



# HOW TO BE A PERSON IN THE AGE OF AUTOIMMUNITY

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“I’m afraid that then dialectics in its total abstrusity is only good for totally sick, ill, and mad people”

*Goethe to Hegel on October 18, 1827*

This begins with the last meal I ate without being afraid. I remember it vividly. My friend Buyong was visiting me in Paris. I had already stopped working at that point because of pain in my joints. I was living off some money I’d saved. I was cautious of anything having to do with French bureaucracy, but mostly avoided seeking financial assistance because I had no idea what the fuck was going on with my body and assumed it was temporary. It was not. I’d moved to Paris after graduating from college in the States. I needed a change and was trying to avoid New York for as long as possible. Paris wasn’t supposed to be a brief stint; I intended to make a life for myself there. In the year I lived there before I got sick, I worked parttime in a restaurant and parttime for a documentary production company.

Buyong and I were at some restaurant in the Marais — the kind of place populated by middleaged French ladies who lunch. This was good. Buyong was in France and I wanted her to have a very French meal in an extremely French place. We were winning. We started off with foie gras, followed by mussels and fries, crème brûlée, two espressos, and some cigarettes. That night, I puked. The next day, I puked twice and shit ten times. Over the course of the following weeks, I continued to puke and shit exponentially: a scatological nightmare. Every cigarette made me puke. I lost over forty pounds and grew weak. My mother, across the Atlantic, cried into the phone. She thought I was dying. I finally took myself to the hospital and was admitted. My rheumatologist suggested I go to the rheumatology ward at the PitiéSalpêtrière Hospital. I was the youngest person in the wing by about thirty years. I’d already had many rheumatologists over the course of that year who couldn’t diagnose my joint pain. Though I arrived complaining of extreme pain in my abdomen, fatigue, and persistent diarrhea, my symptoms were ignored because I was in the rheumatology wing. I was put on steroids for the joint inflammation. The nurses continued to bring me plates of French hospital food: massproduced gems like cow’s tongue, cod puree, and blood sausage. One night, I fainted and knocked my head while I was in the bathroom. They started running every test they could. After a full year of undiagnosed symptoms and an acute crisis in which I spent a total of three weeks in the hospital, finally, I got a diagnosis: Crohn’s disease. That,

and ankylosing spondylitis, one of those diseases that's as awkward to say as it is to live with. Both are autoimmune in nature. Crohn's is a disease of the intestinal tract, while AS affects the spine and peripheral joints. The doctors were sparing in their emotional presence. Of course, this is a critical ability in their profession. They explained to me the incurable and chronic nature of these diseases, that Crohn's and AS are manageable through life-long treatment. At this point, I was struggling to understand. As a young person, I had recognized illness as a momentary state of incapacitation that would always go away. I had spent the whole year hoping my joint pains would be cured with antibiotics, or something. My mind invented increasingly elaborate explanations: maybe I'd contracted a virus from a friend who had traveled abroad; maybe I'd developed a bizarre allergy. But I hadn't.

The doctors insisted on a risky treatment of biologic drugs, either Humira or Remicade. Both are immune suppressants with the potential for terrifying side effects. Humira is selfinjected every two weeks and Remicade is given as an infusion in a chemo center every other month. They told me there was no alternative, but I'd heard that there were other drugs worth trying. I refused to believe that the treatment they offered was my only option. I insisted on a second opinion and asked to be discharged. They sent in medical students, nurses, residents, interns, and doctors to tell me that biologics were the only way. I was eventually taken off of the ineffective antiinflammatory steroids.

