray rather than take chemotherapy should give you a compelling reason to doubt the power of carrot juice and prayer to cure cancer.

It is much more likely that someone will find a cure, manage their symptoms, or gain palliative relief if in the first instance they trust in the accumulate understanding of medical science. Such understanding is imperfect to be sure, and it will not always be able to deliver what patients want most dearly, but there is no more reliable way towards better health.

If magical thinking only encouraged false hope it would be bad enough. But it is sometimes even worse still. At least some forms of magical thinking claim that a more positive or prayerful outlook on the world can reliably prevent serious disease and cure it when it occurs. If that were

the case, then everyone who happened to be seriously ill could cure themselves by developing the outlook. Those who have a grave illness would have it within their control to cure themselves. By implication, if they remain sick, then they have failed to act (think or pray) appropriately on their own behalf. That conclusion is victim blaming pure and simple. To suggest this to a terribly ill person is deeply offensive.

It's not that I can't understand the desperation that might lead one to explore alternatives to evidence-based medicine. I don't fault someone their life-shaking anxiety. But anxiety makes us vulnerable to those who peddle in hope. And not all hope is well-placed. If patients are to act in their best medical interests, they should stay clear of the merchants of magical thinking. They are the problem. Sometimes magical thinking is based on ignorance; other times a cure is being sold and the profit motive corrupts. And, as for those who urge the adequacy of positive thinking or prayer to the task of curing, please just spare us the sermons according to which, by implication, we are responsible for our suffering.

37. Hope Kept Me Eating

The ancient Greek poet Hesiod recounts a tale of the origin suffering. Because Pandora has opened a jar stuffed full of evils by the Olympian gods, “countless plagues, wander amongst men; for earth is full of evils, and the sea is full. Of themselves diseases come upon men continually by day and by night, bringing mischief to mortals silently; for wise Zeus took away speech from them.” But curiously that jar was closed before hope was also allowed to escape.

What are we to make of that? The moral of the legend is ambiguous. Is it an expression of how bleak the human condition is? There really is no hope. But if we could somehow re-open the jar, at least we would have some hope. Or is the idea instead that hope is also an evil, like disease, and accessing it will bring us even further torment? The nineteenth century philosopher Nietzsche, took the latter interpretation. Hope is among the greatest of evils because it prolongs our torment. Acceptance is far better than hope. Let us not imagine something better, but say “yes” to the world as it is. That’s a view that seems curiously close to a kind of Stoicism. Better to focus on the here and now, that which we might control, than to project into the future, which is far beyond our control.

In my diagnosis of magical thinking I worried that in desperation patients often embrace false hopes. We often fix on alternatives to conventional medicine and in doing so forego the more reliable path to a cure, to a longer life, or to palliative relief. When we do that it seems as if hope is not our friend. In those instances hope becomes a servant of disease.

It does seem that there is a danger in hoping. Even the great philosopher of hope, Ernst Bloch, claimed that “there is no hope without anxiety.” As a Stoic might claim, when we project

ourselves into the future, we open ourselves up to anxiety just as much as to hope. If we are concerned to prevent anxiety, maybe it would be better to redirect our attention to the present and foreclose both anxiety and hope. Make no mistake about it; Nietzsche's counsel is not one of despair. On the contrary, he believes that we can only fully affirm the present by foregoing hope.

But, I ask you, could anyone ever really do that? Could a patient so fully live in the present as to have neither anxiety nor hope? Bloch, at least, was doubtful. He asserted that forward-looking projection is fundamental to the kind of minds we have. Like a lighthouse we are constantly seeking to illuminate our future, and in fact it is only because of that that progress is possible.

Just try to imagine a world without hope. All criticism of the present would be left without a strategy, and it could easily fall victim to cynicism. Imagine if the abolitionists had had no hope. Martin Luther King, Jr was fond of quoting the abolitionist, Rev. Theodore Parker, who during the height of the transatlantic slave trade dared to say: "I do not pretend to understand the moral universe; I cannot calculate the curve and complete the figure by experience of sight; I can divine it by conscience. And from what I see I am sure it bends towards justice." Could Martin Luther King Jr. have been the strategic leader of the Civil Rights Movement without hope? Could Nelson Mandela have directed the African National Congress from a prison cell on Robbin Island without hope? Hope is a powerful aid to action. It can play a service role by impelling us to act when our motivation may be weakening.

At two different points while I was in the hospital hope kept me eating. One of the side-effects of the kind of chemotherapy that was administered to me was to shut down of the production of saliva in my mouth as well as the mucus throughout my digestive track. My mouth was as dry as the great Mojave Desert. Eating became a chore. I would be given a roll at breakfast and when I

took a bite and began chewing, I might as well have been sucking on sand. I was miserable and had nothing but aversion to food. The only thing keeping me going was the hope of getting stronger. If I were to weaken myself by insufficient intake of calories I would delay my recovery. So, I ate.

Later I contracted a gastro-intestinal infection and I was plagued by severe diarrhea. I was losing weight. My appetite was also on the wane because the chemotherapy had inflicted heavy damage on my taste buds. Most foods did not taste good (many still don't) and some were positively revolting. The nurses would occasionally warn that if I were to lose much more weight I would have to be put on a nutritional IV at night. I had to eat much more at each meal than felt comfortable. It was unpleasant both because it was so much food and because none of it tasted very good. For a long time after my release from the hospital, when I would imagine the still real possibility of having to return to the hospital for one reason or another, what I found most repellant was the food. Once I did have to be rushed to the emergency room because of a high fever, and I was sobbing at the thought of suffering the food. But at the time, while in the hospital, the hope of renewed strength kept me eating.

There is another thing that the political struggles I mentioned demonstrate. We don't typically hope alone. A community of hope supports every person hoping. The leaders are buoyed by the inspiring sacrifices of the members of the struggle, and the members are carried along by the fierce commitment and rhetorical elegance of the leaders. And my efforts of personal hope were supported by the love of family and friends, near and far, many of whom offered inspiring comments across the ocean via the internet.

Hope is a virtue for tough times. When it's well-placed, hope can help us in the effort to transform our circumstances, in the effort to fix what needs mending. And from illness in our bodies to the injustices in our institutions there is no shortage of that. But in motivating us to change our condition, hope can also change us. Hope plays not only a service role in helping us to achieve our ends. Hope can transform us by increasing our agency. Sometimes, as in the case of the abolitionist movement, the Civil Rights Movement, and the anti-apartheid movement, we are acting to secure human dignity. By enhancing our capacity to be agents of dignity, hope gives expression to our own dignity. Hope can have a dignity-expressing function.

I am not claiming that I left the hospital a more dignified person. The kind of dignity that I am talking about is not measured along a scale like weight or wealth. It is possessed equally by everyone. And although hope allowed me to express a certain determination to be healthy again, it was my own survival at stake, not the protection of the dignity of others. I'm no hero. Hope in the hospital is different in that way from hope in streets. Nonetheless, in both cases hope gives expression to something that we admire in people. And our lives would be far poorer if we were to have to live without it.

38. Sunshine, Suffering, Re-birth, and Freedom

I'm sitting in the standard issue Ikea chair, and I'm wearing an industrial strength, white face mask because I have the sliding doors wide open, exposing me to air born micro-nasties. These things have a revolting polymer stench to them. The sun is warming me while the fresh breeze is cooling me. I hear birdsong all around. BF has gone off to take the waters. MF will only appear from his cave-like bedroom after a few more hours of deep teenage hibernation. The Dog is alongside me allowing the sun's rays to warm his black body. The patients back in the transplant unit are stuck in their stuffy rooms with only their imaginations to torture them over the pleasures they are missing on this delightful Good Friday morning. We patients pass through those rooms in trickles, and with good luck their time in the sunshine will soon come. I imagine them humming the Animals' s classic anthem, "We Got Get out of This Place."

Kant argues that we would be people of better, more sensitive moral dispositions if we were to visit the sick in the hospitals and asylums. Given his moral rationalism, that comment confounds some readers. But regardless of the ultimate basis of morality, a vivid understanding of how we can suffer in body and mind can surely aid us in understanding how we can help others. And according to Kant one of two great principles of moral life is love. The other is justice.

