



# Palliative Legal/Ethics Cases in the United States

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# So What Are We Talking About Today?

- ▶ In the year 2021, we have certain assumptions about what is legal, what is ethically permissible, etc. But things change.
- ▶ For example, consider the California End of Life Option Act and laws in other states.
- ▶ What is now considered legally acceptable was only recently deemed to be. What cases led to this acceptance? Both from a sociologic standpoint as well as the legal standpoint?
- ▶ Why is this important?

# Hippocratic Oath

## c. 275 AD

- ▶ An early (likely the first) attempt to codify medical ethics
- ▶ Most commonly remembered for “First do no harm,” or “Primum non nocere.” This phrase probably actually dates from the 17<sup>th</sup> century.
- ▶ Still pledged at some medical schools (usually in an edited form) upon conferring of medical degrees
- ▶ “I will use treatment to help the sick...but never with a view to injury and wrong-doing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course.”
- ▶ This last sentence is commonly interpreted as a phrase against euthanasia / physician-assisted suicide.
- ▶ Taking a further leap, some people and organizations have also interpreted this as not allowing other types of deaths that we generally now take for granted, such as withdrawal of ventilators / pressors / dialysis / feeds, etc.

# Hippocratic Oath

## c. 275 AD

- ▶ But is the oath still relevant today? Should this decide if terminal extubations, or Physician-Assisted Death, for example, should be allowed? Here are some other relevant quotes from the Oath:
- ▶ “I will not give to a woman a pessary to cause abortion.”
- ▶ “[I will teach all students] who have taken the physician’s oath, but to nobody else.”
- ▶ “I swear by Apollo...and by all the gods and goddesses...”
- ▶ “[I will] hold my teacher in this art equal to my own parents...”
- ▶ “When [my teacher] is in need of money to share mine with him...”

# Hippocratic Oath

- ▶ It should be noted that there are many great updated versions of this which are spoken in medical schools now. Most medical schools which still use the “classic” version will omit the parts about abortion, or giving your attending physicians money, etc.
- ▶ So maybe there is a different person or organization besides Hippocrates that we should base our current ethics on?

# American Medical Association

## 1973

- ▶ “The intentional termination of the life of one human being by another—mercy killing—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association....The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or immediate family.”
- ▶ Does this clear things up?

# American Medical Association

## 1973

- ▶ The AMA in this statement did not clarify what qualifies as “extraordinary.”
- ▶ They did not clarify whether following the decision of a family and, say, removing a ventilator, was a “mercy-killing.”
- ▶ Oddly, this led to some physicians choosing to *not even start* certain types of life-sustaining measures, such as feeding tubes, with the thought that if they have to stop such measures, that would be “mercy-killing.”

# Karen Quinlan

## 1975

- ▶ In April 1975, Karen Quinlan, aged 21, became comatose after taking diazepam along with alcohol. She had not eaten in about two days at the time of ingestion.
- ▶ She felt ill and was taken home. Friends checking on her found her not breathing and called for an ambulance. Mouth-to-mouth was attempted and she began breathing but did not regain consciousness.
- ▶ She was taken to a hospital and placed on a ventilator and eventually was found to be in a persistent vegetative state (PVS). She eventually underwent a tracheotomy due to ongoing need for a ventilator.





# Karen Quinlan

## 1975

- ▶ Initially she was fed via IV.
- ▶ After a few months, IVs became more and more difficult, and in Sept 1975 an NG tube was placed for feeding.
- ▶ Court hearings described that "...she appears to be slightly convulsing or gasping as the oxygen enters the windpipe; her hands are visible in an emaciated form, facing in a praying position away from her body. Her present weight would seem to be in vicinity of 70-80 pounds."
- ▶ "...lying in bed, emaciated, curled up in what is known as flexion contracture. Every joint was bent in a flexion position and making one tight sort of fetal position. It's too grotesque, really, to describe in human terms like fetal."
- ▶ One neurologist later described her (in a hearing) as "an anencephalic monster."
- ▶ The family began to have doubts.



# Karen Quinlan

## 1975

- ▶ Her sister: “Karen’s head was moving around, as if she was trying to pull away from that tube in her throat, and she made little noises, like moans. I don’t know if she was in pain, but it seemed as though she was. And I thought—if Karen could ever see herself like this, it would be the worst thing in the world for her.”
- ▶ Her parents stated that she had twice told them in the past that she would not want to be kept alive as a “vegetable on machines.” No advance directive had ever been written.
- ▶ Her parents decided to remove the ventilator and allow her body to die.



