The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil. – Sarah Palin, former Alaska Governor and 2008 Republican nominee for Vice President of the United States

On December 18, 2009, PolitiFact.com, the nonpartisan, Pulitzer Prize-winning Truth-O-Meter run by the St. Petersburg Times, gave Ms. Palin’s comment the ignominious prize “Lie of the Year.” This dubious distinction notwithstanding, the term “death panel” was thrust into political discourse in 2009, and re-ignited a conversation about bioethics, politics, and death that had grown relatively quiet since the passing of Terri Schiavo in 2005. Careful observers of America’s culture wars will recall that Ms. Schiavo’s tragic saga erupted into an international

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news event with a wildly diverse array of special interest groups, politicians, and media personalities weighing-in on the ethics of end-of-life decision making. What is supposed to be an intensely private family affair, either caring for a loved one who has become gravely ill or sitting by their bedside caring for them as they die, has, we now know, the powder-keg potential to become a public and even a political event. Given the public drama of the politicization of Terri Schiavo’s life and death, and given the plethora of other less heralded cases, can a claim that government does not have interests in matters of life and death be substantiated? Why then has so much vitriol been spewed out toward Palin and other social conservatives who claim to be fearful of any level of government intervention in matters relating to one’s health and well-being? In part, the right to life movement has been central in politicizing private decisions. But the political left has also been a participant in the politicization of living and dying, as we shall show.

We will demonstrate that the law and even the political apparatus increasingly encroach into realms historically set aside for the familial sphere. The most public example of this was in the case of Terri Schiavo, but there have been other less-visible examples, including the recent *In re D.L.H* decision in Pennsylvania. We will also explore how to make sense out of the nonsensical statements made by Palin and the maelstrom set loose by her claims regarding government sanctioned death panels. Unfortunately, there is just enough truth in the claims about government intervention in life and death to lend some legitimacy to the fears of conservatives. And at the same time, it has been the political right that has called on the courts and the political apparatus to intervene in such cases as *Schiavo*. The unfortunate consequence of such governmental and political encroachment into life—no longer a bioethics, but a biopolitics—is that the intensely private moment of our death, when we are supposed to be
surrounded by our friends and family, has become increasingly difficult. Increasingly, it is the political and legal apparatus that creates the conditions that shape these end-of-life moments, and that is a travesty.

To illustrate the difficulty of such family decision making in the current political-legal climate, our essay begins with an examination of Pennsylvania’s recent In re D.L.H. case. Although far less heralded than the Schiavo case, Mr. D.L.H.’s story provides a glimpse of how courts are assessing guardianship of incapacitated persons post-Schiavo. Moreover, our discussion of D.L.H. and brief review of the Schiavo case will highlight our critique of both the political right and left as we explore this question: Is it any wonder that the “death panel” scare emerged when there is so much fear and distrust surrounding government intervention in matters of life and death? Ultimately, we argue that the encroachment of the law, of the courts, and indeed of the entire political apparatus heightens the moral trauma felt by families and erodes a more nuanced, interpretive, and thick moral evaluation that is most appropriately the purview of the patient and her family.

I. The Case of Mr. D.L.H.4

This case of first impression asked Pennsylvania’s intermediate appellate court to determine whether the legal guardians of a lifelong incompetent person could refuse life sustaining medical treatment on behalf of the incompetent. The court held that a guardian does not have the legal authority to decline life-preserving medical treatment on behalf of an incompetent who has neither an end-stage medical illness nor a diagnosis of persistent vegetative state.5 In order to allow Mr. D.L.H. to die, his family would have to produce clear and


5 Id. at 987.
convincing evidence that death is in the incompetent patient’s best interests. Only if the patient was suffering from an end-stage medical illness or a persistent vegetative state (PVS) or facing the prospects of significant and prolonged pain would the court have entertained the parental guardians’ desire to decline treatment on behalf of their adult son.⁶

This case presents a fifty-year-old man who has suffered from profound cognitive impairment since birth and is not able to make or even participate in any decision relating to his estate or person, much less able to execute a legal instrument expressing his desires in regard to personal life sustaining medical treatment.⁷ For reasons not enumerated in the appellate opinion, the trial court had appointed Mr. D.L.H.’s parents as plenary guardians in 2002 – but not health care agents.⁸ In 2007, Mr. D.L.H., who had been in a residence for cognitively impaired people for forty-five years, developed aspiration pneumonia⁹ after swallowing a hairpin and vomiting.¹⁰ His compromised medical condition necessitated transfer to a local hospital.¹¹ The doctors determined that the patient required intubation and the support of a mechanical ventilator, but the adult patient’s parents objected to this course of treatment.¹² In their court-assigned capacity as his plenary guardians, Mr. D.L.H.’s parents would not consent to this course of medical

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⁶ Id. at 986.
⁷ Id. at 973-74.
⁸ Id. at 974.
⁹ As noted by the court, aspiration pneumonia is an inflammation of the lungs and bronchial tubes created by inhaling foreign material – e.g., food, liquids, vomit – into the lungs. Id. at 974.
¹⁰ Id. at 974.
¹¹ Id. at 974.
¹² Id. at 974.
treatment, arguing – in legal terms – that mechanical ventilation was not in their son’s best interest, presumably concerned about the physical and emotional trauma associated with interventions that their son did not have the ability to comprehend.\textsuperscript{13} Despite the parental guardians’ continuing objections, the hospital, nonetheless, proceeded to place Mr. D.L.H. on a mechanical ventilator for a three-week period, during which time his aspiration pneumonia subsided and he no longer required ventilation treatment.\textsuperscript{14}

Following this episode Mr. D.L.H.’s parents filed a petition to grant them authority to exercise the powers of a health care agent on behalf of their son.\textsuperscript{15} The state of Pennsylvania objected on the ground that Mr. D.L.H. was neither terminally ill nor in a permanent vegetative state (PVS), and the trial court denied the parent’s petition.\textsuperscript{16} The parents appealed.