Due to the enforced isolation, when you are a patient in the transplant unit, you don't see much of the suffering of others. But, of course, you are bound to go through some yourself. I do remember clearly my on my last day, when I shared a room for a few hours with two other men, one came in deeply dejected, having returned to the unit after several months of good health on the outside. He had developed diarrhea, and the doctors needed to determine whether he was

suffering from some kind of Graft versus Host Disease. That's when the new, and strictly speaking foreign, immune system begins to attack the organs of one's body as if they are threatening outsiders. It's like adopting a pit bull to protect you, but because it perceives you, not the bad guys, as the threat it goes after you. He sat in his bed, his head bent, and his spirit broken. His elderly parents looked helplessly on. That memory serves as a reminder that so often physical suffering is accompanied by deep mental anguish. As Kant seems to recommend, pictures like that might remind us of our common human frailty. We could use more such reminding these days. In public discussions how often are refugees presented as people who are deeply traumatized and profoundly suffering, rather than as threats to our collective security?

Lent is nearly over, and it is about the mid-point of Passover. The themes of re-birth and freedom from bondage have come up in some of your comments to my posts. I had hoped to be free of the disease and in possession of a new immune system by the end of Lent, and by great good fortune that is the case. But for the next six months or so a disappointing return to the hospital due to complications of one kind or another is not out of the question. I have the immune system of newborn, and I need to be as careful as one is with a newborn when it comes to exposure to germs. One consequences of this is that over the next few months I will need once again to receive all of the childhood vaccinations, mumps, measles, etc. (And, I think you can imagine what I might think of the anti-vaccination crowd.) Meanwhile I hope that the new pit bull-like force in my body knows who its master is.

But with each passing day, it's a bit less likely that serious problems will arise. I passed a milestone this week. Yesterday my doctor told me that I could reduce my check-up visits to once a week, rather than twice. And blood tests reveal that 99 – 100 percent of the blood in my body

now originates from the new stem cells. The transplant has been, at least initially, a resounding success. I suppose my story will become more pedestrian and less compelling as time goes.

That's a good thing. I do still have some blog posts in me, however. So, perhaps I can keep it interesting for a bit longer.

39. Food Aversions

I've been thinking. They should warn patients before chemotherapy that there is a risk whatever they eat in or around that time will be utterly repellant to them later. But here's the problem. Once eating becomes a chore, you seek out old standbys for comfort and satisfaction. The very idea of potato chips right now is almost enough to make me wretch. Sparkling water is out the question. Spaghetti, especially al dente as the pizza place near the hospital made it, is borderline. Fortunately, yogurt still holds its appeal. But I may never eat boiled potatoes again. No great loss there.

I suppose this too will pass.

I am grateful that, in their great wisdom, the good doctors did not allow me to drink beer and red wine in the hospital.

40. Inching Towards Normalcy

The doctor's visit yesterday brought more good news. He further reduced the medications. I'm now only taking about 15 pills a day! That's about half of what I was taking when I was first discharged, nearly four weeks ago now. The main noticeable effects of the reduced medicine intake is that I am bothered far less often by the occasional nausea and diarrhea. Certainly welcome effects!

He also relaxed some of the rules around the house. I am allowed to bathe now. That's in addition to showering, perhaps I should add! I can handle the dirty dishes and take out the trash. BF will waste no time putting me to work.

I still have to avoid groups of people, however, which means I won't be attending the upcoming Bob Dylan concert. I know, I know, he is usually not very good live. Still I would have gone. I saw him one time in Hollywood when he was really on. It keeps you hoping.

While working out today, I felt stronger than any time since entering the hospital. And I could visualize feeling normal again. For the first 18 of the last 19 years the thought that my chronic disease might morph into a life-threatening disease was never buried very deep. I rarely dwelled on it. But I could call it to mind easily enough. Then from last spring onwards, as the planning for the transplant was just beginning, I would wonder to myself where, or if, I would be in a year. I remember telling BF how strange it seemed, how open the future seemed. You make plans, of course. But you also make contingency plans. I planned my memorial service, for example. During the lead up to the transplant it loomed ever present on the horizon of my

thinking. That's all gone now. And I can imagine full health around the corner. That's also strange in its own way after so long. But wonderfully so.

Rutger Bregman's *Utopia for Realists* arrived today in the mail. Written by a Dutch historian, it was a best-seller in the Netherlands. Apparently it argues that a guaranteed basic income, open borders, and a drastically reduced work week are all possible within the relatively near future. Ever the optimist, I can't wait to get started on it.

41. Human Fatigue and Canine Anxiety

I have the feeling that I'll have more energy today. The energy business is difficult. When I lack it, when fatigue really falls like a leaden blanket, I'm left defenseless. The standard issue Ikea chair beckons to me. And I'm reduced to nodding off while doing nothing in particular. It affects everything about my experience of the day. It's the difference between just sitting limply in the chair and responding enthusiastically to e-mails, between dragging myself up the stairs and ascending with gusto, between reading with engaged interest and succumbing to sleep before I know whether Levin will go meet Kitty at her sister's country residence. Fatigue is not some additional thing to deal with in the day; it's the way the day is experienced.

I'm glad that I was warned about it. Otherwise I'd have been seriously worried when the blanket fell unannounced. The nurse who coordinates the transplants spoke with me a couple of weeks ago about fatigue as she advised me on all aspects of life after a transplant. She said it comes seemingly randomly and that there is no good biological explanation of the cause when it smothers a person. There's nothing to be done really, but to check out, put all plans on hold, and hope that no one is disappointed and no deadlines are blown.

I had a long string of good days last week. So good that I began to think her advice seemed kind of quaint. I was now beyond such concerns. But I've heard it said that, "Pride goeth before destruction, and an haughty spirit before a fall." Sunday arrived and I was confined to the Ikea chair. I rebounded enough on Monday to get some work done and to exercise.

Tuesday began well enough. I attended my first ever hospital Yoga class, which in itself was an exercise in humility. It was also socially interesting. There were only four of us in the class, two

of us still bald. Although we were all four from different countries, we were also all veterans of the hematology/oncology department. We shared a comradery, like soldiers who had been in the same battle. We understood better than most people what the other had been through. There was a natural closeness between us, unusual between strangers.

The appointment at the clinic dragged on as the doctor expressed concern that my Creatinine level at 2.1 was way too high, I run chronically high in this regard in any case, but clearly my kidneys were being stressed by a combination of some medication and my failure to drink enough. He ordered a change of medication and sent me off to the day clinic to receive a hydration IV. The whole experience at the hospital lasted about seven hours. Another day offered in sacrifice for longevity. It left me chastened. I need to keep track of my fluid intake, just like the nurses required of me in the transplant unit. At home I had quickly shrugged of that imposed discipline—I prefer my discipline self-imposed—for a more “intuitive” approach, which not surprisingly was insufficient.

At my request on my way back home the taxi driver dropped me off at the pharmacy. From there I walked about a kilometer home. As I approached our house, it was clear that The Dog was a having a bad day too. I could hear him howling from the road along which our row of houses sits. Anxiety had set in at some point, and I wondered how long he’d been in such a panic. How do dogs experience anxiety? Is it imagining some future all alone, the pack never returning? That seems unlikely. Epictetus’s diagnosis that anxiety is caused by allowing images of an uncertain future to worry us seems to require more powers of projection than dogs possess. Is it just the absence of companions in the present that becomes intolerable? Maybe the voice of the BBC broadcaster, which I leave on for him, after a while fails to soothe. But why, then, does it only

happen after some period of time passes? Given our common mammalian heritage, interpreting the behavior as anxiety analogous to what humans experience seems right. But how analogous?

I worried a little about complaints from one set of particularly sensitive neighbors. But not that much. These are the unfortunate ones whose evening is ruined every time we use our gas grill. Usually they let me know of their misery by yelling at me as I grill.

By the time I got settled at home I had about an hour's worth of energy to work on a manuscript before the crushing weight of fatigue sent me to the chair. Fortunately BF had already volunteered to cook dinner and with *almost* no grumbling MF was convinced to walk The Dog. So, I had the rest of the time before dinner and all of it afterwards to consider the contours of the chair before hauling myself upstairs to bed. After ten or so hours of sleep, I feel well-rested today.

One consequence of the new medication regime is that I am back to a twice a week schedule of visiting the doctor for the next couple of weeks. I've laid-off an anti-viral pill in favor of an antiprotozoal substance that is ingested by means of a vaporizer. It is administered at the hospital on a weekly basis at first and thereafter less often. So, I go back to the doctor again on Friday to breathe it all in. I'm sorry for The Dog. I hope to make it home before the anxiety starts up. I just can't seem to talk him out of it before hand.

