Patient Choices: Navigating End of Life

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How Americans Die

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Importance of End of Life Care

• 2.4 million people die every year in the US
  – Vast majority are older Americans
  – By 2030, this will double

• ~ 30% of total Medicare budget is spent in the last 12-18 months of patients’ lives

CDC 2005, Dartmouth Atlas 2005
What Do Americans Die From?

![Bar graph showing mortality rates for various causes from 1900 to 2010. The causes listed include Diphtheria, Senility, Cancer, Accidents, Nephropathies, Cerebrovascular disease, Heart disease, Gastrointestinal infections, Tuberculosis, Pneumonia or influenza, Suicide, Pneumonia or influenza, and Noninfectious airways diseases. The graph indicates a significant shift in mortality rates over the century, with heart disease becoming the leading cause of death by 2010.]
How Do Deaths Occur?

• **Sudden**: e.g. Person has a heart attack at home and dies immediately

• **Middle ground**: e.g. Person gets pneumonia and is hospitalized, then dies after 3-4 week hospitalization

• **Prolonged**: e.g. Person has chronic illness and slowly gets worse over many months or years, sometimes with a final more acute event
How Do Patients Want to Die?

- 75% want to die a natural death if heart or breathing stops.
- 25% are not sure what they want.
- 5% want medical providers to use everything to prolong life.
Deaths in the U.S.

Where Patients Want To Die
- Home
- Not at home

Where Patients Actually Die
- Hospital
- Nursing home or acute care
- Other

CDC 2005, Dartmouth Atlas 2005
ICU and Hospice Care Before Death

Teno, JAMA, 2013
ICU and Hospice Care Before Death

~30% of these hospice referrals were within 3 days of death

40% of late hospice referrals were preceded by ICU stay

Teno, JAMA, 2013
What Are The Options?

1. Think about your values and goals
2. Understand what care during illness looks like and feels like
   - CPR
   - “Life support”
     - Breathing machine (mechanical ventilation)
     - Tube feedings
     - Dialysis for failed kidneys
3. Understand that you can choose to receive or not receive any treatment
Cardiopulmonary Resuscitation (CPR)

• Medical procedure including chest compressions, breathing tube, and strong medications used when someone’s heart or lungs stop

• 18% survive to leave the hospital
  – Lower in people with chronic illness

• Those who do survive usually have lower quality of life than before the CPR and are unlikely to be discharged to home
Life Support in an ICU
Ethics at the end of life

Robert Macauley, MD

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Fletcher Allen Health Care

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Patient preferences

- Competent decision
  - Advance directive: Living Will

- Substituted judgment
  - Advance directive: Durable Power of Attorney for Health Care (DPA-HC)

- Best interests
Patient preferences

• **Competent decision**
  - Advance directive: Living Will

• **Substituted judgment**
  - Advance directive: Durable Power of Attorney for Health Care (DPA-HC)

• **Best interests**
Overemphasis on Beneficence (a.k.a. Paternalism)

• Hippocrates
  - “Conceal most things from the patient, while you are attending to him ... turn his attention away from what is being done to him; ... reveal nothing of the patient’s future or present condition.”
What percentage of physicians would tell a patient he had cancer?
The pendulum swings ...
Patient rights

• A competent patient has the right to refuse any treatment, even if that means the patient will die
  – Established by court cases in the 1970s

• But a patient doesn’t have the right to get whatever treatment s/he asks for
  – May not be appropriate
  – May not be available
What percentage of physicians would tell a patient he had cancer?

- 1961: 10
- 1979: 100
Patient preferences

• Competent decision
  - Advance directive: Living Will

• Substituted judgment
  - Advance directive: Durable Power of Attorney for Health Care (DPA-HC)

• Best interests
Problems with substituted judgment

- Sometimes people surprise us
  - Agreement between patient and surrogate only 2/3 of the time
- Significant emotional burden on surrogates, as a result of the decisions they made
- Not just a matter of what, but a matter of who
WHO GETS TO DECIDE? In most states, statutes give priority to the spouse as decision maker for an incapacitated person, assuming there are no advance directives or previously designated agents. Here are surrogate priorities by state:

- **Red**: Spouse
- **Yellow**: Physician and next of kin
- **Green**: Consensus of “interested persons”
- **Blue**: Equal status for spouse and parent
- **White**: No priority specified

NOTE: Limits on what a surrogate can do vary from state to state

Source: A.B.A. Commission on Law and Aging
Doctor, if you could only ask a patient (whom you know nothing about) one question, what would it be?
Withdrawing and withholding life-sustaining treatment

Or, “once we start something, we’re not allowed to stop it.”
Withdrawing and withholding support

• No ethical difference
  - “There is no ethical distinction between withdrawing and withholding life-sustaining treatment.” (AMA Code of Ethics)

• No legal difference, either
  - “A physician has no duty to continue treatment, once it has proven to be ineffective.” (Barber v. Superior Court, 1983)

• But there is an emotional difference
“There is no ethical difference between withholding a life-supporting measure and stopping it once it’s been started.”