In their appeal, Mr. D.L.H.’s parents argued that as their incapacitated son’s court-appointed plenary guardian, they should have the additional power to exercise his right to decline medical treatment.\textsuperscript{17} The appellate court proceeded to parse the distinction in Pennsylvania law governing “plenary guardians” and “health care agents.”\textsuperscript{18} According to the statutory definitions and distributions of powers, the appellate court determined that health care decisions concerning life preserving medical treatment are the purview of “health care agents,” not “plenary

\textsuperscript{13} Id. at 974.
\textsuperscript{14} Id. at 974.
\textsuperscript{15} Id. at 974.
\textsuperscript{16} Id. at 974.
\textsuperscript{17} Id. at 976.
\textsuperscript{18} Id. at 977-981.
Moreover, the court’s statutory interpretation was bolstered by a common law distinction between the roles and powers of a guardian and those of an agent. On the issue of their power as plenary guardians, the court held that Mr. D.L.H.’s parents did not have authority to decline life preserving medical treatment on their son’s behalf.

Mr. D.L.H.’s parents, however, alternatively asked the court to grant them special and specific authority to decline life preserving medical treatment on behalf of their incompetent son, who admittedly did not have an end-stage medical illness nor a diagnosis of PVS. Citing the parents’ inability to produce clear and convincing evidence that refusing mechanical ventilation was in Mr. D.L.H.’s best interest, the appellate court denied the parents’ request.

A determination that the patient’s death is in the patient’s best interest is, in some sense, not possible to prove. The court wrote that such a determination must be “based upon the medical facts, diagnosis and prognosis of the particular case” and the court’s ability “to conclude, without hesitation, that extending life would amount to an inhumane act that runs so contrary to basic notations of fundamental decency that death furthers the best interest of the incompetent.” It is this last phrase, “that death furthers the best interest of the incompetent,” that seems like an impossibility. On the one hand, the ruling set the standard that one can only refuse treatment when a) the patient lacks capacity, i.e. when the sovereign decision maker

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19 Id. at 981.

20 Id. at 980.

21 Id. at 982.

22 Id. at 984 (citing In re Conroy, 486 A.2d 1209, 1232 (N.J. 1985) ("Under [the pure-objective test], the net burdens of the patient’s life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient’s life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane.").
cannot make his own decision, and b) when it can be proven that death is in the patient’s best interest. Yet the court sets a high and artificial hurdle when it requires proof by clear and convincing medical facts that death is in the patient’s best interests.\(^2\) At the bedside, when crucial determinations are being made about treatment options, life, and the inevitable death of every patient, we usually think of these decisions as founded not on mere facts alone but upon the value-laden nature of the *interpretation* of such facts.\(^4\)

The appellate court noted that Mr. D.L.H.’s parents failed to produce any medical proof that their son’s aspiration pneumonia was a severe, permanent condition or that their son’s temporary discomfort related to the insertion of the breathing tube into the trachea and the use of the mechanical ventilator would result in inhumane amounts of suffering. Accordingly, the court ruled that Mr. D.L.H.’s parents were not entitled to receive the power to decline life preserving medical treatment on behalf of their adult, incompetent child, because in the court’s determination the choice for life was the only reasonable and medically factually grounded decision.

\(^2\) Thus, two standards emerge from the courts. First is the old problem of sovereignty, a problem to which Foucault points us, namely that sovereignty is often most clearly exerted when the sovereign decision maker exerts “power over life . . . through the death he [is] capable of requiring.” *Michel Foucault, The History of Sexuality, Vol. 1* 136 (1978). Sovereignty serves as the ground of all such decisions. A second standard emerges from the first. Where no clear sovereign exists, there must be a determination of who can act as sovereign in requiring the death of the subject. In the case of the sovereign who is his own subject, the only way to demonstrate one’s ultimate sovereignty is to require one’s death through the refusal of treatment. When there is no sovereign, who is there to prove through the use of medical facts that death is in the patient’s best interests? A hard requirement for such medical facts, in the absence of a sovereign, suggests there can be no death.

\(^4\) Kyle L. Galbraith & Joshua E. Perry, *Saturday Morning Postmortem* (correspondence in reply to letters by Felicia Cohn, Mark Aulisio, and John Lantos) 40 *Hastings Center Report*, Mar.-Apr. 2010, at 4-6 (noting that it is often impossible to gather all the facts in the disorienting and fluid end-of-life environment and, moreover, an infinite gap always exists between facts and their interpretation).
We are not given many details in the saga of this patient’s story, and so we are left to speculate on what might have been going on in the minds of Mr. D.L.H.’s parents and professional care providers. As a medical matter, it is not uncommon for severely cognitively impaired patients to have a shortened life span marked by declining health in middle age. Few medical details are given, but it is most likely that D.L.H., who as reported in the court record has been non-communicative for the entirety of his life, was nearing the average life expectancy for patients with similar conditions. Moreover, there is a reasonably good chance that Mr. D.L.H. has been in and out of the hospital with other sorts of infection. In other words, severe cognitive disability, like many other neurologically grounded illnesses, have natural histories in which patients repeatedly get infections and eventually one of these infections takes the patient’s life. Thus, Mr. D.L.H.’s parents might have anticipated that something very much like D.L.H.’s aspiration pneumonia illness of December 2007 would be the first of many similar types of episodes, or series of episodes, that would ultimately contribute to their son’s demise.

