



The Case for Advance Care Planning Throughout Life & Comfort Care at the End-of-life – Why It Is Important

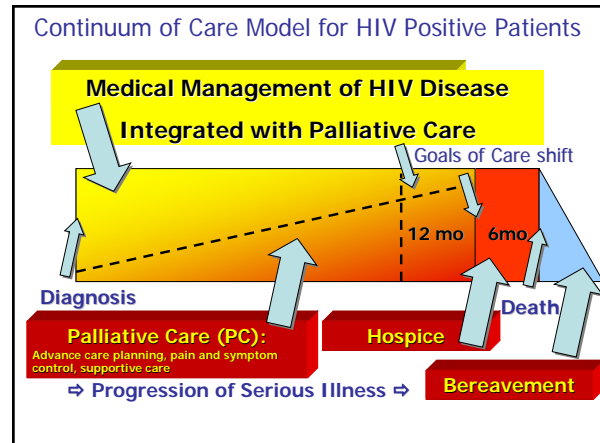
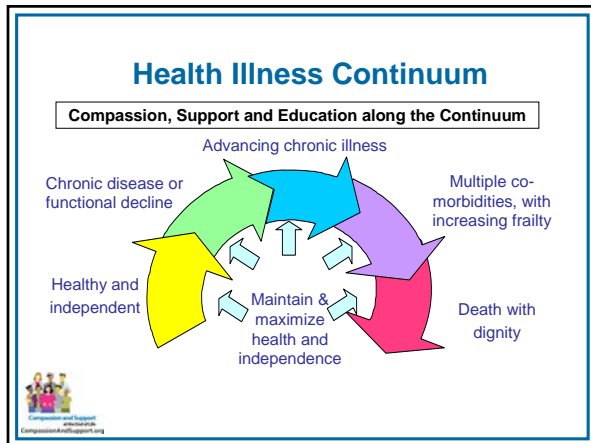

Rivington House Conference
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Objectives

- Identify key pillars of Palliative Care
 - Advance care planning, pain and symptom management, support for patient and family
- Describe integration of palliative care with chronic management of HIV disease
- Define the essential elements of the advance care planning process
- Recognize the need for advance care planning along the health-illness continuum and comfort care at the end-of-life



Palliative Care




- Affirms Life: Dying a Normal Process
- Neither Hastens Nor Postpones Death
- Relief From Pain, Other Symptoms
- Integrates Psychological/Spiritual Care
- Uses Team Approach
- Support System for Family

World Health Organization 1990




Palliative Care





- Interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.
- It is offered simultaneous with all other appropriate medical treatment.

www.capc.org





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Palliative Care Key Pillars



- Advance Care Planning
 1. Community Conversations on Compassionate Care (CCCC) Program
 2. Medical Orders for Life-Sustaining Treatment (MOLST) Program
- Pain and Symptom Management
- Support for the Patient and Family



Palliative Care Provides What Patients Need



- Compassion
- Non-abandonment
- Acceptance
- Clear information that enables determination of the goals of care
- Identification of surrogate decision maker and preferences
- Treatment as a whole person

Bomba, 2001



Palliative Care Provides What Patients Want at End-of-life



- Quality end-of-life care
 - receiving adequate pain & symptom management
 - avoiding inappropriate prolongation of dying
 - achieving a sense of control
 - relieving the burden on loved ones
 - strengthening the relationship with loved ones

Singer, et al. JAMA 1999; 281: 163-8


Palliative Care Provides What Patients Want at End-of-life



- Quality end-of-life care
 - respect uniqueness of individual
 - provide appropriate environment
 - address spiritual issues
 - recognize cultural diversity
 - communication integral between dying person, family and professionals