# Karen Quinlan

## 1975

- ▶ The physicians of record, an internal medicine resident and a pulmonary fellow, both refused to disconnect the ventilator.
- ▶ They felt the AMA guideline of 1973 would consider this to be euthanasia.
- ▶ At a hearing, a judge ruled that since there was no advance directive, the spoken wishes relayed to the parents could not be final. He also stated that there was no “right to die” in the Constitution.



# Karen Quinlan

## Appeal to N.J. Supreme Court

- ▶ Her case was heard a few weeks later.
- ▶ Upon questioning the hospital's lawyers why the patient couldn't be moved to another hospital (where she could be removed from the ventilator by different physicians), the hospital's lawyers stated that would be immoral.
- ▶ NJ Supreme Court cited recent strengths to the right to privacy (via Roe v Wade) to allow the family the right to privacy and liberty to disconnect Karen.
- ▶ “No compelling interest of the state could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient state” –Chief Justice Richard Hughes



# Karen Quinlan

## Early 1976

- ▶ After the decision, one of the physicians of record continued to delay, saying that he would “have to live with this” for the rest of his life.
- ▶ Other hospital officials (and the Vatican) criticized the decision and the family.
- ▶ The physicians refused to remove the ventilator, and instead weaned her off of it over the course of a few months. She eventually came off the ventilator, able to breathe without it.
- ▶ At that point, she was transferred to a nursing home. She spent 10 years in the nursing home without needing a ventilator and eventually died of pneumonia in 1986.



# Karen Quinlan Legacy

- ▶ The year after the Quinlan decision, California passed a law recognizing the legality of advance directives / living wills. Eventually all 50 states passed similar laws.
- ▶ “The case was the first one to draw the attention of the country and the courts to the problem of being a prisoner in a helpless body, supported only by medical technology....Every [decision made today regarding death and patient wishes] is a direct descendant of the Quinlan decision.” –John Fletcher, ethicist
- ▶ Her parents later opened the Karen Ann Quinlan Center of Hope Hospice.



# Nancy Cruzan

## 1983

- ▶ Nancy Cruzan, 24 years old, suffered an auto accident and landed in a water-filled ditch. She was found to be pulseless, but was brought back by paramedics. Unfortunately, she never regained consciousness, and was eventually diagnosed with PVS.
- ▶ A feeding tube was placed, but in 1988 her parents asked for it to be removed, as Nancy had told a friend in 1983 that if injured she “would not wish to continue her life unless she could live at least halfway normally.”



# Nancy Cruzan

## 1988

- ▶ The hospital told them they would need a court order. The family was able to obtain one.
- ▶ The state of Missouri appealed this decision, and ultimately the Missouri Supreme Court ruled that the feeding tube could not be removed, as there was not “clear and convincing evidence” that Nancy would have wanted to die in this situation (since her possible wishes were communicated verbally to a friend and not written).





# Nancy Cruzan

## 1990

- ▶ The parents appealed this to the U.S. Supreme Court.
- ▶ The Supreme Court did make a landmark decision at this time regarding that competent individuals could refuse medical treatments. However, they did not agree that this applied to incompetent individuals.
- ▶ In a 5-4 decision, they ultimately ruled that Missouri was allowed to require “clear and convincing” evidence in the case of an incompetent patient, and thus the Supreme Court ruled that the feeding tube would stay in place.



# Nancy Cruzan

## 1990

- ▶ Eventually the parents did find other friends of Nancy's who also testified that she had indeed stated that she would not want to be in such a state of being.
- ▶ Now armed with "clear and convincing" evidence, they were allowed to remove the feeding tube, and Nancy died 12 days later.