Moreover, in our experience, first as a medical doctor (Bishop) and second as hospital ethics consultants (Bishop and Perry), it seems extremely unlikely that the family said to the doctors, “Please do not intubate and mechanically ventilate our son; we just do not find it to be in his best interests.” Families rarely use the language of “best interests.” In fact, collectively, we cannot recall an instance in which a patient or family has used this precise legal and ethical term of art. The language of “best interests” in the context of a patient who cannot communicate her own wishes is a constructed, artificial language that courts and philosophers use to give moral foundation to how they intend to proceed. Families, on the other hand, who elect to forgo

25 Id. at 974 (“On July 3, 2002, the trial court appointed Appellants as the plenary guardians of D.L.H., finding that D.L.H. was “so severely mentally impaired that he [was] unable to make, communicate or even participate in any decision relating to his estate or person[.]”).
interventions such as intubation and mechanical ventilation usually do so by appeal to a negative language: “We do not wish to put our son through such traumatic measures.”

Indeed, in our experience it is not unreasonable for families to try to prevent extremely negative experiences for young children or even adults with severe cognitive disabilities who will not or cannot understand why they are being treated with prolonged and uncomfortable interventions. While it is true that families will sometimes put a loved one through aggressive treatment if the potential benefit outweighs the burden, it is not uncommon for families to refuse such interventions if the burden seems too great. In other words, it is entirely conceivable that D.L.H.’s parents were acting to prevent their son from going through an especially traumatic experience in which he could never understand why he was being subjected to it. While the court, and the legal lens through which the family’s language is filtered, is focused on “best interests,” such a calculated analysis is a far cry from the existential experience that D.L.H. and his parents most likely endured. While the facts of this case are thin, one can easily see how the legal filter with its appeal to the default legal/ethical principles of agency/autonomy and best interests/beneficence prevents much of the existential angst of the family’s experience from even entering into court proceedings designed to resolve what ought to have been familial decisions in the first place.

The court’s discussion of the common law distinction between a plenary guardian and a health care agent is also very revealing. A guardian, the court states, "is simply the court's bailiff or agent in protecting [the incompetent] and his estate."26 "Although a court-appointed 'guardian' is vested with the care and management of the person . . . under legal disability, the appointee,

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being an officer of the court, is always under the court's control and is subject to its directions as to the person of the ward." 27 Thus, from the perspective of the State, the guardian is the court's agent in protecting the ward. Thus, even though Mr. D.L.H.'s family had been demonstrating care and concern for him and making decisions for him for over forty-five years, the court, in appointing his parents as plenary guardians in 2002, gave them the authority as "court’s bailiff" to do what they already had the responsibility to do. Moreover, this was a responsibility that they had carried out independent of the court’s intervention in 2002. Why, at the age of forty-five, this man who had been incompetent from birth came to be in need of the court's protection is never explained by this court.

Further to the point of distinguishing between agent and guardian, the court recognizes that agency generally, and health care agency specifically “is ‘the relationship which results from (1) the manifestation of consent of one person to another that (2) the other shall act on his behalf and subject to his control, and (3) consent by the other so to act.’” 28 Under common law principles, the court emphasizes that an agency relationship is created “whenever a person authorizes another expressly or by implication to act as his agent.” 29 In other words, the court is saying that a guardian is one appointed by the court who acts as the "court's bailiff" while a health-care "agent" is one authorized or appointed to act based on the decision of another person to confer such power. 30

27 Id.

28 Id. at 980 (citing to Smalich v. Westfall, 269 A.2d 476, 480 (Pa. 1970)).

29 Id. (citing Garbish v. Malvern Federal Sav. & Loan Asso., 517 A.2d 547, 553 (Pa. Super. 1986)).

30 See Restatement (Third) Agency, ß 8.09(2) (2006) ("An agent has a duty to comply with all lawful instructions received from the principal and persons designated by the principal
Is it not odd that the parents, who had cared for Mr. D.L.H. for all his life, should now require the court's blessing to legitimate and effectuate the decisions that they had made throughout the prior forty-five years, and the five years after they had been appointed plenary guardians? Under the statutes governing health care agents in Pennsylvania, the family can only make decisions based on the patient's expressed wishes, especially when the details of a particular patient with a particular illness with particular potential outcomes requires particular judgment on the part of the agent. Apparently, no life or death judgments are permitted to be made by a family that merely carries the designation of “plenary guardian.”

Citing Pennsylvania statutes, the court noted that the authority to make health care decisions is specifically designated to a health care agent—not a plenary guardian. Mr. D.L.H.’s parents’ status as plenary guardians, standing alone, was determined by the court not to confer them with the blanket authority to exercise the power of a health care agent on behalf of their son. The court was particularly concerned with the potential for “abuse” to an

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**Footnotes:**

31 Id. at 981 (citing Pa.C.S. §§ 5456(a) and § 5461(c)).

32 Id.
“unparalleled magnitude.”

“For instance,” the court imagined, “if [Mr. D.L.H.’s parents] – by virtue of their role as plenary guardians – were vested with the unconditional power of a health care agent, then any subsequent judicial review of their decision to refuse life preserving treatment could be rendered meaningless because the incompetent may already be deceased.”

Apparently only a health care agent has the statutory authority in Pennsylvania to object to life sustaining medical procedures on behalf of a principal who is neither at the end-stage of a terminal illness or is permanently unconscious.

A plenary guardian, although empowered to make decisions in the ward’s best interest, does not have the statutorily allocated power to make health care related decisions, and, moreover, is – as “court’s bailiff” – “always under the court’s control and is subject to its directions as to the person of the ward.”

Ultimately the court’s argument is premised on the statutory limitations of a guardian’s powers. Unlike the health care agent, who is obliged to follow the instructions provided by the principal while still competent, the guardian is charged by the court to take only those actions that, subject to judicial review, would be in the ward’s best interests. And of course, as noted earlier it is very difficult to establish by clear and convincing and objective fact that death is ever in one’s best interest.

