

Victims of Progress: Examining the Collateral Damage of Medical Technology

Three days before my sixteenth birthday, my cousin Jake was in a very serious car accident. So serious, that he remained in a coma for about six weeks, and no one expected him to live. More accurately, no one expected him to live on his own, since the medical wonder machines that we refer to as “life support” were keeping him alive. Coming from a large family that is very tightly knit, my father is the youngest of ten brothers and sisters, all I remember hearing for months were the newest details on Jake’s condition. When everything seemed dire, as it did for a time, everyone wondered what my Aunt and Uncle would do. Would Jake, lying in that hospital bed, be kept in some state we call “life” by machines, not walking, not talking, not even opening his eyes, until someone could not take it anymore?

My Aunt and Uncle, Jake’s parents, are very staunch Catholics, and there was no doubt in my mind that they would keep their son on life support for as long as at least one of them was living. I remember trying to discern how I stood on this issue, while I listened to my elders carefully debate. I knew that I would not want my parents to keep me living as a vegetable, but I felt that it was perhaps wrong for me to feel that way, that it was wrong because my family would be shocked by such an idea. I certainly was not starting a campaign to have the plug pulled on my cousin, but I was not sure that would not have been better. My guilt increased when Jake woke up, and began to recover.

When I say that he was “recovering,” I do not mean that he was ever again the person he was before the car crash. Jake makes eye contact and speaks using a keyboard now, but he will never walk again, talk again, or be the strapping young man I remember him being. Jake was in college when the accident occurred, and he didn’t have much use for younger cousins like me, so

I didn't know him well. But he was a football star in high school and was never without a pretty date for a social event, and I have been led to believe that he lived a standard, if a bit reckless, existence. I don't know that boy anymore, or perhaps more accurately, he doesn't exist any longer.

When Jake was awake, and had been moved out of the Intensive Care Unit, my parents took my younger brother and I to visit him. When we walked in, Jake, who had always been built and muscular, lay emaciated and sloppily propped up against his bed pillows. His mother was there, talking to him, though his only response to her was the same stolid stare he gave to everyone, and which could've meant anything or nothing at all. I can easily recall the forced tones of normalcy in the voices of my parents, how it pained me not to hear them speaking of things as they were. When they asked Jake how he was feeling I thought at first that it must be clear he was not feeling great, but then I realized that none of us had any idea what was running through his now damaged mind. I do not know if I said much more than "Hi Jake," after I entered the room, but he took to staring at me in such a way that he made me more uncomfortable than I have ever felt before. His gaze was a heavy, unwavering one, and it sickened and upset me, so much so that I needed to make an excuse to leave the room.

There was nothing grotesque about Jake's appearance that caused me to flee, but his stare had confirmed for me what I had hesitantly thought since I learned of his coma: no one should have to live as he did. I told my parents the night after our visit that if anything in a similar vein were to happen to me, I would expect them to take my body off of life support and allow me to die. I would not want to be such a heartbreaking burden on my family, and the idea of living so dependent and utterly helpless a life seems completely contrary to humanity. I have not seen Jake in years, but on one of my parent's visits to him, since he has begun using the keyboard to

communicate, he asked about me, and typed out the correct spelling of my name. My mother wondered at it and told him that she was impressed because “your cousin always complains that no one ever remembers how to spell her name.” There is something about this that affects me just as much as Jake’s stare; I wonder if I am to him a representation of the trajectory his life was supposed to take. I am about to graduate college and head into the world of jobs and first apartments and real-life ambitions, and he has been arrested in a state that is unlike childhood, adolescence, or adulthood.

