Dedication to Disease

Carl Zimmer has written works on the roles parasites play in everyday life and their etymological evolution. According to Carl Zimmer in "Parasite Rex", the word parasite originated from the Ancient Greek word 'parasitos' literally translating to 'beside food' and was used to refer to officials serving food at temple feasts. A biological crossover of vernacular would not happen for many centuries, however, Aristotle recorded creatures encased in cysts that lived on the tongues of pigs. Eventually this word shed its etymological restraints and became a standard character, featuring its own mask, in Greek comedies (par. 1). The ancient Chinese and Egyptian civilizations made notes of plants that would destroy worms surviving in the human gut (par. 2). According to Zimmer, the fiery serpents that the Bible depicts as plaguing the Isralelites in the desert were described as "quivering strings of flesh", which are now known as guinea worms. In Asia and Africa, someone invented a "cure" for such parasites that would snap in two, if vanked out, leaving one alive portion inside the host body that would cause a fatal infection. This cure involved resting for a week and slowly twisting the worm onto a stick to keep it alive until it was finally free. It is even suggested that this cure was represented in the symbol of medicine itself: two serpents winding around a staff (par. 3). Even as late as 1824, guinea worms were studied in their 'natural environment' and led to the discovery that they were a product of too much acid in the blood. Most scientists of this time came to the conclusion that these entities were presumably generated in the bodies they appeared in, like maggots appearing 'spontaneously' on a corpse. This idea was not tested until the late eighteenth century when scientists and skeptics alike showed how the maggots were actually laid as eggs by flies that then grew into flies themselves. The parasites discussed before were all visible to the human eye, but

in 1673, they were joined by a slew of invisible ones (par. 4). Anton van Leeuwenhoek was the first person to lay eyes on bacteria using a microscope of his own design to study collected rainwater. The Dutch shopkeeper in the city of Delft decided to dedicate his own body to his microscope, studying the rod-shaped creatures he scraped from his teeth before a hot cup of coffee to his loose stool blob with eel-shaped leggy creatures. His body was a microscopic home to parasites (par. 5). Johann Steenstrup, a Danish zoologist, was the first to realize that parasites could break "the rules of the life cycle" as we knew it. Studying the leaf shaped body of the fluke, found in almost any animal a parasitologist looked at, and knowing that flukes laid eggs, and yet no one had ever recorded a baby fluke in its host. Steenstrup would later be proven right on their theory that many parasites chose to travel between host bodies during their life cycles, alternating between different forms from one generation to the next. There is no shame in being a parasite and there is no progress backward or forward; parasites will force their host to change without going in any direction. (Chapter 1)

Megan Milk describes parasites and their function in literature and writing as being "organized around imposition, infection, and itch" (5). The parasite in this context wishes to infiltrate the social body of literature and destroy it from within. Appropriative writing has been categorized as derivative, feeding on the life/blood/brains of other texts, vampiric, however, it does provide a political strategy of inserting the self into otherwise selfless bodies of work. Parasitic experiments create opportunities for 'others' to insert themselves into texts that do not include them. Parasitic writing provides a model for thinking about oppositional appropriative writing; it produces chronic irritation, it sucks, it burrows, and relies on being a direct contrast to the pure machine of conceptual writing. This form of writing insists on bad boundaries, impurity, exploiting power asymmetries, and enacting imposition on the host text and reader. The post-Enlightenment western concept of the self-body-text and its bounded, impermeability, and sovereignty are laid to waste as the parasite form is recognized as vulnerable, susceptible, and permeable. The relationship between host and parasite is usually unethical, one-directional, nonconsensual, and nonmutual. The agent of imposition and occupation may also be an agent of symbiosis, intersubjectivity, and allyship. However, the parasite will always take more than it gives back and is given. This form of writing does not work toward something, it just works, and in this way, the parasite rejects the logic of avantgardism. Parasitic writing will infect and create a system change or tilt. According to Megan, "To write like a tick: find a sweet spot and suck until swollen." (9). The tick will extract the hosts contents, gorging itself while leaving an infectious bite, then detaches and finds another host. The scabies mite enters the skin and travels subcutaneously, chronically irritating the surface, eating tissue and depositing eggs, reproducing itself inside it. The tongue-eating louse functions by "Hang[ing] out in the mouth, siphoning away the tongue's blood supply until the tongue falls out and you have replaced it with your own body" (12). To write in this form means sliding into the host text through the gills, attaching to the tongue with claws, and occupying the mouth with new hungers. The tapeworm absorbs food through its skin and its entire body is a mouth-gut system. To write in this fashion is to impersonate "a consumption machine" (13). The fluke attempts transfiguration, beginning in fecal matter, eaten by a mollusk perhaps, which may be eaten by a bird. The fluke is changing forms for each stage and to write in this form is to be consumed by multiple host bodies while creating rationality through inter-species escapades.