Because the court could find no precedent in which life and death decisions made by the plenary guardian were called into question, the court appeals to analogical reasoning. Since the law explicitly states that plenary guardians cannot decide to sterilize the ward or to give consent to treatments such as psychosurgery, the plenary guardian cannot make such grave “unilateral”

33 Id. at 981.
34 Id. at 981.
35 Id. at 981.
36 Id at 980.
Life, Death (Panels), and the Body Politic  Perry & Bishop

decisions to refuse medical treatment without the scrutiny and permission of the court.³⁷

“Without question,” the court declared, “a guardian's decision to decline life preserving medical
treatment on behalf of an incompetent is manifest and the consequences grave. . . . [T]he
authority sought by [Mr. D.L.H.’s parents] in this case involved an 'extraordinary' medical
decision that threatened D.L.H.'s fundamental rights to privacy and life. Hence, we conclude
that before a trial court could ever grant a guardian the authority to decline life preserving
medical treatment on behalf of an incompetent, the guardian must first petition the court for the
authority to do so, and then prove by clear and convincing evidence that death is in the
incompetent's best interest.³⁸

As noted earlier, it remains unclear what clear and convincing evidence that death is in
the best interest of any patient would look like. The moral calculus by which the court expects
plenary guardians to make decisions in a patient’s “best interests” seems qualitatively different
than the moral deliberation and the moral experience of families who often act as plenary
guardians for their loved ones. The oddity of requiring court scrutiny of what should be a family
decision notwithstanding, the court, in appealing to a rationale wrapped in legal and so-called
ethical “best interests” terminology, creates a standard that seems impossible to satisfy.

Below the surface the D.L.H. case we find warring principles, or more accurately,
warring philosophical stances. Here in the language of the law, we see the two key principles of
medical ethics—autonomy and beneficence—move into the realm of the law under the terms of
agency and best interests. Or perhaps better, the law is such that its principles—agency and best
interests—have moved into the realm of contemporary medical ethics—autonomy and

³⁷ Id. at 981.

³⁸ Id. at 983.
beneficence. In other words, under the legal and medical principles of moral deliberation, all can be boiled down to autonomy/agency and beneficence/best interests. The logic of such legal/ethical deliberation runs something like this: Does the patient have capacity to act as his own agent, which is the necessary and sufficient condition for determining best interests? If yes, follow the agent’s directive. If not, then ask the court to apply the “best interests” test. The best interest test seems, in the court’s conception, to operate as a simple mathematical formula. Measure the number of beneficent points of life and the number of maleficient points that would be required in keeping a patient alive. Add them together. If the number is a negative number, it might be in the patient’s best interest to die; if the number is positive, the patient cannot be allowed to die.

Yet, we have already claimed that families do not make decisions based on such legal (or utilitarian) reasoning, but instead make decisions that sometimes seek to avoid medically intensive interventions for their loved one especially if that loved one has no way to appropriate the trauma into a coherent narrative. Moreover, the kind of moral calculus that the court expects the plenary guardian to deploy—or more likely that the court expects itself to deploy given that even plenary guardians are forbidden from making such grave decisions—is one that cannot possibly have any meaning; for what can it possibly ever mean that death is in the patient’s best interests? The best interest test is nonsensical when it comes to the moral assessment of continuing life in a burdensome way, or allowing death. Instead, in our clinical experience the family engages in a very complicated moral evaluation in which morally thick commitments are put into a complicated conversation with moral experience interpreting medical facts—
themselves value-laden.\textsuperscript{39} Rather than mathematical reasoning, where the various features of a situation can be converted into positive and negative units such that a mathematical sum might come at the end of the deliberation, families are left attempting to compare apples and oranges, qualitatively different features that resist easy conversion into equivalency units.

As a postscript to its holding, the appellate court restated its commitment to balancing individual rights to self-determination with the state’s interest in preserving life and protecting the ethical integrity of the medical community.\textsuperscript{40} “On balance, D.L.H.’s personal right to refuse medical treatment, as maintained through [his parents], carries little weight because [his parents] failed to establish that death was (or would be) in D.L.H.’s best interest,” the court concluded, emphasizing that the state’s interest in these circumstances outweighs an individual’s right to self-determination and refusal of medical treatment.\textsuperscript{41}

We claim that in fact the encroachment of the “state’s interest,” of the law, of the courts, and indeed of the entire political apparatus only serves to heighten the moral trauma felt by families. And indeed, it seems that families no longer have the moral resources to make such decisions precisely because the power of the law has encroached into a realm that had been very private, personal, and indeed, at one point in our history, a course capable of navigation by families.\textsuperscript{42} Surely parents and guardians can look on the particular set of circumstances and

\textsuperscript{39} See Kyle G. Galbraith and Joshua E. Perry, \textit{The Case of Mrs. K}, 39 HASTINGS CENTER REPORT, Sept.-Oct. 2009, at 24-26 (detailing the agonizing process of making a life or death decision on behalf of an incapacitated loved one).

\textsuperscript{40} Id. at 985.

\textsuperscript{41} Id. at 986.

\textsuperscript{42} It is this biopolitical encroachment upon life and liberty that played itself out in the epic battle of Terri Schiavo, discussed at length in Part II.
determine that indeed the burden and perhaps even the terror of prolonged and invasive and, in some instances, medically dubious treatment is so bad that to subject their loved one to it is unbearable, especially if that person cannot enjoy the benefits of life and if the burden borne by the patient cannot be interpreted by the patient as anything other than a terror. But that is a very different moral evaluation than the court claims to be essential in the case of Mr. D.L.H. as it seeks to impose its requirement that all guardians apply the best interest test.

