Case 1

- 79 yr old Hispanic man was admitted to hospice unit. He had lived in the US for 35 years and was a citizen but primary language was Spanish. He was married and had six children. Many of his extended family lived in Mexico. He had presented with anemia, severe back pain. He was found to have multiple lytic lesions and a bone marrow biopsy with a diagnosis of multiple myeloma.
- The oncologist felt that the prognosis was grim ,but since he did not speak Spanish, he deferred to the Primary admitting doctor to discuss the patient's options. The primary doctor spoke with the patient's family who did not want to tell their "poppy" that he was going to die.
- The patient was not offered treatment for his illness and was not told his diagnosis. The family decided to sign their father into hospice and transfer him to an inpatient unit to get better symptom control.

- Is it absolutely necessary to tell patients everything about their illness, or is it reasonable to find out how much they really want to know?
- Culturally, is it assumable he would defer to his family anyway?

Truth-Telling

- Patient-centered assessment of goals

vs. Values/Requirements of health care professionals.

Central conflict is between the ethic of Truth-telling and the fear of causing the loss of hope.

The miserable have no other medicine; But only hope.
--William Shakespeare (1564-1616) Claudio, in Measure for Measure act3, sc.1.

- Factors that often increase hope in the terminally ill include:
  - feeling valued,
  - meaningful relationships, reminiscence,
  - humor,
  - realistic goals, and
  - pain and symptom relief.
- Factors that often decrease hope include:
  - feeling devalued,
  - abandoned or isolated ("there is nothing more that can be done"),
  - lack of direction and goals, and
  - unrelieved pain and discomfort.

Strategies for eliciting patients hopes during a terminal illness ?

- 1. Ask the patient, *"Do you have long term hopes and dreams that have been threatened by this illness?"* Support the patient in recognizing and grieving the possible loss of these hopes.

  2. Ask the person if there are particular upcoming events they wish to participate in--a wedding, birth, trip, etc.

  3. Ask "What are your hopes for the future?" and "Do you have specific concerns or fears?"

  4. Encourage the patient to make short, medium and long range goals with an understanding that the course of terminal illness is always unpredictable.

Case 2

- **67 year old stockbroker who has been living apart from his 60 yo wife for the last year. While undergoing a CABG, he suffers a stroke and general anoxia, leaving him with minor left hemiplegia and disorientation. It is unclear as to the extent to which he will regain full function.**
- **His 35 yo. girl friend with whom he has had a relationship for 3 years and with whom he has been living for the last year, insists that "<u>everything be done</u>".**
- **His wife appears, armed with a durable power of attorney, which he executed four years ago and never revoked. She insists that, should he suffer a coronary arrest, he "<u>not be resuscitated</u>". She claims that his father had a CVA and her husband's wish was never to "linger on life support", despite what the girlfriend might say.**

Should the physicians honor the wife's power of attorney ?

- What are standards for proxy-decision making?
- Would it matter if he had a living will stating he didn't wish to have life-prolonging treatments?

How do we decide?

- ADVANCE DIRECTIVES
  - Living Wills
  - Durable power of Attorney for health care
- State authorized Proxy decision-makers

Standards for proxy decision-makers

- Willingness/availability to act
- Substituted judgment
- Best interest of patient

Helping patients find their way to "a good death"

- Find out about the experiences of family and friends.
- Ask specific questions
- Avoid jargon
- Don't make promises you can't keep.

"Five Wishes" Aging with Dignity in Florida

www.agingwithdignity.org

American Hospital association

www.putitinwriting.org

Physician Orders for Life sustaining Treatment (POLST)

- POLST form is a standardized form designed to converse wishes for life-prolonging treatments into medical orders.
- POLST program was developed in Oregon but similar programs are used in W Virginia, Washington, Wisconsin, Pennsylvania, New York, Utah, New Mexico, Michigan, Georgia, Minnesota and Florida.
- POLST and Advance directives are complimentary.