42. Single Payer Pt. 3

The hospital bill finally arrived in the mail today. 280 euros for 28 days of care, including a life-saving stem cell transplant. Mandatory and publicly financed health insurance is just so tyrannical. When will the masses revolt against it?

43. Still Wearing My Helmet

I took The Dog out for a walk this evening. As I was enjoying the golden light of the sunset filtering through the green foliage of the woods and the birdsong all around me, I realized that two days ago was the one year anniversary of my diagnosis. A year ago, after I left the office of the squat doctor, I met BF in the evening at a reception at a humanities research center near our house. We had lived at this center several years back before we had moved here permanently. And we remain friends with a lot of the people who work there, and each year we make new friends among the visiting scholars.

BF had ridden her bike to the center after teaching all day, and I rode over from our house. As we were heading out to our bikes after the reception I mentioned to her that I needed to talk to her about my appointment that day. She knew that I was going to receive my biopsy results. She looked at me seriously, but then joked, “So are you going to start riding without a helmet?” Her way of asking if the prognosis is bad. I replied, “Well no...not yet...but I think I need to do some more research.” Then I explained that the biopsy was positive for *myelofibrosis*. Neither of us was exactly sure what that meant, but she knew, either from previous conversations or from my tone, that it wasn't good news.

A year ago we had no idea what was in store for us the coming year. I never went back for another appointment with the squat doc. Instead I sought a second opinion, switched doctors, and never looked back. I now realize that, given the diagnosis, things could not have gone more smoothly this past year. But it has been an exercise in coming to terms with the reality that the orientation of one's life can switch dramatically from one day to the next, and not always for the

better. And that possibility—let’s face it—is always there for all of us. As the Preacher in *Ecclesiastes* observes: “The race is not to the swift or the battle to the strong, nor does food come to the wise or wealth to the brilliant or favor to the learned; but time and chance happen to them all. Moreover, no one knows when their hour will come: As fish are caught in a cruel net, or birds are taken in a snare, so people are trapped by evil times that fall unexpectedly upon them.”

The message of *Ecclesiastes* is not supposed to be one of despair. At one point the Preacher also recommends, “Go, eat your food with gladness, and drink your wine with a joyful heart.” The contingency of life and the inevitability of hard times is no reason for nihilism. All that is valuable does not lose its value simply because life is temporary and highly contingent. To think otherwise seems remarkably solipsistic. The finitude of life provides a reason to make the most of the time in which we have to learn, love, grow, create, and improve the world around us. Not to give up on all that.

With the transplant behind me, and the recovery moving along nicely, the orientation of our own lives is slowly shifting again, and most certainly for the better. I hope to be wearing my helmet for many years to come.

44. Same As It Ever Was

I continue to let the days go by. That's been harder than it sounds. Not that I have any big complaints about my physical condition. I really couldn't have asked for things to go any better. If you have to go through this, I don't imagine it could be much easier than I've had it so far. I've been out the hospital nearly two months now, and I have not had a single incidence of fever, vomiting, or prolonged diarrhea—the kinds of things that send you back to the emergency room. I still suffer from food aversions and a weak appetite. I've lost about 10 pounds, but nobody seems worried about that. I am not particularly weak although I am weaker, of course, than when I went in the hospital. Still the last three weeks I've managed to workout—cardio and weights—three days a week and go to yoga once a week. Ice cream and pie have kept the calories coming in. If you know me from Facebook, you know that of late I have been specializing in fresh blueberry pies. They are a crowd pleaser. In January about 6 weeks before the transplant I injured my left knee running. X-rays revealed nothing. I did not have time to get an MRI before the transplant, but the pain persisted. I had to give up running and switched to a spin bike at home and a stationary bike in the hospital. When I got out of the hospital The Dog I went for walks in the woods and I used the spin bike again, but this past week the knee felt good enough for a couple of short and slow runs in the woods. That lifted the spirits of the canine and human both.

No I have no reason to complain about my physical condition. I know people who have had it much rougher afterwards. People for whom the new immune system decided that the old bodily organs were a threat. Graft versus host disease can be a serious problem. The graft, the new immune system, can go after any organ in the body, the host that it registers as foreign. That's

why I am on immune suppressants, which increase my risk of infection. When you talk about this, you'll notice, it's really hard not to ascribe agency and intelligence to the immune system: It "decides;" it "goes after;" it "registers." All of this, as if the immune system is a homunculus taking in its environment and deciding to act according to its purposes. As philosophers of mind will stress, this is really no explanation at all since your left explaining how a bodily system works by positing some little dwarf inside acting, but then there must be an even smaller dwarf in him, and so on. Although it seems so natural to ascribe intelligence and agency to systems within in us, in fact it obscures a difficult and fascinating problem. How does this all work anyway? What is the causal explanation for why the immune system might "recognize" an organ as a threat and "direct" an attack against it? And how can it be explained without an infinite army of ever smaller homunculi?

I remember talking to my hematologist before the transplant about blood production. She was explaining that as the bone marrow becomes more scarred and produces less blood, the spleen and liver slowly, but increasingly, take over more and more of the blood production. That is surprising enough since it's not their function to produce blood, but somehow they have the capacity to do so. But I found another question even more fascinating: How do they "know" to start to produce blood and then to produce more? She smiled and said, "That's still a mystery." That doctors can carry off a stem cell transplant and save a person's life is evidence that medical science understands a lot, but that they don't know what causes the liver and spleen to begin producing blood and how that cause is related to the bone marrow producing less blood shows how much more there is to learn. It's crazy.

Anyway, I am physically well, considering it all. I was warned that my recovery would take at least 6 months, and possibly as long as 12 months. Still, I am frustrated and impatient. I am well enough to feel pretty damn good much of the time although I still proceed more ploddingly than normal, and BF assures me that I am sometimes a bit confused—although I can't say that I have noticed it! But it's like those little dogs I see in the woods that are on very long retractable leads. The leashes are so long that they run along, tail wagging, thinking they are free. That is until the owner pulls the trigger and the leads pulls them back in. Once and while after I have been running along with my tail wagging, I get yanked back and find myself plopped in the Ikea chair or lying on the couch with little will or energy to do much of anything else the entire day. But that, I am told, is part of the process.

I'm in a kind of purgatory. There is every reason to be hopeful that I will just continue to get better. Slowly. But for the meantime, despite often feeling pretty good, I move more slowly, accomplish things less quickly, spend my life mostly in the house, and I must reckon with unannounced and unwelcome fatigue. It's been that way for several weeks now and will probably remain so for some time still to come.

45. Who is That Masked Man?

By doctor's orders I wear a surgical face mask outside of the house. It's green, three-ply, and has elastic bands that wrap around my ears. It has an accordion style construction that allows expansion so as to pull it down below my chin and up above my nostrils. It sits on the bridge of my nose, and near its top edge it has a piece of wire that bends to fit snugly on the bridge of the nose and down the sides onto the cheek bone. This serves to close the gap there. But despite that exhalation still escapes at the top and often fogs my glasses, which are not equipped with a defrost system. That's just one of the annoyances of wearing the mask. This kind of mask is a more comfortable step down from what I used to have to wear. It was a thicker, form fitted white thing with a built in filter near the front. The smell from the inside was repulsive. The green one is a bit more tolerable in that regard.

Apart from walks with The Dog in the woods, my getting out has been limited, again by doctor's orders, to going to the clinic for check-ups and getting meds from the pharmacy. I wear the mask in the taxi—funded by public insurance—to and from the doctor and to the pharmacy. My friend the driver is used to me carrying out my side of our conversation through the mask. He is Afghani and has a son a year younger than mine. Our weekly topics range from children and schools to the Taliban and ISIS. The few times I have been in town people have mostly politely ignored the existence of the mask. Children often stare, but adults in this culture mostly do not smile at strangers on the streets and seem trained to look past people. In the pharmacy, of course, the employees are professional. They are as indifferent to me as they would be to any other customer.

