



Eastern Association for the Surgery of Trauma

28th Annual Scientific Assembly

Sunrise Session 9

The Other Side of What We Do...Providing A Good Death

January 15, 2015

Disney's Contemporary Resort

Lake Buena Vista, Florida



Ethical Framework

- ▶ Ethical Principles most relevant to end-of -life care and advance directives
 - Autonomy (vs. paternalism)
 - Informed Consent (through clear, comprehensive communication)
 - Beneficence
 - Restoration to health (not always possible)
 - Relief from Suffering

Autonomy and Informed Consent

- ▶ This principle of Patient self-determination is fairly intuitive to all of us and often most difficult to achieve in the ICU
- ▶ Our specialty is accustomed to appropriately ignoring autonomy in certain urgent circumstances
- ▶ Informed Consent is necessary for Autonomy to exist, implying lack of coercion, and competency. It also requires good, 2-way communication between the lead physician and patient

Beneficence (2 parts)

- ▶ Restoration to health
- ▶ Relief of suffering
- ▶ When 1st not possible, palliative care strategy, and the choice of informed withdrawal of care often becomes relevant

Legal Framework

- ▶ Laws to support these principles vary by state, but one national law exists.
- ▶ Patient self-determination act of 1990, in response to Cruzan case
- ▶ Recognizes the patient's right to accept or refuse care, and
Requires medicare participating hospitals to facilitate creation of admitted patients' advance directives, and creates some legal protection for physicians in end-of-life decision making

Advanced Directives (In absence of a Competent Patient)

- ▶ Living Will (potentially problematic)
 - Often provides valuable guidance, but can be too general, too narrow, or rendered obsolete by changed life circumstances...although a "surrogate" can be named
- ▶ DPOA for Healthcare (Durable Power of Attorney)
 - More flexible, and provides solid legal framework over surrogate named in living will.

Myths

- ▶ One must have an advanced directive to stop treatment
- ▶ Directives are legally binding
 - not so, they only provide immunity if they follow the directive,
 - Physician may find situation divergent with their conscience, or medically inappropriate, although may then have obligation to transfer

Advanced Directives will stop EMS from resuscitation efforts when called

- Most states require specialized DNR forms in this circumstance




Withdrawal of Support

- ▶ DNR status, Discontinuation of Mechanical Ventilation, etc.
- ▶ All amount to informed refusal of care, and informed refusal by a competent patient is gold standard
- ▶ Advanced Directives are legal frameworks to substitute for above
- ▶ In absence of above, spouse and various other relatives serves as surrogate decision makers. Legal basis of this is more variable by state.

Ethical conflicts surrounding
withdrawal of life sustaining
therapy –

*"I don't want to live this
way!"*

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Medical Director, Neurotrauma Critical Care Unit
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Chief of Trauma
R Adams Cowley Shock Trauma Center



*I'm not afraid of dying; I just
don't want to be there when it
happens.*

- Woody Allen

Have you ever thought
about how you want to
die?

Where do we die?

- Unfortunately, many of us will die in the hospital



A case study: SCI and Withdrawal of Life Sustaining Treatment

- Perhaps in response to greater societal interest in avoiding futile medical treatment...

requests for ventilator removal by patients with quadriplegia...have become more frequent

Maynard FM, Muth AS: The choice to end life as a ventilator-dependent quadriplegic. Arch Phys Med Rehabil 1987; 68:862-864

Is withdrawal of care appropriate?

- A 92 year old male C2 tetraplegic from a fall in his nursing home...
- An 88 year old female C6 tetraplegic from an MVC...
- A 62 year old male C1 tetraplegic from a diving accident...
- A 45 year old female C5 tetraplegic from a fall off a horse...
- A 22 year old male C3 tetraplegic from a GSW...

Making Decisions

- Some patients with cervical spinal cord injuries will ask to be allowed to die
- Respect for patients' autonomy is not only a fundamental ethical principle, but is also sanctioned by law.¹
- There are many published accounts of patients with high-level cervical injuries who have been granted permission by the courts to discontinue life support.²⁻⁶
 - In all these cases, the patients were beyond the acute phase of their injury when they made their decisions.