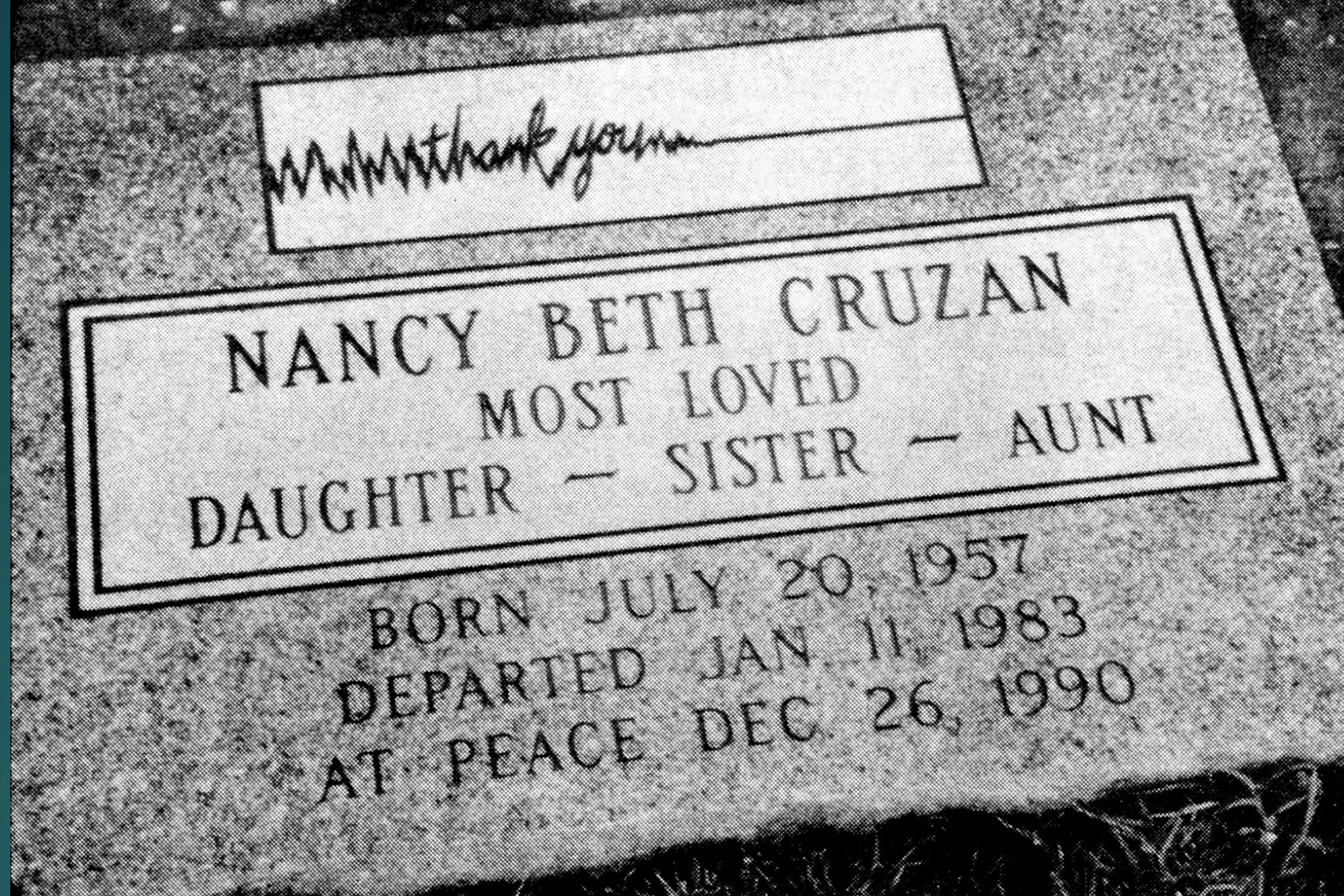
# Nancy Cruzan Legacy

Created national interest in advance directives (300,000 requested from Society for the Right to Die in one month after the Supreme Court ruling)

Increased support for the Patient Self-Determination Act, passed by Congress one year after her death. This Act requires hospitals and nursing facilities to give patients AD information.

Affirmed that it is up to states to decide their own right-to-die standards, rather than the federal government (which led to passing of Physician-Assisted Death laws in some states eventually)





Joe Cruzan: "I would prefer to have my daughter back and let someone else be this trailblazer."

# Elizabeth Bouvia

## 1983

- ▶ Elizabeth, a 25 y/o woman with cerebral palsy, paraplegic, severe degenerative arthritis.
- ▶ She was driven by her father from Oregon to Riverside General Hospital in CA where she was admitted as a suicidal patient, asking them to leave her alone and allow her to starve to death.
- ▶ She described wishes by saying, “Death is letting go of all burdens. It is being able to be free of my physical disability and mental struggle to live.”