I'm a foreigner. This might not be obvious to locals by appearance but as soon as I begin to speak it is. My accent marks me as other right away. MF has managed to escape the curse of the accent, but I never will. But the locals are very gracious about this. I've made an effort to learn the language, and I can make conversation respectably. I get nothing but praise and encouragement for my efforts. Being a foreigner, however, means that I have learned to check my own responses when something I do or say elicits a very different response than I expected. Like the one Monday after Easter when I joined MF in the back yard. He decided to throw knives against a board that I put up for him. I made use of the time to push a non-motorized lawnmower around the yard. Neither activity lasted long. Very quickly a neighbor began yelling at us about the racket we were making. We were only dimly aware that the Monday after Easter was a holiday, and not all aware that that meant it was a quiet day. People here take their quiet time very, very seriously. To the loud Americans the very idea of quiet time is strange. My initial thought was that the neighbor was being outrageous. But I had acquired enough local cultural capital to put together quickly that we were the outrage. So, I hurried MF inside, where chastened we huddled very quietly for the rest of the day.

So, I am not always sure how to respond to people. Sometimes I seek confirmation from local friends. I've been assured, for example, that another neighbor two houses down in our row is the one being outrageous when she yells in response to my firing up the gas grill. The face mask has presented me with new interpretive problems. I mentioned that people don't tend to be warm with strangers. One exception is if you are with a dog. Strange dogs will often be greeted, and typically that requires some acknowledgement of the dog's strange human companion. Twice in the last two months while walking in the woods, The Dog and I have been approached by perfect strangers, and I have been asked after no more than a cursory greeting if I were wearing the mask

because I am especially sensitive to something in the woods. Both times I was taken aback. To me the familiarity seemed odd, almost rude. The people might as well have been asking how much money I earn. In both cases, however, I begrudgingly put together an elevator speech version of my recent health history.

Afterwards, as self-entertainment, I've wondered, what else could I have said? A few thoughts have crossed my mind. Perhaps, "No, no, the mask is so that I don't infect you with my deadly disease." Period. Silence. Or maybe, "No, I'm not from around here, and I'm just not sure how clean you all are." But, of course, the idea that I should take offense at the strangers' questions just might be a cultural miscue on my part, like making noise out in the yard on the day after Easter.

46. Inspiration in the Oncology/Hematology Waiting Room

If they had their druthers nobody would be waiting in that particular room, the one everyone hopes never to have to visit. The dreaded room, the room of the cursed. Like a soldier sitting in a room waiting to be shipped off to war looking around and wondering who will return alive, you can find yourself wondering about the others patients, their stage and their prognoses. Boredom mixed with morbid curiosity and empathy leads to such speculation. Some people chat as if they are continuing conversations they started somewhere else, perhaps from many appointments on the same day or spending time together in the chemotherapy room. But mostly people don't talk while they wait. One time I had a guy sit next to me, who seemed to be barely conscious. Before long he started to spray blood out of the top his hand where a bandage had just fallen off. I leaned away, and his wife yelled in panic. The nurses came running, whisked him away, and cleaned up the mess. That's far more excitement than anyone wants in that room, and thankfully far more than we usually get. Typically we wait in silence, alone with our worries and hopes, and our morbid curiosities.

There is a fairly long wait between the drawing of the blood and the consultation with a doctor where the blood counts are discussed. In between the blood has to be sent to the lab and analyzed, and the results must be entered into the computer system. The waiting time varies between 30 mins. and two hours. So, this past week I decided to get a cup of coffee after my blood was drawn. When I returned to the waiting room I found an open seat, adjacent to which were the belongings of someone who must have been in the back room having blood drawn. I couldn't remember who might be sitting there, but since people tend not to socialize, I didn't much care, I'm nearly done with *Ana Karenina*, and I was looking forward to diving into the

book. I plopped down and got busy with the book. A few minutes later a woman five to ten years my elder sat down. Apparently she looked over to see what I was reading because she immediately she said something to the effect of how nice it was that I was reading *that* book. I wasn't looking for conversation, and I certainly didn't expect it, but I was about to get it.

I didn't really want to stop reading so I replied pleasantly but briefly and returned to the book. But she would not relent, I soon learned that she was from Brazil. After meeting the man who would be her husband on a Pacific cruise about 10 years ago, they each returned home to their respective countries. But then he contacted her telling her that he had a cancerous growth on his throat. She decided to move half way across the world to help with his care. She left behind a grown daughter and elderly mother, At some point after that, they were married. But he's been in and out of the hospital ever since. The details of it all were a bit hard to follow because I was having some trouble with her thick Portuguese accent. So, we switched to English, a language we were both more comfortable in. She told me that while he was in the hospital initially she kept herself busy by learning guitar and singing, first in a Protestant choir and then in Catholic one. A few years back her own health troubles began. Her platelet counts dropped precipitously for unknown reasons. In response she was treated with a high dose of cortisone, which elicited psychotic reactions. The doctors switched to chemotherapy and that seems to be helping. And although she has no one to help her out, she has also been taking care of her husband all along.

She related this whole story without a complaint, an indication of regret, or a trace of self-pity. It was just her life that she was telling me about. I marveled at her strength and spirit. The discussion lasted for at least a half an hour, but she was eventually called into the back room for her doctor's consultation. When she came out, before leaving, she came over to me, smiled,

shook my hand, and pleasantly said good bye. The Stoic philosopher Marcus Aurelius advised that we should strive to be like the cliff against which the waves continually crash, but standing firm tames the fury of the waves; for then we will not be unhappy due to what has happened to us, but remain happy despite what happens. We don't know how we are going to react to hardship when it falls on us, but I could only hope to have her fortitude and sanguinity. I never learned her name, but I will probably never forget our conversation. That day last week I found unlikely inspiration in the dreaded waiting room.

47. With a Little Help from My Friends

I've been pre-occupied by two pictures of personhood since the last post about my encounter with the woman in the waiting room. One is Aurelius's cliff standing firm against the crashing sea. The strength of the rock to stand up against the relentless pounding forces of nature, the decay and destruction of aging and illness, offers an example of a way to live that is meant to secure happiness in the face of calamity. Nature, of course, ultimately wins. Eventually the sea will cause the cliff to erode and crash into the turbulent waters, just as certainly as illness and death come to us all, but the idea is that happiness consists in standing strong for as long as one can. The Stoics generally argue that we do so by not seeking to keep what in any case cannot be kept, and ultimately this includes our lives. Doing so, they know, is no easy feat.

Epictetus begins his manual on stoic philosophy, *The Enchiridion*, by noting that, "there are things which are within our power, and there are things which are beyond our power." It is important to remind ourselves in which category each of the things we hold dear is, so that we do not allow ourselves to make our happiness dependent on what we cannot control. This extends to family and friends. "If you wish your children and your wife and your friends to live forever, you are foolish, for you wish things to be in your power that are not so..." The aim to be able to let go of all that one holds dear would be familiar to many a Buddhist. "Never say of anything, 'I have lost it,' but 'I have restored it.' Has your child died? It is restored. Has your wife died? She is restored." By letting go of it all, the Stoic philosopher can then accept all that happens to her, in the end even death. "Demand not that events should be as you wish; but wish them to happen as they do happen, and you will go on well." As I mentioned in an earlier post, this seems a

hopeless life, but then again, hope is only needed by those who would have events go as they wish. That is precisely what is to be avoided.

The Stoic ideal of strength is in many ways admirable. Surely being able to persevere against the hat require letting go of all one holds dear? Could one truly be happy doing so? Or does a full, rich, and happy life require making oneself vulnerable to the loss of all that enriches one life and the people whom one loves? Just as I have already cast doubt on the ability and desirability to live without hope, which the Stoics seem to recommend, so I also find doubtful the Stoic picture of a person so radically alone.

The second picture comes from John Donne. Perhaps he had Aurelius's cliff image in mind when he penned these words: "If a clod be washed away to sea Europe is the less." When Donne wrote this he may have been embracing a Pauline notion of the Body of Christ, but the image of solidarity expressed in these and other words of "Meditation XVII" are also available to those who interpret life through a purely secular lens. When in the 19th Century John Stuart Mill sought to provide an account of a progressive morality entirely on secular grounds of human happiness he also had an inspiring vision of what human solidarity could do: "All the grand sources, in short, of human suffering are in great degree, many of them almost entirely, conquerable by human care and effort...[E]very mind sufficiently intelligent and generous to bear a part, however small and unobtrusive, in the endeavor, will draw a noble enjoyment from the contest itself, which he would not for any bribe in the form of selfish indulgence consent to be without."

We all rely crucially upon others to become who we are and to thrive in the activities of making a life. From the cradle to the hospice room we make our lives together, even if we fancy we live

on a libertarian archipelago. As I have mentioned before, I owe my life to an anonymous donor and a social-democratic healthcare system. Mine and my family's well-being is owed to all the friends who helped and supported us while I was in the hospital. The community that I enjoyed through the comments to this blog helped me to fight off anxiety and loneliness while I was otherwise isolated in the hospital.

