Denied: Privacy, Dignity, Death

When I think about memories, I think about sights, sounds, smells. Mostly, I think about feelings: the way I felt at a certain place at a certain time. When a memory is vivid, when I can remember the granules of time that make up a minute, an hour, a day, I find that those are the moments that define our lives. And I can picture four days so clearly, even fifteen years later. I was nine years old, in the fourth grade, and from what I can recall, generally happy in life. One afternoon, I got off the school bus and walked through my front door. Both of my parents were waiting for me; the only time I remember seeing both of my parents at home in the middle of a workday was on September 11, 2001.

With my hand in hers, my mommy sat me down on the sofa in our family room and told me my daddy had cancer. I got off the sofa and gave my daddy a hug, but I wasn't sure why. I equated a cancer diagnosis to a minor illness, no worse than a stomach flu or a cold. You go to the doctor, take your medicine, and get better. So why was mommy blotting away the tears that streamed down her face with a Kleenex? At nine years old, you can't comprehend the gravity of cancer, and you certainly cannot comprehend, much less be told, that your father has a diagnosis of stage four esophageal cancer, which carries a mortality rate of 95%[1]. I didn't learn this information until several years after my father had passed; he fought a courageous, eighteen-month battle, one he and everyone around him except for myself, knew he would eventually lose.

The second, third, and fourth days came toward the end of those eighteen months. The second was the Thursday, August 31. My daddy was on the phone with his friend, sitting on a couch next to one of many strategically placed trashcans around the house. I sat on the adjacent

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[1] (2021). *Survival Rates for Esophageal Cancer*. https://www.cancer.org/cancer/esophagus-cancer/detection-diagnosis-staging/survival-rates.html#written_by.

recliner, watching television, eating McDonald's my daddy had gotten me on the way home from summer camp. He asked his friend how his holiday weekend had been; in 2006, Labor Day took place on Monday, September 4. My daddy had developed a blood clot in his leg, which I believe was deep vein thrombosis (DVT), a common side effect for individuals receiving chemotherapy to treat cancer[2]. Although uncommon, the blood clot in my daddy's leg likely caused him to have a series of small heart attacks and strokes. It was impossible for me to know this, but I still think back to that conversation, and wonder to myself if I could have done something.

The third day was the worst day. I had been staying at my aunt and uncle's house, which I eventually realized was to keep me unaware of the fact that my daddy had been in-and-out of the hospital over the past several days for persistent chest pain. They were hosting a barbecue at their home the day before Labor Day. I hadn't expected either of my parents to show up, but my mommy came shortly before sunset. Again, she took my hand, and led me to one of my cousin's bedrooms. She sat me on the bed and looked up from the floor. She told me about the heart attacks and strokes, words by this time I knew were indicative of something very wrong, and she told me that daddy was being taken to a place called hospice. She explained that hospice was where people went to be comfortable while they waited to pass away. I hugged her, and we cried, and then they took hold. The butterflies. The butterflies that have colored my life ever since I found out that there was an invisible, uncontrollable clock counting down my daddy's time on Earth. The butterflies that caused severe anxiety, panic attacks, depression, chronic migraines, and gastrointestinal distress. My uncle took me to a baseball game the next day, in an effort to make me feel better and make the most of the last day of summer. The butterflies refused to go away, and so, at the suggestion

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[2] (2020). *What is Venous Thromboembolism?*. https://www.cdc.gov/ncbddd/dvt/facts.html.

of my uncle, I prayed. I must have said a hundred Hail Mary's, and while that helped, I knew the butterflies would be back.

The fourth day was the one time I was allowed to visit my daddy in hospice. My mommy had been sleeping at the facility, and I'd been bounced from family member to family member until the fateful day came. That was when I learned the very real difference between living and being alive. My daddy was lying helpless in a bed, previously occupied by countless others in the twilight of their lives, now blind, deaf in his left ear, and paralyzed on the right side of his body. The tumor in his esophagus had grown so large he could no longer eat or speak. The room was full of family, a pre-season football game playing in the background. I'm sure everyone there wanted to create some semblance of normalcy, but there's nothing that can prepare you for seeing your father in a diaper, unable to respond to your greeting with anything other than moans. I didn't stay long. I don't think anyone thought it was appropriate for me to be there, and I didn't know if that was meant to be our goodbye. I told him I had scored "Advanced" on all metrics the State used to measure academic progress. He was the enforcer of education in the household, and based on the way he thrashed in his bed, I could tell he was proud. I told him I loved him, gave him a hug, and that was it.

