Preserving Human Dignity at the End of Life
A Survey of Federal and State Laws

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By enacting a measure explicitly prohibiting physician-assisted suicide, the legislature in the State of Idaho dealt a significant blow to the agenda of euthanasia advocates in 2011. This victory for life should light a fire within those who want to protect dying, elderly, sick, and disabled Americans. Compassion & Choices, the Death with Dignity National Center, and other euthanasia advocacy groups deceptively claim that unbearable suffering and patient choice are the justifications for their mission to export the practice of physician-assisted suicide (and then euthanasia) to all 50 states. While the people of Idaho firmly closed the door on this anti-life effort, it is time for the 12 other states that have not explicitly prohibited the practice to follow.

While the United States Supreme Court did not rule on an end of life case until 1990, states have enacted end of life laws since the beginning of the nation. In fact, Anglo-American common law has addressed hastening death at the end of life for at least 700 years by punishing or prohibiting suicide, assisted suicide, and murder.1

This primer is designed to educate and to encourage lawmakers and citizens to continue the fight against the culture of death promulgated by supporters of euthanasia, physician-assisted suicide, and other measures intended to shorten life, and to ensure that other end of life laws do not inadvertently cause harm to vulnerable Americans.

ISSUES

Current federal and state laws generally address three broad end of life areas: (1) advance planning and related issues; (2) palliative care and treatment for acute and chronic pain; and (3) assisted suicide and euthanasia. Issues related to the first and second areas are addressed below; assisted suicide and euthanasia are addressed in the following article.

Advance Planning

Advance planning can serve an important purpose. Without a healthcare proxy, patients will find that many healthcare providers and institutions will make important decisions for them, or a court may appoint a guardian completely unfamiliar with the patient and his or her wishes. Thus, advance directives are intended to allow a person to state his or her preferences regarding future healthcare decisions in the event he or she later becomes unable to do so. Such documents take several forms, such as living wills, durable powers of attorney for healthcare decisions, “informal statements
of preferences,”

and “Do Not Resuscitate” (DNR) orders. Additionally, some states are creating registries to promote the adherence to advance planning documents within the medical community.

Yet while advance directives are widely accepted and promoted in the United States, they are not always effective. One study listed the following reasons why advance directives are sometimes unhelpful: failure of patients to complete advance directives; failure to understand the form’s language and implications of their decisions; failure to revisit advance directives when “goals and preferences for care” change; proxy decision makers often do not understand patients’ wishes; frequent unavailability of advance directives when needed; and confusion among healthcare providers over when to apply the directives. The study concluded that “advance directives typically do not affect patient care.”

These challenges have accelerated the nationwide movement toward the newest advance directive option: the “Physician Orders for Life Sustaining Treatment” (POLST) form. Created first in Oregon in 1991, it was designed “to convert patient preferences for life-sustaining treatment into immediately actionable medical orders” using standardized forms that provide specific treatment orders for cardiopulmonary resuscitation, medical interventions, artificial nutrition, and antibiotics.

The advent of the POLST Paradigm has shifted the timing of advance planning from when individuals are healthy to when they are potentially facing the end of life. It also directly involves healthcare providers in the planning—they execute the forms as medical orders. Further, POLST forms are followed by first responders, making a POLST form more like a DNR order than a living will, extending the “decisions beyond the administration of CPR in an emergency situation to the use of other life-sustaining measures in the course of long term care, including but not limited to the administration of antibiotics and ‘artificially administered nutrition.’”

Thus, as POLST forms gain traction across the country as the documents primarily relied upon by first responders and emergency room personnel, the withholding or withdrawal of antibiotics and/or nutrition/hydration may become as widely accepted as the withholding of CPR.