The supposedly chronic nature of the diseases got me searching for other options, and ultimately a more holistic view of the body. From my hospital bed, I would look up alternative treatments and scroll through Crohn's forums on my smartphone. Some people with Crohn's had their colons removed through multiple surgeries and were still dependent on medication. Some people quit their medications, adopted specialized diets, or went on extended fasts, and they claimed to be cured. I believed them and I still do. My doctors told me there is a lot of misinformation on the web. This is true, but I was willing to listen to the suggestions of people who actually lived with the disease over advice from those who merely studied it. Suspicious of anyone who tells me there is a singular approach to anything, I decided to leave. I crawled out of the hospital and all the way back to my apartment. I still don't know how I came out of that flare without the help of medication, but I do have a hypothesis. Before receiving a colonoscopy, I was put on a liquid diet for a few days. The night before the procedure, I drank a foul lax-

ative preparation. Since Crohn's manifests as ulcers in the intestines, every time I ate it was like putting sandpaper to an internal open sore. Resting my bowels allowed me to slow down the flare. Eventually, I was able to eat soft foods such as bananas and avocados. I rested in my apartment until I had enough strength to leave. Incapable of taking care of myself physically or financially, I got on a flight home to Philadelphia as soon as possible. The day after I landed, my knees started to swell and I couldn't walk again. Eventually, my digestive system gave way, too. This was my second flare, with many to come. The story continues as such: constant fatigue and discomfort punctuated by the brief, high dramas of flares and successive hospitalizations. I spent the greater part of two years lying down in a bed. These kinds of experiences are difficult to narrativize. There is no story arc. In "On Being Ill," Virginia Woolf writes:

Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to light...it becomes strange indeed that illness has not taken its place with love, battle, and jealousy among the prime themes of literature. Novels, one would have thought, would have been devoted to influenza; epic poems to typhoid; odes to pneumonia...But no; ...literature does its best to maintain that its concern is with the mind; that the body is a sheet of plain glass through which the soul looks straight and clear.

This is, of course, the romantic view. Sometimes it's not true; sometimes I'm the same asshole I was before I got sick. But as Susan Sontag once wrote, "illness exacerbates consciousness." As such, my life has been irrevocably changed by the experience of illness. There is a lot of shame associated with disease. Disease is not polite conversation, and at my age, a career — not wellness—is the expected goal.

I give voice to this period of my life not as an inconvenient period, but as a profound one worthy of being shared. I want to valorize my time in ways that have nothing to do with work, to say a big "fuck you" to every person at a dinner party who has ever pointedly asked me, "So...what do you do?" because I haven't "done" much in a long time. The story I'm telling here is equal parts a processing of the trauma of illness and an exploration of how



the body is treated under the regime of capitalism. Stories of illness like mine should not be kept away in beds and in hospital wards. They should be written so that we can understand the body as something beyond a sheet of plain glass.

The experience of sickness is profoundly alienating. The difficulty of communicating illness is evident in the poverty of language available to us to describe our physical ailments. *We express by simile: it feels like someone is stabbing me repeatedly with a sharp knife. It feels like someone is grabbing my intestines and squeezing them. It feels like I'm trapped in my own body.*

In *Illness as Metaphor*, Sontag speaks of the influential eighteenth century French physician Marie François Xavier Bichat, who called health “the silence of the organs” and disease “their revolt.” Under the influence of that image, only when we are sick do we become aware of our otherwise static, humming organs. Then there’s the parlance of doctors, which is a language of war. *Your immune system is your body’s defense system. It has gone AWOL. We are here to defeat it.* A militaristic approach is the prevailing ideology regarding autoimmune disease. My particular manifestation of autoimmunity is very specific — it occurs in my intestines and my joints—yet the basic mechanism is the same across a wide range of illnesses and symptoms. The immune system is perplexed and is driven to hyperactivity. *Autoimmune* — attacking the self. The immune system mistakes its own bodily materials for foreign agents and is confused about the distinction between self and other.

Autoimmune disorders are difficult to diagnose. For ankylosing spondylitis, the average time between the onset of symptoms and diagnosis is eight to twelve years. I was lucky; I only had to wait one year. But the process of diagnosis can often be discouraging and upsetting. Several specialists offered the wrong diagnoses, treated me with drugs unrelated to my condition, and called me hysterical — a hypochondriac. In contrast, I was also treated well by some very sympathetic and nurturing nurses. It reminded me that mediocre treatment is not necessarily the fault of individuals, but of understaffed hospitals. At the same time, I’m not the only one who has felt infantilized by doctors.