Informed consent and end-of-life care

“I want everything done.”
“I’m a full code.”
Some thoughts

• Despite what people say…
  – Nobody really wants “everything done”
  – Nobody really wants to receive CPR or be intubated

• But some people are willing to undergo a lot in order to achieve a specific goal
  – Longer life?
  – Improved quality of life?

• But to make an informed decision, you need to understand the chances of achieving that goal
Cardiac Arrests and CPR on TV: Fact vs. Fiction

Prognostication and its Role in End-of-Life Decision Making

Benjamin T. Suratt, MD, FCCP
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Associate Professor, UVM College of Medicine
The Three Branches of Medicine

- **Diagnosis**
  - “Explicatory” – Etiology & pathophysiology

- **Treatment**
  - “Managerial” – Plans for action to reverse disease

- **Prognosis**
  - “A prediction of the probable course and outcome of a disease.”
Does Prognosis Matter?

• Cornerstone of informed consent
• Rise in chronic illness
• Fundamental to End-of-Life decision making:
  – ‘End of Life’ = Prognosis
  – Drives advanced directives
  – Defines eligibility for hospice, and now PAS
  – Integral to treatment decisions
• “Highest priority for seriously ill patients, eclipsing their interest in treatment options or diagnostic details.”

“Physicians regard prognosis with anxiety and disdain, and they avoid it if possible.”

(Christakis, 1999, pg. 84)

Are we unable or unwilling?
How good are we?

Predicted vs. observed survival in 468 ill hospice patients. Diagonal line represents perfect prediction. Circles above the line represent patients in whom survival was overestimated; those below line are patients in whom survival was underestimated.
How good are we?

• Accurate (+/- 33%) only 19.7% of the time
• Physician specialty influences accuracy:
  – Medical subspecialties (excluding Oncology): 10.1%
  – Geriatric or General Internal Medicine: 16.7%
  – Oncology: 22.9% (least likely to be over-pessimistic)
  – Other: 26.9% - 36.7%
• Diagnosis alters accuracy:
  – Cancer more often accurate than cardiopulmonary.
• No influence on accuracy:
  – MD age, sex, self-rated optimism, years in practice
How good are we?

• 57% of physicians believe their training in prognosis is deficient (Arch Int Med, 1998;158:2389)

• Prognosis is understudied
  – Only 4% of published studies 1946 – 1976

• Prognosis is not a focus in training
  – As treatment options have increased prognosis has receded.
Training in Medical Prognosis

Fig. 2. Change in proportion of chapter length devoted to selected clinical tasks between 1892 and 1988

How good are we?

• The longer the doctor-patient relationship the greater the error in prognosis.
• Rates of conveying prognosis very low and quite variable.
• Why does the doctor-patient relationship influence prognosis?

Prognostication
Prognostication in Medicine

- **Hippocrates (400 B.C.)**
  - “Conceal most things from the patient, while you are attending to him … turn his attention away from what is being done to him … reveal nothing of the patient’s future or present condition.”

- **Oliver Wendell Holmes, Sr. (1860)**
  - “Your patient has no more right to all the truth you know than he has to all the medicine in your saddlebags… He should get only as much as is good for him.”

- **AMA Code of Medical Ethics (1947)**
  - “Grant reasonable indulgence to the mental imbecility and caprices of the sick.”
How willing are we?

- “Beneficence”
  - Paternalism

- “Nonmaleficence” (*Primum non nocere*)
  - Hope and its effects on patient health
  - The ‘Terminal’ diagnosis and physician behavior
  - The self-fulfilling prophecy:
    - “A nonrational, quasimagical process”
Where do we go from here?

• Gradual change:
  – 1961: 90% of physicians generally did not inform patients of cancer diagnosis
  – 1977: 97% of physicians prefer to disclose this information

• Patient rights: Right to know, autonomy

• More attention to end-of-life care and prognosis

• Better predictions:
  – “Scoring” systems
  – Probabilistic vs Temporal
• Temporal approach:
  "What is the approximate duration of survival for this patient?"

