

## LAST RIGHTS: THE RIGHT TO DIE, 25 YEARS AFTER CRUZAN

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By Pamela Gulley, M.D.  
Psychiatrist, ABPN, FAPA  
CRAFT, Biggs, Fulton State Hospital  
Assistant Clinical Professor, UMC Dept. of  
Psychiatry

“The boundaries which divide Life and Death are at best shadowy and vague. Who shall say where the one ends, and where the other begins?”

-Edgar Allan Poe

The Modern Right to Die Movement is due to:

- Changes in medicine (“Medicalization” of death; development of technology)
- Changes in the legal system (Increased rights to privacy; right to death a “Pro-choice” issue?)

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### MEDICAL CHANGES

- Longer life expectancy; chronic illness more common with increased possibility of physical suffering for extended periods
- Changes in technology result in new medical issues, such as PVS (Permanent vegetative state)
- Death in hospitals rather than at home; less exposure to death and dying

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### LEGAL CHANGES

- Griswold v. CT, 1965
- Eisenstadt v. Baird, 1972
- Roe v. Wade, 1973

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The U.S. Constitution Due process clause (5<sup>th</sup> and 14<sup>th</sup> Amendments) enable a person to make personal choices without interference by government.

These three cases confirmed that citizens have a right to liberty in making personal choices.

All competent persons have a self-determined liberty to make choices they believe will benefit them.

*At Liberty to Die: The Battle for Death with Dignity in America*,  
by Howard Ball, New York University Press, NY, 2012.

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Furthermore, the right to refuse treatment is well-recognized and long standing.

A competent person has a near absolute right to refuse life-sustaining treatment, even if refusal means he will die.\*

What happens when a competent person is in an incompetent PVS state?

\*At Liberty to Die: The Battle for Death with Dignity in America, by Howard Ball, New York University Press, NY, 2012.

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### Karen Ann Quinlan, 1976

- 21 year old New Jersey woman who quit breathing on 4/15/75; revived but in PVS.
- After 3 months, her parents requested her respirator be removed. Her physician, Dr. Morse, refused.
- Her father, Joseph, went to court asking respirator be removed and he be appointed her guardian.
- Case heard 10/20/75; Judge Robert Muir rejected the request, ruling in favor of Dr. Morse and the hospital, and barred her parents from playing any role in her medical decision making, instead appointing an attorney guardian-ad-litem to advocate for her.

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### Karen Ann Quinlan, 1976

- A week later, her parents filed an appeal with the New Jersey Supreme Court, which heard the case and announced their ruling in favor of the parents on 3/31/76.
- The hospital again refused to comply, but after 2 months, Dr. Morse suggested weaning her off the respirator, which he did with parents' consent.
- The hospital wanted her out; 22 hospitals turned her down until she was finally accepted by a nursing home.
- She didn't die as expected, but lived ten more years, dying on June 11, 1985.

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**Cruzan v. MO Department of Health, 1990**

- Nancy Beth Cruzan was a vibrant 27 year old woman who was in a car accident January 11, 1983. She was in cardiac arrest 12-14 minutes until revived and taken a hospital in Carthage, then to Freeman Hospital in Joplin.
- She was in a coma; a gastrostomy tube was placed for nutrition.
- A month later she started developing contractures of her limbs.
- CT scans showed severe brain damage.
- Serial EEGs showed progressive deterioration; "flat background activity...suggestive of a vegetative, comatose state."

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**Cruzan v. MO Department of Health, 1990**

- She was transferred to the MO Rehabilitation Center, Mt Vernon, on 10/19/83.
- Her family signed a "No DNR" form for her in August, 1986.
- In May, 1987, 4 years after her MVA, her family requested the hospital discontinue nutrition and hydration.
- The Living Will statute passed in MO in 1985 (the year Ms. Quinlan died) specifically stated that feeding tubes are NOT treatment, so could not be refused.
- The MO Department of Health refused their request.

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**Cruzan v. MO Department of Health, 1990**

- Her parents petitioned the court; Judge Teel granted their request to withdraw nutrition and hydration as requested.
- MO Department of Health appealed to the MO Supreme Court, who reversed Judge Teel's decision, "clear and convincing" evidence of patient's wishes regarding withdrawal of treatment is required.
- Her parents appealed to the US Supreme Court, whose majority, 5-4, supported the state's position.

