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Resolving Ethical and Legal End-of-Life Dilemmas

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Actionable Medical Orders

- Difference between living will/advance directive type document vs. actionable medical order
  - **Is it signed by a physician? = actionable**
- Is it completed appropriately according to the law? Ask social worker to confirm it is legitimate.
- American Bar Association: POLST program legislative comparison chart as of 6-1-17 https://www.americanbar.org/content/dam/aba/administrative/law_aging/POLST_Legislative_Chart.pdf

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POLST/POST/MOST/MI-POST/TPOPP Etc.

- **Alabama:** Portable Physician Do Not Attempt Resuscitation Order (DNAR)
  - adph.org/administration/assets/AdvanceDirective_2016_R.pdf
  - alabamapublichealth.gov/providerstandards/assets/faqportablephysiciansdnarorder-rules.pdf
  - Other end-of-life (EOL) laws: alabamapublichealth.gov/providerstandards/palliative-care.html
- **Michigan:** Physician Orders for Scope of Treatment (MI-POST) http://www.honoringhealthcarechoicesmi.org/
  - Other EOL laws www.michigan.gov/mdhhs/0,5885,7-339-73971_7122_3183_4895---,00.html

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- **Florida:** Physician Orders for Life-Sustaining Treatment (POLST) www.polstfl.org
  - Other EOL laws and resources: elderaffairs.state.fl.us/doea/hospice_eol.php
- **Indiana:** Physician Order for Scope of Treatment (POST) www.indianapost.org
  - Other EOL laws and resources www.in.gov/isdh/25880.htm
- **Kansas:** Transportable Physician Orders for Patient Preferences (TPOPP) www.practicalbioethics.org/programs/transportable-physician-orders-for-patient-preferences
  - Other EOL laws www.kansasjudicialcouncil.org/Documents/Legislation/2009%20Legislation/Proposed/uniformact.jan09.withcomments.pdf

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- **Tennessee:** Physician Orders for Scope of Treatment (POST) www.tn.gov/health/health-program-areas/health-professional-boards/hcf-board/hcf-board/advance-directives.html#post
  - Other EOL laws: www.tn.gov/health/health-program-areas/health-professional-boards/hcf-board/hcf-board/advance-directives/advance-directives-faq.html
- **Texas:** Medical Orders for Scope of Treatment (MOST) http://www.northtexasrespectingchoices.com
  - Other EOL laws: www.hhs.texas.gov/services/health/palliative-care
- **Wisconsin:** Emergency Care Do No Resuscitate Order (DNR) https://www.dhs.wisconsin.gov/forms/f4/f44763.pdf
  - Other EOL laws: https://www.dhs.wisconsin.gov/guide/end-life-planning.htm

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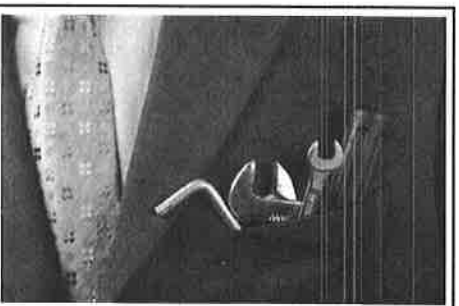

Using the Right Tool: Law vs. Ethics vs. Personal

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You are the patient and said, "NO"

- If you tell me no surgery/feeding tube/antibiotic etc. Do you mean it? Do you want me to respect your refusal?
- What if you wrote, "No…," in your directive? Did you mean it? Do you want me to respect your refusal?
- What if you told somebody you know that you wouldn't want ____? Should I listen to them? Should your family be able to override your wishes?
- What does the law in your state say? What is law's #? Is your NO absolute?