Are Advance Directives Final in decision making

- All AD are intended to be influential and binding.
- Disagreements and disputes are always possible.
  - Families /Surrogates can contest
  - Physicians are not compelled to act unethically or against their medical judgment.

Case 1-A turn for the worse

- Pt. experiences a witnessed ventricular fibrillation cardiac arrest. He receives successful defibrillation and the resuscitation, lasted 20 minutes; although unresponsive, he has reactive pupils. It is discovered that his hematocrit had dropped and that he had a gastrointestinal bleed from the anticoagulation, which has responded to therapy.
- **What do you say to his family about his chance of meaningful recovery?**

- It is 72 hours hours later and he remains unresponsive; his pupils are now unreactive; he has no motor response or brainstem reflexes. The nurse reports that he had myoclonus 12 hours ago. Family want to withdraw life-prolonging treatments.
- NOW WHAT IS HIS LIKLIHOOD OF RECOVERY?

Pooled clinical signs in the Prognosis of Postcardiac Arrest Coma

	LR of Poor Neurologic Outcome			
	Positive		Negative	
	Onset	72 hr	Onset	72 hr
Absent Corneal Reflex	13	-	0.6	-
Absent Pupil Response	10	3.4	0.8	0.9
Absent motor response	4.9	9.2	0.6	0.7
Absent withdrawal to pain	4.7	-		0.2
Seizure or myoclonus		1.4		0.8
GSC <5	3.5	2.8	0.3	0.3

- Earnest et al, *Neruology* 1979;Edgren et al *Crit Care Med,*1987;Levy et al, *JAMA* 1985; Chen et al, *Crit Care Med* 1996 Snyder et al, *Neurology* 1980;Widjiks et al, *Ann Neurol* 1994; brain resuscitation clinical trials I,ii,iii (1979-1992).

The Bottom Line

- From metanalysis of 2000 patients: patients who lacked pupillary and corneal reflexes at 24 hours and had no motor response at 72 hours, the chance of meaningful neurologic recovery was small. *Booth et al, JAMA Evidence-Based Clinical Diagnosis,2009*
- In study of 210 patients who had any of these 3 clinical findings , 0 ever regained an independent lifestyle. *Levy et al, JAMA.1985.*
- No clinical findings have LRs that strongly predict good neurologic outcome.

What if the patient was brain dead?

- In 1968, Harvard Medical School convened a committee to explore the issue of patients with irreversible coma, coining the term 'brain death'.
- 1981 – The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research refined a "whole brain standard" which became the basis for the Uniform Determination of Death Act.

Clinical determination

- Unresponsiveness, lack of receptivity, the absence of movement and breathing, the absence of brainstem reflexes.
- Rule out medical conditions that may confound the clinical assessment
  - Severe acid-base, electrolyte, or endocrine
  - Hypothermia
  - Absence of intoxication

Establishing Brain Death

- In the absence of brain stem function, spinal reflexes can still create movement:
  - Trunk muscles may contract, giving the appearance that the person is trying to rise
  - Arms may rise, facial twitching, head may turn side to side

Criteria Used

- **Clinical examination**
  - Abscense of Brainstem reflexes
    - Doll's eyes, calorics
  - Apnea testing
    - The absence of respiratory drive with a $PaCO_2$ of 60 mm or 20 mm above patient's baseline
- **Confirmatory testing** is optional in the US, but required in Europe, Central and South America, and Asia
  - Cerebral angiography / MRA
  - EEG
  - Transcranial Doppler ultrasound
  - Nuclear imaging

Case 2

- **A 72 yo woman ,living in a nursing home, is evaluated after 10 days in ICU. She was admitted with severe urosepsis, in shock ,requiring pressors for several days. She developed acute renal failure requiring dialysis. She is now afebrile , being given piperacillin/tazobactam.**
- **She is intubated on ventilatory support with O2 sat 94% on FiO2, 0.60 . She is hemodynamically stable but is still oliguric and receiving hemodialysis. She has been off sedation for 3 days, but remains lethargic and confused. She has minimal secretions and appears very weak. She is being weened slowly from the respirator but a tracheostomy is planned, if necessary, for transfer to a long-term acute care facility when she is stable.**
- **She has a living will and has expressed the desire not to be kept on life support if there was no hope for recovery. There is no health care proxy and family members cannot be located.**

- Should a feeding tube be placed?