Notably, POLST forms may suffer from the same inadequacies of other advance planning documents, and POLST programs are also plagued by their own potential problems. Because a physician is directly involved in the execution of a POLST form, a patient may feel pressured by his or her physician’s perspective and physical presence to make certain designations. Additionally, end of life care is expensive, and the widespread use of POLST forms forms may increasingly be viewed as a legiti-
mate or even expected cost-containment measure. Patients may be pressured into making decisions about end of life care based on personal or societal financial concerns rather than what is in their best interests. Further, POLST may be harmful to people with disabilities who are not at the end of life. A task force in Oregon has noted that persons with significant disabilities, developmental disabilities, and/or significant mental health conditions have been subject to biases resulting in under-treatment and/or had their chronic health conditions mistaken as an illness [sic] nearing the end of life.”

While laws pertaining to advance planning are generally the purview of state legislatures, in recent years the federal government has become more involved in promoting the use of advance directives. For example, the Patient Self-Determination Act (PSDA) requires healthcare institutions that receive federal funding to ask patients if they have an advance directive, and to provide written information to patients elucidating their “rights under State law” to make decisions concerning medical care, “including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives.”

Advance planning, when done voluntarily and with appropriate safeguards (e.g., appointing a durable power of attorney rather than relying upon a written document alone), can be helpful and life-affirming. However, states have the responsibility to ensure that life-sustaining care cannot be easily withheld or withdrawn from incapacitated patients, particularly when implementing a POLST program.

**Surrogate Decision-Making and Refusal of Life-Sustaining Care**

Over the last few decades, services that were once considered basic “humane care” have been redefined as “medical treatment,” and may therefore be rejected by individuals in their advance planning documents, or by surrogates when patients are incapacitated. For example, food and water supplied through a feeding tube has been redefined by some as “medical treatment,” with the term “artificial nutrition” coined to analogize the process to “medical treatment” rather than “humane care.”

Today, the American Medical Association (AMA) defines “life-sustaining treatment” as “including, but not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration” based upon the subjective goal of “patient autonomy.” Remarkably, the AMA notes that “[e]ven if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis.”

Nonetheless, many states still treat nutrition/hydration as care that cannot be easily withdrawn, at least by surrogate decision-makers. Twenty-three states “impose explicit limita-
tions on substituted consent to forgo life-sustaining treatments via their advance directive or default surrogate laws. These limitations either focus on all life-sustaining interventions or on only artificial nutrition and hydration."

Additionally, in the absence of any form of advance directive, some states have a rebuttable presumption in favor of continuing food and water and restricting the powers of healthcare proxies or surrogates to remove artificial nutrition and hydration.

Such laws protecting patients from the arbitrary withdrawal of nutrition and hydration are constitutional. In *Cruzan v. Missouri Department of Health*, the U.S. Supreme Court held that the Constitution does not forbid states from requiring “clear and convincing evidence” of a patient’s wishes before the withdrawal of food and hydration. Thus, states may legitimately seek to safeguard patients through the imposition of heightened evidentiary requirements.

Ultimately, there is disagreement even among like-minded individuals over whether nutrition and hydration should be considered “medical treatment” that can be refused or withdrawn, and if so, under what circumstances and by whom. Feeding does not treat a disease; rather, it meets a basic human need. Without hydration and nutrition, a person will die in a short period of time regardless of his or her medical prognosis. Therefore, while the provision of “artificial” nutrition and hydration requires medical intervention, it should be provided unless a patient explicitly refuses it, its provision is excessively burdensome to the patient, or the patient cannot assimilate it. Further, when a patient has been diagnosed as being in a “persistent vegetative state” (PVS), he or she has not lost human dignity and is entitled to nutrition and hydration. States should maintain or enact statutes to ensure that nutrition and hydration are not withheld or withdrawn from an incapacitated patient not facing imminent death.