In “The Autoimmune Epidemic,” Donna Jackson Nakazawa writes, “Fortyfive percent of patients with autoimmune diseases have been labeled hypochondriacs in the earliest stages of their illnesses. Some of this, no doubt, has to do with the fact that 75 percent to 80 percent of autoim-

mune disease sufferers are women, who are more easily dismissed by the medical establishment when hard-to-diagnose symptoms arise.” In my case, this was echoed by friends and family who suggested that my pain was psychosomatic or the result of depression. Often, the identities of people with invisible disabilities do not fit neatly into either disabled or able-bodied communities.

Autoimmune diseases are being diagnosed with increasing frequency and boomed in the postwar era of unregulated development. The Mayo Clinic reports that the number of patients with lupus has tripled in the United States over the past forty years. Incidences of multiple sclerosis have risen at a rate of 3 percent every year in the U.K. and Scandinavia. Multiple sclerosis rates have doubled in the past forty years in Germany, Italy, and Greece, and type 1 diabetes has increased fivefold in the same time period. According to the NIH, twenty-four million Americans live with autoimmune disease.

Because of the rapid spread of autoimmune disease in industrialized nations, Nakazawa states, “Scientists the world over have dubbed it ‘the Western disease.’” The medical community remains unsure as to its origins, but often cites genetic factors. Others, unsatisfied with this weak causal explanation for these “Western” afflictions, have been exploring the environmental triggers of autoimmunity. One’s immune response is partially genetic. If you are not predisposed to autoimmunity, you are not likely to develop an autoimmune disease. Yet to not take into account environmental factors seems like a sanitization of a bizarre phenomenon, a reliance on the hermetic discourse of a medical field governed by specific protocols. I don’t mean to blame anyone specifically for the illnesses they have endured, but humans have likely participated in the creation of this situation. Our bodies have absorbed environmental degradation and the consequent chemical toxicity load.

If we explore the alternative to the medical community’s elusive explanation, we are left with a disease that is the result of unchecked capitalist production and its runoff. Just as autoimmune disorders have the confused body attacking itself, capitalism has humans attacking the natural world. Capitalism delineates a boundary between human society and the natural world; by separating them, it becomes easier to exploit the latter. What we are left with is bodies that are confused: incapable, on molecular level, of maintaining the basic boundaries that are constitutive of self. Mimicking, on a molecular level, the degrees of alienation and commodification that happen

to the body on a social and economic level.

There are currently no known cures for most autoimmune diseases. They are discussed as chronic conditions that must be in a lifelong process of mitigation through biomedical means. My doctors would plead with me, as I shuffled into their offices with my walker, to take Humira. Biologics are a new class of drugs, barely a decade old, used to treat a few autoimmune conditions. Humira, which carries a black box warning, is an exact clone of a human antibody. It's a human protein cultivated in the bodies of mice. These biologics function as immunosuppressants, essentially shutting down the body's immune system to prevent it from attacking itself.

But, left without its defenses, the body becomes vulnerable to fatal cancers, other autoimmune diseases, and opportunistic infections; Humira's medicine technology counteracted my body's self-destructive but "natural" behavior. Forget the dualistic mode of thought, in which nothing was wrong with me, but something was wrong with my body. The idea is that I was deficient, and the only way to become the optimal version of myself was to embrace a drug that would make me do no more than function, all for \$3,000 a month.

My doctors' assurance was that I would get well. I would be able to get a job with benefits that would allow me to pay for insurance. Biomedical treatment operates on a capitalist understanding of time. Rather than embracing the regenerative powers of the body, the idea is to get back to work as quickly as possible. It is the body's radical autonomy that resists commodification. To spite our optimal productivity, it gets sick. Sickness can be masked and treated but the body responds nonetheless. It reacts. It may take longer to recover than is convenient to your boss. We do not have time to get you better. We have time to make you functional. "You are too young to live like this!" became my wellintentioned doctors' refrain. "What a shame! We can get you back to work! You should be out living your life!" And so, they perpetuated the supposed narrative of health and death: illness is something which comes late in life, right before the end. They acted as if I was experiencing an inconvenience. As if I wasn't living my life anyway. They didn't understand that this experience had stripped and shed a light on me, making it simply impossible to carry on as before. There was no return to "normal."