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Cruzan v. MO Department of Health, 1990

- The case returned to Judge Teel's court.
- At a new hearing on 11/1/90, the standard of "clear and convincing" evidence was met; more witnesses were found who could testify to Nancy's wishes regarding withdrawal of treatment.
- Judge Teel granted their request to withdraw nutrition and hydration on 12/13/90.

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Cruzan v. MO Department of Health, 1990

- The next day the Cruzans notified the hospital of Judge Teel's decision. Her doctor immediately went to her room, removed her gastrostomy tube, and she was moved to hospice.
- MO Governor John Ashcroft called the hospital and requested the doctor reinsert the tube. He refused. The hospital administrator reiterated the request; the doctor refused. "The tube's out and there's no reason to put it back in."

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Cruzan v. MO Department of Health, 1990

- Nancy finally died on December 26, 1990.
- Her gravestone reads:
- Born July 20, 1957;
- Departed January 11, 1983;
- At Peace December 26, 1990.

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In re: Guardianship of Estelle Browning, 1990

- On 11/19/85 a competent Ms. Estelle Browning executed a Living Will in Florida that directed she did not want life-prolonging procedures or nutrition and hydration if she had an irreversible terminal condition and death was imminent.
- On November 9, 1986 at 86 years old she had a massive stroke. A gastrostomy tube was placed 11/20/86. The next day she was sent to a nursing home.

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In re: Guardianship of Estelle Browning, 1990

- Her 80 year old second cousin, Doris Herbert, was appointed her guardian.
- Two years later her guardian requested that her feeding tube be discontinued per her Living Will. A neurologist testified she was in a PVS.
- Request was denied because death was not imminent.

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In re: Guardianship of Estelle Browning, 1990

- Her guardian appealed to the Florida Supreme Court, which did not rule until a year after Ms. Browning's death in 1989 (with NG tube still in place).
- The Florida Supreme Court held that the Living Will allowed Ms. Browning the right to refuse any treatment through her designated surrogate.

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**Terri Schiavo, 1990-2005**

- Mrs. Terri Schiavo was a young, 26 year old married woman from Florida who suffered a cardiac arrest on 2/25/90. She was revived via CPR after more than 15 minutes. She never regained consciousness, and remained in a PVS.
- After 8 years, her husband and parents were advised that there was no hope for recovery.

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**Terri Schiavo, 1990-2005**

- Her husband, Michael, was appointed her guardian. He petitioned the court to have her feeding tube removed on 5/11/98.
- After a week long trial his request was granted, in February, 2000, by Judge Greer.

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**Terri Schiavo, 1990-2005**

- Her parents opposed this decision; they firmly believed she could still recover. Through various court, political, and legislative means continued to oppose him for the next 5 years, until her death on 3/31/05.
- More than 30 judges were involved; all the Florida judges who got involved supported her husband's request.

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### Physician-Assisted Death (PAD)

- “The double effect”—a practice that occurs when a physician provides painkilling medication to his terminal patient to relieve pain, with the possibility that the treatment may indirectly hasten death.
- Freud is believed to have possibly died due to the “double effect.” (Arch Intern Med/Vol 159, July 26, 1999, 1521-1525 and Vol 160, January 10, 2000, 117-118)

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### State Legislation for PAD

- In 1990 all states prohibited PAD, and provided criminal prosecution for physicians who provided assistance in dying.
- In 1990, the first state to pursue legislation for PAD was Washington, through Ballot Initiative 119. It failed 54% to 46% in November, 1991.
- In 1992, California proposed “The California Death with Dignity Act” through Proposition 191; it also failed 54% to 46% in November, 1992.

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### State Legislation for PAD

- Beginning in 1992 all pro-PAD legislation focused on **passive** assistance of physicians in dying (lethal medications but taken by the patient).
- From 1997 to 2011 over 12 states organized PAD initiatives; all but two lost.

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#### The Oregon Death with Dignity Act, 1994

- The Oregon Death with Dignity Act (Measure 16) passed by a 51% to 49% vote in November, 1994.
- Specifically prohibited euthanasia.
- Challenged in multiple venues; Gonzales v Oregon, 2006. Held that the U.S. Attorney General (Gonzales) lacked authority under the Controlled Substances Act to criminalize the use of drugs in Oregon's assisted suicide law.