On September 13, 2006, my aunt picked me up from school and family started arriving with no rhyme or reason at her house. Eventually, my mommy arrived, gave me a big hug and said, "We lost our daddy today." That day isn't as memorable: I had been prepared, and I had known it was coming. I even acted like it was an event. I remember saying to my friends on the playground, "You can come to my daddy's funeral if you want." A detached, blasé attitude was my coping mechanism, and it was the only thing that kept the butterflies from consuming me.

I spent many years since striving to be an artist, specifically a fashion designer. This was something my daddy knew when he passed. Perhaps I chose to pursue that path, even when my passion for it started to wane, because it was all my daddy knew and would ever know about me and my future career. When I began college, and started an extremely rigorous art and design program, I finally realized that I was unhappy. I began to engage with the liberal arts, learning about the world and challenging my beliefs. College is where I learned about physician-assisted suicide, and began questioning everything I had understood about my daddy, his illness, and life after a cancer diagnosis. I couldn't help but wonder, did he have to suffer? Did he have to go through agonizing chemotherapy and radiation treatments? What choice would daddy have made if he had one? Would we have taken a long family trip somewhere exotic and beautiful, and at the end of said trip he would take a handful of life-ending prescription pills with a glass of wine (or, in my daddy's case, a tumbler of Crown Royal)? Regardless of what choice he would have made, that option wasn't available to him, and is still not available across 80% of the country[3].

According to the American Medical Association, physician-assisted suicide can be defined as the facilitation of death by a physician for a patient by providing the necessary means and/or information to enable a patient to perform a life-ending act[4]. The American Medical Association advocates against physician-assisted suicide, stating,

> "It is understandable, though tragic, that some patients in extreme duress – such as those suffering from a terminal, painful, debilitating illness – may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good. Physician-assisted suicide is fundamentally

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[3] (2021). *Death with Dignity Acts.* https://deathwithdignity.org/learn/death-with-dignity-acts/.

[4] (2022). *Physician-Assisted Suicide*. https://www.ama-assn.org/delivering-care/ethics/physician-assisted-suicide

> incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks. Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life.”

The American Medical Association goes on to assert that physicians should not abandon a patient once it has been determined that no cure is possible or available, must provide effective, quality communication and emotional support, and must provide appropriate comfort care and adequate pain control. Conversely, the same list of requirements also asserts that physicians must respect a patient’s autonomy. The American Medical Association also states that, “Physicians are expected to uphold the ethical norms of their profession, including…respect for patient self-determination.” Physicians are also expected to “honor patients’ informed decision to refuse life-sustaining [note, not saving, sustaining] treatment, and respect basic civil liberties…” These guidelines on ethics seem to contradict one another: how can a physician respect a patient’s right to refuse life-sustaining treatment and respect their basic civil liberties, but allow them to suffer, in pain, without intervening?

I can only imagine this was one of many questions asked of a terminally ill patient like Brittany Maynard. In 2014, Maynard, a 29-year-old advocate for terminally ill patients’ right to die with dignity, herself dying of brain cancer, took a lethal medication prescribed by a doctor and died “‘as she intended – peacefully in her bedroom, in the arms of her loved ones”[5]. Maynard’s life ended strategically, in Oregon, one of only ten states nationwide that have laws allowing terminally ill patients with a prognosis of less than six months to live to end their life with the assistance of a physician, who cannot be prosecuted for prescribing medications to hasten death[6].

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[5] Schabner, Dean. (2014). *Brittany Maynard, Advocate for Death With Dignity, Ends Her Life*. https://abcnews.go.com/Health/brittany-maynard-advocate-death-dignity-ends-life/story?id=26644431.

[6] (2021). *Physician-Assisted Suicide Fast Facts.* https://www.cnn.com/2014/11/26/us/physician-assisted-suicide-fast-facts/index.html.

Physician-assisted suicide, or physician-assisted death (PAD) as is the preference of many proponents, is mandated by State Law in Colorado, the District of Columbia, Hawaii, Maine, New Jersey, New Mexico, Oregon, Vermont, and Washington; California and Montana can mandate physician-assisted suicide by Court Ruling.