Cystic fibrosis is a rare genetic mutation that affects the pancreas, lungs, and other organs. It is a progressive disease that close to 40,000 children and adults are living with in the United States. An estimated 105,000 people across 94 countries have been diagnosed with CF.

Mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene cause the CFTR protein to become nonfunctional. When this protein is not working properly, chloride- a component of salt- is unable to move to the cell's surface. Chloride usually attracts water to the cell's surface, breaking up thick and sticky mucus in various organs. This mucus, in the lungs, can clog airways and trap germs, like bacteria, leading to inflammation, respiratory failure, and infections. In the pancreas, this buildup of mucus prevents the body from absorbing food and key nutrients by preventing the release of digestive enzymes. Improved medical treatments and care mean that people with CF can expect to live fulfilling lives into their 30s, 40s, and beyond. People with CF can have a variety of symptoms, including: 1. Very salty-tasting skin, 2. Persistent coughing, sometimes with phlegm, 3. Frequent and persistent lung infections, 4. Poor growth or weight gain despite a good appetite, and 5. Frequent greasy, bulky stools or difficulty with bowels.

Cystic Fibrosis is a word I heard for the first time while breastfeeding my three week old daughter. Raye Jules Devlin was born on July 31st, 2018 at 12:14 am, weighing 6 pounds and 4.5 ounces. My husband had been deployed to the Middle East in May of 2018. Unable to return home for the birth of his first child, I was watching the tears fall from his face through an IPad propped up on the table beside my hospital bed. Over the course of three weeks, from her birth to the phone call I received from LCMC in Metairie, Raye had lost weight; she was now 5 pounds and 4 ounces. The doctors assured me over the phone that I should do no research on my own and that the majority of the things I would Google would scare me. The first visit to Dr. Davis' office consisted of a sweat test, designed to calculate the amount of sodium or salt in a person's sweat. Raye scored incredibly high on this test, which confirmed the results from the Newborn Screening. Cystic Fibrosis has only been a mandatory screening for the last fifteen years. The

next step was to get her on a pancreatic enzyme that worked best for her specific mutation and her specific challenges. The first pancreatic enzyme she was prescribed was Creon. These capsules do not come in a liquid form, which meant I was required to empty capsules into a baby spoon, cover the granules with vogurt, and then make sure she swallowed them before every feeding. Now four years old, Raye has evolved with her treatments of care. She now takes Pertzye, another pancreatic enzyme, which has proven to help her retain weight better. Orkambi, the genetic mutation specific modulator, is taken by mixing the packet of granules with a fat containing food every twelve hours. Ursodiol, Cyproheptadine, Famotidine, and Pulmozyme are also given every day. Cyproheptadine is an antihistamine that has the main side effect of increased appetite, because of this it must be cycled on for 20 days and off for 10. As she has gotten older, she has also been fitted for an Airway Clearance Vest, which is a machine that inflates a vest with tubes of air and then shakes at a frequency of 20 hertz. This machine lasts for twenty minutes a day and must be done twice a day, unless she is sick in which case the vest is done four times a day. Pulmozyme is an inhaled synthetic protein that breaks down excess DNA in the pulmonary secretions of people with CF. This medicine is administered through a nebulizer which must be sterilized after every use. People with CF are also steered away from tap water and distilled water as sterilized water is the best for preventing infections from bacteria and other pathogens in tap water. Orkambi requires close monitoring for liver failure and because of this Raye must complete a full comprehensive metabolic panel of blood work every three months.

In this exercise of Milk and Zimmer's view on parasites, the research nor the researchers who wrote these articles will be discredited. This is simply an exercise to make something new out of that research and provide a fresh set of eyes to view that research. Dissecting these researcher's articles provided me with new insights into the field of research literature and this parasitic experiment is aiming at providing a new audience with similar feelings. The self I am inserting into this experiment is the idea of babies as parasites, the self as a parasite, and motherhood as an act of parasitizing one's self. This is a warning: this experiment will contain descriptions and images of mature content.







