

Getting the Most out of MOST: A Win-Win for All

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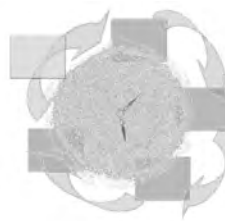


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Objectives

- ✓ Describe failure of PSDA & DNR
- ✓ Discuss benefits of connecting advance directives to physician orders
- ✓ Review the MOST form
- ✓ Identify barriers to implementation and ways to overcome barriers

“The Future
depends on
what we do in
the present.”



Mahatma Gandhi

Win-Win for ???

- | | |
|-------------------|-------------------------|
| ■ Patients | ■ ICU staff |
| ■ Physicians | ■ Primary Care MDs |
| ■ Families | ■ Hospice med staff |
| ■ Nurses | ■ Palliative care staff |
| ■ ER personnel | ■ Social workers |
| ■ EMS personnel | ■ CFOs |
| ■ Risk managers | ■ Ethics committees |
| ■ LTC & ALF staff | ■ Administrators |

The way we die has changed

- Early 1900's life expectancy = 50 years
- Prior to antibiotics people died quickly
- MDs focused on caring, comfort, listening
- Sick were cared for at home
- Focus on technology, life expectancy increased after WWII
- Shift in values – death denying culture
- Aggressive/life prolonging tx at any cost
- Death is the enemy – “Do everything”
- Demand for ICU beds has increased

CAUSE OF DEATH AND SOCIAL TRENDS – Pendulum swing

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases/ Communicable Diseases	Chronic Illnesses
Average Life Expectancy	50	76
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Medical
Disease/Dying Trajectory	Relatively Short	Prolonged

The way it was.....1900, Franklin Co, VA



More house calls than hospital admissions



Transportation



What we want isn't what we get

- ~80% wish to die at home
- Over 85% say they want spiritual needs met
- Over 90% want well-managed pain
- ~25% die at home
- ~6% have talked to their minister
- ~11% have talked to their MD

1st Wave of Common Law Cases and the Development of Medical Advance Directives



1975 - Quinlan Case (New Jersey)

- Karen Ann Quinlan (1975-1985)
 - First "Right to Die" case
 - 21 yrs. collapsed after alcohol and Valium April 14, 1975 (New Jersey)
 - Suffered brain damage and remained in a "persistent vegetative state."
 - Karen kept breathing for almost 10 yrs. after the respirator was unplugged



1979 NC Establishes Declaration of Right to Die a Natural Death Act

- **Response to the Quinlan Case:**
- **NC established the Living Will Statute:**
 - **Article 23 of G.S.90 (1979)**
 - **Specifying procedures for withholding medical treatment in end-of-life situations**

1991- 2nd Wave NC Develops Health Care POA



Nancy Cruzan (Missouri)

- Cruzan Case (1983-1990) - U.S. Supreme Court affirmed the "right to die" and the right to forgo treatment (Missouri)
- Article 3 of GS 32A enacted in 1991, authorizes designation of a "health care agent" in a HCPOA



3rd Wave Terri Schiavo Case

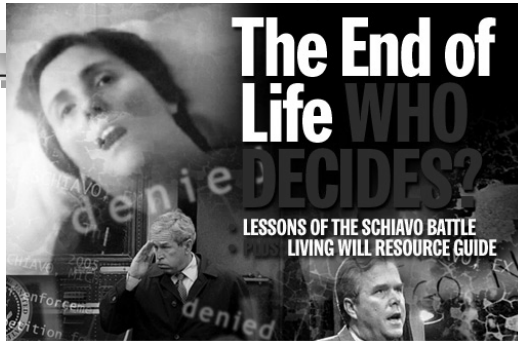


3rd Wave Terri Schiavo Case (Florida)

- Terri Schiavo (1990-2005)
 - 26 yrs. heart stopped for 5 min. Feb.25, 1990
 - 1998 husband/legal guardian petitioned to have feeding tube removed
 - After 2 wks w/o food or water, Terri died on March 31, 2005
 - Autopsy showed brain had shrunk to half normal size and Terri was blind



Terri's Legacy



Is there a 'bad guy' in this case?