The Stoics have important lessons to teach us about finding happiness in letting go of much that we cannot control, including coming to accept the inevitability of our own deaths. But I doubt that the Stoic sense of individualism can give the social character of our well-being its due. Can we be in love, in friendship, and in solidarity with others whom we can simply let be "restored." I think not, and Epictetus might agree. In fact that may be the point. The commitments of love and solidarity necessarily render us vulnerable to the losses experienced by others and to our loss when we lose them. But these commitments also literally give us life and enrich it. Invulnerability is neither a possibility, nor an ideal worthy of our striving. There may be something tragic in that state of affairs. But given what's to be lived, it's not so clear that on balance it's tragic, rather than just human.

48. Springtime on My Face

It may be summer outside now (and I do like that), but it's still springtime on my face and head. Like crocuses peeking out from the ground in April, early this month the hair under my nose started to bust through my skin. After a while I had a passable mustache and a scraggly goatee. My scalp in comparison has been lagging. At first some adolescent peach fuzz appeared up there. I confess that I shaved this stuff twice. I told myself that doing so was necessary, like on a pubescent boy's cheeks, to get the real manly stuff to grow (where it still would) on top. But the truth is that I have gotten used to the bald scalp, recently supplemented by a mustache and goatee. I am told variously that I look like Mr. Clean, Michel Foucault, and Telly Savalas. (Bruce Willis has not come up.) And I flatter myself that these are meant as compliments. But after going bowling for BF's birthday, a friend of hers asked if anyone mistook my head for a ball! Ouch. But that gives me an idea. A tattoo of three finger sized holes at the top... Still, I think I can get away with the look (without the holes), and there are whispers that some people even find bald heads on men attractive. Recovery is easier in that way for us, I suspect, than for women. When BF had chemo a good many years ago, she tried to embrace the Sinéad O'Connor look, but it was not so easy. There were far more strange glances to contend with. It's a privilege that I enjoy; I know. But it does leave me with a gut wrenching choice now: To grow it back or not?

49. Feeling the Love...and the Likes

If you are feeling down about the number of responses that you get to your Facebook posts, simply announcing that you have had cancer or some other life threatening disease, for example one that requires a stem cell transplant, is a sure-fire way to up your likes. It worked like a charm for me! Seriously, when I went public on Facebook the outpouring of well-wishes was enormous. And subsequent photos (in which I am starting to look better, I dare say) have garnered far more than the historic average of likes for me. And then there's the excessive flattery that you really want to believe. It's a good example of one the very good roles that social media can play. There are so many people that we care about who are not directly in our lives, but we maintain a thread to them via social media, hearing about mostly the good things, but occasionally about the bad too. Prior to Facebook, these friends would rise to the surface of my thoughts from time to time, but most of the time images of them slumbered just below the surface of my consciousness.

If telling people that you have a life threatening disease that requires a risky medical procedure is difficult, appearing before them afterwards in relatively decent shape is truly wonderful. When close friends first came to the house after I returned from the hospital, I could see the sparkle in their eyes, evidence of the worry they had experienced, the love they felt, and the wonder they now had. "He's alive; he made it!" Recently at the encouragement of a dear colleague, BF and I attended a work related BBQ where people saw me for the first time since before I had gone into the hospital. Because of the haphazard way in which I had told people what was going on with me, many had only heard it second hand, and perhaps didn't even have an accurate account of it all. When I walked in I was overwhelmed by the expressions of love and joy. So many faces

looking in wonder. “He walks! Wow, he looks pretty good for what he’s been through, really, don’t you think.” So many handshakes and hugs, and germs! (It was my first appearance in a large group without wearing the surgical mask.)

There is something strange but lovely in realizing that so many people have been worried. It has taken being in front of people, being seen by them, and recognizing that I am being seen by them to make me fully appreciate this fact. Imagining it was not really enough. It took seeing it in people’s responses to me. Jean Paul Sartre makes a lot of these kinds of experiences in his discussion of “The Look.” It’s a claim with a Hegelian lineage, but he contends that we come to understand ourselves as persons, especially in moments of shame and pride but presumably not only such experiences, by experiencing others seeing us as persons. In a characteristic bit of a flourish, he claims: “I am for myself only as I am a pure reference to the Other.”

I’ve made no secret of my fondness for John Donne’s Meditation XVII. Experiences in which we come to understand ourselves through others give a special meaning to the claim of not being an island. After those kinds of experiences it’s hard to dismiss the claim as a piece of sentimentalism. The experiences need not necessarily be pleasant ones; Sartre is focused particularly on shame, for example. But they certainly can be, and they have been for me when I’ve seen the wonder and joy in the eyes of my friends and colleagues.

50. Disease, Bodily Alienation, and Transhumanism

One of the things that Havi Carel says in her excellent book *Illness* is that in serious illness one experiences a kind of alienation from one's body. Suddenly you recognize that things are going on, going on *in* you, that you were totally unaware of, that you can't control, and that may cause you serious harm, and that may even kill you! I recall when I was first diagnosed with *essential thrombocythemia*. It was nineteen years ago now; I was in my late 30s and living in South Africa. For over a month I'd had a bad case of the runs. The doctors were trying to figure out what was going on with my gastro-intestinal tract. And in the course of doing so, they did routine blood work. The results didn't help in figuring out what was affecting my gut, but they showed that my platelet count was way out of whack, about five times higher than normal.

Suddenly, I had other problems to worry about. I was told to take it easy. They didn't want me keeling over due to a "thrombotic event"—think heart attack or stroke. I was told to make an appointment with a hematologist as soon as possible. Something was up with my bone marrow. Most likely a *myeloproliferative neoplasia*, a group of diseases including a kind of *leukemia*, in which one or more of the three main kinds of blood cells proliferate. The immediate thing to do was to check for *leukemia*, which can be done by a bone marrow biopsy—my first of many groan inducing, eye moistening experiences of being put under the corkscrew. (Those who want more detail on what that's like should read my posts [“Patience, Dear Patient”](#) and [“First Thoughts and Second Opinions.”](#)) *Leukemia* is ruled out if no abnormality is found on chromosome 22, called *the Philadelphia chromosome* because it was first discovered by researchers at the Fox Chase Cancer Center and U Penn Medical School in the City of Brotherly Love. After several nervous days of waiting, I received the negative result.

With other possibilities ruled out, *essential thrombocythemia* was the diagnosis of exclusion.

Life with a chronic disease was the new normal for me. The good news, most people diagnosed with the disease have normal longevity. The bad news is that most people diagnosed are in their 60s and 70s. Being in my late 30s, I would have decades to live with increased risk of *acute myelogenous leukemia* or *myelofibrosis*. (The latter tailed me on two subsequent intercontinental moves, and finally caught up with me in Germany last year.) Meanwhile the diarrhea had not abated. At one point the docs had me carrying around bucket to gather a 24 hour sample.

Imagine my pleasure! I recall distinctly feeling back then that as a relatively young man my body seemed to be betraying me. “Wait a minute, I thought we had an agreement—ok, a tacit one maybe—but an agreement nonetheless! I don’t abuse you too much, and you keep ticking along for several decades.” Suddenly my whole system seemed to be in mutiny.

In time the gastro problems were abated by an enzyme treatment, and I settled into the routine of taking the platelet reducing meds that were then new on the market. Most medications are approved after trail testing that does not go on for years. Being among the first post-trial users of the medication, I had the satisfaction and worry of knowing that I was contributing to science by helping to discover what the long term effects were. A couple of decades, passed without me obsessing about my illness...much.

After my *myelofibrosis* was diagnosis I had to go undergo several standard physical examinations in preparation for the stem cell transplant. A thorough dental examination revealed an abscessed front tooth. Dental infections and chemotherapy induced dead immune systems are a bad mix. So, a week before entering the hospital my lower front tooth was pulled and I was given a temporary fakie. When I wear it is hardly noticeable, when I don’t I look straight outta

Breaking Bad. In my case there was also some concern about possible hemorrhoids, which could be aggravated by chemotherapy induced diarrhea. (A shockingly recurring theme in this piece!) So, the docs ordered my digestive tract to be scoped. The whole thing, all 8 ½ meters of it.