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Quinlan NJ Supreme Court 1976

- After using drugs and alcohol at a party, Karen Ann Quinlan had two 15 minute anoxic episodes. Was comatose then PVS.
- Her father wanted to be made the guardian for making healthcare decisions and to turn off ventilator. After many years, court allowed withdrawal.
- Instead of being taken off the vent, she was weaned very slowly because of her physician's values and lived for 10 years.
  - ***"The individual's right to privacy grows and the state's interest weakens as the bodily invasion increases and the prognosis dims."*** **Privacy extends to healthcare decisions even if they may end up in death**
  - **The act of withdrawal is equal to withholding a treatment**
  - **A surrogate can decide to withdraw/withhold**

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- ***"If Bob could understand what has happened to his body and life, what would Bob want us to do?"***
- **We get this language from Quinlan:**

> We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death. . . .

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What About Withdrawing/Foregoing Artificial Nutrition and Artificial Hydration?

"medically prescribed nutrition"
"artificial nutrition"

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Bouvia v. Superior Court Supreme Court of California 1986

- 29 y/o woman with cerebral palsy, quadriplegic, completely bedridden and in constant pain. She was **not** terminal.
  - Wanted the right to remove unwanted feeding tube
  - Wanted hospital to keep her comfortable while dying
- Court decided:
  - **A non-terminal, competent adult can refuse treatment even if the refusal will cause death**
  - **Patient has the right to stop treatments but can not force the hospital to participate**
- After given the right to stop feedings, she chose to live

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Cruzan v. Director of Missouri Dept. of Health - Supreme Court 1990

- In 1983, Nancy Cruzan suffered an anoxic event because of a car accident. Was comatose then PVS. Initially there was hope. After years of artificial nutrition/artificial hydration, her parents asked to have G-tube removed.
- ***"Patients have the right to refuse life-sustaining treatments and this right is worthy of the highest protection of the constitution. This right to refuse includes the right to withhold or withdraw nutrition and hydration."***

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Reasons People Give to Talk You Out of Honoring Directive/POLST

- 1. She wrote it a long time ago.
- 2. She wrote it before she got sick.
- 3. She didn't know what she was signing.
- 4. The family says, "We don't agree with what she wrote and if you do it, we will sue you."
- 5. Even though she said she wouldn't want to live like this, she is happy.
- 6. She was being coerced or is a victim of elder abuse

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Surrogate Consent Statutes

- Default Surrogate Consent Statutes: American Bar Association as of January 1, 2018

https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf

- Look at your state's Hospital Association, Bar Association, or Palliative Care and Hospice Association if available
- Review your hospital's policy and procedures

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Should Decision Maker Be Removed?

- In re Livadas in New York: Court removed demanding surrogate because demands went against stated wishes in advance directive and failed to appreciate her mother's true medical condition
- Cardoza v. USC University Hospital: The surrogate's sister sued because the surrogate was not complying with advance directive (Hospital should have removed agent.)
- Bernstein v. Superior Court, California: Conservator was replaced because of demands for aggressive care that offered no benefit and significant suffering

Thaddeus Pope, JD

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"Care-grieving is the grief and loss we experience when we care for and about another person." Viki Kind

- Sadness
- Anger
- Resentment
- Exhaustion
- Loneliness
- Wanting to withdraw
- Shock
- Short tempered and irritable
- Can't bear to face what the future holds

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Cost of Family Caregiving? We Die Earlier

- The telomeres in blood cells of caregivers were shorter than those of the controls, and that the level of the telomerase repair enzyme among caregivers was also lower.
- Caregivers also had fewer lymphocytes and a higher level of cytokines, molecules key to inflammation response, than did the control group.