PSDA outcome: focus on paper

- 20 years post-PSDA only +/- 30% have an AD – most of those are Living Wills
- Charts with AD but no corresponding DNR order
- Charts with DNR but no corresponding AD
- Documentation has NOT meant good conversation
- Saying the right thing to the right people at the right time has not been the norm
- Finding/taking time has been a problem

Poor Communication

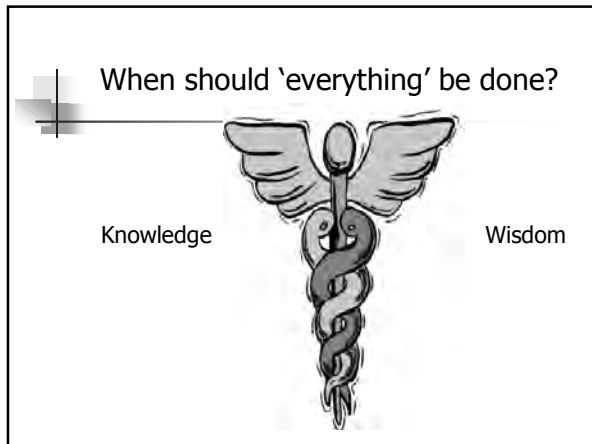
- Patients, family members and MDs seem reluctant to initiate the conversation
- Healthy myth: these conversations are difficult to have – but they are easy to avoid
- Comfort and skill levels are low
- Even if discussed with primary care MD, when these decisions are made another MD is usually in attendance
- Wrong place, wrong time, wrong message

Fragmented healthcare system

- Specialist, ER & ICU MDs don't know pt.
- Decisions sometimes made based on risk-avoidance rather than patient's best interest
- Critical communication often occurs in the midst of crisis with too little info available
- **Advance directives are not a substitute for an MD order**
- LW's have little actual impact in most clinical settings

Why the Patient Self-Determination Act (1991) has failed:

- Only 25% of Americans have documents
- Family unaware of documents or wishes
- Not available when needed
- May not be applicable to a patient's current condition
- Advance Directives do not immediately direct care
- Emphasis on paperwork instead of conversations



Advance Directives

- Documents completed in advance, in order to guide future medical decision-making
- Living Will (express preferences)
- Health Care Power of Attorney (appoint a future surrogate decision maker)
- Hypothetical
 - Based on a potential, future health state
 - Must be interpreted or appoint an interpreter

Isn't It Time We Talk?

Yes, but....

- What to say?
- Who to say it to?
- When to say it?
- What words do I use?
- What do I need to know before I talk?

1. Definition of advance care planning
2. Why and how to plan ahead for uncertainty
3. Description of treatment setting options
4. Definition of various treatment options
5. Worksheets on beliefs, values and options
6. Having the conversation – who, when, where, what and how?
7. Living Will & HCPWA documents



Changes in NC laws – Oct '07

- Informed consent
- New Living Will form
- New Health Care Power of Attorney form
- New MOST form – a physician order set
- Old ADs are still, and will remain valid

Advance Directive Limitations

May not be available when needed

May not be specific enough

Does not translate immediately into medical order



Literature Review on Advance Directives, June 2007
<http://aspe.hhs.gov/daltcp/reports/2007/advdir.htm>



From PSDA to POLST to MOST

- 1991 - Patient Self Determination Act
- 1991 - POLST form developed in Oregon
- 2002 - POST in West Virginia
- 2007 - MOST in North Carolina



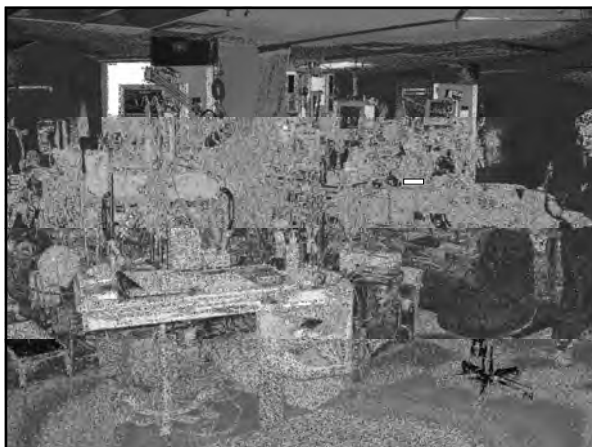
It's not about the documents!