# Elizabeth Bouvia

## Life History

Age 5 – parents divorce

Age 10 – abandoned by her mom and goes to group home

At some point her dad begins caring for her again

Age 18 – told by her dad that he can no longer care for her

She then begins to live on her own with a live-in nurse and finishes a high school degree

Age 23 – graduates from San Diego St. with a bachelor's degree and enters a Master's program in Social Work

Age 24 – marries an ex-convict and becomes pregnant, then miscarries. Abandoned by husband who stated that he “could not accept her disabilities, a miscarriage, and rejection by her parents.”

A few days later, she presents to Riverside General Hospital



# Elizabeth Bouvia

## 1983

- ▶ Under care by psychiatrist for 4 months. He would not allow her to starve. She hired a lawyer and contacted the ACLU.
- ▶ A judge ruled that the hospital could begin force-feeding her.
- ▶ Aides would place plastic tubing in her mouth, and she would bite through it to avoid feeding.
- ▶ Eventually there would be three attendants at her bedside for feeding to hold her down, while another would place an NG tube through her nose to pump nutrition directly into her stomach.



# Elizabeth Bouvia

## 1983

- ▶ She eventually left Riverside General, and presented to a hospital in Mexico where she thought she would be allowed to starve herself.
- ▶ This hospital as well would not allow that, so she checked out.
- ▶ She could not find any facility which would be willing to take her without her agreeing to eat, and she eventually gave up and took solid food again.





# Elizabeth Bouvia

## 1983

- ▶ “Being allowed to die when there’s no need for her to die—this is a dangerous precedent.” –Habeeb Bacchus, one of her physicians
- ▶ “She needs to learn to live with dignity.” –Law Institute for the Disabled
- ▶ “There is no other reasonable option [besides force-feeding].” –Judge Hews, who decided her case
- ▶ “I had the feeling that the judge, the doctor, and the hospital had found Elizabeth Bouvia guilty—guilty of not playing the game. It was as though the Easter Seal Child had looked into the camera and said being crippled was a lousy deal and certainly nothing to smile about.” –Arthur Hoppe, columnist



# Elizabeth Bouvia

## 1985

- ▶ Eventually in 1985 she ended up at a hospital in High Desert, where she was force-fed again. At this time she weighed 70 lbs.
- ▶ She again petitioned a court. Judge Warren Deering ruled against her and said that “saving her life is paramount” and that her right to privacy did not extend to “suicide by starvation.”



# Elizabeth Bouvia

## 1985 / Legacy

- ▶ She appealed to a higher California Court of Appeal who ultimately sided with her. “In [her] view, the quality of her life has been diminished to the point of hopelessness, uselessness, unenjoyability, and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She is not to be faulted for so concluding....As in all matters, lines must be drawn at some point, somewhere, but that decision must ultimately belong to the one whose life is in issue.”
- ▶ Competent adult patients now had the right to refuse medical treatment. This occurred five years before the Cruzan case was finally decided. Elizabeth Bouvia had finally won.



# Elizabeth Bouvia

- ▶ Now with the freedom to stop eating, Elizabeth...decided not to die. She chose to continue living instead. She struggled with depression for many years.
- ▶ In 1992 her former lawyer committed suicide. Elizabeth said, "Jesus, I wish he could have come in and taken me with him."
- ▶ It is not known where Elizabeth Bouvia is today, but as of 2018 she was rumored to still be alive.



# American Medical Association

## 1986

- ▶ In 1986, the AMA clarified their 1973 position statement, which had said that mercy-killing is wrong and did not state whether physicians could be involved in cessation of life support.
- ▶ In 1986, they stated that physicians could indeed withdraw feeding tubes and ventilators from irreversibly comatose patients, after consulting with the patient's family.

# Catherine Gilgunn

## 1989

- ▶ Patient was elderly and admitted to Massachusetts General Hospital
- ▶ She suffered irreversible neurological injury and became comatose during her hospitalization.
- ▶ Her daughter stated that the patient had said she would want everything done to keep her alive as long as possible.
- ▶ Despite this, physicians sought to make her DNR, and were ultimately successful. She died later in the year after the DNR was put in place against family's wishes.
- ▶ The physicians were then brought to trial by the family.