Interestingly, at the end of its opinion the court noted in dicta that if Mr. D.L.H. had been “in a medically-certified PVS,” then a surrogate decision maker, i.e., a close family member, would have been empowered to make a decision on behalf of the incompetent patient regarding life-sustaining medical treatment.\footnote{Id. at 986.} This final comment by the court highlights the contested and arbitrary nature of the space in which power to make decisions over life and death is exercised. Medically speaking, there is no reason to have asked the question, “Is Mr. D.L.H. in a persistent or permanent vegetative state?” In fact the only reason that this would have come up has more to do with the historical reverberations of the Terri Schiavo case, to which we now turn.

\section*{II. Terri Schiavo and the Politicization of Life}

Terri Schiavo, twenty-six years old, suffered a cardiac arrest on February 25, 1990.\footnote{LOIS SHEPHERD, \textit{IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO} 15 (2009).} Before paramedics could restore her heartbeat, her brain was deprived of oxygen for several minutes. She never again regained consciousness and after a brief period of time in a coma she
entered a vegetative state.\textsuperscript{45} In this condition Ms. Schiavo was unable to swallow, and a percutaneous endoscopic gastrostomy (PEG) tube was inserted into her stomach to facilitate the delivery of artificial nutrition and hydration (ANH).

Ms. Schiavo was neither “brain dead” nor “minimally conscious.” She was in a persistent vegetative state (PVS). As the Schiavo case illustrated, PVS is not easy to diagnose. It requires careful and prolonged consideration of multiple factors including age at the time of injury, mechanism of injury, and length of time without recovery. As determined by a Multi-Society Task Force study of patients who met the definition of PVS, patients with non-traumatic brain injury showing signs of recovery at three months had only a 1 percent chance of good recovery or moderate disability, while a persistence of the condition beyond six months resulted in a statistically impossible chance of good recovery or even moderate disability.\textsuperscript{46}

Yet, Ms. Schiavo’s parents did not accept their daughter’s medical diagnosis, and when Michael Schiavo, her husband, petitioned the Florida guardianship court to discontinue her life support, Mr. and Mrs. Schindler, Terri’s parents, objected.\textsuperscript{47} What followed were seven years of court hearings and appellate reviews at both the state and federal levels, as well as dramatic

\textsuperscript{45}The term “vegetative state” describes “a body which is functioning entirely in terms of its internal controls. It maintains temperature. It maintains heart beat and pulmonary ventilation. It maintains digestive activity. It maintains reflex activity of muscles and nerves for low level conditioned responses. But there is no behavior evidence of either self-awareness or awareness of the surroundings in a learned manner.” \textit{In re Jobes}, 529 A.2d 434, 438 (1987). This state has also been described as a “twilight zone of suspended animation where death commences while life, in some form, continues.” \textit{Rasmussen by Mitchell v. Fleming}, 741 P.2d 674, 678 (1987).

\textsuperscript{46} Multi-Society Task Force on PVS, \textit{Medical Aspects of the Persistent Vegetative State (1)}, 330 \textit{NEW ENG. J. MED.} 1499 (1994); Multi-Society Task Force on PVS, \textit{Medical Aspects of the Persistent Vegetative State (2)}, 330 \textit{NEW ENG. J. MED.} 1572 (1994).

\textsuperscript{47} \textit{In re Guardianship of Schiavo}, 780 So. 2d 176, 177-79 (Fla. Dist. Ct. App. 2001).
political interventions by the Florida state legislature, Florida governor, United States Congress, and President George W. Bush.\textsuperscript{48}

Having initiated the legal proceedings in 1998, Michael Schiavo’s request to discontinue his wife’s ANH was granted by Judge George Greer in 2000.\textsuperscript{49} Greer’s determination was premised on two findings. First, the court found the medical evidence “overwhelming” that Terri Schiavo had been in a PVS for the previous ten years and was without “hope of ever regaining consciousness and therefore capacity. . . unless an act of God, a true miracle, were to recreate her brain.”\textsuperscript{50} Having determined that Ms. Schiavo was unable to make her own medical decision, Judge Greer then considered whether clear and convincing evidence could establish Ms. Schiavo’s wishes regarding her continuing medical treatment. Like most Americans, Ms. Schiavo did not have a living will, and thus Judge Greer had to rely on oral testimony from those family members and friends who knew her best and could recount previous statements that Ms. Schiavo had made on the topic of indefinite life support and being “kept alive on a machine.”\textsuperscript{51}

\begin{footnotes}
\item[49] In re Guardianship of Schiavo, 780 So. 2d 176, 177 (Fla. Dist. Ct. App. 2001).
\end{footnotes}
Judge Greer ultimately concluded that Ms. Schiavo had made credible statements supporting the relief her husband requested, and he ordered the cessation of ANH.\textsuperscript{52}

The case, however, did not conclude in 2000. Rather, Ms. Schiavo’s parents – the Schindlers – launched a series of appeals and pleas for consideration of additional medical evidence that ultimately resulted in another hearing before Judge Greer.\textsuperscript{53} Attempting to establish that new treatments would offer their daughter “sufficient promise of increased cognitive function,” the Schindlers failed to meet their evidentiary burden, and again the court ordered the ANH to cease.\textsuperscript{54}