- Schloendorff v. Society of New York Hospitals, 211 N.Y. 125, 127, 129; 105 N.E. 92, 93 (1914).
- Somerville J. Quadriplegic chooses job search over death. American Medical News, February 2, 1990;6.
- Maynard PM, Rudy AS. The choice to end life as a ventilator-dependent quadriplegic. Arch Phys Med Rehabil 1987;68:862-864
- Ridley B. Tom's story: a quadriplegic who refused rehabilitation. Rehabil Nurs 1989;14:250-253.
- Fleetwood J. Solving bioethical dilemmas: a practical approach. Nursing 1989;19:62-64
- Gardner BP, Theocleous F, Watt JWH, Krishnan KR. Ventilation or dignified death for patients with high tetraplegia. BMJ 1985;291:1620-1622.

○Our own biases...

SCI and Withdrawal of Care

- A common statement made by able-bodied people in reference to quadriplegic spinal cord injuries is
 - "I would rather be dead than end up like that."

Quality of Life

- Misconception:
 - People with spinal cord injuries all have a uniformly poor quality of life.
- Fact:
 - In a sample of 128 patients with injuries at the C4 level or higher,
 - >90% reported that they were "glad to be alive"
 - 63% rated their quality of life as good or excellent.
 - 64% of those who were dependent on a respirator
 - 54% of those not dependent on a respirator

Whiteneck GG, Carter RE, Charifue SW, et al. A collaborative study of high quadriplegia. Washington, D.C.: National Institute of Handicapped Research, 1985.

Quality of Life

- Hall *et al* undertook a follow-up study
 - Their study population comprised 91 people with complete cord lesions at C4 and above.
 - In response to the question: 'are you glad to be alive?', 88 out of 91 people responded 'yes'.
 - Among the ventilator-assisted group, 83% rated their QOL as either excellent or good, as did 72% of the respirator independent group.
 - Compared to the 1985 study findings, the follow-up study in 1994 found that the participants were much more active and demonstrated higher self-esteem ratings.
 - The researchers concluded that the high levels of activity and community integration exhibited by their participants, the satisfaction they reported with the quality of their lives and their longevity clearly demonstrated that people with high lesion tetraplegia have the potential for excellent QOL.
- This has been replicated in multiple studies

Hall KM, Harper B, Whiteneck GG. Follow-up study of individuals with high tetraplegia (C1-C4) 10 to 21 years post-injury. *Top Spinal Cord Injury Rehabil* 1997; 2: 107-117
K Whalley Hammett. Exploring quality of life following high spinal cord injury: a review and critique. *Spinal Cord* 2004;42: 491-502

Quality of Life

- A review of 5,200 SCI patients
 - Suicide is 2 - 6 times higher in SCI patients than in the general population
 - 9% of deaths over a 32 year period were due to suicide (91% were not)
- The suicide rate for SCI patients is significantly elevated, but it is not out of proportion with rates in other serious illnesses.
- Most importantly, the vast majority of SCI patients neither attempt nor complete suicide.

Charifue S, Gerhart K. Behavioral and Demographic Predictors of Suicide after Traumatic Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*. 1991;72: 488-92.
Maynard FM, Muth AS. The choice to end life as a ventilator-dependent quadriplegic. *Arch Phys Med Rehabil* 1987; 68: 862-864. *Globe and Mail*. Woman makes plea to end life. *Globe and Mail*, 29 November, 1991, Section A-6.

Quality of Life

- 168 Locked In Syndrome members of the French Association for LIS were invited to answer a questionnaire on medical history, current status and end-of-life issues.
- They self-assessed their global subjective well-being with the Anamnestic Comparative Self-Assessment scale (+5 to -5)
- Of 65 patients
 - 47 patients (72%) professed happiness (median ACSA +3)
 - 18 unhappiness (median ACSA -4).