Is this in accord with the patient's desires?

- Insertion of a tube into a vein to provide IV hydration or into the stomach to provide tube feeding are medical procedures.
- Patient have the right to refuse any and all medical procedures that they consider invasive, burdensome, or undesirable for other reasons.
- Providing hydration to someone who is dying does not reverse the underlying disease that will result in the patient's death.

- There is no fool proof objective test for evaluating whether a tube feeding is needed or not.
- **There are two questions/Answers involved**:

1. **Clinically**-What can tube feeding do for the patient and are there any harms? Answer: medical.

2. **Ethically**-Whether a tube ought to be undertaken? Answer: based on patient's own values and goals.

Historical Legal perspective

- Nancy Cruzan, 1983 – MVA, significant brain injury, PEG tube placed. NOT vent dependant.
- Later that year, the parents requested the removal of the PEG.
- The Missouri Supreme Court refused to allow this, as there was a living will statute in Missouri, but Ms. Cruzan had not established one. Available testimony from a previous roommate was deemed insufficient to allow withdrawal of nutrition.

Cruzan cont'd.

- Later that year, further evidence of Cruzan's wishes were discovered, and the Missouri courts allowed the withdrawal of nutrition.
- Nancy Cruzan died two weeks later

Then came the Schiavo case

- Terri Schindler-Schiavo, 1990 – cardiac arrest with resultant anoxic injury. Not vent dependant.
- 1993 – Terri's parents file suit to have Michael, her husband , removed as guardian. Case dismissed.

Time line of Schiavo case

- 1998 – Husband petitions for feeding tube removal
- 2000 – District court allows withdrawal
- 2001 – Appeals court allows withdrawal
- April 2001 – Both Florida and US Supreme Courts refuse to intervene, tube is removed on April 24th

Time line (cont'd)

- April 26, 2001 – another district judge orders feeding to resume.
- Oct 2002 – after a year of multiple appeals, the parents' lawyer alleges abuse by the husband was responsible for her brain damage, based on a bone scan from the early 90's. This would later be refuted on autopsy.
- Oct. 15 2003- Tube was again removed under court order. Oct 19, The Advocacy Center for Persons with Disabilities, Inc. files a federal court lawsuit that claims that the removal of Ms. Schiavo's PEG tube is abuse and neglect.

Schiavo cont'd.

- **Oct.20 2003-** Florida House of Reps/Senate pass "Terri's Law," that allows the governor to issue a "one-time stay in certain cases ; Oct 21 Governor Bush issues an executive order directing reinsertion of the PEG tube and appointing a guardian ad litem.
- **2004**- Florida's Supreme Court, unanimously affirming the trial court order, declares "Terri's Law" unconstitutional.
- **2005** – US Congress intervenes to refer case to Federal Courts. Federal Court refuses to intervene, finding no objectionable actions by the state courts.
- **2005**-Tube was removed on 3/25 and Ms. Schiavo dies 6 days later .

State Law Summary

- The state does not have an interest in keeping people alive against their advance directives.
- Guardian / family can be sufficient evidence of desired wishes in the absence of specific advance directives.

How to avoid conflicts with patients and families

- Stay in touch
- Get everyone on the same page
- Let families vent
- Sit everyone down and talk
- Address spiritual needs

Questions

- Are there specific life-prolonging devices/procedures that be considered for withdrawal and others that should not?
- Does withdrawal of devices unrelated to the terminal diagnosis constitute assisted suicide or euthanasia ?

Defibrillators & Pacemakers: Ethical and Legal Analysis

- Disabling of such devices does not constitute euthanasia or assisted suicide, the underlying disease process causes the patient's death.
- The intent of treatment withdrawal in such cases is to honor and respect the patient's / surrogate's decision that the pacemaker/defibrillator should be disabled.