Why YOU Are Key to End of Life Care Decisions

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Mrs. S

- 88 year old woman with critical AS, CAD
- Refused surgery in past, now inoperable
- Lives with family, still functional
- Orthopnea, reduced exercise tolerance
- Elevated neck veins, clear lungs, no edema
- Maximal medical therapy
- Has not completed advance directive

Outline

- An Overview of Dying in America
- Why End of Life Care is Suboptimal
- Starting ‘The Conversation’
- Advance Directives and POLST
- Cultural and Spiritual Issues

Top Five Causes of Death

1900		2005	
Influenza, pneumonia	11.8%	Heart Disease	26%
Tuberculosis	11.3%	Cancer	23%
Gastritis, enteritis	8.3%	Stroke	6%
Heart Disease	8.0%	COPD	5%
Stroke	6.2%	Accidents	4%

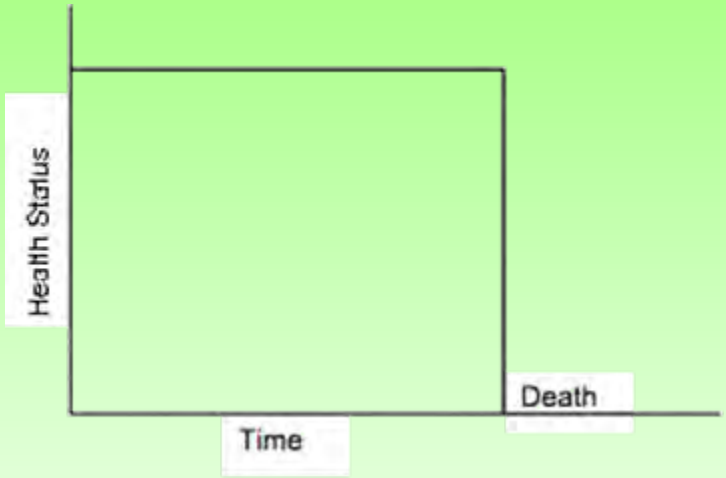
Brim et al., 1970

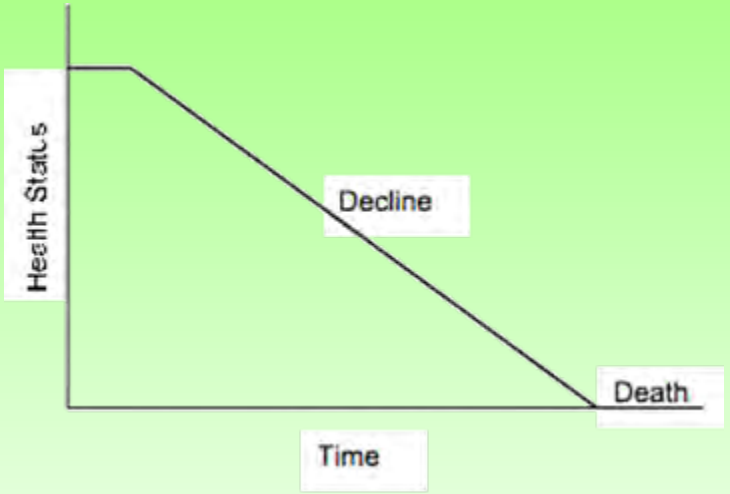
National Center for Health Statistics

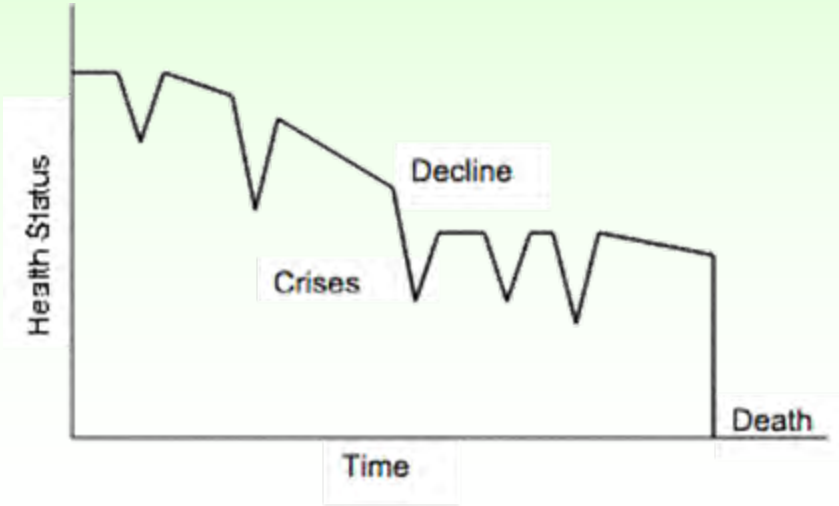
How We Die

- 90% of deaths chronic disease
- 10% of deaths sudden death or rapid decline

Patterns of Functional Decline







Where We Die

- 90% prefer to die at home
- 50% die in hospital
- 23% die in nursing facilities
- 23% die at home

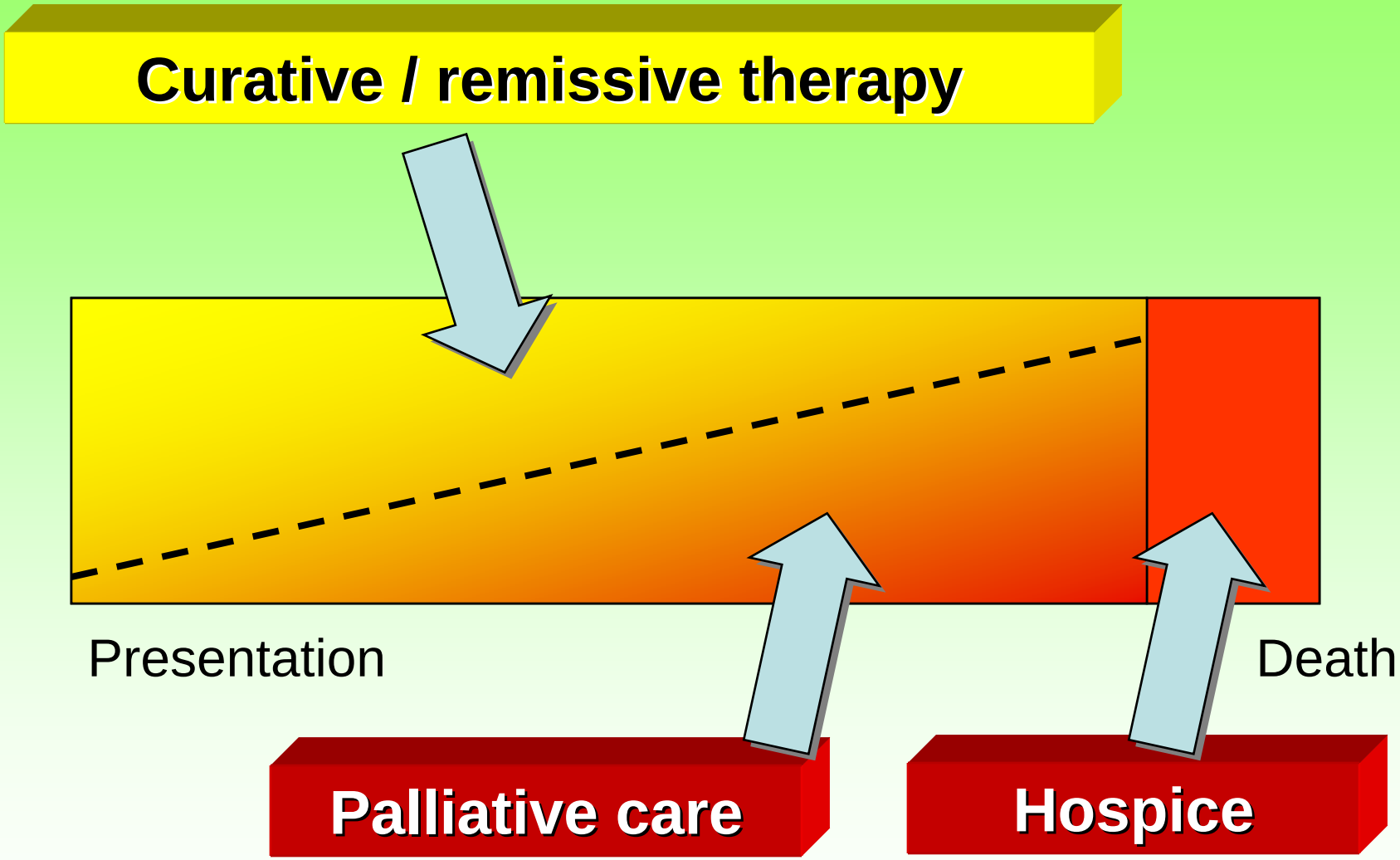
Satisfaction with Care

- Institutional death
  - Unmet needs
  - Poor communication
  - Lack of support and respect
- Death at home with hospice
  - Higher satisfaction
  - Fewer concerns with care