McGraw, et al. Conn Med 2002; 66 (11); 655-64

Needs Assessment and Evolving Realities Honoring Patient Preferences for EOLC



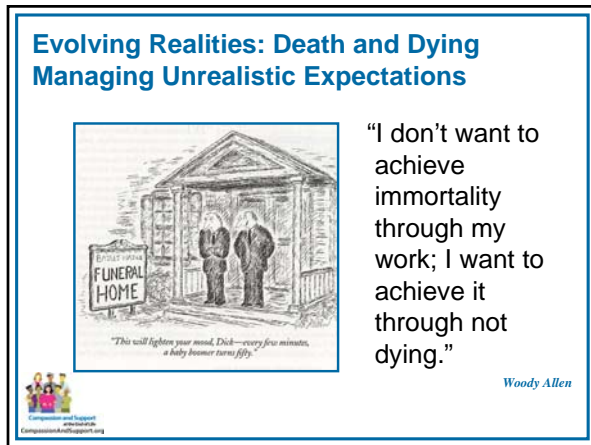
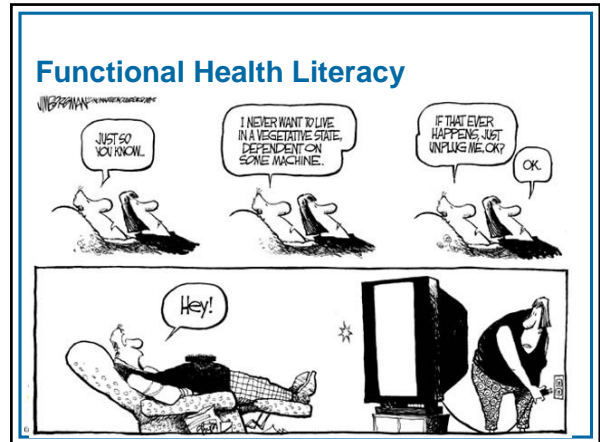
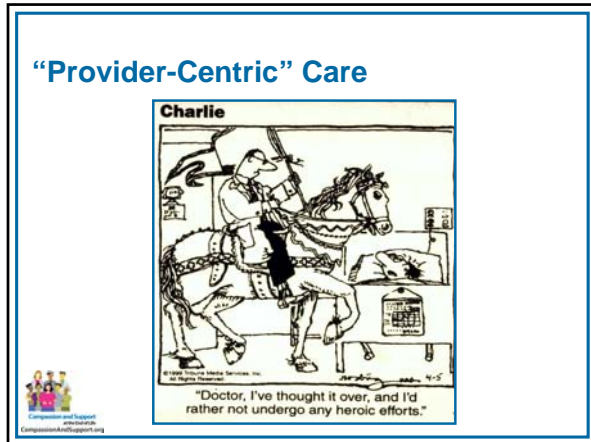
- Life expectancy has increased
- Increased prevalence of chronic diseases
- Death in America often seen as "optional"
- Planning for the future is not just for the old, disabled or chronically ill
- Gaps in care and quality issues
 - location of death, pain management, treatment preferences and hospice admissions
- Regional Variations in Site of Death
- Regional Variations in Cost of Care at EOL
- Healthcare Professional Communication Skills
- Functional Health Illiteracy

Professional Barriers to Effective EOLC



- Lack of acknowledgment of importance
 - introduced late, funding inadequate
- Fear of addiction, exaggerated risk of adverse effects
 - restrictive legislation
- Discomfort communicating "bad" news, prognosis
 - misunderstanding
- Lack of skill negotiating goals of care, treatment priorities
 - futile therapy
- Personal fears, worries, lack of confidence, competence
 - avoidance of patients, families
- Perhaps reflection on personal expectations will bring insight into patient, family expectations, needs

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Regional Variation Site of Death: National and State Data

	Deaths at home	Deaths in a Hospital	Deaths in a NH
Oregon (Nat'l Benchmark)	35.10%	32.50%	32.40%
National Mean (Average)	24.90%	50.00%	25.10%
New York	21.20%	61.80%	17.00%

Benchmarks, 2001, Launch of Community-Wide EOL/Palliative Care Initiative

- ### Regional Variations in Medicare Spending
- Large regional variations in the percentage of deaths occurring in hospitals
 - High-spending regions
 - more inpatient-based and specialist-oriented care
 - however, no improvement in
 - health outcomes, including mortality rates
 - quality of care
 - access to care
 - patient/family satisfaction
 - Good predictor of how hospitals treat patients under 65 with chronic disease

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End-of-life Care Cost Savings

- Dollars are wasted on unwanted, unnecessary and futile treatments
- Reducing amount spent on ineffective treatments will help reduce the total cost of end-of-life care
- Cost savings estimate: 3.3 % of total costs ⁱⁱⁱ
- 3.3% x \$1.4 trillion = \$59 billion