ACSA Rating	N of Locked In Syndrome patients
-5	1
-4	2
-3	3
-2	2
-1	1
0	2
+1	8
+2	6
+3	10
+4	12
+5	5

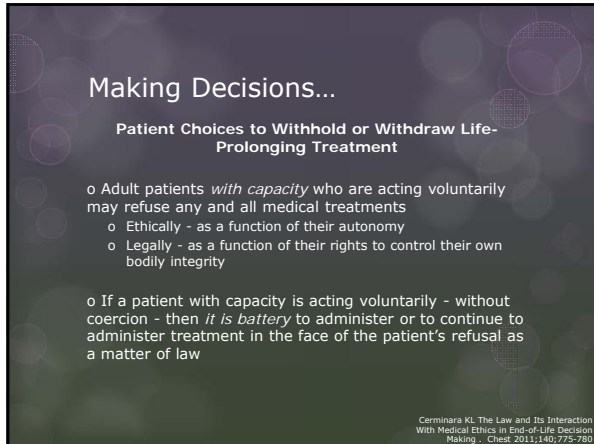
Bruno M, Bernheim JL, Schnakers C and Laureys S. Locked-in: don't judge a book by its cover. J Neurol Neurosurg Psychiatry, 2006;75:2

Life Expectancy

Age at Injury	No SCI	For persons who survive the first 24 hours					For persons surviving at least 1 year post-injury				
		Motor Functional at Any Level	Para	Low Tetra (C5-C8)	High Tetra (C1-C4)	Ventilator-Dependent-Any Level	Motor Functional at Any Level	Para	Low Tetra (C5-C8)	High Tetra (C1-C4)	Ventilator-Dependent-Any Level
20	58.6	52.6	45.2	40.0	35.7	17.1	53.0	45.8	41.0	37.4	23.8
40	39.4	34.1	27.6	23.3	19.9	7.3	34.5	28.2	24.2	21.2	11.4
60	22.4	17.7	12.8	9.9	7.7	1.5	18.0	13.2	10.4	8.6	3.2

Spinal Cord Injury Facts and Figures at a Glance.
<https://www.nscisc.uab.edu/> February, 2011

- What about when a patient (or family) raises the question of terminating life support while the patient is still in the ICU?

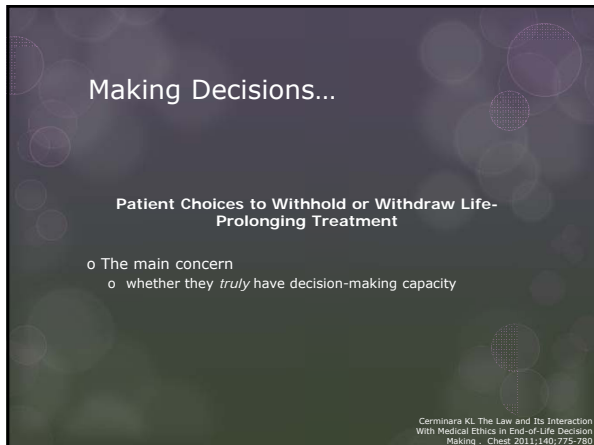


Making Decisions...

Patient Choices to Withhold or Withdraw Life-Prolonging Treatment

- o Adult patients *with capacity* who are acting voluntarily may refuse any and all medical treatments
 - o Ethically - as a function of their autonomy
 - o Legally - as a function of their rights to control their own bodily integrity
- o If a patient with capacity is acting voluntarily - without coercion - then *it is battery* to administer or to continue to administer treatment in the face of the patient's refusal as a matter of law

Cerminara KL. The Law and Its Interaction With Medical Ethics in End-of-Life Decision Making. Chest. 2011;140:775-780.