Six days into the dying process, Ms. Schiavo’s tube feedings were resumed at the order\textsuperscript{55} of Florida Governor Jeb Bush, acting at the behest of the Florida state legislature who had worked feverishly to pass “Terri’s Law.”\textsuperscript{56} This legislation, prompted by “tens of thousands of phone calls and emails”\textsuperscript{57} to Florida politicians and “a deafening talk radio roar”\textsuperscript{58} from

\begin{footnotesize}
\begin{enumerate}
  \item In re Guardianship of Schiavo, No. 90-2908GD-003, 2000 WL 34546715, at *7 (Fla. Cir. Ct. Feb. 11, 2000).
  \item See generally In re Guardianship of Schiavo, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001); In re Guardianship of Schiavo, 792 So. 2d 551 (Fla. Dist. Ct. App. 2001); In re Guardianship of Schiavo, 800 So. 2d 640 (Fla. Dist. Ct. App. 2001).
  \item Exec. Order No. 03-201 (Fla. 2003).
  \item H.B. 35-E, 2003-E S. Spec. Sess. (Fla. 2003). Popularly referred to as “Terri’s Law,” the legislation did not actually mention Theresa Schiavo by name, but pursuant to its narrowly crafted operating provisions, the new law could only apply to Ms. Schiavo.
\end{enumerate}
\end{footnotesize}
conservative religious broadcasters, gave Governor Bush authority “to issue a one-time stay to
prevent the withholding of nutrition and hydration from a patient [who without] . . . written
advance directive . . . [was ] found to be in a persistent vegetative state . . . [and if] . . . a member
of that patient’s family has challenged the withholding of nutrition and hydration.”

Challenged by Michael Schiavo, Terri’s Law was found by the Florida Supreme Court to
be “an unconstitutional encroachment on the power that has been reserved for the independent
judiciary,” and Ms. Schiavo’s artificial nutrition and hydration was ordered to be removed for a
third time. Despite the best efforts of President Bush and the U.S. Congress to usurp the Florida
judiciary and continue Ms. Schiavo’s life sustaining treatments, Terri Schiavo died on March
31, 2005.

Again, we are left to speculate on several questions. Schiavo’s husband—Michael
Schiavo—and her parents—Mr. and Mrs. Schindler—worked well together in the early years
after Terri’s injury. However, by the mid-1990s Michael Schiavo began to have a series of
doubts about continuing to keep his wife alive via artificial nutrition and hydration delivered
through the PEG tube. Consequently, the relationship between Mr. Schiavo and the Schindlers
began to be strained as Michael Schiavo decided to withdraw the PEG tube and the fluid and

58 Joshua E. Perry, Biblical Biopolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and
Beyond, 16 HEALTH MATRIX 553, 599-600 (2006).


60 Bush v. Schiavo, 885 So. 2d 321, 324 (Fla. 2004). But see O. Carter Snead, Dynamic
Complentarity: Terri’s Law and Separation of Powers Principles in the End-of-Life Context, 57
FLA. L. REV. 53, 81 (2005) (arguing that there is nothing intrinsically judicial about guardianship
and end-of-life decision making).

61 See generally Anne E. Kornblut, After Signing Schiavo Law, Bush Says “It is Wisest to Always
nutrition. Confronted with an inability to reach a family consensus regarding withdrawal of life-sustaining measures, Mr. Schiavo petitioned the guardianship court of Florida to function as a proxy decision maker for his wife, in order to have an independent person determine whether or not to discontinue life-prolonging medical procedures. Rather than settling the question of Terri’s life within the boundaries of the home, the political apparatus of the courts was brought in to settle the life-and-death question of sovereign decision.

Why did Michael Schiavo petition the Florida guardianship courts in the first place? Why wasn’t this decision made at home? We can only speculate that he must have either feared reprisal by the Schindlers or personally lacked the resources or the fortitude necessary to act unilaterally in a manner consistent with what he claimed to be his wife’s view of the good life. Likewise, why did the Schindlers spend five years appealing – tragically and pathetically – to both constitutional courts and courts of public opinion? Perhaps they too lacked the capacity to reconcile themselves to the reality of their daughter’s condition and reach a mutually agreeable decision with their son-in-law. At some fundamental level there was clearly an irreconcilable family fissure that resulted in both sides repeatedly appealing to the crass power of the sovereign state, which, of course, is only capable of adjudicating and understanding life in terms such as “best interests” and “agents.” As with Mr. D.L.H., Ms. Schiavo’s fate was removed from the locus of private, family determinations and placed into the hands of a state sovereign, which is precisely the fear inartfully described by Sarah Palin’s disingenuous reference to “death panels.”

III. The Sovereign, (bio)politics, and death panels

Michel Foucault noted that the sovereign, historically understood as the King, was the

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one with the power and the right to decide who lives and who dies. The debate around the fate of Terri Schiavo, the court’s reasoning in the case of Mr. D.L.H., and the specter of so-called “death panels” are each ultimately related to our struggle to lay claim to this sovereignty in our contemporary, democratic context. Is sovereignty over one’s life and death ultimately located solely within that one individual? In other words, have we each become a sovereign unto our selves, with only ourselves as the sovereign’s subject? Such a notion of absolute self-governing autonomy may be fine as long as our Self – the 21st century autonomous American King – retains the capacity (mental, psychological, physical) to make life and death decisions. The challenge, of course, follows higher brain injury or sustained end-of-life deterioration when one enters that “twilight zone of suspended animation where death commences while life, in some form, continues.”

In the vegetative state, coma, end-stage dementia, or other compromised states of consciousness or cognitive ability, decision-making powers otherwise assumed by the individual, autonomous Self must be assumed by another. Whether to resuscitate, maintain artificial nutrition and hydration, fight infections with increasingly potent antibiotics, perform invasive, complicated, and expensive procedures, surgeries, or even transplantations are choices with life or death consequences that must be made by some other. Once one loses the ability to make rational choices, she can no longer be her own sovereign, and a barren space between life and

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63 Michel Foucault, The History of Sexuality, Vol. 1 135 (1978) (arguing that the sovereign “evidenced his power over life only through the death he was capable of requiring.”).


liberty is created. In this contested space, the normative questions arise regarding who should wield the power to make life and death decisions.