(Teno, 2004)

Important Factors

- Physical
- Spiritual
- Preparation for the end
- Psychosocial


Curative / remissive therapy
Presentation
Death
Palliative care
Hospice

Key Points

- Causes of death have changed
- Most deaths follow chronic disease
- Care of the dying is less than optimal (institutional, associated with pain/suffering)

Why is end of life care less than optimal?

Why is end of life care less than optimal?

- “The most avoided conversation in America” (Pauline Chen, MD)
- Institutional glide path (Joanne Lynn, MD)

Do Patients Want to Talk

- Prognosis
  - Almost all want qualitative information
  - Balance hope and realism, honesty and ambiguity
- Advance Directives
  - 95% thought worthwhile (after having a discussion)
- Spirituality

Physician Factors

- Unaware of patient preferences
  - 47% know when pt doesn't want CPR (SUPPORT)
- Lack of communication skills (Tulsky, 1998)
  - 5.6 minute conversation
  - MD spoke 3.9 minutes
- Uncertainty about prognosis

Benefits of End of Life Conversations

- Patients (Wright, 2008)
  - Less aggressive care, earlier hospice
  - Better quality of death
  - No increase in worry or depression
- Caregivers
  - Less depression, better QOL
- Physicians (Jackson, 2008)
  - Closer relationship to patient
  - Better job satisfaction
- System: less cost (Zhang, 2009)

Key Points

- We don’t want to talk about it
- We’re not very good at talking
- Talking has benefits to patients, caregivers, and ourselves

The Conversation

- Which patients
- Initiating and guiding the conversation
- Words or topics to avoid
- Goals
- Barriers

Who Should We Talk With

- Elderly
- Serious, chronic illness
  - CHF
  - COPD
  - Dementia
  - CKD
  - Cirrhosis
- Multiple hospitalizations, recent discharge
- ‘would you be surprised if…’
- Other opportunities

Initiating the Conversation

- Assess patient's understanding
  - *how do feel things are going,* or
  - *have you given any thought to how you wish to be cared for should your illness worsen?*
- Explain the rationale
  - *I want to talk with you about plans for your future care*
  - *I'd like to spend some time talking to you about the future course of your illness so that I have a clear understanding of your wishes*

Topics to Cover

- Decision-maker: Identify a surrogate
- Disclosure: Patient's preferences for receiving and sharing information
- Delight: What gives meaning and value to patient's life

Words to Avoid…

- “there is nothing more to do”
- “do you want us to do everything?”
- “you have failed…” or “are failing…” (treatment)
- “withdrawal of care”

Communication Tips

- Use empathy
- Respond to emotion
- Allow sufficient time
- Avoid medical jargon
- Use positive language
- Clarify ambiguous terms (‘burden’, ‘vegetable’

Barriers to Communication

- Time
- Language/Cultural Barriers
- Training

How Much Time?

- Expert Conversations
  - Audiotaped discussions by expert authors
  - Less verbally dominant
  - Mean 14 vs. 8 minutes
  - Less information about treatments, procedures
  - More psychosocial, lifestyle discussion

Key Points

- Have the discussion with selected patients
- Take your time (may need more than one visit)
- Focus more on values than on specific procedures

Advance Directives and POLST

- Emphasize the discussion, not the document
- Living will
- Durable power of attorney for health care (DPAHC)
- Physician Order for Life Sustaining Treatment (POLST)

Advance Directives

- Result of Patient Self Determination Act, 1990
- Desire to avoid painful, prolonged death
- Fear of overtreatment
- Allow exercise of autonomy when capacity is lost

Living Wills

- Specifies what treatments are desired
- Usually standard language
- Often very specific
  - Permanent unconsciousness
  - Incurable, irreversible condition close to death

DPAHC

- Names a health care agent
- Activated at time of incapacity
- Can be activated immediately
- Power to make almost all health care decisions
- Allows individuals to be disqualified
- No hierarchy in Calif. if no directive