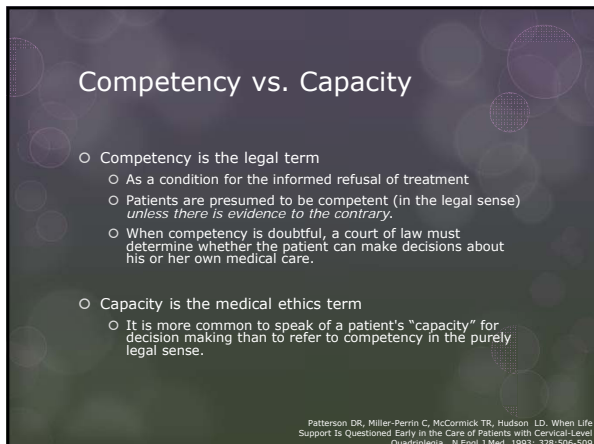


Making Decisions...

Patient Choices to Withhold or Withdraw Life-Prolonging Treatment

- o The main concern
 - o whether they *truly* have decision-making capacity

Cerminara KL. The Law and Its Interaction With Medical Ethics in End-of-Life Decision Making. Chest. 2011;140:775-780.



Competency vs. Capacity

- o Competency is the legal term
 - o As a condition for the informed refusal of treatment
 - o Patients are presumed to be competent (in the legal sense) *unless there is evidence to the contrary.*
 - o When competency is doubtful, a court of law must determine whether the patient can make decisions about his or her own medical care.
- o Capacity is the medical ethics term
 - o It is more common to speak of a patient's "capacity" for decision making than to refer to competency in the purely legal sense.

Patterson DR, Miller-Perrin C, McCormick TR, Hudson LD. When Life Support Is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia. N Engl J Med. 1993; 329:506-509.

Deciding capacity...

- Competence (or capacity) must be established on the basis that the patient is
 - capable of assimilating and understanding information about their condition
 - appreciates the personal relevance of this information
 - is capable of discussing it with others
 - is able to form judgments by weighing the information they have acquired

Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians: Withdrawal of life-sustaining treatment. BMJ 2002;325:175

Deciding Capacity...

- The factors that can influence the thinking of a patient with recent cervical injury are
 - the environment of the intensive care unit
 - medication use with impaired lucidity
 - impairment of communication
 - temporary psychiatric complications
 - emotional reactions that can temporarily color their judgment
 - medical factors
 - undiagnosed minor head injuries*

Patterson DR, Miller-Perrin C, McCormick TR, Hudson LD. When Life Support Is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia. N Engl J Med. 1993; 328:506-509
*Morris J, Roth E, Davidoff G. Mild closed head injury and cognitive deficits in spinal cord-injured patients: incidence and impact. J Head Trauma Rehabil 1986;1:31-42

Deciding Capacity...

- Are these just Suicidal Ideations?
 - Transient suicidal thoughts are common in patients who have recently suffered catastrophic trauma
 - In one study of patients with high SCI, 50% reported suicidal ideas, such as "wishing to be dead."*
 - Depression, with or without suicidality, complicates the evaluation of capacity to refuse life-sustaining treatments

Powell T, Lowenstein B. Refusing Life-Sustaining Treatment After Catastrophic Injury: Ethical Implications. Journal of Law, Medicine & Ethics. 1996;24:54-61.
*Whitenack GG, Carter RE, Charlifue SW, et al: A Collaborative Study of High Quadriplegia. Englewood, Colo. Craig Hospital. 1988

Deciding Capacity...

- Studies suggest that hospital staff members *overestimate* the suffering and depression that a patient hospitalized with a SCI will have
 - Estimates of depression-scale ratings by staff members are worse than those submitted by the patient¹
- Staff members have been found to regard a depressive outlook as a *more appropriate characterization* of this type of patient than an optimistic outlook²

1. Cushman L, Dijkers M. Depressed mood in spinal cord injured patients: staff perceptions and patient realities. *Arch Phys Med Rehabil* 1990;71:191-197

2. Westbrook MT, Nordholm LA. Effects of diagnosis on reactions to patient optimism and depression. *Rehabil Psychol* 1985;31:79-84

Deciding Capacity...