Damjanovic, A. K., Yang, Y., Glaser, R., Kiecolt-Glaser, J. K., Nguyen, H., Laskowski, B., Zou, Y., Beversdorf, D. Q., & Weng, N. P. (2007). Accelerated telomere erosion is associated with declining immune function in caregivers of Alzheimer's disease patients. *Journal of Immunology*, 179, 4249-4254

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Compassion and Communication

- Don't ignore the problem; solve before it gets worse
- Communication and a good process is key
- The patient/family still needs us - don't disengage
- Don't take frustrations out on family or patient
- Keep your compassion, humanity and humility
- There is more to the story – listen for the why
- Ask for help – Conflict management requires experts, resources, and supportive, cooperative team

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Best Opening for Family Conference

- **Don't** start with the medical details. Instead, *"I only know ___ as a patient. Can you tell me more about ___?"*
  - Builds trust and humanizes patient for everyone
  - Helps family get partially out of denial
  - Provides information to use when you explain what medicine can/can't do for this person's life
- **Contextualize the medical plan into the life who will be experiencing it.** *"We could do dialysis, but he will never get to play with his dog." "Even if we do ____, he will never work in the garden, read his favorite book ..."*

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You are the patient who said, "YES"

- What if you say yes to a treatment?
- What if you wrote yes in your advance directive?
- If you told someone yes, would want the treatment?
- Is the YES absolute?
- Can your family say NO if you said YES?
- Can the physician go against your request?

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Non-Beneficial Treatment Requests

- Use Your State's Law
  - What is the legal status regarding ineffective treatment (futility) requests in your state? http://www.thaddeuspope.com/medicalfutility/futilitystatutes.html
- Use Your Hospital Policies
  - Update/Create Hospital Policies
- Use Your Ethics Committee

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ATS/AACN/ACCP/ESICM/SCCM – Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in ICUs

(American Thoracic Society, American Association for Critical Care Nurses, American College of Chest Physicians, European Society for Intensive Care Medicine, and Society of Critical Care)

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Four Categories of Disputed Treatments in ICU

(Use recommended policy and process to resolve these ethical and legal conflicts.)

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Disputed Treatment Request #1

- Requests for futile intervention *("futile" only used here)*
  - **Interventions that cannot accomplish the intended physiological goals**
- Explain reasons requested intervention is ineffective and explore the surrogates reasons for request
- If conflict persists, consider
  - Second opinion to help clarify medical facts
  - Enlist communication experts to help empathically **communicate the clinical reasoning behind refusal** and **provide psychosocial support**

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Disputed Treatment Request #2

- Requests for **potentially inappropriate** treatment
  - Treatments that have a least some chance of accomplishing the effect that is sought by the patient or surrogate
  - Clinicians believe that competing ethical considerations justify refusing requested treatment

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- Example: Clinician believes …
  - Not admit to ICU: End-stage dementia and multiorgan failure
  - Dialysis for patient with PVS
  - Inappropriate to continue mechanical ventilation for patient with widely metastatic cancer
  - Place trach in child with prolonged respiratory insufficiency and severe irreversible neurological impairment

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Disputed Treatment Request #3

- Requests for potentially inappropriate treatment in **time-sensitive situations**
  - In setting of rapidly deteriorating clinical condition
  - Precludes or reduced conflict resolution process
  - **Clinicians have high degree of certainty that treatments requested are outside the bounds of acceptable practice**

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Questions to Assess Moral Issues in Time-Pressured Situations

- Am I certain that this requested treatment is outside of the boundaries of accepted practice?
- Would I be willing to have the rationale for my decision publicly reviewed in an appeals board or court?
- What are the consequences to the patient, surrogate, team, or institution as a result of implementing this decision?
- Am I sure that sex, race, socioeconomic status, ability to pay, or other psychosocial factors are not entering into my decision?

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Disputed Treatment Request #4

- Legally proscribed or legally discretionary treatment: treatment may accomplish effect desired by patient, but the laws, applicable judicial precedent, or public policies prohibit or permit limitation of use.
- Challenges handled by relevant body that governs the rule
- Examples: Circumvent organ allocation policy; or patient seeks assisted suicide where action is illegal; or state has "medically ineffective treatment" statute, and patient has multiorgan failure, progressive metastatic cancer, and there is a reasonable degree of medical certainty CPR wouldn't prevent death.