Advance Directive Positives

- Allow the patient's voice to be heard when they lack decisional capacity, promote autonomy
- Good features:
  - Promote patients' understanding of their values, goals, and preferences
  - Serve as a basis for discussion with proxy

Limits of Advance Directives

- Not completed
- Not available in medical record
- Provider unaware of document
- Inaccurately predict future preferences
- Fail to apply to specific circumstances
- Inaccuracy of proxy decision maker
- Fail to alter clinician behavior
- DNR misinterpreted as comfort care

POLST

- Signed medical orders
- Addresses range of life-sustaining interventions
- Allows for choosing or foregoing treatment
- Brightly colored, clearly identifiable, standardized form
- Recognized and honored across all treatment settings

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 1/1/2009)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name	
First /Middle Name	
Date of Birth	Date Form Prepared

A — Cardiopulmonary Resuscitation (CPR): *Person has no pulse and is not breathing.*

Check One

☐ **Attempt Resuscitation/CPR** ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

(Section B: Full Treatment required)

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B — Medical Interventions: *Person has pulse and/or is breathing.*

Check One

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Do Not Transfer to hospital for medical interventions. Transfer*** if comfort needs cannot be met in current location.

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: _____

C — Artificially Administered Nutrition: *Offer food by mouth if feasible and desired.*

Check One

☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube.

☐ Long-term artificial nutrition by tube.

Additional Orders: _____

D — Signatures and Summary of Medical Condition:

Discussed with:

☐ Patient ☐ Health Care Decisionmaker ☐ Parent of Minor ☐ Court Appointed Conservator ☐ Other:

Signature of Physician

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Physician Name	Physician Phone Number	Date
Physician Signature (required)	Physician License #	

Signature of Patient, Decisionmaker, Parent of Minor or Conservator

By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Signature (required)	Name (print)	Relationship (write self if patient)

Summary of Medical Condition	Office Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

CA AB 3000 (Wolk)

- Does not mandate use of form
- Requires form be honored
  - Unless new orders issued
- Requires
  - Physician signature
  - Patient or surrogate signature
- Provides immunity

Advance Directives vs. POLST

- Advance Directive
  - For every adult
  - Requires decisions about myriad future treatments
  - Clear statement of preferences
  - Needs to be retrieved
  - Requires interpretation
- POLST
  - For the seriously ill
  - Decision among presented options
  - Checking of preferred boxes
  - Stays with the patient
  - Actionable medical order

Evidence Supporting POLST

- Hospices
  - 96% DNR
  - 78% want more than lowest level of Rx
  - Preferences honored 98% of time
- Nursing facilities
  - 88% DNR
  - 77% want more than lowest level of Rx
- EMTs find form useful
- PACE Program: care matched POLST instructions 80-90%

Key Points

- The document is only as good as the discussion that produced it
- Advance directives should be encouraged, but be aware of limits
- Consider using POLST

True or False?

- Non-white patients are less likely to complete advance directives
- African Americans are more likely to desire aggressive treatment
- Asian Americans are more likely to make decisions as a family

True or False?

Doctors …

- are more likely to play golf on Wednesdays
- are likely to interrupt patients in less than 18 seconds
- believe in ‘doing something’ even if there is little data to support it

Cultural Barriers

- Every encounter is cross cultural
- Large diversity *within* cultural groups
- Stereotypes vs. generalizations

San Mateo County Census

White, not Hispanic	46%
Latino	23%
Asian	24%
Black	3.3%
Two or more races	3.2%

SM County, Languages

Foreign Born	32%
Language other than English at home	41.5%
Speak English less than ‘very well’	18.5%

Culture and End of Life Care

- Culture bubbles to the surface
- Autonomy vs. beneficence
- Definition of family
- Gender roles
- Care of the elderly
- Power
- Communication patterns
- Language

Common Conflicts

- Communicating bad news
- Locus of decision making
- Attitudes towards advance directives

Cross-Cultural Skills

- Self awareness
- Active listening
- Bearing witness
- Cultural humility

Recommendations

- Ask patient centered questions
- Work with professional interpreters
- Follow patient’s preferences where possible

Summary

- Better end of life care is desperately needed
- YOU can make a difference by starting the conversation
- Time and culture are surmountable challenges