Emmanuel Levinas tells us in his *Totality and Infinity* that “the face is present in its refusal to be contained”.¹ Perhaps what I saw, what Jake was showing me, when he turned his face and eyes upon me, was the true essence of Jake. That is to say, that even though Jake was now contained in a damaged body and mind, the fundamental nature of him still existed, and he could show it to me through what was for me an intense and moving moment of eye contact. I do not think that this was all I experienced in that moment, however, because why would that have made me so emotionally and physically uncomfortable? One could argue that seeing a glimpse of the vibrant individual within a pathetic container would be disturbing enough, but it felt more that Jake’s essence, that indescribable something that is solely his, was speaking directly to that part of myself. The heavy and lucid stare that Jake leveled on me did not have any questioning hesitation in it, nor was there any anguish of a plea for help. In the midst of a cooing mother and my awkwardly chipper parents I felt him tell me without words that he would rather be dead.

“The face puts me in question,” it “demands justice,” and “opens the primordial discourse whose first word is obligation,” Levinas tells us.² In front of Jake, I felt called into question. Throughout the debates about whether or not he should be kept on life support, I kept secret my

conviction that he should be allowed to die. It was as if Jake had seen that in my face which might have been exerting a “refusal to be contained,” and he was holding me accountable for my lack of action.³ Levinas thinks that the face of the other “is what forbids us to kill,” and he may still be right; I certainly was not about to do anything that would end Jake’s life.⁴ Nor, I think, was he asking me to, rather he was giving me the unhappiest validation of a gut feeling that I have ever experienced.

Now that Jake speaks with a keyboard, I have wondered what could come of an intimate discussion with him. There is little probability that I would ever be able to visit him alone, but if I could, what would I say? I certainly could not come right out and ask him if he wants to be dead. Even if I could present the question tactfully, I doubt that he would answer in the affirmative. I maintain that the Jake who told me he would rather be dead is not the one who I would be speaking with. The few times I have seen him in recent years, I have noticed that his gaze seems glassy and detached. The facts are that his brain is no longer what it once was, and never will be again. Arguments about the nature of the self aside, I doubt anyone would try to tell me that he is the same person as before. That being said, what I do know to be true is that the man I refer to as my cousin Jake becomes very frustrated and irritable often, and there is something in his frustration that reminds me of an animal in a cage. Perhaps there is a glimmer in him of the old essence, and because of that I have never questioned the sense I get that Jake would not have chosen his current lot.

What I do question, however, are the decisions of his parents. Jake’s life is filled with hospitals, medical rehabs, and surgeries to fight the infections he frequently gets because of his feeding tube. I reject the idea that life is always the right choice. We as a species have waged a war on death with modern technology and though there have been beautiful victories, there is

also a great deal of pain. Pain that we have extended to suit the purposes of the healthy and grieving. There is what Daniel Callahan calls an “unending human effort to understand and pacify death” that has led to the transformation “of an extended critical illness...into an extended dying”.⁵ We are striving to discover the secret to a dignified death, but I am not certain that technology is the answer, at least not in every case. Is it dignified that Jake will now die as half the man he was, without a miraculous and uplifting recovery story? I see no dignity in extending the dying of our loved ones, and subsequently extending our own grief.

There is a sense that we as human beings do a great disservice to our kindred in comas or vegetative states, either perpetually on life support or eventually left to battle with devastating and irreversible brain damage. It is interesting though, that we don't do the same disservice to our pets, our “domesticated animals,” who are in our lives so fleetingly. When one is told that their dog is afflicted with cancer and that they are and will be in great pain until their death, we decide without hesitation to “put the dog down” and euthanize it. We cannot bear to be the reason that the beloved pet would suffer for one more second, and yet we keep our family members alive in suspended animation for years even after the doctors tell us that there has been no change in their condition, and that there is still no hope. It is clear that keeping our loved ones alive has more to do with our peace of mind than that of the unfortunate individual, but by refusing to pull the plug we are only sustaining our own agony.

I do not believe it is unfair to say that we would find keeping a dog in pain alive cruel. Yet, when a terminally ill patient in pain asks for euthanasia, we deny them. The dog cannot even give us consent, but we favor the assumption that they would probably rather be dead than a cognizant request from another person to be allowed to die. Is there a way in which we hold other people to a higher standard that suggests that we should tolerate pain until the “natural”

end? And if so, why isn't this cruel? We are not only doing an injustice to the unfortunate individuals, but to our living counterparts and ourselves.