- Suicidal Ideations
 - One study found no difference between the decisions made by depressed and by nondepressed patients regarding end-of-life treatment for hypothetical patients with grim prognoses.*
 - Neither a past experience with depression nor even a current depression *prove* that a patient lacks decision-making capacity.
 - Appropriately, a thorough evaluation of depression and pain control must comprise part of any evaluation of a patient's capacity to refuse life-sustaining treatment.**

*Lee M, Ganzini L. Depression in the Elderly: Effect on Patient Attitudes Toward Life-Sustaining Therapy. *Journal of American Geriatric Society*. 1992;40:983-88.

**Quill T, Cassell C, Meier D. Care of the Hopeless: Potential Clinical Criteria for Physician Assisted Suicide. *New Engl J Med*. 1997;337:1330-34.

**Powell T, Kornfeld D. On Promoting Rational Treatment, Not Rational Suicide. *Journal of Clinical Ethics*.

Making decisions...

Incapacitated Patients: “Voice” Through Statutes, Rules, and Regulations

- A patient without decision-making capacity *retains the right to refuse treatment*
 - Statutory living wills
 - Surrogate or proxy designations
 - Physicians Orders for Life-Sustaining Treatment instrument
- To the extent that patients without capacity can display emotion or express opinions, their actions and expressions should be taken into account in determining whether to withhold or to withdraw treatment.

Cerminara KL The Law and Its Interaction With Medical Ethics in End-of-Life Decision Making . *Chest* 2011;140:775-780

- What about when a patient (or family) raises the question of terminating life support while the patient is still in the ICU?

Con Position

- Because newly disabled patients have "limited experience with disability and lack information about their options and outcomes, some level of paternalism may be justified in their early care and rehabilitation."
- 3 reasons why the competence of patients with recent traumatic injuries may be questioned
 - May not be able adequately to evaluate the risks and benefits of rehabilitation, the results of which may take months or years to appreciate.
 - That it takes time—of an unspecified amount—to cope with the threat to self-identity posed by catastrophic injury.
 - That surrogates may also have impaired judgment because they also suffer from the first two problems.

Caplan A, Callahan D, Haas J. Ethical and Policy Issues in Rehabilitation Medicine. Hastings Center Report. 1987;17(4):51-520.

Con Position

- Opt for a kind of *temporary suspension* of patient autonomy
 - During which significant decision-making authority will go to the health care team, which may "initially ignore or override patient and family choice."
- The difficulty with this proposal is not the "idea of a temporary abridgment of autonomy" but from
 - The question of how long to accept such an infringement on patients' rights
 - How to determine what constitutes a sufficient opportunity to appreciate disability.

Caplan A, Callahan D, Haas J. Ethical and Policy Issues in Rehabilitation Medicine. Hastings Center Report. 1987;17(4):51-520.

Con Argument

- Some experts suggest that patients may require *5 years* to establish an optimal quality of life after an SCI
- Although there is no empirical evidence, experts advise that patients should be counseled to wait approximately *2 years* before deciding to have life-sustaining treatment withdrawn

Patterson DR, Miller-Perrin C, McCormick TR, Hudson LD. When Life Support Is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia. N Engl J Med. 1993; 329:506-509.

Con Argument

- Health care professionals responding to a request for ventilator removal by a person with quadriplegia must consider their own attitudes about the value of life for people with severe physical disability.
- Able-bodied people respond sympathetically to a request for ventilator removal because they may assume that they would feel the same if in similar circumstances.
- Some assert that withdrawing life-sustaining treatment from people with a stable, if severe, physical disability reflects an *"attitude of discrimination toward and devaluation of people with disability."*

Maynard FM. Responding to Requests for Ventilator Removal From Patients With Quadriplegia. A. Rugeberg, Gazette International Networking Institute's Fifth Annual Conference on Independent Living and Post-Polio Rehabilitation

Pro Argument

- Patient Autonomy
- The Ethics Committee of the American Academy of Neurology has published a position statement strongly defending the right of "competent but profoundly paralyzed patients to cease all treatments."