When I went into the examination room, they asked me if I consented to having polyps removed if any were found. “Sure, might as well find out if I have colon cancer too!” Then, unexpectedly, they asked if I wanted to be put under a general anesthetic or to be awake to watch it all on their high definition screen. It would be uncomfortable, they said, but not terribly painful. My curiosity got the better of me and I chose to stay awake. Just to be clear, I had been given plenty of very effective purging medication; so things were promised to be pretty empty inside.

During the exam there was more than one moment when, feeling the probe push from the inside of my intestinal lining, it seemed like the creature from the movie *Alien* was going to pop out my gut. Uncomfortable to be sure. But the high definition view made the price of admission more than worth it. It was as if I were watching out the window of a submarine. My insides turned out to be an alien underwater wilderness, undulating like a mass of mollusks in the waves. How weird to look at all that watery flesh and to think, that’s me. But how could it be? It’s me *and* it’s another world! I’ve never been there before; I know nothing about it. Problems could arise down there, betrayals festering into carcinogenic polyps, and I’d be none the wiser for quite a while, perhaps even for too long.

My gut is as foreign to me as the bottom of the ocean. It is its own ecosystem, teeming with microbial life, all of which I am totaling unaware of most of the time, and only bluntly aware of when something goes wrong. I don’t direct the undulations to do my bidding. I don’t intend the flesh to carry out its digestive tasks. But I am certainly more directly dependent on that region

than I am the ocean's depths. And I can't go on very well without it doing its business. If I could have my bone marrow scoped, I would probably have a similar reaction. It's not so much that illness alienates us from our bodies, as it is that in illness we come to appreciate that we already are alienated from many parts of our bodies. And we could not live unless we were. We could not possibly direct it all, set it to work serving our purpose. Bodily alienation makes our conscious experience possible.

Alienation from my body is bound up with my limitations. If I could control it all, I would certainly sing better, play the guitar better, and have made it into Rock n' Roll Hall of Fame. My talent-set would be unlimited. My physical decline would be more ordered and graceful, and perhaps even seize to exist. I could stop any nascent malignancy in its tracks by sending my immune system SWAT force out to get it. And then, with unlimited time, choices would lose their poignancy. I wouldn't have to decide between being a philosopher and a rock star. I could take 40 years to get good at one thing and 40 more to get good at another. Then move on to something completely different. Comedy, perhaps.

Various parts of me could be replaced and I could carry on just fine. Better in fact. My transplant has shown that. I have heard people marvel at what an improvement their new hips are. Bit by bit this stuff is replaceable. And I'm not lost in the shuffle of the parts. That thought suggests one way that bodily alienation could be fully overcome. Over time, all of my parts, piece by piece, might be replaced by polymer membranes, fiber optic cables, and semi-conductors. And with each new part a monitoring and control device might be installed, giving rise to multiple feedback loops and full control. This post-human person would seem to enjoy several advantages. Longevity without decrepitude certainly seems appealing *caeteris paribus*.

But there is one problem. I doubt that the result would be me. Along the path of transition from my biological self to that post-biological, post-human person, I would disappear. The person who comes to exist, let's assume for a moment that it is a person, in the process of shedding my body parts is someone else. Without my body (at all), I am nothing. What's in it for me to bring that post-biological person into existence? I would seem to have no personal stake in it.

If what I am suggesting is right, it's seems doubtful that I could exist in any way other than alienated from my body. One intuitively plausible, but I think ultimately unsatisfying, objection is that as long as the post-human person has my memories it's me. If we could get the technology right, I could exist that way and be unalienated from my physical, post-biological, existence. In response to this, recall the character Rachael in the movie *Blade Runner*. She looks just like a human, an adult woman; she feels just like a human; and she even has memories of her childhood. But she is not biologically human. She has been constructed by the Tyrell Corporation. And she has been programmed with the memories of the daughter of the corporation's owner, Eldon Tyrell. Although she has the daughter's memories, she is not identical to the daughter. You might think that seems plausible but only insofar as the daughter is still alive. (In the movie we don't know if that's the case.) But consider that if the daughter died, Rachael would not suddenly in a flash become her. Rachael is either her all along or never. And the former seems utterly implausible. Having someone's memories is not enough to make one that person.

My focus has been on our personal fates in of overcoming our bodily alienation. Two of the most influential philosophers of the nineteenth century, Hegel and Marx, saw alienation as a great social evil. In their own different ways they developed accounts of alienation and

recommendations for how it might be overcome. What about the desirability of overcoming bodily alienation on a social scale over time? Imagine generations of people in the future undergoing a gradual transformation to post-humanism. Do we have reason to see the eventual transition of our species into post-human beings in full control of their artificial bodies as attractive? I declared that *caeteris paribus* longevity without decrepitude is appealing. But in this case the *caeteris* definitely are not *paribus*. For reasons roughly similar to my personal case, it's hard to see why we would want to celebrate the extinction of our species and the creation of new artificial long-living post-humans.

Disease can be bad for all sorts of reasons—it limits our abilities, it disrupts our plans, it can be costly, and it can hurt to name just a few. We have very good reasons to want to reduce the disease burden both within our generation—where it is especially inequitable—and for future generations. That does not mean that it makes sense for me to want to transcend my biological existence, or for us to want to extinguish our species on behalf of other beings who would not experience bodily alienation. After all, what are those future post-humans to us? Utilitarians may disagree; we have a reason to desire a world with less or no physical suffering. Hence, we have a reason—perhaps an obligatory one—to seek the means, through post human transformation, to that end.

Moreover, a disease free post-human world might have an appeal beyond confirmed utilitarians. Those who take rights seriously may claim that if the outcome is better and no one's rights are violated—imagine all the replacement of parts and organs over the generations is consensual—then we have reason to pursue it. To cast the net more widely still, throw in the additional constraint that the introduction of the technology at each step along the way is consistent with

realizing equality of opportunity and a fair distribution of wealth. If we could manage the just introduction of an eternal or at least very long living post-humanity to take our place in a more egalitarian post-human society wouldn't that seem like a compelling goal? The reduction of suffering due to disease and ill health is doubtless good. So, one might think that every step we take in that direction consistent with justice, short of extinguishing our humanity, is surely good. If that is true, then the last step—the humanity extinguishing one—must also be good.

I am not convinced that every step would be on the whole good. In each case one has to weigh the gain of disease eradication against the loss. Doubts might arise regarding whether each aspect of being human can be adequately compensated for by sophisticated machine performance. Some of the things that we accomplish seem especially valuable because we, not something else, are doing it. Two examples that come to mind are the beauty of the human voice in song and the pleasures of sexual intimacy.

And, I'm not confident that by the end the post-human beings could be capable of conscious experience. There would be no overall benefit by replacing mortal suffering humans with immortal, non-suffering post-biological zombies. (Not of the flesh-eating variety, of course. That would make the argument too easy for me.) Consciousness as we've known it thus far arises in organisms. How this happens, and the relationship between consciousness and biology are not known and are the subject of much controversy among philosophers and psychologists. But we should not suppose that a bunch of sophisticated machines will be conscious. I assumed earlier for the sake of the argument that they would be persons. In fact, I think we have reason to question that assumption. And that certainly throws the worthiness of the aim of a post-human world into doubt.

Replacement of a great many human parts will probably produce gains for human well-being in the coming years. More profound alternations could conceivably come through the use of genetic technology. As the capacity for alteration becomes more powerful, it will be important to gain more clarity than we now have about what we can replace with losing more than we gain. Discussions about that seem to be running behind technological developments presently. Less urgently, but no less important, are the debates about whether the long term aim should be healthier humans or post-humans.

51. Dem Fingernails

The great American naturalist, John Muir, once said, “When we try to pick out anything by itself, we find it hitched to everything else in the Universe.” This is a striking expression of metaphysical holism, the idea that individual things and their properties are not isolated objects, but parts of a larger interconnected whole, a complex system, in which apparently isolated objects are connected to one another by their roles in the system. Whether that’s true of reality in general, I’m not going to hazard an opinion. But complex systems certainly exist, and they are especially interesting to some mathematicians, philosophers, biologists, and medical scientists.

This calls to mind a song that I learned as a school child that went like this:

The leg bone’s connected to the knee bone,
 The knee bone’s connected to the thigh bone,
 The thigh bone's connected to the hip bone,
 Now shake dem skeleton bones!

The idea that parts of an organism are interconnected members of a complex system is something that patients also need to keep in mind. This was driven home to me last week when I went in for one of my now bi-weekly check-ups.