Consider that both the right and left, the socially progressive and the socially conservative, politicize life – at the end of life – in terms of both the “good” life and in terms of “bare” life. On the right, one finds those who argue it is the mere existence of bare, biological life that is deserving of life. Period. In other words, bare life is the condition for the possibility of the good life, and as such it is a good and sufficient condition for the sustenance of life. The move made by social conservatives seeking to protect bare life is similar to those concerns articulated by the first social contractarians, namely, those without political status must be protected from those with the power to define life and make a determination of what life is unworthy of life. Regardless of station, if one is alive then that one is deserving of the benefits of living in the *polis*, i.e., the benefits of seeking the good life.

For instance, reflecting on the *Schiavo* case, Dr. James C. Dobson, founder of the evangelical Christian advocacy organization Focus on the Family and a spokesperson for much of socially conservative America, stated that Terri Schiavo’s death was the result of a “cooperative effort between the judiciary and the media to kill an innocent woman.” Such a statement highlights a concern over the judiciary’s power over life and death, i.e., the power of the court as sovereign decision maker. Another advocate on the Christian evangelical right, Tony Perkins, president of the Family Research Council, identified “the battle” as being “with

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Mr. Perkins, a former Congressman, argued that Terri Schiavo should be “the face of the fight to confirm prolife judicial nominees . . . that respect life and to oppose those who subscribe to this growing culture of death.” For many social and religious conservatives, “bare” life—the mere biological life of each body within the body politic—has become the politicized foundation for a fight against those perceived to have the power to define life and death. Yet, what advocates and leaders who fight for “a culture of life” fail to realize is that life and death have fluid parameters with boundaries that are (bio)political.

On the left, the question is not whether one has bare life, for it is not bare life that is the ultimate desire. Rather, social progressives want the good life, and what constitutes the good life is the life that empowers the subject with sovereignty to make decisions about pursuit of the good life. When that is no longer possible, in a situation like persistent vegetative state or profound cognitive disability, one may abandon oneself from the normal protections afforded by the polis. Like social conservatives, social liberals are also fighting over the ground terms of the social contractarians. Where the social conservatives focus on life as the condition for the possibility of the good life, social liberals focus on the good life such that when that is no longer possible, life may no longer be good. Bare life may be a necessary condition for the possibility of the good life, but in the absence of the possibility for the good life—in the absence of a


68 Id.

69 John T. Parry, “Society Must Be [Regulated]”: Biopolitics and the Commerce Clause in Gonzalez v. Raich, 9 LEWIS & CLARK L. REV. 853, 863-77 (2005) (“[T]he issue in Raich was the provision of marijuana to seriously ill people for the purpose of alleviating their pain. The power “to make live and let die” is neither a metaphor nor a theoretical frolic. Biopolitical regulation of populations is concrete—individuals will live or die or will suffer more or less pain as a result of it.”).
sovereign subject, a self subjecting itself to the Self—bare life, the left suggests, is not a sufficient condition to warrant full protection.

In contrast to a focus on “bare” life, social and religious progressives tend to emphasize primarily those aspects of “good” life. Specifically, those on the left tend to privilege liberty and the freedom to choose a “quality of life” that justifies possession of mere biological life and opens up the possibility of forfeiting the good life that cannot be lived. Consider the comments of John Shelby Spong, the retired American bishop of the Episcopal Church Diocese of Newark, New Jersey and a recognized scholar and activist on socially progressive end of the religious spectrum: “There is a fine line . . . between expanding life and postponing death. I do not believe that life and existence are the same. . . . I do not ever want life to be defined as extended time.”

As for his own life, Spong notes that he wants to “wring every ounce of sweetness possible” out of the length of his days, but also does not want to live “one moment beyond the time” when his life loses “meaning” and contact with those he loves. For Spong and many on the left, there exists a potentially large gap between the good life and mere life, with the former demarcated by one’s freedom and power to choose for oneself. If one can be one’s own sovereign, then one’s life deserves the law’s protection. If, however, one’s own authority has been compromised, then the protections afforded those with bare life come into question. What is a thin line for those politicizing bare life becomes a large opening for those who biologize the good life (the life within the polis). In other words, on the left, if the good life of sovereign decision is not possible, the subject can be abandoned from the protections afforded by the polis.

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71 Id.
Both sides of the political-social-religious spectrum, thus, are engaged in determinations of what constitutes life that is worthy – or unworthy – of protection. Both sides are engaged in the same discourse that has animated political liberalism from the very beginning. What sovereign can abandon a subject from the protections of the polis? In *Schiavo*, it happened to be those who would argue that bare life deserves protection that brought the power of the state to intervene into the sphere of familial life and decision. In *D.L.H.*, it was those who believed that the good life was threatened for Mr. DLH—and therefore that he could be abandoned from the protections—that brought the power of the state to intervene.

What the cases of Mr. D.L.H. and Terri Schiavo illustrate are the limitations of law, medicine, and politics for the task of decision making at the end of life. Sovereignty is insufficient; defining the proper agent covers over the actual features of the experience that families are weighing in the balance. In the case of Terri Schiavo, the fact that her husband sought the intervention of the guardianship court of Florida is already indicative that he lacked the resources to make such decisions because it is no longer what families do. Yet, more importantly, Schiavo’s case illustrates the tragedy of what is lost. For Terri and Michael, what is lost is the possibility of the good life that she and Michael had planned for themselves. For the Schindlers, what is lost is the possibility to take care of Terri in her darkest hour—a good way to be family, no doubt. For Mr. D.L.H., the appeal to the lack of sovereignty and the need for the court to protect D.L.H.’s life—his bare life—only hides the fact that his parents had for more than fifty years cared for him and acted to give him the best life possible, and in their well-informed and responsible role as loving family, they were protecting him from the trauma of an eventual prolonged, frightening, and invasive stay in an intensive care unit.
It was not that long ago that death was defined within communal boundaries and with communal practices. With the rise of organ transplantation, for example, a shift occurred whereby death came to be understood as occurring in the body, specifically in the brain. Against all communal sensitivity, such medicalization of death declared that which appears to be alive to actually be dead and subtle shifts in how we think about end-of-life decision making have followed over the last few decades.