One needs only to look at Jake's mother to instantly see how caring for her son has affected her. The already naturally slender woman is painfully thin and pale. She is the one who is always at Jake's bedside, trying to make him comfortable and manipulating his limbs in an attempt to prevent blood clots. I admit that I don't know much of my aunt's hobbies or interests, but I know that whatever they were, they have been forgone in order to become the constant caretaker. Surely Jake does not want to be constantly left alone, but I doubt he wants to see his mother live an empty life. Not to mention that Jake is not her only son, and her relationships with her other son and daughter cannot be what they once were, now that her time is so absorbed with a single undertaking. Why does Jake's mother shoulder this suffering and disperse it to the rest of the family? I would argue that the fight against death is not worth pursuing if a shadow of a life is the price you pay, especially when you are fighting for a life other than your own. I do not mean to suggest that every person in need of constant and exhausting care should be abandoned by their family, or that there are not such cases in which a person is born with disorders or illnesses that require them to always live in such a state. I restrict my point to cases like Jake's, where his life has become what it is due to a choice made by his parents. That is not to say that my aunt and uncle wished to see Jake suffer or live as he is, but they chose to keep him on life support despite knowledge of major and irreversible brain damage. The result of this choice has made a lasting negative impact on their family unit, for not only have they taken on the burden of caring for Jake, they have given him the burden of being a burden.

I mentioned earlier that Jake often gets frustrated now, but this frustration is not because of the actions of those who care for him. He is rather frustrated with his own futility, and his

inability to do for himself any longer. When Daniel Callahan recalls the people he has seen die what we would describe as “peaceful deaths” he notes: “they grieved for those who would have to bear their loss. They sought to put those around them at ease, anxious not to carry others down with them”.⁶ I would argue that even those who do not get to die a particularly peaceful death do attempt to or desire to shoulder their suffering in a way that takes as much pressure off of their loved ones as possible. It is in this way that we seek to protect the people we care about and to prevent ourselves from becoming a victim of our own deaths. Conversely, Jake has become a victim to his life, rather than his death. Jake was not permitted to “find [his] own meaning for death and die [his] own death”.⁷ If we trace what has brought him to the current point in his life back to its origin, one could say that he chose to drive somewhat recklessly and those choices were what led to his cataclysmic accident. There, behind the wheel of his car, he made the last personal decisions of his life, the last decisions that were his own. Perhaps if Jake had not been put on life support and he died just after that crash, we could have called his death his own. It would have been seen as tragic and devastating, youth cut off in his prime, but Jake would have owned it. Now his death may be utterly inconsequential because he lives a life that he cannot take control of.

Jake’s parents, and many parents in the same position, have made their choices because “the greatest threat to the self is that of death, the utter destruction and disappearance of the self”.⁸ In our human consciousness, and the collective idea of medicine, death should be avoided at all costs. It is with this in mind that Callahan addresses our use of modern medicine to stave off death, but I think his assertion that “this is not to say that death is necessarily the worst fate that can befall the self” is more important to the current discussion.⁹ I knew the first time that I saw Jake after his accident that his fate was one that I considered less desirable than death, and I

knew when he made eye contact with me that he agreed. My concern is that our obsessive and oftentimes counterproductive work towards avoiding death has produced these fates worse than death that we are content to leave our loved ones in so long as we are satisfied that we have not let them die. No matter how many times we wish for our own quick, painless, and peaceful death, it is as if we would rather watch a person suffer indefinitely rather than let them slip through our fingers.

Consider the idea that we must now allow people to die. I stated previously that Jake had not been “permitted” to die as his actions alone would have caused him to, and many like him are kept alive because others are given the decision to pull the plug or not. It seems so crass to say, “pulling the plug,” it makes someone’s death as simple as the flick of a switch, yet the simple act is weighted so heavily. When the living and healthy loved ones are given such a choice, no one wants to be “responsible” for the unfortunate individual’s death. One does not get to pretend or wonder if the death could have been their fault or not, like the members of a firing squad who may or may not have had guns loaded with blanks. It is too straightforward for our taste, and much too weighty, a decision that will allow someone to die. Note that earlier I stated that no one ever wants to be the reason why their pet would continue to suffer, yet we will be bystanders to human suffering as long as we do not have to take responsibility for their death.