For quite some time now—I can’t really remember for how long—I’ve noticed that my fingernails had an odd wave in them. Every one of my ten nail has it; it runs nearly the width of the nail. At about the mid-point the nail dips down and then back up again. And a couple of my nails have superficial cracks in them that run the better part of their length.

These nail deformities appeared at some point in the past six months since I've been out of the hospital. I haven't given them much thought, but I have found myself rubbing my fingertips over my thumbnail to catch a wave. And I improvised an arm chair oncological theory that went like this. Chemotherapy kills cancer cells because it kills quickly reproducing cells. It kills hair cells for the same reason. Fingernails are fairly quickly growing. So, the fingernail deformities are probably the legacy of chemotherapy that I received in March. The fact that my toenails are not similarly affected is explained by their comparatively slow growth.

An elegant and *a priori* plausible theory that served the purpose of satisfying me and encouraging me not to think too much about my odd finger nails. But, it turns out that I will not win any Nobel prizes in medicine for the theory because it is probably just flat out wrong. The connection is more likely to be to the immune system!

This past week I could not see my regular post-transplant doctor because he was on vacation. Instead I saw the doctor who oversaw my transplant. And for some reason, although I never mentioned my nails to the post-transplant doc, I felt moved to mention them to her. I have no arm chair psychological theory about why I did that, but I did. To my great surprise she wasn't impressed with my oncology. She examined my nails pretty closely, showing definite interest. And finally she declared that the deformities were consistent with Graft versus Host Disease!

You might recall from some of my earlier posts that this disease in its manifold forms is one of the main things that doctors watch for after a stem cell transplant. It amounts to the immune system (the graft) telling some organ of my body (the host) to piss off! I've compared the immune system before to a guard dog. In *The Republic* Plato compares the best guardians of the city to good guard dogs, friendly to their own and hostile to foreign threats. With Graft versus

Host Disease it is as if the guard dogs have confused who the foreigners are. The danger is that any organ could be targeted. Obviously it would be dangerous if it were my brain, or my heart, or my lungs. My fingernails, not so much...I think. I suppose that this will pass without event. The dogs will go back inside in due course. But, of course my oncological credibility is already in doubt.

The doctor and I also discussed the diarrhea that I still suffer from periodically, and she mentioned the possibility that I've developed a case of lactose intolerance, which apparently can occur after a transplant. She told me to cut back on milk and that if I still have occasional bouts of the runs, they'll need to scope me again to see if my digestive track might also be traumatized by snarling dogs. Having gone along for that ride once, I may choose to sleep through it a second time. But with any luck, there will be no need for that and I'll have no further details to share.

Today is the six month anniversary of my transplant. I'm pleased to report that I've been feeling good and have just traveled to a conference for the first time since the transplant. We had some excellent discussions on the ethics and politics of climate change. Assuming more and more of the duties of work feels good.

52. Traversing the Rim of the Valley of the Shadow of Death

When I checked into the hospital I knew that I was leaving behind a loving family life, an enriching professional routine, and the company of good friends. When the door sealed me inside the germ controlled room, my life would be very different. I felt confident that I would emerge from the bubble eventually. I was calm about my prospects. But they were far from certain. The doctors had downgraded my survival chances from 70-80 percent to 60-70 percent. But apart from having blood counts that caused my GP to shake her head in dismay, I was strong and healthy. Even if I was increasingly feeling the drag of anemia. I had exercised regularly for years, in part in anticipation of the eventual need for a transplant. And I was bolstered by the thought that the risk was worth it, given the alternative prognosis of steady decline over just a few years.

I wondered how people who are sent off to war feel? Or what it's like to descend into a coal mine every day? How do people face the risks of death that their life circumstances present to them? I didn't feel like I was descending into the Valley of the Shadow of Death, it was more like I was traversing close to the rim. The Valley was there in plain sight, and if things went wrong, I might find myself slipping into it. But I wasn't there yet.

I had gotten close death once before. It was in Soweto when I was watching some members of a youth theater group that BF and I worked with. Three teenagers stormed into the dimly lit hall waving guns and brandishing knives. They wanted the valuables of the grownups. But they were young, amateurish, and erratic. None of which set me at ease. They lined the children and adults against a wall. Was it to fleece us or to execute some of us? As it happened we were standing in

front of a stage curtain, behind which was a door exiting the hall. We managed to slip several children behind the curtains, and they snuck out through the door. The robbers got wise to our activities and ordered us all to lie down on the floor. That felt like an execution pose. As I laid there with my arms around sobbing children on each side, I expected to hear a shot and then the lights would go out. I imagined a sharp, but very brief pain, then darkness. Yet, I found myself overcome with peace. There was nothing I could do, and I was surrounded by people who needed my comfort. I remember looking at the light streaming through the high windows at an angle towards the floor. In the light beam bits of dust sparkled like flakes of gold as they gently floated downwards. Time slowed down. But it was all over in less than 10 minutes, and then we stumbled into the bright daylight stunned that we were still alive.

Plato records a conversation between Socrates and his friend Crito. Socrates was falsely accused and sentenced to death on the charge of corrupting the youth of Athens. Crito visited him in his jail cell and presented a plan for his escape. In the course of the discussion Socrates argues that we have no reason to fear death for it is either like a dreamless sleep, like nothing at all you might say, or it is an opportunity for us to enjoy the company and conversation of our friends. Fear of death is irrational because it's doubtful that after death we'd have any experiences worthy of fearing.

Socrates could not imagine that following death a person would survive in some kind of eternal torment as punishment for her misdeeds. Christianity had not yet made that terrible idea seem plausible. Fortunately Christianity was eventually subject to an internal critique. Hosea Ballou and other Universalists argued that eternal torment for a sin is inconsistent with the idea of an infinitely loving, knowing, and powerful deity. The demands of justice and of mercy might often

conflict, but surely if there is a perfectly just and merciful God, She would not assign infinite torment for an earthly crime. Socrates's alternative of either nothing at all or nothing to be feared could be rehabilitated.

Socrates's views about death were more complicated than I have let on. He certainly wasn't cavalier about his life. But he thought that living correctly was of the utmost importance, indeed more important than whether one continued to live. And that's the thrust of his response to Crito. Because he thought he had a duty to obey the authority of the Athenian laws come what may, he was willing to accept his punishment even though it meant his death. You might disagree with his claim about the solemn duty to obey Athenian laws—I certainly would—but the idea that there are things more important than merely surviving seems right.

Towards the end of his life Martin Luther King, Jr. was remarkably prescient about his death. On the night before his murder he said, "Like anybody, I would like to live a long life; longevity has its place. But I'm not concerned about that now. I just want to do God's will." Was King strengthened by the thought of an afterlife? Perhaps. But what I find noteworthy is the idea that it is the kind of life, not life at all costs, which was most important to him.

I've wondered if that idea is not only true, but also helpful in facing down death? Suppose you are taken hostage and threatened with death unless you provide information that would lead to the death of several innocent people. If you think the threat is credible, you certainly wouldn't welcome death, but it might seem better than the alternative. If one has a firm grip on what is important, death may be easier to face than the alternative of losing one's integrity.

But life rarely presents most of us with such dramatic circumstances. Terminal disease takes us away, sometimes slowly and almost certainly without fanfare. Or we confront the choice of whether to have a risky medical procedure. Or we live on with the risks that our chronic diseases pose. In comparison to Socrates and King our lives and deaths are usually mundane.

We are probably biologically hardwired to fear death, at least immediate death. Our ancestors who feared death would have been more likely to survive and reproduce. Some amount of death anxiety is probably natural. But our genetic inheritance would need only to trigger fear in situations of physical conflict. Having a deadly disease, I can assure you, is not quite as exhilarating as having a big carnivore bearing down on you. Flight or fight need not kick in with a bad prognosis. The good news is that suggests the possibility of some control over the fear.

Socrates's aim was to convince with arguments that the fear of death is irrational. Would accepting his conclusions really help with the fear? His view—or Plato's anyway—is that it can, that our emotions can listen to our reason. We are not simply at the mercy of our emotional responses, but we can cultivate a measure of rational control over them. That sort of rational therapeutic approach to fear is also a central theme in the writings of the Stoic philosopher Epictetus. If that view is correct, it's important if there really is no reason to fear death.