I am uncomfortable, *itchy*, scratchy. My skin feels afire with the sins of generations of women that came before me. I am burning for I am a woman and this is mine and mine alone to bear. Begotten from the initial twings of pain I have felt for years, culminating to this epicenter of emotional and physical violence that I have chosen to inflict upon myself. I am alone with my thoughts but a voice is cutting the mental fog through iPad speakers that drew me from the brink of death itself like a warm knife slides through our countertop butter, sitting in a little red dish ordained with a rooster atop. Sweet flashes of the five years we have spent together light me with a new fire, determination to overcome this feeling of being split in two. Consciousness returns, I am self-aware and back. I am struck with the soreness of my throat, a scream I do not recognize is escaping my gritted teeth while I claw into an arm that reaches for me with a desperation that I will soon come to know very well. It's hairy. Like really fucking hairy. Dad? Oh, sweet relief. I know that the man attached to this hairy arm would rather die himself than let something of malice happen to me, someone who just 14 minutes ago was screaming at the top of his own lungs that little bean needed to hurry up so they could share a birthday. How could I do this though? It felt like weeks that I had been laying here being poked and prodded with needles and monitors. It had only been twenty-four hours at this point but my brain was telling me to give up while my body was pushing like a tugboat, hauling ass to make up time because there was something important on the line. My life, it felt like. Here comes the vomit. Fuck me. As if childbirth didn't come with enough things to go wrong, now I'm on

this bed grasping at the little thin plastic blue bag with sweaty hands. Throwing up has never been easy for me, even during all day sickness (cause ya can't really call it morning sickness if it lasts all day), I struggle to breathe properly and everything goes white. More vomit, more sweat, more tears. But oh, sweet bliss as the drugs run through my veins, numbing from the small of my back to my splotchy painted toenails. Funny how once I could no longer rationalize this amount of pain, my body succumbed and gave one final hoorah while the sounds of gasps, clapping, and hands running over an itchy hospital gown that adorned my upper body grated against my inner ears, breaking my body out in tiny hills where hairs sprouted. Her voice. I can't hear it. Why isn't she crying? Why can't I see her? I'm moving my head as fast as I can but three nurses and a doctor stand before me pulling and pushing a needle with string in and out of an area I lost feeling in long ago. My dad has his back to me, he cut the cord, but why is he crouched over that little plexiglass table with that nurse? I close my eyes for a moment and awake to that hairy armed man brushing hair out of my face and handing me the most angelic set of eyelashes I have ever seen on a head before, wrapped in a pretty pink and blue blanket. They told me the cord was wrapped around her neck and that's why I never heard her cry out for me. She is absolute perfection, all six pounds and four ounces of super heartburn inducing hair riddled body.

Three weeks later, I would hear the word 'Cystic Fibrosis' for the first time in my life and no one could stop the irrevocable damage those words inflicted on the fleshy casing around that empty but now drumming cavity in my chest.

Fitzgerald:

Background: There is a paucity of research examining the impact of informal caregiving on parents of young children with cystic fibrosis (CF). The aim of this study was to examine caregiver burden and identify risk factors associated with high caregiver burden in mothers and fathers of young children with CF. Oh they mean how I have spent every day for the last one thousand four hundred and sixty days prepping seven medications twice a day, feeding high fat and protein foods to her for three meals a day, paying well over five thousand dollars out of pocket for medications and treatments, ensuring she consumes enough calories to keep just above the five percentile for BMI just to be told that a G.I. tube would be our next option, constantly fighting with her about how she can't just eat whenever all of the other kids are eating because she needs enzymes before every meal, finding new and exciting shows for her to watch twice a day as a treat for doing her airway clearance vest for twenty minutes each session, or maybe it's just the fact that I have to explain to her everyday that I made her special and that she can't do all of the things her friends are doing or want her to do because she may get overheated too quickly, exert too much salt out of the cells that are already overflowing with chloride, or I don't have her inhaler with me so running too fast isnt option. They mean stuff like that right? Life's dedication to a lifelong challenge.