According to Editorial Research conducted by CNN, "Physician-assisted suicide differs from euthanasia, which is defined as the act of assisting people with their death in order to end their suffering, but without the backing of a controlling legal authority." The Vatican and Catholic Church do not seem to differentiate between euthanasia and physician-assisted suicide, or perhaps do not care to acknowledge the distinction. According to *The Washington Post*, in 2014, Pope Francis denounced "'the false sense of compassion' [in reference to] those who [regard] euthanasia as 'an act of dignity.[7]'" Pope Francis has repeatedly criticized the right to die movement, calling euthanasia, "'A sin against God, the Creator.'" The Pope's commentary followed similar sentiments from Ignacio Carrasco de Paula, President of the Pontifical Academy for Life and the Vatican's top official on Ethics and Biology, and Medicine, who directly condemned Maynard's decision and said in a statement, "Assisted suicide is an absurdity. Dignity is something different to putting an end to your own life.[8]"

Shortly before her death, Maynard spoke to *CBS This Morning* in October 2014, stating, "I'm not ashamed to attach my name to what I think is a right that should belong to all terminally ill Americans…Cancer is ending my life. I am choosing to end it a little sooner, and in a lot less pain and suffering." In learning more about Maynard, her bravery, her advocacy, her determination

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[7] Mckenna, Josephia. (2014). *Pope warns against the 'false sense of compassion' in euthanasia*. https://www.washingtonpost.com/national/religion/pope-warns-against-the-false-sense-of-compassion-in-euthanasia/2014/11/17/2b795502-6e8c-11e4-a2c2-478179fd0489_story.html.

[8] CBS. (2014). "Brittany Maynard's mother delivers sharp response to Vatican criticism." Uploaded on November 19, 2014. YouTube video, 2:49 min. https://www.youtube.com/watch?v=8kRyeN0gNrM.

to expand the rights of terminally ill Americans, I began to feel a sense of melancholy. My daddy's 2006 death far-predated the progress that has been made since, and would have hardly been accepted by many members of our devout Roman Catholic family. But my question still lingers: what choice would he have made, if he had a choice to make?

The debate over physician-assisted suicide goes beyond the rights a terminally ill patient should have and the dignity of choosing how one dies in the face of a fatal prognosis: it enters the seldom-examined realm of privacy, and the choices an individual has the right to make, in the privacy of their home, so long as those choices do not harm anyone else. In spite of the American Medical Association's assertion that "physician-assisted suicide is fundamentally incompatible with the physician's role as healer," prolonging death simply for the sake of doing so does not seem to match the professional values outlined.

As Maynard asserted, the right to choose how one dies in the face of a terminal illness should be a right extended to all Americans; I would go so far as to argue that the right to die by choice and with dignity is a civil liberty, defined by Cornell University's Legal Information Institute as "rights guaranteed by the Constitution…natural rights which are inherent to each person. While they are commonly referred to as 'rights,' civil liberties actually operate as restraints on how the government can treat its citizens[9]." Physician-assisted suicide may not be explicitly codified as a civil liberty (at least outside of the states where it is possible to acquire such assistance), however, a civil liberty that has been enumerated is the right to privacy. If it is not possible to argue, at this time, that physician-assisted suicide is a civil liberty on its own merits, perhaps it is possible to do so through the lens of privacy extended to individuals, which has been

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[9] (2022). "*Civil Liberties*." https://www.law.cornell.edu/wex/civil_liberties.

repeatedly affirmed by the United States Supreme Court, even in cases involving an individual's body and health which almost certainly fall under the purview of a physician.

In the landmark Supreme Court case of *Griswold v. Connecticut* (1965), the Court found in a 7-2 decision that the Constitution protects the right of marital privacy against state restrictions on contraception. Further, the Court ruled for the first time in its history that a right to privacy can be inferred from several amendments in the Bill of Rights[10]. In his majority opinion, Justice William Douglas wrote, "The association of people is not mentioned in the Constitution nor in the Bill of Rights. The right to educate a child in a school of the parents' choice—whether public or private or parochial—is also not mentioned. Nor is the right to study any particular subject or any foreign language. Yet the First Amendment has been construed to include certain of those rights[11]." Why then, is the right to die with dignity in the face of a terminal illness not subject to the same liberties as those outlined by Justice Douglas?

A subsequent landmark Supreme Court case, *Roe v. Wade* (1971), found in a 7-2 decision that the fundamental "'right to privacy,'" as written in the majority opinion by Justice Harry Blackmun, is inherent in the Due Process Clause of the Fourteenth Amendment[12]. The Due Process Clause protects a pregnant woman's choice to undergo an abortion, a procedure that would surely violate the ethical standards outlined by the American Medical Association. The Supreme Court found, however, that the Due Process Cause of the Fourteenth Amendment protects against state action the right to privacy, and a woman's right to choose to have an abortion falls within that right to privacy. Justin Blackmun also noted that the state does have legitimate interests in protecting both the health of pregnant women and the "'potentiality of human life,'" but what if that

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[10] (2022). "*Griswold v. Connecticut*". https://www.oyez.org/cases/1964/496.

[11] Douglas, William. (2022). "*Estelle T. GRISWOLD et al. Appellants, v. STATE OF CONNECTICUT*".https://www.law.cornell.edu/supremecourt/text/381/479.