There is much to be said for modern medicine and the ways in which it saves and sustains life. We no longer have to fear that women and children may not make it through childbirth; technology allows doctors to pinpoint complications and avoid them. Infants and young children can be easily treated for colds and afflictions that once struck down many before life even began. The medical community can beat diseases that were once seen as terminal, and we are able to wholly eradicate diseases like polio or smallpox from entire countries. We have so many

effective weapons to use against the natural forces in our bodies that there are times when we feel like we could not possibly lose any fight. Technology has given us more hope and life than people even a hundred years ago could have imagined, yet it has also given us an obsessive need for control.

Jake's parents were given the option to take him off of life support during the weeks that he was in a coma, and there is no guarantee that he would've lived or died had they chosen to pull the plug. It is doubtful that he would've lived for very long after the accident if not for the amazing medical technology we have today, but Jake has paid the price for cheating death. He will never walk or speak again. He only has use of his left index finger and thumb. He has a feeding tube that is constantly causing infections, and though speech therapists are working with him on learning to swallow, he only eats normally on rare occasions and with very heavy supervision. There is no recovery for Jake, and there is no brighter future. The technology that saved his life may have performed a medical miracle, but it has only cursed it's recipient. Jake has no control over his life anymore, and his parents don't have any control over their son's recovery. Despite all that the doctors can and have done for Jake, neither Jake, his parents, nor the medical professionals have won the battle in this situation. Jake suffers because those around him refused to let him die. Where is the pity for these unfortunate guinea pigs of progress? I am not suggesting that Jake should be euthanized. I do not know if he desires to die at this point, nor do I think he's lucid enough to handle that kind of decision. But, I am loathe to watch his life continue the sad way it does, knowing that different decisions could've prevented all of his pain and frustration. Jake is a victim of progress, one of the many, who's needs and happiness have been sacrificed to the will of technological ambition and a strange moral paradox. We do not

want to watch people suffer, but we do not want them to die, therefore we seem unable to make clear and concise decisions that would benefit unfortunate individuals like Jake.

Having spent so much of the past few weeks writing this and thinking about Jake, I plan to visit him over my holiday break. Maybe I will not tell anyone but my parents about it, and I'll get to speak to him alone. Perhaps I can attempt to construct a conversation, to communicate with and learn about this blood relative who had no time for me before the accident, but seems to remember the unusual spelling of my name that troubles so many without brain damage. It is possible that I may find myself to have been completely wrong; that Jake has a zest for life I hadn't been able to pinpoint so early in his recovery. The problem is that I don't believe that at all, and I am afraid of finding confirmation in his eyes.

Notes

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- ¹ Emmanuel Levinas. *Totality and Infinity: An Essay on Exteriority*. trans. Alphonso Lingis. Pittsburgh: Duquesne University Press, 1969. 194.
 - ² Emmanuel Levinas, *Totality and Infinity*, 201, 294, 207
 - ³ Emmanuel Levinas, *Totality and Infinity*, 194
 - ⁴ Emmanuel Levinas. *Ethics and Infinity*. Pittsburg: Duquesne University Press, 1982. 86.
 - ⁵ Daniel Callahan. *The Troubled Dream of Life: Living with Mortality*. New York: Simon & Schuster, 1993. 1.
 - ⁶ Daniel Callahan, *The Troubled Dream of Life*, 221
 - ⁷ Daniel Callahan, *The Troubled Dream of Life*, 222
 - ⁸ Daniel Callahan. *False Hopes: Why America's Quest for Perfect Health Is a Recipe for Failure*. New York: Simon & Schuster, 1998. 142.
 - ⁹ Daniel Callahan, *False Hopes*, 142