They often asked me about what I did *before* I became sick. As if *that* was me, and *this* a brief interlude of discomfort. In fact, most discussions

in doctors' offices are about pain or discomfort. These are important issues. Proust wrote, "Illness is the doctor to whom we pay most heed; to kindness, to knowledge, we make promise only; pain we obey."

As my life came to be ruled by the sensation of pain, it became impossible to think about anything *except* the sensation of pain. But pain is only the partial story of the body, a symptom of an underlying problem, whether an injury or a systemic issue. Pain is the body calling out for your attention. I wanted to be healthy again, not simply living without pain. I wanted a medical practice that addresses the true health of the body.

I resisted starting Humira for this very reason. My doctor explained that the way to eliminate the pain and inflammation was to clamp down my over-active immune system. Doing this would prevent it from attacking my joints and my intestines, leaving me painfree. But it didn't take care of the underlying problem: my immune system is confused. Eliminating my immune system sounded like a bad — an incomplete—idea.

Most of my friends and family urged me to take what was offered. Even the people that I'd identified or had selfidentified as radical or leftleaning were suspiciously unsuspecting of the biomedical industrial complex: that every other industrial complex demanded rigorous scrutiny, but in matters of health and the body, medicine was unmarked and depoliticized. Here I was in the hospital, having my body completely compartmentalized — treated not as a living organism but as an alienated collection of symptoms. What I realized through these visits, and my increased aversion to biomedical intervention (even while it was keeping me alive) was a resistance to a cyborgian present. I was in a futuristic nightmare, watching my body change and having no control over it; getting postindustrial noise MRIs; having a blood transfusion and feeling two pints of someone else's cold blood course through my veins; getting a colonoscopy, where I was knocked out and a fiberoptic camera was stuck up my ass and through my intestines. I asked for a copy of the video, a request they did not take seriously, nor find humorous. I am not a neoLuddite. I am wholly indebted to modern science and technology for keeping me alive and in little pain. I believe in the specificity of cases. Sometimes biomedical treatment is inevitable and sometimes it is not, but I find expressions of the body purity problematic. Our bodies are not discrete entities. They constantly interface with organisms and substances in our environment. Body modification and augmentation is an ageold human practice. We have always been cyborgs.

Intellectually, I embrace the idea of being a cyborg, but in the midst of my health crisis I became opposed to this new identification. Faced with feeling less and less human, I clung to a particular idea of humanity denied through current medical practices. My symptoms also made me feel human, in a particularly disagreeable way.

The primary, most easily identifiable symptom of Crohn's disease is diarrhea. In my worst flares, I would shit upwards of thirty times a day. I sacrificed entire days to incessant shitting. I was forced into more intimate relations with my body — relations that underscored my lack of control, thus my lack of civility, and ultimately my body's radical realness. Nothing killed my ego more quickly than being an adult and having people I don't know (nurses) or people I know well (my father) take away my bedpan and wipe my ass.

I'm nowhere near the first person to take shit seriously. Scholar Cindy LaCom cites the theoretical underpinnings of our shit adverse culture in "Filthy Bodies, Porous Boundaries: The Politics of Shit in Disability Studies": Lacan suggested that the only thing distinguishing humans from animals is that we are ashamed by our shit. In "The Power of Horror," Kristeva writes, "Excrement and its equivalents (decay, infection, disease, corpse, etc.) stand for the danger to identity that comes from without: the ego threatened by the nonego, society threatened by its outside, life by death." Shit reminds us of the fact that we shit, that we are in part biological process, not just social relations. Bataille saw the liberatory potential of human excrement and all the abject substances humans expulse in order to live.

IRA political prisoners in Northern Ireland during the "No Wash" protests of the '70s and '80s put this strain of thought into practice by refusing to wash. They shit, pissed, and vomited all over their cells. Women stopped using menstrual paraphernalia. They stopped performing social order and stopped conducting their bodies as expected.