• Probabilistic approach:
  "What is the approximate probability that this patient will be alive (0%-100%) after some time period?"
• “In our rush not to abandon patients therapeutically at the end of life, we abandon them prognostically.”

• “As a result of a failure to prognosticate let alone prognosticate accurately, patients may die deaths they deplore in locations they despise.”

(Christakis, 1999, pg. xiii)
Bibliography

• Christakis NA, 1999, “Death Foretold: Prophecy and Prognosis in Medical Care,” University of Chicago Press.


Navigating Serious Illness

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Fletcher Allen Health Care
Definition of Palliative Care

Palliative care is a specialty that aims to relieve suffering and improve quality of life for patients with serious illness, and their families.

It is provided at the same time as all other desired medical treatment.
Palliative Care is …

• Pain and Symptom Control
• Help with decision making
  – Eliciting goals and values and then clarifying pros and cons of treatment options for the individual
  – Disease preparedness
    • Discussing disease-specific problems and options ahead of time to either prepare to make the best in the moment decisions vs. making in advance decisions
• Psycho-Spiritual support
• Focus on making life as good as possible for anyone with serious illness
Medical Decisions and Role of Goals of Care

Question:
• What is the best treatment for a serious illness?

Answer:
• DEPENDS… on goals

Goals of Medicine
• Treatment of disease?
• Relief of suffering?
Goals of Care

Treatment of disease
- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolongation of life

Relief of suffering
- Comfort
- Best quality of life
- Staying in control
- A good death
- Support for families and loved ones
Life is a Highway

- Exit ramps: events, that if allowed a natural course, will lead to the end of life
  - When to prevent death
  - When to allow death

- Country Road vs. Highway
  - 2 paths, destination is the same
Exit Ramps

- Under what circumstances would you accept the exit ramp?
  - Burdens of treatment outweigh benefit
    - CPR when seriously ill
    - Intubation/breathing machine when unable to recover
    - Hospitalization when unable to recover
  - Road + destination = not acceptable
    - Road conditions: not acceptable quality of life near the end of life
Under what conditions would your goals of medical care be comfort, only?

- In advance end of life discussions:
  - Identify, in advance, treatments that would not be helpful or desired, sometimes...
  - Help prepare for in the moment decisions
  - Help prepare surrogate decision makers
  - Reduce stress on individual and family
  - Are associated with better quality of end of life care and loved-one bereavement
    - No impact on survival or anxiety
    - Reduced use of ineffective burdensome treatments at the end of life
Big Picture Health Care Goals:

• I want my life sustained as long as possible by any medical means

• I want treatments to sustain my life only if I will:
  – Be able to communicate with friends and family
  – Be able to care for myself
  – Living without incapacity pain
  – Be conscious and aware of my surroundings

• I only want treatments directed towards my comfort
Patient Values Questionnaire

• What do you value most about your life?
• How do you feel about death and dying?
• Do you feel life should be preserved as long as possible?
  – If not, what kinds of mental and physical conditions would make you think that life-prolonging treatments should no longer be used?
• Would you imagine reasons for temporarily accepting treatments for conditions you described?

www.vermontethicsnetwork.org/patientvaluesquestionnaire.html
Patient Values Questionnaire

• How much pain and risk would you be willing to accept if your chance of recovery from an illness or injury were good (50-50 or better)?
• What if your chances of recovery were poor (less than one in 10)?
• What other beliefs or values do you hold that should be considered by those making medical decisions if you become unable to speak for yourself?

www.vermontethicsnetwork.org/patientvaluesquestionnaire.html
Highway vs. Country Road
Same destination, alternative routes

- Not every exit ramp is a dead end
- Identify priorities and tradeoffs
- Choose road that best suits values and goals

- Example: Hospice

- What would it look like if I:
  - Wanted all of my care at home and not come back to the hospital
  - Decided to stop or could no longer receive chemotherapy
  - Didn’t want to start dialysis
What would my medical care and life look like if I prioritized comfort and quality of life over controlling disease?

What is the trade-off in doing so?
How are Goals of Medical Care Discussed:

• Prognosis:
  – What can one expect?
  – What can we control?
  – What can we not control?
  – Identify ambiguity: range of what is possible

• Determine Goals of Care
  – Goals for now
  – Alternative goals when illness worsens

• For conflicting goals: how do you prioritize them?

• Determine medical plan of care and treatments that best matches goal
Practical Tips

• Start decision-making early

• Think about your goals and values
  – What is important to you?
  – What quality of life is acceptable?