ⁱⁱⁱ Terry Sanford Institute of Public Policy, Duke University.
www.pubpol.duke.edu /courses/pps255s/2004/w-team-a/benefits.htm, 2004

Thoughtful EOLC Discussions Benefits

- Improve quality; reduce cost
- Only 31% of patients with advanced cancer at EOL had had discussions with physicians about EOLC
- Patients who had EOL conversations had significantly lower costs in their final week of life, over \$1,000 less
- “Higher costs were associated with worse quality of death”

Arch Intern Med. 2009;169(5):480-488

Thoughtful EOLC Discussions Benefits

- “End-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals.”
- “Aggressive care is associated with worse patient quality of life and worse bereavement adjustment.”

Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment
JAMA. 2008;300(14):1665-1673

Advance Care Planning

Compassion, Support and Education along the Continuum

Advance Directives

<p>Traditional ADS</p> <p>For All Adults</p> <p>Community Conversations on Compassionate Care (CCCC)</p> <ul style="list-style-type: none"> ▪ New York ▪ Health Care Proxy ▪ Living Will ▪ Organ Donation ▪ State-specific forms 	<p>Actionable Medical Orders</p> <p>For Those Who Are Seriously Ill or Near the End of Their Lives</p> <p>Medical Orders for Life-Sustaining Treatment (MOLST) Program</p> <ul style="list-style-type: none"> ▪ Do Not Resuscitate (DNR) Order ▪ Medical Orders for Life Sustaining Treatment (MOLST) ▪ Physician Orders for Life Sustaining Treatment (POLST) Paradigm
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www.CaringInfo.org

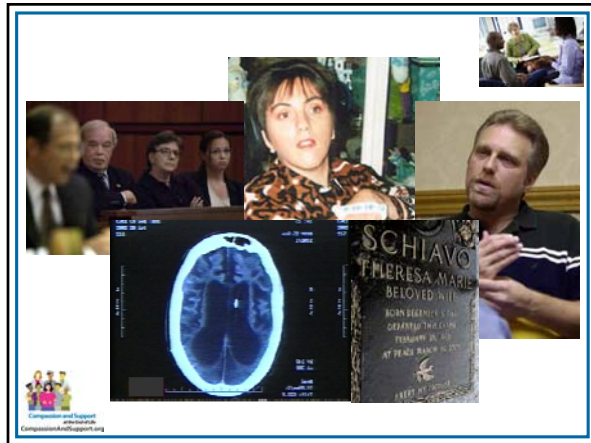
www.CompassionAndSupport.org
www.Polst.org

Community Conversations on Compassionate Care Five Easy Steps

1. Learn about advance directives
 - NYS Health Care Proxy
 - NYS Living Will
2. Remove barriers
3. Motivate yourself
4. Complete your documents
 - Have a conversation with your family
 - Choose the right Health Care Agent
 - Discuss what is important to you
 - Understand life-sustaining treatment
 - Share copies of your directives
5. Review and Update

CCCC video on-line with Five Easy Steps

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How to Clarify Values and Beliefs

- Your values
- Your personal beliefs
- Your spiritual beliefs
- What makes life worth living
- What really matters to you
- Your hopes and wishes
- Your goals for care
 - Quantity vs quality of life

How to Choose a Health Care Agent

- Knows me well
- Understands what is important to me
- Will talk about sensitive wishes now
- Will listen to my wishes
- Willing to speak on my behalf
- Would act on my wishes
- Can separate his/her feelings from mine
- Will be available in the future
- Lives close by or willing to come
- Could handle responsibility
- Can manage conflict resolution
- Meets legal criteria

Practical Issues: Review & Update, Accessibility

- Review & update
 - Periodically
 - Major life events
 - Newly diagnosed chronic illness
 - Advancing chronic illness
 - After complicated life-sustaining treatments
- Keep a copy and provide a copy
 - Health Care Agent and Alternate Agent
 - family members / loved ones
 - primary care physician and specialists
 - primary hospital/ care facility
 - spiritual adviser

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Medical Orders for Life-Sustaining Treatment (MOLST Program), A POLST Paradigm Program

- Improve the quality of care people receive at the end of life
 - effective communication of patient wishes
 - documentation of medical orders on a brightly colored pink form
 - promise by health care professionals to honor these wishes
- Complements the use of traditional advance directives

A Project of the Community-Wide End-of-life/Palliative Care Initiative

MOLST: Who Should Have One?

