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**Basic Care, Human Dignity,
and Care for Medically
Vulnerable Persons**

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Physical and cognitive disability should not mean one's situation is considered "end of life," yet too many persons who are not dying are described this way.

Earlier this year, Oregon's state legislature considered a bill that would have increased the number of medically vulnerable persons at risk of an untimely death. Oregon's SB 494 would have redefined food and water delivered by a cup or spoon—everyday utensils—as a regulated, physician-controlled form of “medical care” rather than the “basic and ordinary” care that common sense suggests. In Oregon, patients who are awake, conscious, and aware—but were unable to feed themselves due to disability, brain injury, or lack of physical mobility—would have faced the real chance of being denied food and water.¹ Fortunately, despite Oregon's Senate passage in a 17–13 vote, the House referred the bill to a committee where it was tabled for the session.

However, as disconcerting as such a bill is, a much less understood and equally pernicious reality is this: It is already legal in every state to withhold or deny food and water by means of a feeding tube to patients who are not actively dying and not facing any active “end of life” issue.² In simpler terms, it is presently legal in every state deliberately to bring about the end of a patient's life by denying a nonterminal person food and water. We tend to call these “end of life” cases—but that's often papering over the fact that it was our medical system that sought to end their life. This practice flies in the face of human and medical experience, which has long held that so long as someone could metabolize food and water, then it would be wrong to deny them this vital and basic form of care. A landmark 1986 California case, *Bouvia v. Superior Court* set precedent for classifying food and water as “medical treatment” depending on the circumstances of its consumption.³

Wesley J. Smith, author, attorney, and bioethicist, has written compellingly on the essential issue connecting nourishment and medically vulnerable persons. “Does every human life have equal and incalculable moral value simply and merely because it is human?” asks Smith. “Answer yes, and we have a chance of achieving a truly humane, free, and prosperous society. Answer no, and we are just another animal in the forest.”⁴ So many of us unconsciously embrace a utilitarian sort of ethical perspective, where we judge the quality of one's life by what someone can do or by another arbitrary determinant. Embracing Wesley J. Smith's broader and more liberal understanding of human dignity is today a radical act of love and empathy for medically vulnerable persons—but understanding how we came to this point requires taking a few steps back in time.

Drs. Fred Plum and Byron Jennett developed the term “Persistent Vegetative State” (PVS) in 1972 for a particular set of patients who had experienced a brain injury.⁵ PVS is understood as a “clinical condition of complete unawareness of the self and the environment.” Yet, patients diagnosed as PVS do have brain function.⁶ They are routinely anesthetized, because we suspect that they can feel pain.⁷ They respond to stimuli.⁸ They breathe on their own and can live normal life spans.⁹

Following Plum and Jennett, the *American Academy of Neurology* in 1989 took the then-new position that there was “no medical or ethical distinction” between discontinuing medical treatment for patients diagnosed with PVS and denying them food and water by means of a feeding tube.¹⁰

However, the nature of the PVS diagnosis is problematic, namely because it is one of the most arbitrary and subjectively applied diagnoses in clinical practice. Adrian M. Owen writes in *Detecting Awareness in the Vegetative* that “[t]he vegetative state is one of the least understood and most ethically troublesome conditions in modern medicine.”¹¹ The research backs up this contention in stark terms, starting with Childs et al.’s 1993 study *Accuracy of diagnosis of persistent vegetative state* and the later 1996 Andrews et al.’s *Misdiagnosis of the vegetative state*, which found patients routinely misdiagnosed “vegetative” as high as 48 percent¹² and 43 percent¹³ of the time, respectively. A more recent 2009 study by Schnakers et al., *Diagnostic accuracy of the vegetative and minimally conscious state* found a misdiagnosis rate of 41 percent—and crucially found that 10 percent of those misdiagnosed during their study had emerged even from their less serious “minimally conscious state.”¹⁴

Encouragingly, new research seems to be revealing not only the dangers of the PVS diagnosis but also hopeful signs about the brain’s ability to heal.

The first, somewhat tentative, development is a positive trend among some physicians to reconsider simply the way they speak about medically vulnerable patients.

A 2010 report *Unresponsive wakefulness syndrome* released by the European Task Force on Disorders of Consciousness led by Laureys et al. (coauthored by nearly a dozen physicians, neurologists, and scholars) proposes the abandonment of “PVS” language in favor of “UWS,” or “unresponsive wakefulness syndrome.”¹⁵ The authors correctly identify not only the dehumanizing and morally corrosive impact that “vegetative” language has on long-term patients but also the negative impact the label can have in denying treatment to patients who might otherwise recover from their diagnosis:

Over the last three decades, a growing number of physicians and healthcare workers have felt uncomfortable when referring to patients as *vegetative* ... Despite clear evidence that vegetative patients are not uniformly hopeless, once stamped with the diagnosis *vegetative state*, clinical practice shows it often is difficult to change the label, and the first signs of recovery of consciousness are too often missed ... Given [stated] concerns regarding the negative connotation inherent on vulnerable patients awakening from coma, who sometimes never recover any voluntary responsiveness but may (probably more often than initially believed) recover minimal signs of consciousness, we here propose to change the label

vegetative state, thus hoping to make it easier to change their management and standards of care.