It's about the conversation.

Are we asking, "Do you want to live?" instead of "What kind of care do you want?"

It's about choice, values and principles

- The patient's right to choose
- The clash of values, beliefs and attitudes
- Principles of medical ethics:
 - Autonomy
 - Beneficence
 - Distributive Justice
 - Knowledge vs. Wisdom
- Stick to "What are the goals of care?"

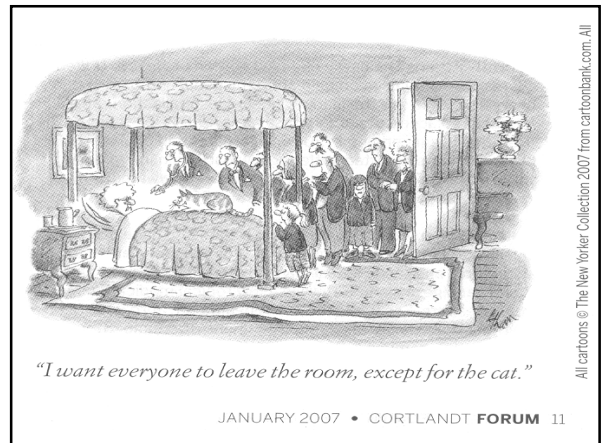


Technology of Critical Care



It's the people, not the paper

- Advance Directives are no substitute for **Advance Care Planning**.
- It's not a hard conversation to have. It's easy to avoid, but once started, people want to talk.
- It's about giving the gift of peace of mind that patients will be comfortable and have their wishes honored.



Facilitating the conversation

- Move ACP upstream – out of acute care
- Change organizational and community culture to accommodate ACP, hospice & palliative care, use of MOST form
- Normalize the topics and the process
- Promote HCPOA, not Living Will
- Educate the public and the professional

Check list for success

- Knowledge of benefits and burdens of each treatment option
- Timing & length of discussion
- Appropriate place
- Individual-specific content
- Understandable language
- Relationships & facilitator skills
- Connect Advance Directives to MD orders

Introducing the forms

Set the stage with the right language.

"Do you have an advance directive?" vs. "What kind of care do you want?"

"We have some important papers for you to sign" vs. "We want to provide the best possible care for your mother."

"This MOST form lets us know if you want us to start your heart again if it stops" vs. "We have a tool designed to help honor your wishes."

Encourage conversations about end of life care wishes in a new, different and better way.

A step in the right direction: Do Not Resuscitate (DNR) order



- Medical Order
- Issued by a physician (NP or PA)
- Not hypothetical; immediately "in effect"
- No interpretation, immediately directs care in the event of a cardiac arrest

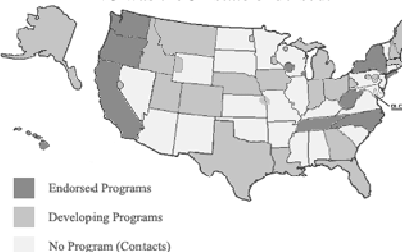
DNR DOES NOT MEAN DO NOT TREAT

- 78 % of long term care residents with DNR wanted other treatment options
- 20% of hospice patients want limited additional interventions



Endorsed States as of 10-2010

NC was the 5th state endorsed.