We police our own bodies for the greater social order in a variety of ways. Only clean, sanitized bodies are allowed to participate. There were many things that I was unable to do while I was sick. For a whole year, I fucked no one. There were some technical issues, but that doesn't mean I didn't want to. I had the stamina of someone on her deathbed, but beyond that, to be sick and to desire is a faux pas. My doctors were anxious for me to get back to work, but some human activities were never discussed. Sexuality is the right of those designated as "healthy" in our culture. A quick scan of



contemporary popular culture suggests that aside from the most able-bodied (white, straight, cis-bodied, and of means), it is repulsive and “unnatural” for the sick, the disabled, or the elderly to talk about or openly engage in sexual conduct.

The abject body aside, it is difficult to conceptualize the body in general under the current cult of health. Descartes discusses the body in mechanical terms. Sontag notes the metaphor of the body “as a factory, an image of the body’s functioning under the sign of health.” What happens when our bodies “revolt” and the factories stop functioning so smoothly? Perhaps they are trying to tell us something about their working conditions.

We are at a point at which the highly efficient mechanization of the body of the factory worker under capitalism has given way to the virtualization of our labor through the Internet (and through the extraction of our labor from other places).

The advent of the smartphone has usurped leisure time from the working able-bodied. According to the Critical Art Ensemble, a tactical media collective, people with smartphones are cyborgs who can be accessed at all time as autonomous 24-hour workstations. We’ve moved from a system based on the production and consumption of goods to a mystical finance capitalism. The increased virtuality of labor, not unlike the administering of biomedical technology, is meant to make life more convenient. Increased ease of life is the ideal that we assume technology fulfills. And yet as advanced capitalism has deemed the physical body an obsolete, outdated tool, the body still remains. It continues to fail under capitalist conditions and gets pathologized as illness. The body is another inconvenience that must be enhanced and optimized.

As our society views itself as approaching pure rationality, our bodies become subject to utilitarianism. In “Flesh Machine,” Critical Art Ensemble writes, “[The body] will be made to function instrumentally so that it may better fulfill the imperatives of pancapitalism...physical perfection will be defined by an individual’s ability to separate he/rself from nonrational motivation and emergent desires, thus increasing he/r potential devotion to varieties of political-economic service.” Capitalism objectifies the body. It views the body as an exploitable resource and attempts to render it indestructible and unstoppable with the aid of technology. Nothing is sacred; all is fair in the service of capital. In the U.S., there are no limitations on hours clocked in, and there are no mandates for employers to provide sick days to their

employees. The body's natural weaknesses and limitations are ignored. I'm hesitant to take an evolutionary approach, but our bodies have not changed for hundreds of thousands of years. What we do with them is radically different from our humble beginnings. I'm primarily concerned with whether these technologically engaged practices lead us toward increased autonomy or increased subservience.

Health and wellness become an ideological tool deployed to normalize the body in the interests of capitalist production. This is made all the more effective and complicated because wellbeing is naturally desired by the patient and can be administered through selfcare. The paradox is that I want to feel better more than anything else.

I've been sick and unemployed for what feels like a long time. Before I became sick, I was fairly industrious. In college, I produced cultural events and lectures, I started clubs, I negotiated with the school administration, I took five to six classes per semester. I often did more than was expected of me and I spread myself thin. I went from incredible levels of productivity to spending most of my time alternately convalescing in a bed or puking in a toilet. I was chronically fatigued; getting dressed in the morning required a gargantuan effort. And on some days, holding a book or feeding myself was exhausting. Expectedly, I developed feelings of guilt over my inability to be a productive member of society: moralizing my disability as sloth, viewing my body's natural limitations as personal failure. I was anxious to get back to work. I still occasionally have these feelings of anxiety, but for the most part they have subsided. After my fourth flare, I gave up on the idea of being employed for a while, accepted that it wasn't a viable option for me. The pace of my life slowed down. I stopped multitasking. I became more forgiving with myself. I realized that there was nothing wrong with me. A German activist group called the Socialist Patients' Collective (SPK) addresses the internalized desire to work by casting the relationship between patients and doctors in a Marxist framework. For the SPK, everyone is sick under capitalism. For some, their bodies make them more aware of this. The SPK was formed in 1970 and existed for about a year. Before their dissolution, they managed to put out some fiery propaganda. Their slogan was, "Turn your illness into a weapon." They also wrote, "Sickness is the condition and result of capitalism." As a perpetual patient, this rhetoric is refreshing. The chronically ill are often cast as victims of fate or genetics. Rarely are we politicized or allowed to

relate our personal experiences to larger social or cultural phenomena. As far as doctors are concerned, our diseases are empirical facts and not much else.