Pro Argument

- Ms B was a 43 year old professional woman who in 1999 had a hemorrhage in her upper spinal cord who was rendered quadriplegic and dependent on artificial ventilation.
- She remained adamant that living on a ventilator would be intolerable to her because of the level of dependence on others and the lack of control over her own body she would have, and she requested to have her ventilation discontinued.
- The clinicians treating her felt unable to carry out her wishes, and Ms B took the clinicians to court

Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. Withdrawal of life sustaining treatment. BMJ 2002;325:175

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Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. Withdrawal of life sustaining treatment. *BMJ* 2002;325:175

Pro Argument

- Judge ruled that Ms B was indeed competent to decide on her treatment, and therefore her decisions about her treatment, whatever they were, must be respected.
- Precedent
 - "a mentally competent patient has an absolute right to refuse to consent to treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death."

British Medical Association. Withholding and withdrawing life-prolonging medical treatment: guidance for decision making. London: BMJ Books, 1999.
General Medical Council. Withholding and withdrawing life-prolonging treatments: good practice in decision-making. London: GMC, 2000.

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British Medical Association. Withholding and withdrawing life-prolonging medical treatment: guidance for decision making. London:BMJ Books,1999.

General Medical Council. Withholding and withdrawing life-prolonging treatments: good practice in decision-making. London:GMC,2002.

Pro Argument

- Instances were cited where individuals faced with the same decision as Ms B opted for rehabilitation and later said that they were pleased to have done so.
- To extrapolate from such anecdotes to Ms B's circumstances would be invalid.
 - Had she opted to start rehabilitation, Ms B might over time have changed her values.
 - However, testing whether this might happen would be *illegal* as *well as unethical*.
- With acceptance of patients' autonomy comes the inevitable uncertainty whether the patient might have changed her view later.

Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. Withdrawal of life sustaining treatment. BMJ 2002;325:175

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Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. Withdrawal of life sustaining treatment. *BMJ* 2002;325:175

Middle Ground

- Action steps before a request for ventilator removal be honored
 - to preserve the ethical integrity of the medical profession
 - to maintain respect for a patient's autonomy.
- Patients:
 - Obtain independent legal counsel.
 - Discuss the request with family, significant others, and spiritual counselors.
 - Meet with peers and learn about their lives.
 - Learn about all possible rehabilitation outcomes.
 - Participate in independent psychological evaluations.
 - Consult with a medical ethics committee.
 - Discuss plans and concerns with all members of the health care team.
- Health Care Providers:
 - Maintain communication with the patient and family.
 - Enable patients to complete their action steps.
 - Formulate an opinion about a patient's capacity for making decisions about his or her own welfare.

Maynard FM. Responding to Requests for Ventilator Removal from Patients With Quadriplegia. West J Med. 1991; 154(5):617-619

- Maynard FM. Responding to Requests for Ventilator Removal From Patients With Quadriplegia. *West J Med.* 1991; 154(5):617-619

[illegible]

- It is not a decision...it's a process

The Health Care Providers' Role

- Clinicians may feel unable personally to carry out a patient's request to withdraw from life sustaining treatment.
- Where this occurs, the clinicians have a duty to find someone else to carry out the patient's wishes.

Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. *Withdrawal of life sustaining treatment.* BMJ 2002;325:175

- Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians. Withdrawal of life sustaining treatment. *BMJ* 2002;325:175

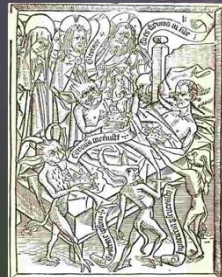
The Health Care Providers' Role

- When a patient chooses to withdraw from life sustaining treatment, helping that person achieve a "good" death is a legitimate goal for healthcare professionals.