Methods: This was a cross-sectional study of parents of young children with CF. A total of 213 families were invited to complete the CarerQoL questionnaire, a validated tool composed of two parts: (i) the CarerQol-7D which describes the care situation in terms of the negative and positive effects of caregiving and (ii) the visual analogue scale (VAS) which measures happiness on a scale from 0 to 10 (0 = completely unhappy and 10 = completely happy). The utility score (US) is a weighted average of the subjective burden derived from the CarerQol-7D (0 – 100); higher US indicates reduced burden. Differences in mother-father dyad median utility scores were examined using Wilcoxon signed rank test. Generalised linear mixed models were used to identify factors associated with high caregiver burden.

Results: At least one parent from 195 families completed the questionnaire (130 mother-father dyads, 189 mothers and 137 fathers). Fathers had a significantly higher median utility score than mothers [(89.2 (IQR 79.6–96.5) vs. 84.7 (74.5–88.0) p b 0.001]. Factors found to be significantly associated with higher caregiver burden were increasing child age (OR 1.02; CI: 1.00–1.04), having a child ever positive for Pseudomonas aeruginosa (Pa) (OR 2.48; CI: 1.30–4.73) and

being a mother (OR 1.65; CI: 1.02–2.65). No shit father's scored higher. They are always the optimists in these situations. My own husband once refused antibiotics because he wasn't convinced she couldn't fight it off herself. It being a culture that had a heavy growth of Staph in her lungs. Two days later of me being home all day to care for her and I finally filled it. Those fathers were out of the home for work, usually Monday-Friday and only got glimpses of the burdens the mothers face and conquer daily, day after motherfucking day with no paycheck, no real results being seen, while still expecting the house to be neat, clothes to be washed, dishes to put away, dog to be cared for, bills to be paid, and somewhat of a social life maintained.

Conclusions: This study contributes new findings to the sparse literature on caregiver burden of parents of young children with CF. Increasing child age and infection with Pa, associated with higher morbidity, were linked to greater parental burden.

Challenges for caregivers of young children with CF include; ambiguity about disease progression, financial strain due to direct and indirect costs associated with care, adherence to complicated treatment schedules, frequent outpatient clinic visits, disruption to family life due to hospitalisation and complexity with making plans due to uncertainty about changes in their child's health status. Planning her funeral will break me. And I don't mean metaphorically. I mean a literal psychotic break. I already worry about otherwise frivolous things that could harm her and worry about her making friends and the prospects of that dropping lower and lower as she stays about the size of the average two year old while approaching five. and those chances of making friends dropping even more when they see her getting pulled from classes for meds and looking like she is getting special treatment from the school staff. even thinking about the chances of her having the ability to play with her friends like she wants too with a G.I. tube sticking out of her perfectly rounded little tummy, cause they make caps for them but nothing says be my friend like warning people not to be too rough with you, or you might have to go to the hospital to have your tummy tube cleaned. And don't you dare start thinking oh this lady has lost her mind because until you live it, you don't get a say. But you have a point i guess, i cannot shield her from life or love or sickness for my sake or peace of mind because i refuse to be a selfish parent. we took a vow, my husband an i, to never helicopter parent our children and so far it's really fucking hard. everything is scary, everything is a threat to her life and on her life. she's starting school this august and that brings a whole new level of threats, not just biological warfare but the

threat of physical warfare is something that sits hard within my stomach like stones i have swallowed every day for the last one thousand seven hundred and twenty-five days to date.

In general mothers and fathers of children with CF reported comparable VAS scores (where higher scores indicate being in a happier state) with caregivers of other children with chronic illness like haemophilia and autism spectrum disorder [13,19]. In this study fathers reported significantly higher median utility scores compared to mothers and being a mother was also found to be independently associated with increased caregiver burden.

In this study, the vast majority of mothers identified themselves as the primary carer for the child. Studies have shown that informal caregivers may have limited time to pursue their own interests. A study by Quittner [20] found that mothers of children with CF had minimal time for recreational activities in comparison to the control group (mothers of children without a chronic disease) and they also spent more time on household activities and childcare at weekends.