A fundamental insight about human dignity is that we possess it regardless of our physical or mental condition, and regardless of our stage of life. Embracing the language of “unresponsive wakefulness” and abandoning the pejorative “vegetative” language cannot occur quickly enough for patients whose moral status is compromised by the way our words shape the reality of their diminished medical care.

A second, much broader, basis for rethinking the care of medically vulnerable patients comes in the area of medicine from Dr. Joseph J. Fins in his recent New York Times op-ed, *Brain Injury and the Civil Right We Don't Think About*.¹⁶ Dr. Fins confirms for the public at large what has been common knowledge among those in medicine: that neuroscience has not come close to understanding the brain in its wholeness, and that neuroscientists are particularly unclear about the brain's abilities.

Indeed, Dr. Fins' findings suggest that the brain has some capability to “rewire” itself after experiencing catastrophic injury. Fins notes that these findings are vitally important to those diagnosed in a PVS, underscoring the incredible rates of PVS misdiagnosis. In other words, persons who experience a debilitating brain injury and diagnosed as forever being in a PVS, nonetheless can experience a “rewiring” of their brain, so much so that they can emerge from a PVS condition. Fins recounts the story of “Maggie,” a remarkable patient who was once thought to be in a PVS but was actually in a “minimally conscious” condition, wherein one has the ability to communicate, even if in rudimentary ways. Not infrequently, stories of incredible recovery appear from patients diagnosed as PVS, yet who fully recover. Juan Torres¹⁷ and Martin Pistorius¹⁸ are just two examples of individuals who not only recovered from their apparently impossible diagnoses, but revealed that they were aware and could share detailed memories from their time in their “vegetative” state.

Why is this important? Fins explains the same devastating scenario that the European Task Force on Disorders of Consciousness considered in its report: that once a patient is determined to be in a PVS, “insurance benefit companies will deny (them) access to rehabilitation.” Naturally, the denial of rehabilitative care to those patients perhaps most in need of aggressive rehabilitation only stands to marginalize them further. Tragically, this marginalization goes one step further. A PVS diagnosis not only results in denial of insurance benefits, but also leads physicians to seek to convince the family decision-makers for medically vulnerable patients—who, it must be underscored, are not dying—to “allow their loved one to die” by denying them food and water by means of the feeding tubes they rely on due to their brain injury. Because these decisions are often presented in the same way as decisions about terminal patients who are actively dying and whose bodies are in the process of shutting down, families often consent to this misrepresented means of euthanasia by omission.

What Dr. Fins and the authors of the European Task Force on Disorders of Consciousness both confront is the importance of changing our language to reform bioethics and the practical way medically vulnerable patients are cared for. Too many neurologists remain caught in the paradigm established by Santiago Ramón y Cajal, a Nobel Laureate and one of the founders of modern neurology, who asserted in simple terms that the brain is “hardwired.” A hardwired brain, by implication, would lack the capacity to “fix” itself after injury.

A third and final basis for hope for rethinking the care of medically vulnerable patients comes in the area of law, led by thinkers like Robert A. Destro, a Catholic University of America law professor. In his 2009 paper, *Learning Neuroscience the Hard Way*, Destro writes that, “The doctrine of the unchanging human brain has had profound ramifications, none of them very optimistic. It led neurologists to assume that rehabilitation for adults who had suffered brain damage from a stroke was almost certainly a waste of time.”¹⁹

As punctuated here, such old-fashioned views do not have a sound basis in reality. Yet until language, medicine, and law sufficiently reflect the principle of the essential human dignity of persons regardless of their state or condition, and until a more robust clinical approach for medically vulnerable persons becomes the norm, this conversation must necessarily continue.

No one should die from lack of food and water. No one should live being thought of as a vegetable, suffering not only from their injury but also a diminished moral status. And no one should be functionally exiled by a medical system that treats them as hopeless.

Simple principles, but very difficult ones to enshrine in practice.

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³ *Bouvia v Superior Court*, 179 Cal. App. 3d 1127, 1135-36, 225 Cal. Rptr. 297. (Ct. App. 1986)

⁴ Smith, Wesley J, “More Than ‘In God’s Image.’” *First Things* 24 July 2015; accessed at: <https://www.firstthings.com/web-exclusives/2015/07/more-than-in-gods-image>.

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