**Futility Protocols and Patient Treatment Pending Transfer**

“Futile care theory” is rapidly penetrating hospital care protocols. This theory provides that a doctor or institution may unilaterally withhold medical treatment because a healthcare provider believes that a patient’s quality of life is not worth continuing or it is simply not cost effective to do so, despite the wishes of the patient or patient’s family. It contradicts “choice” and “patient autonomy;” instead, futile care theory, while not directly endorsing assisted suicide or euthanasia, creates the risk inherent in those more extreme measures that subjective devaluation of the worth of another’s life will lead to death, in this case by deliberate medical neglect. Futile care theory, if not checked by proper legal and ethical standards, could undermine the principle of the equal dignity of all human life, and allow doctors, hospitals, or even third-party payors to determine which
lives are of sufficient “quality” to be worth caring for and sustaining.

Patients who desire to receive care that is refused by a medical professional or institution based on futility protocols benefit from state laws requiring life-sustaining treatment pending transfer. States that do not currently provide this protection should enact laws providing that if a healthcare provider declines to follow a patient’s instructions, the provider must promptly inform the patient or proxy of that refusal, provide continuing care to the patient until a transfer can be effected, and make reasonable efforts to assist in the transfer of the patient to a willing healthcare provider or institution.

Pain Management and Palliative Care
Pain management and symptom control are critical issues for terminally-ill patients. Yet, a 2004 study published in the *Journal of the American Medical Association* points out that nearly 25 percent of families report that their loved ones did not receive good care at the end of life, especially in managing pain. Both physicians and patients are often ill-informed when it comes to the breadth of possibilities in end of life care. Among the most cited barriers is that doctors remain uneducated about palliative care and specifically about the most current techniques in proper pain management. Medical schools and nursing schools are generally not teaching palliative techniques to students, nor do textbooks and lectures address the use of pain medications. As a result, healthcare providers enter their professions ill-equipped to manage chronic pain.

In the states, the organizations exerting the most influence on pain management law and policy are the state medical boards and hospital accreditation agencies. But while the medical profession is taking positive steps to improve its own practices in pain management, legislation can assist these efforts by encouraging more education, protecting doctors from litigation for prescribing certain medications for pain management, and fostering more communication between doctors and patients about pain management and palliative options, including palliative sedation.

However, palliative sedation should *not* be used when there are other means to alleviate suffering—and there usually are. With today’s modern medicine—advanced pain medications, antidepressants, anti-anxiety medications, implantable devices for pain management, improved surgical procedures, relaxation techniques, and counselling—“it is believed that nearly 98 percent of all pain in the terminally ill can be properly managed.”

If death is imminent, it is not essential to initiate artificial hydration for a sedated patient; however, ethical issues arise if sedation is continued for more than one or two days without hydration—the patient will become dehydrated, which can lead to death. Highlighting the concerns raised by palliative sedation without nutrition and hydration, Dr. Michael Irwin, a prominent member of the Voluntary Euthanasia Society in the UK, equated “terminal sedation” to “slow euthanasia.” Irwin writes that terminal sedation without hydration is tantamount to euthanasia “because the comatose patient often dies from the combination of two intentional acts by a doctor—the induction of unconsciousness, and the withholding of food and water.”
Because of these dangers, states should enact laws encouraging better education for doctors on the proper use of palliative sedation.

**KEY TERMS**

- **Advance directive** is a legal document expressing an individual’s healthcare decision preferences in the circumstance where he or she becomes incapacitated or unable to make those decisions. A **living will** is a declaration, signed and witnessed (or notarized), instructing physicians and healthcare providers as to what treatments to withhold, withdraw, or provide if the person is in a terminal condition and unable to make the decision to refuse certain medical treatment. A **durable power of attorney for health care** is a document, signed and witnessed (or notarized), designating an agent to make healthcare decisions for the person if the person is temporarily or permanently unable to do so. A **combination advance directive** provides an agent specific instructions to follow in healthcare decisions if the person is unable to so. An **informal statement of preferences** specifies preferences when a patient has not elected to create a formal, legal document.