AR Smyth:

The last half century has seen a dramatic improvement in the life expectancy and quality of life for people with cystic fibrosis (CF) [1]. Much of the early improvement in these outcomes has been attributed to the frequent use of 14 day courses of intravenous antibiotics, particularly for those patients who have chronic pulmonary infection with Pseudomonas aeruginosa [2]. Furthermore, long term antibiotic regimens are used in CF such as oral azithromycin and inhaled antibiotics (e.g. <u>colistimethate sodium</u>, <u>tobramvcin</u> and aztreonam). Each of these approaches will contribute to the selection of resistant organisms in the CF airway. Patients with CF may therefore develop chronic pulmonary infection with multi-drug resistant organisms including: P. aeruginosa; methicillin resistant Staphylococcus aureus (MRSA); Burkholderia cepacia complex and non-tuberculous mycobacteria, particularly Mycobacterium abscessus [3]. simpler terms, this means that the medications that are prescribed to help fight the symptoms of CF in specific areas of the body come with their own risks of contributing to other awful symptoms, case in point, Raye. She now cultures Staph in every culture, spaced out to test every three months, and her growths vary from light to heavy, she now has methicillin resistant bacteria that grows in her lungs literally all day every day and we just wait for it to become heavy enough to present symptoms like excessive coughing to the point of vomiting, fever, chills, ear infections, among many others.

Hayley Kimball:

Individuals with cystic fibrosis (CF) are at high risk of clinically significant anxiety, which can be related to lower treatment adherence and poorer health outcomes. Additionally, up to half of the parents/caregivers of children with CF experience clinically significant anxiety. Ya no shit

huh? Our kids are diagnosed with a life long, progressive disease that will likely force us to bury them six feet under the cold ground, have them incinerated, or donate that precious perfect body to be worked on as a cadaver. I know that sounds dark and maybe I am a bit macabre now that anxiety pretty much has full reign over my decision making as a mother but what the hell else am i supposed to rely on? Research has focussed on CF youth aged 13 years and older, leaving anxiety among school aged children (aged 6-12 years) largely unstudied. This review aimed to synthesize research on anxiety among children with CF and their parents, examining prevalence, risk factors, and relationships between parent and child factors. Four electronic databases were searched, and publications were included if participants were children (or parents of children) with CF with a mean age between 6 and 12 years, and a standardized anxiety measure was used. Data from fourteen studies were extracted for descriptive synthesis; however, no studies focussed exclusively on the age range of 6–12 years. Results generally indicated that anxiety is highly prevalent in both child and parent populations; anxiety was the most prevalent mental health condition among children with CF, and anxiety was higher among CF populations than control populations among both children and parents. However, there were disparities, with some papers finding low rates of anxiety, and results on the relationship between anxiety and health outcomes varying greatly. Several risk factors were identified, but few were corroborated. There is an overall deficiency of research in this area, particularly examining the relationships between parent and child anxiety, and anxiety and health outcomes. Hmm. wonder why no one wants to do research on families suffering from these incurable diseases....Further research on suitable screening and intervention practices is also required. More research? on this bullshit? How about we focus our efforts a little on finding a real cure instead of placating parents and patients with drugs that have wild ass side effects, sticking them with G.I. tubes as four years old, and charging enough to make even millionaires go broke in the process? Forgive me for being crass but dealing with this shit is a pain in my ass.

Lucy Allen: We are currently witnessing transformative change for people with cystic fibrosis with the introduction of small molecule, mutation-specific drugs capable of restoring function of the defective protein, cystic fibrosis transmembrane conductance regulator (CFTR). However, despite being a single gene disorder, there are multiple cystic fibrosis-causing genetic variants; mutation-specific drugs are not suitable for all genetic variants and also do not correct all the multisystem clinical manifestations of the disease. For many, there will remain a need for improved treatments. Those patients with gene variants responsive to CFTR modulators may have found these therapies to be transformational; research is now focusing on safely reducing the burden of symptom-directed treatment. However, modulators are not available in all parts of the globe, an issue which is further widening existing health inequalities. and not to mention that companies like Vertex and Chessi are charging ON THE

LOW END twenty three thousand dollars for this medication. A life saving medication, which costs more than a used car in most places. and that's the reality of it every fucking month if you don't have insurance and god forbid you try and figure out how to submit the correct paperwork the government needs to Medicaid because I have tried three times and waited on the phone for more than three days time (if accumulated) trying to figure out why she keeps getting denied for services she obviously qualifies for.

<u>J Guo: Current Prices versus Minimum Costs of Production for CFTR Modulators</u> CFTR Modulators are those fancy things I explained that are a biologic medicine that infiltrate the cell wall and change that cells malfunctioning protein made by the CFTR gene. pretty fucking crazy what they can make to change the literal cells of your body, huh? so there are four different CFTR modulators on the market currently and they each have specific age groups in which they have been cleared by the FDA to be given. They are also specific to genetic mutations within respective CF patients.