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Ethical Solutions: Bioethics Knowledge, Communication and Conflict Resolution Skills

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Four Boxes Bioethical Approach

- Jonsen (philosopher), Siegler (physician), Winslade (lawyer) approach to evaluating ethical dilemmas
- Guides conversation but not answers
  - **Medical indications**
  - **Patient preferences**
  - **Quality of life**
  - **Contextual features**

Albert Jonsen, Mark Siegler, & William Winslade's *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine 7th* Edition. McGraw Hill, 2010

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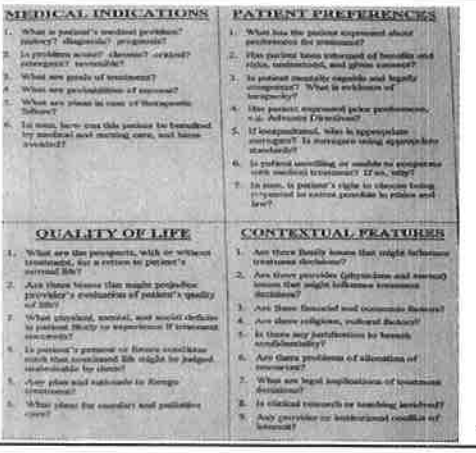

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Beginning Questions to Discuss

- Do we know patient's choice and/or values that could guide the decision? If not, who decides?
- Will it be medically beneficial/effective?
- What is the patient's quality-of-life goal?
- What are the benefits, risks and burdens, both short term and long term?
- What will it get him? What will it cost him?
- Should we try a time-limited trial?
- What about patient's culture and religion?

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Cultural Resources

- https://ethnomed.org/patient-education/diabetes/diabetes-patient-education-materials Cultural foods that affect blood sugar, fasting holidays, audio for Low Literacy and the Blind
- http://depts.washington.edu/pfes/CultureClues.htm Culture Clues reference guides for 10 cultures https://healthreach.nlm.nih.gov/patient-materials# https://www.thinkculturalhealth.hhs.gov/education/physicians - 9 hours of CME
- What Language Does Your Patient Hurt In?: A Practical Guide to Culturally Competent Patient Care by Suzanne Salimbene
- Culture and Nursing Care – A Pocket Guide Edited by Juliene G. Lipson, et. al.

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Some of Viki's Favorite Resources

- Low Literacy Decision Guides – Vent, CPR, feeding tubes http://coalitionccc.org/tools-resources/decision-guides
- Go Wish Cards www.gowish.org (English and Spanish)
- Thinking Ahead Project http://www.coalitionccc.org
- 2-part documentary www.considertheconversation.org
- My Stroke of Insight: A Brain Scientist's Personal Journey by Dr. Jill Bolte Taylor
- They're My Parents Too by Francine Russo
- How to Say it to Seniors – Closing the communication gap with our elders David Solie, MS, PA
- Well Spouse Association www.wellspouse.org
- www.MedicalFutility.Blogspot.com – Thaddeus Pope JD

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23 Decision Aids Certified by Washington State Health Care Authority

medicalfutility.blogspot.com

"patient decision aids for the end of life"

- CPR: advanced cancer
- CPR: advanced disease
- CPR: advanced heart failure
- CPR: advanced liver disease
- CPR: advanced lung disease
- CPR: a closer look for people with a serious illness
- Decisions about dialysis for patients 75 and older
- Goals of care: advanced cancer
- Goals of care: advanced dementia
- Goals of care: advanced disease
- Goals of care: advanced heart failure
- Goals of care: advanced lung disease
- Goals of care: family meetings in the ICU
- Goals of care: skilled nursing facility
- Hospice: advanced cancer
- Hospice: skilled nursing facility
- Hospice: an introduction
- Supporting decisions involving extremely premature infants
- CPR decision aid
- Help with breathing decision aid
- Long-term tube feeding decision aid
- Medical care for serious illness
- Advanced lung cancer patient decision aid

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