- **Do-not-resuscitate (DNR) order** is a medical order intended for use when death is imminent, and typically pertains to withholding cardiopulmonary resuscitation (CPR) when a patient is in a “terminal condition” or “permanently unconscious state” (i.e., no brain waves, no heartbeat).

- **Double effect** is a traditional doctrine justifying palliative sedation. The doctrine holds three requirements: (1) the action itself (e.g., sedation) is not morally wrong; (2) the secondary effect (e.g., unconsciousness) is not merely a means to accomplish the intended benefit (e.g., pain relief); and (3) proportionality exists between the intended effects and the unintended secondary effects.

- **Physician Orders for Life-Sustaining Treatment (POLST)** are immediately-actionable medical orders that provide “specific treatment orders for cardiopulmonary resuscitation, medical interventions, artificial nutrition, and antibiotics.”** POLST are also known as Medical Orders for Life-Sustaining Treatment (MOLST), Physician Orders for Scope of Treatment (POST), Medical Orders for Scope of Treatment (MOST), or Clinician Orders for Life-Sustaining Treatment (COLST).
• **Futile care theory** proposes that physicians or other healthcare providers may unilaterally disregard requests for life-sustaining treatment made by a patient or a family member if the quality of the patient’s life is deemed not “worth” living. Such guidelines on how to deny requested life-sustaining care have been adopted and put into practice by some hospitals.23

• **Hospice** is “support and care for persons in the last phase of an incurable disease so that they may live as fully and comfortably as possible.”24

• **Opioids** are “strong pain medications derived from opium, or synthesized to behave like opium derivatives. Examples of opioids include morphine, codeine, oxycodone, methadone, and fentanyl.”25

• **Palliative care** is “an approach [to medicine] that emphasizes pain relief, symptom control, and spiritual and emotional care for the dying and their families.”26 It generally entails the use of analgesic medications, such as codeine and morphine.27 However, other pain relief techniques, such as physical therapy and neurosurgery, are also used.28

• **Palliative sedation** is the controlled administration of sedatives to a terminally-ill patient whose death is imminent, to the minimum extent necessary to render intolerable pain, which cannot be otherwise relieved, tolerable. While palliative sedation may render a patient unconscious, that is not the intent. Properly administered, palliative sedation does not cause death.29 The National Hospice and Palliative Care Organization (NHPCO) issued a statement supporting the option of palliative sedation delivered by “highly trained healthcare professionals” for “the small number of imminently dying patients whose suffering is intolerable and refractory.”30

• **Proportionality** is a principle used to “argue that the benefits of any intervention should outweigh the burdens of that intervention. . . . [I]nterventions with any risk of harm should be administered only to the degree necessary to confer the desired amount of therapeutic benefit.” Specifically, “[i]n palliative sedation, proportionality is used to argue that any level of sedation in excess of that required to render suffering tolerable as defined by the patient cannot be justified.”31

• **Persistent vegetative state** is a clinical diagnosis of a condition in which an individual has lost cognitive neurological function and awareness of his/her surroundings with certain characteristics of maintaining sleep-wake cycles, responding to stimulation in only a reflexive way, and showing no evidence of meaningful response to the environment.32

• **Terminally ill** means a patient is expected to live 6 months or less.33
• **Imminent death** is a prognosis of death within 14 days, or “days to weeks.”

**MYTHS & FACTS**

**Advance Planning**

**Myth:** The refusal of medical treatment is always left by doctors and hospitals to the discretion of the patient or the patient’s family.

**Fact:** Futile care theory is becoming more prevalent, and promotes unilateral decisions by physicians or institutions to withdraw or withhold medical treatment if the life is considered “unworthy” of preservation, regardless of the wishes of the patient and the patient’s family.

**Nutrition and Hydration and Advance Directives**

**Myth:** When food and hydration is withdrawn, the patient dies from an underlying disease or condition.

**Fact:** When food and hydration are withdrawn, the person may die from starvation and dehydration. If a patient is not in the process of dying, a deliberate decision to remove or withhold food and water is tantamount to euthanasia.