# Catherine Gilgunn

## 1989

- ▶ After deliberation, the jury found the physician to be NOT guilty of neglect or imposing emotional distress on the patient's daughter.
- ▶ No appeal was ever filed.
- ▶ Essentially, this case set precedent for physicians to be legally allowed to refuse treatment for patient if they felt that treatment was futile.

# Terri Schiavo - 1990

- ▶ Terri Schiavo was 27 years old when she suffered anoxic brain injury, possibly due to an extreme hypokalemia-caused arrhythmia
- ▶ Now in a PVS, she required a PEG tube for feeding
- ▶ She underwent attempted PT, OT, SLT for the next four years, with no improvement in her overall status
- ▶ Medical providers at this time told her husband, Michael, that she had no chance of meaningful recovery. He made her DNR, but then changed back to Full Code when her parents strongly opposed
- ▶ For various reasons, the relationship between the parents and husband broke down and became contentious





# Terri Schiavo

## 1998

- ▶ Eight years after the initial brain injury, her husband asked to remove the feeding tube, to allow her to die. He stated that at one time in the past, Terri had mentioned to him that she wouldn't ever want to live in a vegetative state. Her parents completely disagreed.
- ▶ Two years later, a court finally agreed to removing the feeding tube, due to the "clear and convincing" evidence they cited
- ▶ Her parents appealed multiple times, up to the Florida Supreme Court, and were denied each time.
- ▶ At one point her parents said that even if Terri had asked them to remove the tube, they would not do it.
- ▶ Finally, her parents appealed to federal court and were heard.



# Terri Schiavo

## 2003

- ▶ At this point the case was well-known to the media and highly publicized
- ▶ Governor Jeb Bush, of Florida, President George W. Bush, among others all praised the parents' efforts to keep Terri alive. In the meanwhile, both sides continued the argument in court.
- ▶ In fall of 2003, the Florida legislature passed *Terri's Law*, which would allow Jeb Bush to issue a one-time stay of a judge's order to remove a feeding tube in certain cases when a patient is in PVS. Governor Bush immediately enacted the law after the Judge ruled in favor of removing the tube.



# Terri Schiavo

## 2004

- ▶ The Florida Supreme Court ruled 7-0 that *Terri's Law* was unconstitutional, as it worked against the separation of powers, and allowed “the executive branch to interfere with the final judicial determination in a case.”
- ▶ It was appealed yet again to a federal court, who declined to hear the case.
- ▶ Having been defeated by the judicial branch, her parents turned to the U.S. Congress.



# Terri Schiavo

## 2005

- ▶ Congress attempted to subpoena Terri Schiavo, so they could put her in “witness protection program” and thus have control over the feeding tube. This attempt failed.
- ▶ Congress attempted to pass a federal version of *Terri’s Law* and President Bush flew back from vacation in Texas and signed the bill at 1:00 in the morning.
- ▶ Senator Bill Frist, in the meanwhile, reviewed videos of her and declared that she did not seem to be in PVS, contradicting multiple other physicians who had examined her.
- ▶ A federal judge once again examined the case and determined Congress and Bush, etc., to be legally in the wrong.
- ▶ Various activists, family members, etc., began holding vigils, going on cable news shows, etc., being very vocal about her case.
- ▶ Despite everything, the feeding tube was eventually removed in March, and Terri died 13 days later on March 31, 2005.



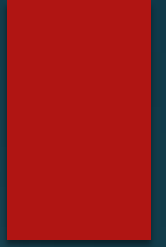
# Terri Schiavo

## Legacy

- ▶ The end of the Schiavo cases marked a general change in public opinion, or at least an awakening.
- ▶ Attempts in Congress to nullify laws such as Oregon's Death with Dignity Act essentially stopped after Schiavo's death.
- ▶ There was a noted increase in percentage of Americans who in polls stated that they believed issues surrounding death should be decided by a patient, their family, their medical provider, without government input.
- ▶ Her case and the abundance of media coverage sparked discussions about "life at all costs" and gave many people a different view of how death can look in certain situations.



Questions? Discussion topics?



# Thank you!

Laws are like cobwebs, for if any trifling or powerless thing falls into them, they hold it fast, but if a thing of any size falls into them it breaks the mesh and escapes.

--Anacharsis

Show me a hero, and I'll write you a tragedy.

--F. Scott Fitzgerald