Following the logic of SPK, being ill appears to be a de facto resistance to the established social order, to capitalist production and subsequently to the engendering of material relations between humans. Disease necessitates unemployment and unemployment is a social disease. When we are sick, we enact unintended resistance to an economic system that privileges efficiency over resilience.

Of course, illness predates capitalism, but the physical impairments that make the condition of wagedependence unlivable were not always disabling. The social model of disability maintains a clear distinction between disability and impairment. Impairment is an illness, injury, or congenital condition that causes loss of ability or partial ability to function. Disability, in contrast, signifies a particular relationship to one's environment. Disability is the reflection of barriers that prevent people with impairments from participating in society. For example, when I have difficulty walking, it is a physical impairment. I am disabled not by my physical impairment, but by the fact that many buildings don't have ramps or elevators. Capitalism is an economic system that assesses bodies in terms of labor power, designating certain bodies as useful and others as not. Physical or mental impairment as an excuse for exclusion from social or economic life is endlessly reinforced under this system.

So what does this resistance by way of illness look like? Sometimes it looks like leisure. Ah yes, leisure: the time we have when we are not at work, the time that we own. According to the Situationists, leisure is a cruel trick: it's our precious time sold back to us as a commodity. After my many hospitalizations, there was always a period of convalescence. Convalescence is a bourgeois activity much like leisure. Sontag writes, "The Romantics invented Invalidism as a pretext for leisure, and for dismissing bourgeois obligations in order to live for one's art. It was a way of retiring from the world without having to take responsibility for the decision." I was at times grateful for catching a break from my own high standards for myself. I imagined myself a nineteenth century waif relaxing in a Swiss sanatorium. I was able to convalesce for many reasons, including the fact that I lived at home and was financially supported by my mother. Under the Affordable Care Act, I am covered under her insurance plan for six more months. I am blessed. I live

in a country where I have access to medical care, albeit at great cost. When I was first hospitalized in the States, I stayed for five days and left with a \$52,000 bill – most of which was covered by my insurance. In France, I was hospitalized for three weeks and left with only a bill for the television in my hospital room. Everyone is minimally covered in France, yet as a low-income resident I qualified for 100 percent coverage.

I suffer from a disease that is not stigmatized or associated with so-called deviant or immoral behavior, unlike people with HIV or hepatitis. I am allowed to be a victim and no one assumes that I got what I deserved. While I was sick, my time was not economically exploitable in the Marxist sense. I could not contribute to the work force. What happens when time is not money? I spent a whole year mostly lying in a bed producing nothing; extremely bored. Maintaining remission and taking care of myself required a lot of my time. In order to justify my unemployment, I still thought in capitalist time designations, and would tell people that taking care of myself was a “fulltime job.” If I was not seeing a specialist, getting medical tests, or in physical therapy, I spent most of my time on the Internet, probably as bored as you were at work. For many chronically ill and disabled people, the Internet is an invaluable social space. I was bedbound and it became my life. Nerds have lived virtual lives since the advent of virtuality, but for those of us whose physical bodies can seem like a burden or an ontological prison, the Internet functions as a utopia of sorts.

No one knew I was sick. My Facebook presented an able-bodied version of myself stagnant for many months. On the net, my healthy self was frozen in poses of youthful exuberance, running around the city of Paris, wining and dining. Really, I was immobile in my mother’s one-bedroom apartment in Philadelphia, at times in a wheelchair, at times needing assistance for basic activities like brushing my teeth or holding a glass of water. To this day I have very few images of this period of my life. The day a friend decided to post a picture of me using my cane was a big day for me.