**Myth:** A persistent vegetative state (PVS) is a certain diagnosis and the person has no chance of recovery.

**Fact:** PVS is a clinical diagnosis based on subjective assessments from an attending physician. For instance, Louis Viljoen was diagnosed as PVS in 1996 following an accident. But by 2005, he had regained consciousness, demonstrated his good sense of humor, and remembered everything from before his accident.

In many instances, patients will wake instantaneously without any warning within the first month of being in a persistent vegetative state. Regardless of a PVS patient’s potential for recovery, however, he or she is a person with dignity, is not “dying,” and is entitled to humane care.

**Pain Management and Palliative Care**

**Myth:** Pain is an unfortunate and untreatable consequence of certain illnesses.

**Fact:** More than 90 percent of cancer pain can be controlled with proper treatment and approximately 95 percent of all chronic pain in the terminally ill can be likewise controlled, commonly through use of opioids.

**Myth:** Palliative medications result in unbearable side effects and may hasten death.

**Fact:** Fears about side effects and the hastening of death are unfounded. In fact, those patients with severe pain actually become tolerant of palliative medicines, minimizing side effects. There is also no evidence that pain medications hasten death if such medications are used correctly. In addition, doses can be increased to alleviate intensified pain as diseases progress.

**Myth:** Opioids may cause addiction, even in patients experiencing severe pain.

**Fact:** “[T]he fact that when narcotics are prescribed for the legitimate purpose of treating pain, they essentially never cause addiction. In studies of addiction with a total population of over 24,000 patients, only seven could be documented as having become totally addicted as a result of receiving opioids for pain relief.”

**Myth:** Opioids pose a great risk for respira-
tory depression leading to hastened death, even when monitored carefully.

**Fact:** Where the pain is properly assessed and dosages are carefully monitored, the chances of causing an overdose in a suffering patient are extremely unlikely.43 “[E]mpirical studies have failed to show an association between increases in doses of sedatives during the last hours of life and decreases in survival. Therefore, when dosed appropriately to relieve specific symptoms, palliative medications do not appear to hasten death.”44 In fact, morphine use may prolong life by enabling a suffering patient to breathe more easily and effectively.45

**Myth:** If a physician prescribes or administers high doses of medication to relieve pain or other discomfort in a terminally-ill patient, resulting in death, he or she will be criminally prosecuted.

**Fact:** If the death was not intended, such treatments are not murder or assisted suicide.

**Myth:** In the small percentage of cases where a patient cannot be kept conscious while pain relief is administered, there are no legal options and assisted suicide is necessary.

**Fact:** Palliative sedation is legal, even in states not authorizing assisted suicide, to relieve intractable symptoms.