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#### Other states allowing PAD

- The Washington Death with Dignity Act (Initiative 1000) passed by a 58% to 42% vote in November, 2008.
- Vermont passed similar legislation in 2013.
- PAD is technically legal in Montana; Montana's Supreme Court ruled in 2009 that existing state laws do not prohibit physician assisted death.
- A trial court in New Mexico ruled that terminally ill patients have a right to obtain physician aid in dying.

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#### Concerns by opponents of PAD

- "The Slippery Slope"—Opponents suggest that PAD protection could have unintended consequences for the disabled, elderly, mentally ill, and even for those terminally ill patients who might have second thoughts.
- Hemlock Society, later changed to Compassionate Choices, considered aggressive by some. Book "Final exit promoted "self-deliverance"
- Similar legislation in Belgium allow for PAD in psychiatric patients, non-terminal disabled patients, elderly, and even in terminal children.

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**Concerns by opponents of PAD**

- Dr. Jack Kevorkian practiced euthanasia via his “Merciton” device; he assisted in over 130 deaths, including many non-terminal patients, starting in 1990 and ending with his arrest in 1999 for 2<sup>nd</sup> degree murder. He was paroled after 7 years, and died in 2010.
- Dr. Lawrence Egbert has been called the new “Dr Death.” He is a 87 year old retired anesthesiologist from Maryland belonging to the group Final Exit Network. He lost his medical license in January, 2015, for assisting in several “death events” as an “exit guide.”

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**Who asks for Physician Assisted Death?**

- Statistics for the 1998-2007 period in Oregon’s Death with Dignity program—
- 341 terminally ill patients died after taking the meds; accounts for <1% of deaths in Oregon.
- 97.4% white and well educated.
- 82% had cancer; 7.6% had ALS
- 86% were in hospice care; <1% were uninsured
- Average age 69 years; range 25 to 96 years.
- Most common reasons cited—Fear of losing autonomy (89%); life less enjoyable (87%); loss of dignity (82%)

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**Brittney Maynard, 2014**

- 29 year old married woman in California diagnosed with incurable Stage 4 glioblastoma moved from California with her husband to Oregon to participate in Oregon’s Death with Dignity Act.
- She developed seizures, confusion, weight gain, and other problems as a consequence of her illness and its treatment.
- She died on her own terms on November 1, 2014.

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### Physicians and PAD

- Recent surveys show physicians are split on PAD issue. A slim majority favor it. The AMA opposes it.
- Although physicians may support the idea for patients, they are more uncomfortable offering it.
- A Medscape report 12/16/14 titled "Life and Death Decisions that Keep Doctors Up at Night" has "physician-assisted suicide" at the top of the list.
- Many cite lack of training in dealing with dying patients as a concern, and more specifically, how to approach and evaluate patients requesting PAD.

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### Hospice and Palliative Care

- Palliative care and hospice may address many of the concerns of dying patients and thereby avoid the need for physician assisted death.
- In 1974 there was only one palliative care hospice facility in the United States; in 2010 there were 5000 or so programs in all 50 states, caring for >1 million pts.
- The majority of terminally ill patients in the United States do not have hospice.
- It is estimated that >1/2 terminally ill patients still die in hospitals, without palliative care, and many in pain.

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### Advanced Directives

- The Patient Self-Determination Act (PSDA) was passed in 1990. It was sponsored by MO Senator John Danforth after Cruzan to let individuals know their right under state law to have an advance directive to guide their medical care, especially at end of life.
- Personal experience...

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Advanced Directives—Top take away point!!!

- National Health Care Decisions Day ([www.nhdd.org](http://www.nhdd.org)) is an annual event designed to get patients and health providers to think about their own end-of-life treatment choices.
- Go to this website to find, print off and complete your own medical health care directive!!!

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#### Recommended resources

To learn more:

The Long Goodbye: The Deaths of Nancy Cruzan, by William Colby, Hay House, 2002.

You Don't Know Jack, DVD, 2009, starring Al Pacino as Jack Kavorkian

How to Die in Oregon, DVD, 2009; follows several patients who requested physician-assisted aid in dying under the Oregon Death with Dignity Act.

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## QUESTIONS?

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