Over the months I have become more stable. I reluctantly started Humira, the drug that I had avoided for over a year. I told my doctors that I wanted to try to heal myself holistically and they skeptically agreed to monitor me while I took myself off of the steroids that had gotten me out of the previous flare. My gastroenterologist told me that I wouldn’t last a week without my medication. I adopted a raw diet, exercised regularly, slept a lot, meditated daily, went to acupuncture, and went to psychotherapy. I took no pills, ex-

cept for some vitamins that I had been deficient in, and I lasted two months, to the surprise of my doctors. Then everything started to go downhill again.

I remained in this cycle of watching my health deteriorate rapidly, followed by long months of recovery. The minute I felt well again, I would start flaring and the cycle would continue. After the last course of steroids, I decided to go with Humira for some more stability. I was desperate for relief. It's too early to tell, but I think it is helping make the daytoday more manageable. I'm trying to accept this as the step I had to take, while still hoping for a less detrimental option in the future.

I'm still highly suspicious of the biomedical industrial complex. Over the past few years, I have found myself completely and inextricably tied to this world in a way that I didn't want to be. I desire an alternative and I still believe that one day I won't need this medication to live. Yet, currently, I'm fully dependent on Humira for my functionality. It is difficult to conceive of resistance to something that I need right now. The current battle is to not to let ideological extremes play out on a mental or physical level. I have a tendency to think it is allornothing with my health. If I'm pumped full of toxic drugs, I can eat crap all day, never exercise or sleep, start smoking and drinking again. If I'm off of medication, I have to eat clean, exercise daily, and sleep a minimum of eight hours per night. Definitely no drugs or alcohol. For the moment, I'm trying to find a middle ground that means taking my medication diligently, taking care of myself, and allowing for vice in moderation.

I left my mother's place and have been living in New York City for a month now. I am on the hunt for work and an apartment, much like the quarter million people who move here every year. For everyone hustling in this metropolis, it can be quite stressful. I try to stay calm and not worry about the twoyear gap on my resume. I've dealt with worse things. In college, I used to work my body to the bone, swallowing fistfuls of amphetamines to get as much done as possible. I can't handle that anymore. I still struggle with deadlines, but I refuse to make them at the expense of my body. My body has aged considerably. I need those eight hours of sleep. I need nutrients.

When I first started dating my current partner, they asked me, "What is it that you want?" I said, "To be happy and healthy." "That's what old people want." I said, "I've been through some things that old people go through." My experience has made me less invested in notions of success and more invested in notions of happiness. At the risk of sounding condescending and



corny, I will say that I feel simultaneously late in the game and over the game. I have no idea what it's like to work fulltime, in the same place, for over a year. I'm 25, so not having that experience makes me feel left behind. Yet sometimes, my peers' office concerns seem as absurd as a Dilbert comic strip. Unlike my oversubscribed friends, I'm learning how to say "no," and I refuse to overbook myself.

Since we associate illness with old age, it's no surprise that we view the elderly as the ultimate refuse of our capitalist system. Just look at how we treat them. I still don't have the wisdom of an old person. Despite my wariness towards my doctors' capitalist urgings, I crave normalcy. I can't wait to get back to work. I'm at a place in my life where I'm trying to find out whether I am capable of making a living on my own or whether I need to take my social security appeal more seriously. In all of this uncertainty, all I can do is try to be my own advocate and remain medically informed.

My hair and bones have thinned from previous medications. I still have trouble with stairs. I'm still exhausted. I've been diagnosed with a third autoimmune condition, Graves' disease. Now I get to see three different specialists. I know that the rest of my life might be spent mitigating side effects. But already there have been improvements: I've gained the weight back. I only shit once or twice a day. I can walk for longer than two minutes without being in pain. I'm learning to navigate this disease, anticipating flares before they spiral out of control. I try to remain in the present. My next flare may come in six days, six weeks, six months, six years — or never. This condition of existence requires an openness to the ebb and flow of things, an understanding that everything changes — for better or worse.



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