- Anyone choosing:
 - Do not resuscitate
 - Allow natural death
- Anyone choosing to limit medical interventions
- Anyone eligible/residing in LTC facility
- Anyone who might die within the next year

Health Care Proxy / Living Will vs MOLST

- Health Care Proxy / Living Will**
 - completed ahead of time
 - applies only when decision-making capacity is lost
- MOLST**
 - applies right now
 - not conditional on losing decision-making capacity
 - set of actionable medical orders
 - approved by NYSDOH for use in **ALL** settings, including the community

POLST Paradigm Program

- Endorsed Programs
- Developing Programs
- No Program (Contacts)

Paradigm of communication, documentation, and system responsiveness
POLST Paradigm Program, June 2009. www.polst.org

MOLST

Page 1: **DNR**

- Complete Section A, B, C for DNR
- Section D: Advance Directives

Page 2: **Life-Sustaining Treatment**

Page 3 and 4: **Renew/Review**

Supplemental Documentation
Forms for DNR: Adult and Minor


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Capacity Assessment


- Capacity is the ability to:
 - take in information,
 - understand its meaning and
 - make an informed decision using the information
- Capacity allows us to function independently
- Both medical and legal determination
- Ability to choose agent vs ability to make health care decisions

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8-Step Protocol





1. **Prepare for discussion**
 - Understand the patient and family
 - Understand the patient's condition and prognosis
 - Retrieve completed Advance Care Directives
 - Determine "Agent" (Spokesperson) or responsible party
2. **Determine what the patient and family know**
 - re: condition, prognosis
3. **Explore goals, hopes and expectations**
4. **Suggest realistic goals**
5. **Respond empathetically**
6. **Use MOLST to guide choices and have patient/family share wishes**
 - Shared medical decision making
 - Conflict resolution
7. **Complete and sign MOLST**
8. **Review and revise periodically**



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Developed for NYS MOLST, Bomba, 2005


Communicating Prognosis

- Physicians markedly over-estimate prognosis
- Accurate information helps patient / family cope, plan
- Offer a range or average for life expectancy
 - Minutes to hours, hours to days, days to weeks, etc

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Reviewing goals, treatment priorities



- Goals guide care
- Assess priorities to develop initial plan of care
- Review with any change in
 - health status
 - advancing illness
 - setting of care
 - treatment preferences
- Gradual shift in focus of care
- Expected part of the continuum of medical care

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Healthcare Professional Communication Barriers



"There's no easy way I can tell you this, so I'm sending you to someone who can."

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Language to Describe Goals of Care

- Hope for the best, plan for the worst
- No missed opportunities
- Meet your needs and goals, understanding what is possible and what we wish could happen, but cannot
- We want to give the best care possible until the day you die, enjoy the time remaining, how ever long that is
- We'll do everything we can to help you maintain your independence
- We want to ensure that your father receives the kind of treatment he wants
- Your grandmother's comfort and dignity will be our top priority

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Listen through the Patient/ Family Ear





- He's "stable"
 - Pt on pressors, vent, dialysis, no changes
- He is getting better
- Do you want us to do CPR?
- She has a chance of surviving if we do CPR
- Do you want to "trach" him?
- He has a chance of coming off the ventilator and going home

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Language with Unintended Consequences

- Do you want us to do "everything"?
- Will you agree to discontinue care?
- It's time we talk about pulling back
- I think we should stop aggressive/ heroic therapy
- Despite trying these treatments for several days, and around the clock, expert care, he is unfortunately too sick to respond.
- We will change goals of care to respect her wishes
- We will intensify care; his comfort and dignity are our highest priorities
- Let's discontinue treatments that are not providing benefit.





Clarifying Hopes and Fears

- What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?
- What are your biggest hopes about the end of your life?
- What are your biggest fears about the end of your life?