[12] (2022). "Roe v. Wade." https://www.oyez.org/cases/1971/70-18.

potentiality no longer exists? If faced with a terminal diagnosis, wherein an individual will die in six months or less under the most excruciating of circumstances, shouldn’t the rights applied to pregnant women in *Roe v. Wade* be extended to those whose potentiality of human life have been depleted by illness?

In the third of the three prominent privacy cases argued before the Supreme Court, the Court held in a 6-3 decision in *Lawrence v. Texas* (2003) that the State of Texas may not make it a crime for two individuals of the same sex to engage in sexual conduct, as it is a violation of the Due Process Clause of the Fourteenth Amendment[13]. Writing for the majority of the Court, Justice Anthony Kennedy wrote, ‘“Their [referring to couples of the same sex] right to liberty under the Due Process Clause gives them the full right to engage in their conduct without intervention of the government.”’ The themes presented in each case run parallel to one another, and represent the federal judiciary’s vested interest in protecting the civil liberties of individuals on the basis of privacy.

That vested interest is not solely based on the implicitly implied right to privacy, but on the basis of an individual’s right to choose what he or she, as a consenting adult in the privacy of his or her own home, has the right to do within the confines of the law as protected by the Constitution of the United States of America. Although not explicitly enumerated, the rights of terminally ill patients should be considered civil liberties and protected under established precedent. Proponents of the right to physician-assisted suicide have formed the non-profit organization Death with Dignity, which not only outlines why the terminally ill should be guaranteed certain civil liberties, but simultaneously dismisses the positions of organizations like the American Medical Association. The American Medical Association argues that physician-

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[13] (2022). “Lawrence v. Texas.” https://www.oyez.org/cases/2002/02-102

assisted suicide is incompatible with the role of a healer. Death with Dignity makes it clear that physicians who offer such services do so of their own volition and free will; as outlined by Death with Dignity, “There are no lists of healthcare providers who participate in assisted-dying laws, for both confidentiality and safety reasons. Provider participation in the law is strictly voluntary…Any physician licensed to practice in a ‘death with dignity state’ is allowed to participate if they agree. The law also says every physician has the choice not to participate.[14]”

In further contrast to the American Medical Association, according to a 2016 Medscape survey, 57% of medical doctors favor physician-assisted suicide; this represents an increase of 11% in only six years, imagine how much that percentage has increased in the six years since Medscape’s last survey? Additionally, several medical associations have endorsed physician-assisted suicide, including the American Public Health Association, the American College of Legal Medicine, and the American Medical Student Association. How do these statistics and endorsements further the correlation between physician-assisted suicide and the implicitly implied right to privacy? According to Death with Dignity,

> “…aid-in-dying laws require your provider to advise you *not* to take the medication in a public place…laws also stipulate consequences for taking the medication in a public place by allowing governmental entities that incur resulting costs to recoup them from your estate. An additional issue is the need for a funeral home to be able to reach the area to remove your remains; most funeral homes refuse to do so in a public place.”

It is not only clear that the states which have enacted laws to assist the terminally ill value each patient’s right to privacy, but there are a number of laws in place to protect the patient and ensure each one meets the standards necessary to make such a request. For example, “Patients must meet

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[14] (2021). “*Frequently Asked Questions*.” https://deathwithdignity.org/learn/faqs/

stringent eligibility requirements, including being an adult, state resident, mentally capable, able to self-administer and ingest the medications, and having a terminal diagnosis with a prognosis of six months or less to live. There are no exceptions." Other laws in place to protect patients and the sanctity of the practice of physician-assisted suicide include a mandate that two physicians, one of whom is the patient's attending physician and thereby familiar with the patient's case, must confirm the diagnosis. Each physician must be licensed by the state to practice medicine and certified to prescribe medications. Additionally, requests for life-ending medication must be stopped immediately if there is any suspicion or evidence of coercion. These are only three examples of laws out of scores that exist in the ten states that have chosen peace over pain, individuals over institutions, dignity over death.

When I think about all this information, this research, the amount that I've learned about physician-assisted suicide, or physician-assisted death, or simply the right to die with dignity, the more I wish my daddy had the choice. In retrospective conversations with my family, it seems evident my daddy was determined to undertake his unwinnable fight, but what if he hadn't? What if he chose to die peacefully, at a time and place of his choosing, surrounded by loved ones, who would never know of the butterflies that come while you wait for someone you love to die? If I was terminally ill, with less than six months less to live, I'd like to think that's how I'd go, or, at least have the option to choose that's how I go. Forty states have yet to grant terminally ill patients the civil liberty to choose how to end their pain and suffering, in private, with the love and support of their family, friends, and caretakers. Until they do, we'll just have to settle for butterflies.

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