• Learn all you can about the treatments available, and their burdens and benefits
  – Talk to trusted health provider(s) to get this information
  – Take someone with you to these visits
Practical Tips

• Talk to your family and loved ones
  – Decreased burden on family members if they know your wishes
• Ask your providers for help and a recommendation if you want one
• Once you’ve decided
  – Tell your loved ones and providers
  – Complete the paperwork
Paperwork and Forms

• Advanced Directive
• Durable Power of Attorney for Health Care
• COLST (Clinician Order for Life Sustaining Therapy)
## DNR/Commande Clinique

**Clinical Orders**

- Do Not Resuscitate (DNR)
- Cardiopulmonary Resuscitation (CPR)

**For Patient Who Is Breathing and/or Has a Pulse**, Go to Section B-G, Page 2 for Other Instructions. **Clinicians Must Complete Sections A.1 Through A.5**

### A.1 Basis for DNR Order

- Informed Consent – Complete Section A.2
- Facility – Complete Section A.3

#### A.2 Informed Consent

<table>
<thead>
<tr>
<th>Name of Person Giving Informed Consent (Can be Patient)</th>
<th>Relationship to Patient (Write “self” if Patient)</th>
</tr>
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<tbody>
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**Signature (If Available)**

### A.3 Facility (required if applicable)

- **I have determined that resuscitation would not prevent the imminent death of this patient and the patient’s wishes were respected.**

<table>
<thead>
<tr>
<th>Name of Other Clinician Making this Determination (Print Here)</th>
<th>Signature of Other Clinician</th>
</tr>
</thead>
<tbody>
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</tbody>
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### A.4 Facility DNR Protocol (required if applicable)

- **This patient is □ not □ in a health care facility or a residential care facility.**

<table>
<thead>
<tr>
<th>Name of Facility:</th>
<th>Signature of Other Clinician</th>
</tr>
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</table>

- **If this patient is in a health care facility or a residential care facility, the requirements of the facility’s DNR protocol have been met □ (attach here if protocol requirements have been met).**

### A.5 DNR Identification (optional)

- **I have authorized issuance of a DNR Identification (ID) to this patient.** Form of ID:

<table>
<thead>
<tr>
<th>Date of Issue</th>
<th>Signature of Issuer</th>
</tr>
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</table>

### A.6 Clinician Certification and Signature for CPR/DNR (required)

<table>
<thead>
<tr>
<th>Patient’s Agent or Guardian</th>
<th>Address or Phone</th>
</tr>
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</table>

**I certify that I am the clinician for the above patient, and I certify that the above statements are true.**

<table>
<thead>
<tr>
<th>Signature of Clinician</th>
<th>Printed Name of Clinician</th>
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**DIRECTIONS**

**Send Form With Patient Whenever Transferred or Discharged**

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## Orders for Other Life-Sustaining Treatment

**If Patient Resides in a Breathing State but has No Pulse and/or No Respirations**

- **Intubation and Mechanical Ventilation Instructions:**
  - If patient has DNR order and has progressive or impending pulmonary failure, without acute cardiopulmonary arrest:
    - **Do Not Intubate/Multi-Lumen Airway (DNI)**
    - **Total Period of Intubation/Multi-Lumen Airway and ventilation**
    - **Intubation/Multi-Lumen Airway and long-term mechanical ventilation if needed**

**Transfer to Hospital**

- **Do not transfer unless comfort care needs cannot be met or if severe symptoms cannot be otherwise controlled.**
- **Transfer**

**Antibiotics**

- **No antibiotics.** Use other measures to relieve symptoms
- **Determine use or limitation of antibiotics when infection occurs, with comfort as goal.**
- **Use antibiotics**

**Artificially Administered Nutrition**

- **Offer food and liquids by mouth if feasible.**
- **Feeding Tube**
  - **No feeding tube**
  - **Total period of feeding tube (Goal: )**
  - **Long-term feeding tube**
- **Parenteral nutrition or hydration (e.g. IV fluids or Total Parenteral Nutrition)**
  - **No parenteral nutrition or hydration**
  - **Total period of parenteral nutrition or hydration (Goal: )**
  - **Long-term parenteral nutrition or hydration**

**Medical Interventions**

- **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction, and manual treatment of airway obstruction as needed for comfort. Oxygen and fluids by mouth, if feasible.
- **Limited Additional Interventions** Includes case described above. Use medical treatment and IV fluids as indicated. Avoid invasive care if possible.
- **Full Treatment** Includes case described above. Use defibrillation and intensive care as indicated.

**Other Instructions**

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**Give Copy to Patient and Representative**

**Send Form With Patient Whenever Transferred or Discharged**
Questions?

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