Consider again Foucault’s observation that the sovereign – if truly sovereign – must be able to demonstrate a “power over life . . . through the death he [is] capable of requiring.” In the cases of both Mr. D.L.H. and Ms. Terri Schiavo, neither had the capacity to be his or her own sovereign. Neither person had the rational capacity to make the choice for life or death. Lacking the power to choose as a rational agent, they each entered a contested political space between life and death where some other had to make the political determination between bare life and the good life. Both D.L.H. and Schiavo experienced forms of bare life, perhaps only because they lacked the capacity to decide. For D.L.H., his biological condition was severe mental


73 Beginning with the seminal and high-profile cases of Karen Ann Quinlan (In re Quinlan, 355 A. 2d 647 (N.J. 1976)), Paul Brophy (Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626 (Mass. 1986)), and Nancy Cruzan (Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990)), courts have been increasingly called upon because of physician refusal to yield to the traditional authority of familial and community decision making. And thus, families have become too willing to abdicate responsibility for the courts to make difficult end-of-life decisions, e.g., Michael Schiavo’s appeal to the court, and doctors are increasingly unwilling to listen to families, e.g., Mr. D.L.H.’s parents, thereby further increasing the role and the power of the courts. The culmination of such abdication and encroachment was manifest in the robust way that Terri Schiavo’s life was politicized and in the more quiet and subtle way that the court reaches its determination in the situation involving Mr. D.L.H.

impairment, such that he was unable to make, communicate or even participate in decisions relating to his life. For Schiavo, her biological condition was cerebral devastation, such that she was determined to be in a permanently vegetative state, unable to live without a surgically-implanted tube delivering artificial nutrition and hydration. For many, both Mr. D.L.H., a fifty-year with profound mental retardation since birth, and Ms. Schiavo, who at the time of the first judicial decision in her case had been determined to be in PVS for over ten years, are exemplars of those with bare life deserving of political protection. For many others, however, these persons did not enjoy a good life – characterized primarily by a capacity for autonomous, free-will decision making – and thus were beyond the political norms of those typically deserving of bare life protections.

In both instances, the power to make a life and death decision was at stake. For Mr. D.L.H., who the court emphasized was not in a PVS, “the state’s interest in preserving life and maintaining the ethical integrity of the medical profession” were found to outweigh his common law right to refuse medical treatment and his parent’s inability to establish that death would be in his best interest. In other words, having never experienced the good life, Mr. D.L.H.’s bare life would be protected. Conversely, for Ms. Schiavo, who the court emphasized has been in a medically diagnosed PVS since her anoxic brain injury at the age of twenty-six, the death of her

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75 Both Mr. D.L.H. and Terri Schiavo sat along a line that demarcates the inside of the polis, where one’s life receives full state protection, from the outside of the polis, where one is not normally afforded the state’s life protections. With the court’s final comments regarding the distinction between patients in a diagnosed persistent vegetative state and the non-PVS status of Mr. D.L.H., the Pennsylvania court separates those like Mr. D.L.H., who has been recognized by the court to be “profoundly mentally retarded,” from those, like Terri Schiavo, who the court finds to be suffering in a PVS. The line marking inclusion and exclusion and who has the authority, or sovereignty to abandon a human being from the protections of the law is, ultimately, a politicized space marked by arbitrary gradations of mental competence or conscious awareness. Life itself – in both its “good” and “bare” manifestations has become fully politicized. Seemingly all aspects of 21st century life in the United States have become politicized, and, perhaps unsurprisingly, so too have life and death.
good life left her suspended between bare life and a not yet dead. Having tasted of the good life, as evidenced by the “clear and convincing evidence” brought forth by her husband, her bare life would ultimately be sacrificed to the loss of even the possibility of a resumed good life. In both cases, the boundaries of what constitutes bare life became a matter of law and legal decision. And politics.

Given that the courts and the entire political apparatus have been brought to bear solidly at the bedside, can there be any wonder that a growing number of people in American society wonder out loud whether “death panels” are on the horizon? Hasn’t the political apparatus been deployed by one side or the other to achieve goals other than goals for the person in the diminished conscious state? Indeed, there is an ugly element on either side of the political aisle that is inherent in this biopolitics of life and death. Constituting our decisions regarding the life and death of Mr. D.L.H. and Ms. Schiavo in accordance with law elides the violence of constituting power – of inclusion and exclusion – that accompanies the sovereign decision of life and death. It is precisely such unspoken concerns that animate the anxiety around our speculation of “death panels.”

We have seen that in the case of DLH, the courts have taken away the decisional authority of parents who had for 50 years made decisions on their son’s behalf. We have seen families unable to navigate and negotiate decisions and this at least in part because the hard edge of the court has been willing to intervene. We have seen doctors increasingly appeal to law rather than to families simply to protect themselves from criminal or civil allegations. We have seen judges making appeals to medical facts as if medical facts exist independent of their interpretation. We have seen the courts place all of the attention on the agent, the sovereign, precisely because it is this term that is the foundation of liberalism. We have seen the judiciary,
the legislature, and even the executive branches of the polis reach deeply into decisions that should be the purview of families. For both social conservatives and social liberals, we have seen lines drawn either including or excluding either bare life or the good life from the protections of the law.

The political apparatus, however, cannot help but do violence to those who make decisions and to those on whose behalf decisions are made. There is little doubt that D.L.H.’s family cared for him as demonstrated by 50 years of care. There is little doubt that they were trying to spare him some level of suffering. There is little doubt that both Michael Schiavo and the Schindlers loved and cared for Terri. Yet in the midst of the politicization of life, in the midst of this our biopolitics, all of the stuff that makes life as a family good is lost.