One of the things about death that is strangely disconcerting is that it's forever. When the lights go out for each of us, the universe will continue to exist for a very, very long time, and for the entirety of that time we will be absent. Entertaining that thought can be like placing yourself on the precipice of a very high tower. But it's not so clear why that's so. There is nothing similarly disconcerting about the thought that it all went on for a very, very long time before any of us arrived on the scene. When I read Roman history I am not overcome with dread that I did not

exist. Why is a future in which I'm absent, more disconcerting than a past without me? Perhaps because some small part of that future could have been mine, but won't be. I might have lived a little bit longer, adding an infinitesimally small unit of time to a life whose duration is already puny from a cosmological point of view. But that tiny "could have been mine" doesn't really seem all that significant. It's hard to avoid the thought that there is some narcissism at work when vertigo arises from the thought of an infinite future without us. If that's correct, this is another place where philosophical therapy might help with the control of our emotional responses.

The fear of death is often the fear of dying. Loss of capacity can be demoralizing. And pain really is fearful. Both of these are, however, less certain than death itself. Dying need not always include either of them. We can reasonably hope to avoid some the very worst of what we have good reason to want to avoid. And the legitimate fear of these things is in an important reason in favor of putting patients in control of the end of their lives.

There is no trail available to us other than those that traverse the rim of the Valley, and one day each of us will slip. Knowing that, some try anxiously to avoid thinking about it, while others anxiously dwell on it. Rational therapy for our emotions aims for a third response. There is something to be gained from keeping in mind that the path does not go on forever; for the rarity of the opportunities afforded us is a reason to treasure them. Yet, anxiety can inhibit our capacity to do so. Not only is there often little to fear, but fearing itself undermines the quality of the life that fear aims to protect.

53. The Examined Illness

In the record of the trial of Socrates, when he is given a chance to seek some sort of commuted sentence instead of the death penalty, he is uninterested in pleading for a lesser penalty.

Alternatives that would prohibit him from living as an itinerant philosopher in Athens are especially uninteresting because, he claims, the unexamined life is not worth living. I have long despaired at the way that phrase has been unreflectively appropriated by many members of my profession. Without much searching you can find it on many department websites, bulletin boards, and office doors. Little thought seems to have gone into considering the implication that almost no one's life is worth living. Now perhaps that's uncharitable; perhaps it's been the subject of solemn discussions at many department meetings, which have concluded that telling the rest of the world that only members of the Philosophy Department and their students have lives worth living is a clever way to boost enrollments or generate external funding.

If you saw a sticker on a locker room door that said "Football Is Life" you might find it cute and amusing. Maybe, that's just how the rest of the world looks at philosophers who post the quotation of Socrates on their webpages. Of course, the rest of the world might not look at philosophers quite that way if they thought that they were sincerely citing the Socratic claim.

If I think Socrates's famous claim is both false and disastrous public relations, it's not because I disvalue the examined life. I merely think that there are many ways to live well. I try to live mine well without disvaluing many other perfectly reasonable and admirable choices. I certainly do not believe that I have chosen the only life worth living.

In these essays I've tried to pursue an examined approach to my experience of illness, treatment, and recovery. When I started writing I did not know whether I would survive. I approached my circumstances unable to accept the consolations of thoughts like "it would all work out for the best," or "it was happening for a reason." The reason it was happening was that my bone marrow was diseased. Nothing more. Disease and serious illness often strike quite randomly. And when they do we quickly become subject to the impersonal forces of biochemistry and pharmacology; we must trust in the training, competence, and goodwill of strangers known to patients as "their doctors and nurses." We rarely think about this beforehand and are usually totally unprepared for it when it happens. Suddenly there we are, subject to a standard treatment protocol.

During my twenty-five days of hospitalization I wrote daily blog entries. I planned the blog as a means by which to keep family and friends informed and to keep me busy. It was to be my project in the hospital. I thought that if I had to suffer the experience, then maybe I could make something good come of it. I wanted to write something that would be good. Even if I didn't survive, if in the end it was mostly just suffering and loss, it wouldn't only be that; there would be my record, which maybe would be good, I hoped. That would be a little piece of redemption. It wouldn't make the whole thing worthwhile, by any means. But on balance, objectively, it would be better than without the writing.

That's a pretty impersonal way to think about it, of course. As soon as I started writing in the hospital I found that I depended on it. I depended on the routine. Some days it was not easy to sit at the table and write in the midst of the fog and fatigue of chemotherapy. But that routine was part of an effort to exert a modicum of self-assertion during a time in which I was otherwise rendered nearly completely a patient. My Livingroom/bedroom was somebody's workspace, my

schedule was somebody's work routine, my immune system was being systematically crushed, and my prognosis was out of my hands.

I also depended on the writing in another unexpected way. I would usually start writing in the late afternoon and write till supper time. I might make a revision or two after eating, and then I would upload my account of the day's activities and my condition. I would read or watch TV, knowing that around the world at the end of the day over a glass of wine or while commuting to work on the train with a cup of coffee people were reading. I'd lie in bed at night knowing that I was in people's thoughts, concerns, and prayers. I was not alone. Come morning the replies would already have begun to trickle in. I was buoyed by the good wishes and the conversation. My nightly prayers were answered each morning by my readers. Even in that sterile and locked down hospital room far from so many family and friends I wasn't living in isolation.

It seems fair to ask what an examined illness can teach. I hesitate to say much that might be conceived as advice because I realize that it could have been much worse, indeed that it often is much worse for people with diseases similar to mine. I had it comparatively easy. The oncological psycho-therapist in the transplant unit told me of a patient who had been there, mostly in isolation, for 6 months. I didn't exactly earn an advanced certificate in suffering and staring down the grim reaper till he blinked.

True, most people do not engage in activities that stand a 40 percent chance of killing them. But, in light of the alternative, most anyone would have taken the risks that I did. I did nothing remarkable in that regard. I don't at all stand out by my choice. I also did not "beat" cancer. All I did was follow my doctors' orders, more or less. I haven't honed a talent for surviving, although that would be nice.

My illness and recovery has, however, been an occasion to think about living well, even under the threat of death. I never felt particularly mad about what befell me. And if I had, I would have hoped that I would have realized the absurdity of that since in my case there was no person or no agency to blame. I've felt nothing but appreciation for most of my doctors and all of my nurses. I found the experience of putting myself wholly into the trust of others for my care caused me to feel tremendous gratitude for their competence and good will. I also feel enormous gratitude to the stranger who was willing to donate his stem cells, and thereby save my life.

And I am grateful for the fine system of government-financed health insurance in Germany. Systems like the German one are pillars of post-war European social democracy. Their importance both for what they do, and what they say about what humanity is capable of, cannot be over-emphasized. Not only do these systems provide excellent healthcare for everyone regardless of income, but they show that political mobilization in the service of intelligent institutional design can promote the well-being of everyone.

Driven by fear, greed, glory, and the lust for power, humans kick up wicked whirlwinds of violence and destruction. Even as I write, parts of the world seem trapped in desperate civil wars, conditions of life described by Hobbes as, "solitary, poor, nasty, brutish, and short." Often these end only when the war-makers suffer complete exhaustion, populations have been decimated, and survivors have been scattered as desperate refugees far from home. Who has not been tempted by cynicism when witnessing the pain and despair that humans are capable of creating? But the pillars of social democracy provide evidence that intelligent design and investment can produce institutions that channel human motivation for the broad benefit of humanity. I have no doubt that my doctors and nurses are caring people. They are motivated to help others. But they

are also interested in making a living, enjoying vacations, supporting their families, advancing their careers, and being recognized for their contribution to science and to their clinic. Social democratic institutions have been able to harness human motivation for tremendous benefit.

In preparation for the end of the US Civil War Abraham Lincoln reminded Americans that they can live as friends and not only as enemies, and that doing so requires nothing less than activating the better angels of our nature. Cynicism is a creeping disease that steals hearts already suffering pain and loss. It is also sometimes a fashionable stance of the well-educated who have known very little about such loss. The better angels are too weak, the cynic sneers. One tonic against the corrosive influence of cynicism is to keep alive “in the mystic chords of memory” our tremendous accomplishments, including the development, advancement, and application of medical science to the benefit of humanity.

The project of living well isn't just for the healthy. Living well includes living well with disease, and eventually living well facing death. I asked BF to write the epilogue, if it came to that. But the blog ended without the need for such an epilogue.

My illness was rare; my suffering was not. Being a patient is part of being alive. Nearly all of us go through it eventually. The virtues of patience, courage, trust, and hope serve us well. And a measure of good humor can't hurt. All of that I've learned by experience, and perhaps I've also managed to convey it in these essays.