Sensky T. Patients' autonomy and values conflict with the responsibilities of clinicians: Withdrawal of life-sustaining treatment. BMJ 2002;325:1192

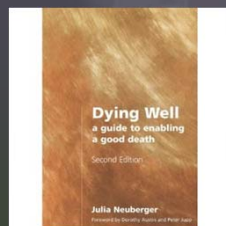
Ars moriendi

- The *Ars moriendi* ("The Art of Dying") are two related Latin texts dating from about 1415 and 1450 which offer advice on the protocols and procedures of a good death
- Explain how to "die well" according to Christian precepts of the late Middle Ages.



A "Good Death"

- In 1997 The Institute of Medicine (IOM) defined a good death as:
 - "A decent or good death is one that is:
 - free from avoidable distress and suffering for patients, families, and caregivers
 - in general accord with patients' families' wishes
 - and reasonably consistent with clinical, cultural, and ethical standards"



Dyer KA. "Definition of a Good Death or an Appropriate Death" About.com. Updated: November 9, 2006

A Good Death

- "Good death ideology" upholds the ideals of
 - Dying with dignity
 - Peacefulness
 - Preparedness
 - Awareness
 - Adjustment
 - Acceptance

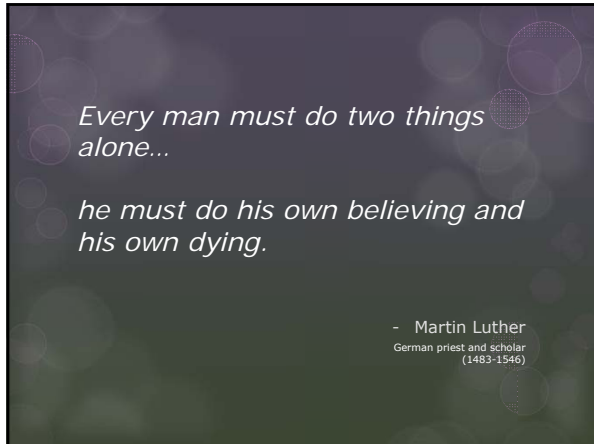


Hart B, Sainsbury P, Short S. Whose dying? A sociological critique of the "good death." *Mortality*. 1998;3(4).

How to Provide a Good Death to our Patients...

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

A good death...





Tough, But Routine Cases Involving Withdrawal of Care.

The Other Side of What We Do: Often the Harder Side!

Jeffrey A. Claridge, MD, MS
Division Director; Trauma, Burns, Critical Care, and Acute Care Surgery
MetroHealth Medical Center, Case Western Reserve University

Case 1. Patient wishes vs. Families wishes

- 83 y.o. who had C2 – C3 fracture with quadriplegia. Had ORIF within first 24 hours of presentation.



Case 1.

- 83 y.o. who had C2 – C3 fracture with quadriplegia. Had ORIF within first 24 hours of presentation.
 - Eventually completely woke up (within days) with a lucid period of about a week and we were able to determine from the patient that he did not want a tracheostomy (On Vent) or PEG. He is vent dependent and still a quadriplegic.



Case 1.

- 83 y.o. who had C2 – C3 fracture with quadriplegia. Had ORIF within first 24 hours of presentation.
 - He then began to deteriorate with some slowly progressive renal failure.
 - Family wishes to have full care, including tracheostomy and PEG.
 - Initially refused to let us remove is ET tube.
- **Now What?**
 - Ethical Issues : For discussion
 - Legal Issues: For discussion



Reasonable Tools to Use



- Be Patient (at least 24 hours often is needed); give it if you can
 - Always frame it as “what would your Dad want”, not... what do you want;
 - “If he was standing here, what would he say...”
- Have consultants who have seen patient talk with them
 - Neurology, Neurosurgery, etc (make sure you talk with them first)
- Consider second opinion from another faculty who has not seen patient
- Get Palliative Care Consult
- Get Ethics Consult (We have a team which has Ethics and Legal representatives)

Case 2: Of the Disappearing Family

- 20 y.o. trauma patient with devastating head injury. The team discusses over the day that we are concerned that patient may be brain dead. You explain what that means and will do a brain death exam in the evening.
- The appropriate exams are done and it was determined the patient is brain dead.
- Family is NO WHERE to be found or reached.
- What do you do now? When do you pronounce? When do you DC supportive care?
 - Ethical Issues: discussion
 - Legal Issues: discussion
- Does this make a difference if he is an organ donor?