Number one: Trikafta. which is elexacaftor, tezacaftor, and ivacaftor and approved for anyone ABOVE AGE FIVE with AT LEAST one copy of the F508del mutation or one copy of 177 specified mutations.

Number two: Symdeko. that only has two modulators which are tezacaftor and ivacaftor and is approved for anyone ABOVE AGE FIVE with TWO COPIES of the F508del or A SINGLE COPY of one of 154 specified mutations.

Number three: Orkambi which has lumacaftor and ivacaftor and is approved for anyone ABOVE AGE ONE who has TWO COPIES of the F508 del mutation.

Number four: Kalydeco which has just ivacaftor.

(Raye is a DDF508 or Double Delta F508 mutation and on ORKAMBI) so what are these big ass words attached to the drugs?

Ivacaftor- potentiator that binds to the defective protein at the cell surface and opens (and holds) the chloride channels so that chloride can flow through.

Tezacaftor- corrector that helps CFTR protein form the right shape, traffic to the cell surface, and stay there for longer periods of time.

Lumacaftor- corrector that helps CFTR protein form the right shape, traffic to the cell surface, and stay there longer, though only about A THIRD of the CFTR protein reaches the cell surface and those proteins do not open enough to allow chloride to pass through the cell membrane.

Background: While the clinical benefits of CFTR modulators are clear, their high prices render them inaccessible outside of the world's richest countries. Despite this, there is currently limited evidence regarding global access to these transformative therapies. Therefore, this study aims to estimate the minimum costs of production of CFTR modulators, assuming robust generic

competition, and to compare them with current list prices to evaluate the feasibility of increased global access to treatment.

Methods: Minimum costs of production for CFTR modulators were estimated via an algorithm validated in previous literature and identification of cost-limiting key starting materials from published routes of chemical synthesis. This algorithm utilised per kilogram active pharmaceutical ingredient costs obtained from global import/export data. Estimated production costs were compared with published list prices in a range of countries.

Results: Costs of production for elexacaftor/tezacaftor/ivacaftor are estimated at \$5,676 [\$4,628-6,723] per year, over 90% lower than the US list price. Analysis of chemical structure and published synthetic pathways for elexacaftor/tezacaftor/ivacaftor revealed relatively straightforward routes of synthesis related to currently available products. Total cost of triple therapy for all eligible diagnosed CF patients worldwide would be \$489 million per year. Comparatively, the annual cost at US list price would be \$31.2 billion.

Conclusions: Elexacaftor/tezacaftor/ivacaftor could be produced via generic companies for a fraction of the list price. The current pricing model restricts access to the best available therapy, thereby exacerbating existing inequalities in CF care. Urgent action is needed to increase the availability of triple combination treatment worldwide. One strategy based on previous success is originator-issued voluntary licenses.

All this to say that the shit is overpriced and for no fucking reason other than that the drug manufacturers and those shareholders and the FDA all profit from selling it at astronomical prices for people that do and do not have insurance. even with insurance (and a damn good plan at that) one month's supply of Orkambi costs one hundred and fifty dollars, Ursodiol (which is compounded at a local Specialty Pharmacy) costs seventy dollars for a FIFTEEN DAY SUPPLY. But i must buy it because it keeps her alive and i must not complain because really now she could have it worse im sure. And i cannot complain when she fills my life with so much joy that just the thought of waking comes with a sense of adventures to be had, memories to be made, coring out portions of my brain specifically for those moments that just scream out to my inner child saying TAKE THE FUCKING MENTAL PICTURE ALREADY SHE"S GROWING UP AND BEFORE YOU KNOW IT SHE WILL BE GONE

now what to do i do?

keep learning, keep pursuing, keep fighting, keep donating, keep supporting. this fight is not hers to fight, nor her burden to bear. i must fight, i must win, for i am all that stands between her angelic little head adorned with the sweetest set of hairs, atop the mightiest of three foot shoulders, and the stench that wafts from my bruised five foot rotting flesh suit. my own mortality mocking the ways in which i stare at her face while she's far away from pain and discomfort, dreaming of pegasi that take our family to waterparks, catching glimpses of the smile pricking the corners of her rose pink lips.

how the hell am i ever going to survive without her? You're right. i can't. so i wont.

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