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Endnotes

3 S.E. Hickman et al., The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End of Life Care: Potential State Legal Barriers to Implementation, 36 J. L. MED. & ETHICS 119 (Spring 2008).
4 Id.
5 See L.G. Black, The Danger of POLST Orders: An Innovation on the DNR, ETHICS AND MEDICS 35.6 (June 2010) (citing L.R. Robley, POLST Sweeps the Nation, NURSING CRITICAL CARE 4.1, 19-20 (Jan. 2009)).
7 See Mahon, supra, at 801. The law also prohibits an institution from “condition[ing] the provision of care or otherwise discriminate[ing] against an individual based on whether or not the individual has executed an advance directive,” and requires the institution “to ensure compliance with requirements of State law (whether statutory or as recognized by the courts of the State) respecting advance directives at facilities of the provider or organization . . . and to provide (individually or with others) for education for staff and the community on issues concerning advance directives.” The Patient Self Determination Act, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388 (codified at 42 U.S.C. §§ 1395cc(f), 1396a(w) (1994)).
8 Wesley J. Smith, FORCED EXIT: THE SLIPPERY SLOPE FROM ASSISTED SUICIDE TO LEGALIZED MURDER 51 (2003).
11 Id.
12 Hickman et al., supra, at 121.
15 M.J. Silveira et al., Patients’ Knowledge of Options at the End of Life: Ignorance in the Face of Death, 284 J.A.M.A. 2483 (2000) (“A national poll conducted by the American Medical Association in 1997 found that 40% of respondents did not know it is legal to give pain medicine that could have the additional effect of hastening death (double effect), and 35% were not familiar with the terms hospice or palliative care.”) (emphasis in original).
16 See, e.g., M.W. Rabow et al., End of life Care Content in 50 Textbooks from Multiple Specialties, 238 J.A.M.A. 771 (Feb. 2000) (“In general, students and physicians feel ill prepared to provide end of life care.”).
and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients, 39 J. OF PAIN and SYMPTOM MGMT. 914, 915-16 (May 2010) (providing that the National Hospice and Palliative Care Organization (NHPCO) does not endorse the use of palliative sedation for “existential suffering” and stating that “[p]roperly administered, palliative sedation of patients who are imminently dying is not the proximate cause of patient death, nor is death a means to achieve symptom relief in palliative sedation.”).  


19 Id.  

20 Black, supra.  

21 Nina Shapiro, Terminal Uncertainty: Washington’s new “Death With Dignity” law allows doctors to help people commit suicide—once they’ve determined that the patient has only six months to live. But what if they are wrong? SEATTLE WEEKLY, Jan 14, 2009, available at www.seattleweekly.com/content/printVersion/553991 (last visited Jun 9, 2009).  

22 Hickman et al., supra (emphasis added).  

23 See Smith, supra, at 196-213.  

24 Center to Advance Palliative Care Manual: How to Establish a Palliative Care Program (C. F. Von Gunten et al., eds. 2001).  


30 Kirk & Mahon, supra, at 915 (defining “refractory suffering” as “suffering that cannot be adequately controlled despite aggressive efforts to identify tolerable therapy that does not compromise consciousness”).  

31 Id. at 917.  


33 Kirk & Mahon, supra, at 917.  

34 Id. at 916.  


37 J. Wishik, MEDICAL AND LEGAL ASPECTS OF NEUROLOGY 23 (2005).  


41 Task Force, supra, at 162. Even the two percent of patients requiring sedation can die peacefully, without suffering. American Geriatrics Society, Brief as AMICUS CURIAE Urging Reversal of the Judgments Below at Part III.D, Vacco v. Quill, 521 U.S. 793 (1997); Hendin, supra, at 14.  

42 R. Ryan, Medical Practice: Palliative Care and Terminal Illness, 26 NAT’L CATHOLIC BIOETHICS QUARTERLY 313, 316 (2001).  

43 Id. at 318. See also J.E. Brody, Facing Up to the Inevitable: In Search of a Good Death, NEW YORK TIMES, Dec. 30, 2003, at F5 (according to Elizabeth Ford Pitorak, director of the Hospice Institute of Hospice of the Western Reserve of Cleveland, no evidence supports that such drugs hasten death); S.E.M. Buzzee, Comment, The Pain Relief Promotion Act: Congress’s Misguided Intervention into End of life, 70 U. CIN. L. REV. 217, 242 (2001); Lo & Rubenfeld, supra, at 1815; L. C. Kaldjian et al., Internists’ Attitudes Towards Terminal Sedation in End of Life Care, 30 J. MED. ETHICS 499 (2004) (“Although physiological concerns exist about the possibility that opioids and benzodiazepines may hasten death by suppressing respirations, there is a paucity of empirical data to support these concerns. . . . Even more provocative are suggestions that sedation toward the end of life may actually prolong life rather than hasten death, due to dampening of increased metabolic demands caused by pain and distress in patients who are fragile.”).  

44 Lo & Rubenfeld, supra, at 1815.  

45 Ryan, supra, at 318.