Case 3: My Cousin Woke up After a Coma

- 24 y.o. female s/p MVC that has been pronounced brain dead and family is adamant that patient will wake up.
- They had a cousin who was in a coma and woke up!
- Family becomes threatening and points at you and states “that is the guy who wants to kill our sister.”
- Staff becomes concerned over the number of people and safety.
- Now What.
 - Ethical Issues
 - Legal Issues

Coma man wakes after 19 years

by ROSALIND RYAN, femail.co.uk

An American man has finally woken after spending nearly 20 years in a coma.

The first word Terry Wallis, 39, uttered was “Mom” after catching sight of his mother sitting by his bedside.

His second word was “Pepsi” closely followed by “milk”.

Terry Wallis lost consciousness when he was involved in a car crash in Mountain View, Arkansas, in July 1984.

As a result of the crash, he spent 19 years in a coma and his injuries left him a quadriplegic.

Terry Wallis' wife, Sandi, said, “It's been hard dealing with it. It's been hard realising the man I married can't be there.”

His daughter, Amber, was a newborn at the time of Terry's accident.

She is now a young woman - and the inspiration for Terry's recovery. He says he wants to walk again for her.



Opinion 2.035 - Futile Care

Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care, as defined in Opinion 2.03, “Allocation of Limited Medical Resources,” and Opinion 2.095, “The Provision of Adequate Health Care,” not on the concept of “futility,” which cannot be meaningfully defined. (I, IV)

Issued June 1994.

Futility?

J Gen Intern Med. Oct 2004; 19(10): 1053-1056.
doi: [10.1111/j.1525-1497.2004.40134.x](https://doi.org/10.1111/j.1525-1497.2004.40134.x)

When Is Medical Treatment Futile?

A Guide for Students, Residents, and Physicians

[Deborah L. Kasman](#), MD,MA¹

Futility

- To complicate matters further, some ethicists claim medical futility is an ancient concept and inadequate for modern ethical deliberations.
- In Hippocrates's time, medical knowledge was limited and disease processes frequently overpowered patients.
- Modern medical knowledge and progressive technologies have dramatically altered our ability to sustain life.
- Discerning when medical interventions merely prolong dying is a distinctly modern challenge.
- Opponents of using medical futility for ethical arguments worry that physicians have a trump card to overpower families with less knowledge, thereby delivering paternalistic care.
- Some also argue medical futility is a smoke-screen to hide rationing of resources and costs for end-of-life care.
- These scholars state futility should never be evoked in medical decision making and prefer using *standards of care* combined with the *best interest* of the patient to solve end-of-life dilemmas.

Some Helpful Points: : If treatment is deemed medically futile by physicians, but the family wants "everything done," what is the next step?

- It is important to explain futility to families.
- If practitioners feel there is essentially no chance of meaningful recovery, this needs to be stated explicitly to the family.
- Families always hope their loved one will improve.
- If practitioners know that at best, the status quo will be maintained until further decline naturally ensues, physicians need to empathically yet succinctly state this, and then allow families' time to process this information before steadfastly recommending withdrawal or withholding aggressive treatments.
- When physicians redefine "doing everything" into actions which prevent prolonged suffering, they help support families through their painful experiences.
- The physician who unveils a family's values, clarifies medical standards of care, explicates effectiveness from benefits versus harms, and respectfully explains alternative care plans is more likely to find common ground with patients.
- It is important that physicians are not forced into practicing medicine which conflicts with their moral or fiduciary responsibilities.

What Resources are there for Staff:

- An area that we need to improve.
- Everyone doesn't have:
Dr. Robert Smith!