Hoping and Preparing

- "Lets hope for the best..."
 - Join in the search for medical options
 - Open honest exploration of improbable/experimental therapy
 - Ensure fully informed consent
- "...and prepare for the worst."
 - Make sure affairs (financial/personal) are settled
 - Think about unfinished business
 - Open spiritual and existential issues



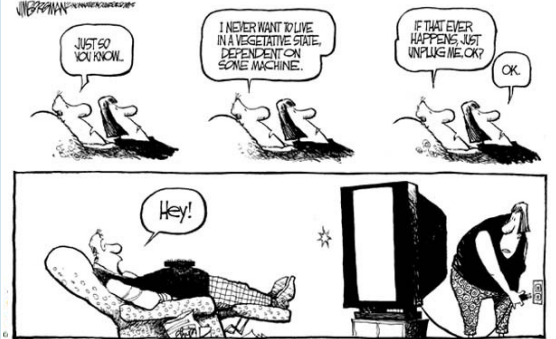


Informed Medical Decision Making

- Will treatment make a difference?
- Do burdens of treatment outweigh benefits?
- Is there hope of recovery?
 - If so, what will life be like afterward?
- What does the patient value?
 - What is the goal of care?





Functional Health Literacy



CPR: In-hospital Arrests

- Physicians overestimate the likelihood of survival to hospital discharge
- Literature
 - Survival 6.5%-32% - average 15%
- At least 44% of survivors have significant decline in functional status



Arch Intern Med 1993; 153:1999-2003
Arch Intern Med 2000; 160:1969-1973



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Public Perceptions

- 67% of resuscitations are successful on TV
- Educating patients
 - 371 patients, age >60yrs
 - 41% wanted CPR
 - After learning the probability of survival only 22% wanted CPR



NEJM 1996; 334:1578-1582
NEJM 1994; 330:545-549
Acad Emer Med 2000;7(1):48-53



DNR Discussions

- Physicians speak 75% of the time and use medical jargon
- After discussions
 - 66% did not know that many patients need mechanical ventilation after resuscitation
 - 37% thought ventilated patients could talk
 - 20% thought ventilators were O2 tanks



JGIM 1995; 10:436-442
JGIM 1998; 13:447-454



Language Issues

- How we talk about DNR orders is important
 - “The message behind the term ‘do not resuscitate’ is predominantly negative, suggesting an absence of treatment and care. The reality is that comfort care and palliative care are affirmative and, for these patients, more appropriate interventions”.



Charlie Sabatino, American Bar Association Commission on Law and Aging



Long Term Artificial Hydration and Nutrition

- Risks and benefits vary in the individual
 - depend on age, overall health status, goals for care, timing and course of disease
- Often hard to predict outcome
- Decision based on goals for care
- When someone is dying, AHN
 - Does not prevent aspiration
 - Does not improve comfort
 - Does not change prognosis or prevent dying



Long Term Artificial Hydration and Nutrition

- Can be discontinued at any time
- **When burden outweighs benefits**
 - patient repeatedly pulls out tube
 - quality of life deteriorates
 - excessive agitation
 - terminal condition
 - recurrent aspiration





Artificial Hydration and Nutrition Patient/Family Discussion

- Focus on the underlying disease process as cause of decline and loss of appetite
- Emphasize the active nature of providing comfort care
- Recognize concerns about “starvation”, inadequate nutrition or hydration and potentially hastening death that many individuals deal with in facing this decision and address these issues
- Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food and drink





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Recommendations Patients with Dementia

- Careful hand feeding
- Family support and helping them to understand that the inability to eat or lack of desire to is part of advanced illness and the dying process
- Liberalize diet (sweets, sours)
- Xerostomia (sips of liquid, meds)
- More frequent feedings




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Tube Feeding/ PEG Tubes

- Provider Resources
 - [Approach to Adult Unable to Maintain Nutrition](#)
 - [Flow Chart Reference Sheet](#)
 - [Checklist for Global Assessment](#)
 - [Tube Feeding Worksheet](#)
 - [Benefits and Burdens of PEG Placement](#)
 - [Legal and Ethical Issues](#)
- Patient/Family Resources
 - [Community-wide Clinical Guidelines on PEGS/Tube feeding](#)




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Healing Approaches to the End of Life

- Broader model of healing
 - Death as natural end-of-life cycle
 - Opportunity for growth and closure
 - Maintaining integration; avoiding disintegration
 - Finding meaning and maintaining connection
 - Commitment to face the unknown together
- Professionalism



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THANK YOU

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