Idaho & Colorado were endorsed on 1-27-2011
(PA, MT, MA, MD, LA, SC, VA coming soon)

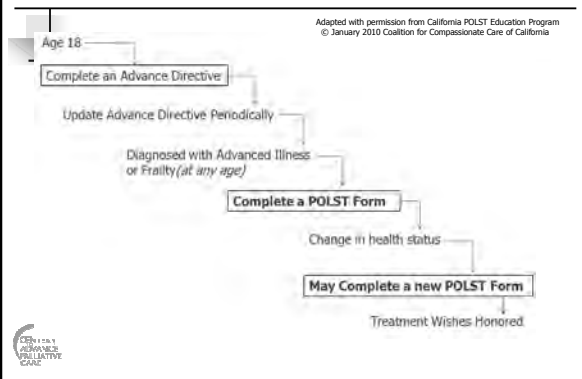
The POLST Paradigm

www.polst.org
www.ncmedsoc.org (search for EOL resources)
www.caringinfo.org
www.kidneyeol.org
www.carolinarendoflifecare.org
www.compassionandsupport.org
www.hospicecarecenter.org
www.seriousillness.org/piedmont

What is the **MOST** form?

- A physician order
- Completed by any qualified provider, signed by MD, PA or NP
- Complements **but does not replace** advance directives
- Voluntary; can be revoked at any time

How Advance Directives and POLST Work Together



Rationale

- AD may not be readily available
- AD may not have prompted needed conversation or been specific enough
 - No provision for tx in LTC or home
 - May not cover topics of most immediate need
- AD may be overridden by a treating MD
- AD does not automatically translate into an MD order

Honoring Patient Preferences Across Care Settings

- Portable medical order
 - Travels with patient (hospital, home, nursing home)
 - Available when needed (point of care)
- Standardized and easily identified
 - Bright color (find it among other paperwork)
 - Same form for all settings
- More than a DNR order
 - Accept or reject other types of treatment
- Issued by physician, PA, or NP
 - Discuss prognosis, risks, and benefits of treatments
 - Opportunity to answer questions and make recommendations

The MOST Form up close

- Top left: Physician order sheet based on:
 - Patient's medical condition
 - Patient's wishes
 - Like the (Yellow) Portable DNR:
 - MOST travels with PT
- EXCEPT:**
- Includes more detail and direction
 - Must be signed by MD, PA or ANP **and** Pt or Pt's Agent
 - Must be updated at least once a year



Medial Orders for Scope of Treatment (MOST) form



- More than a DNR order
- Guide care even when patient has not arrested
- Options to receive or withhold treatments
- Avoid inappropriately limiting or providing other types of treatments

Sections A and B

- Section A: patient has no pulse and is not breathing
 - Options include "Do" and "Do Not" resuscitate
- Section B: patient has a pulse and/or is breathing
 - Three options are available:
 - Full scope of treatment
 - Limited Additional treatment
 - Comfort measures

Section A: CARDIOPULMONARY RESUSCITATION



- Attempt Resuscitation (CPR)
- Do Not Attempt Resuscitation (DNR/no CPR)
- Only one option should be selected.
- Only applies if there is no pulse and the patient has stopped breathing
- (cardiopulmonary arrest)

CPR Survival Rate

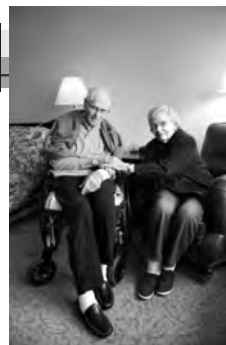
- Generally, only 10-15% survive to hospital discharge; many with impairments
- Lower rates of survival (<5%)
 - Unwitnessed arrest
 - Certain types of heart rhythms
 - Multiple chronic diseases
- Survival for LTC patients 0-3%

Inaccurate Perceptions of Survival



- General belief of 65% survival after CPR
- 67% of resuscitations successful on TV
- Probability of survival influences choices
 - Nearly one-half of older adults changed their mind about wanting CPR after hearing about the true probability of survival

NEJM 1996; 334:1578-1582
NEJM 1994; 330:545-549



GIVEN AN OPPORTUNITY
ONLY 12% OF
LONG TERM
SKILLED
NURSING
FACILITY
RESIDENTS
WANT ICU CARE

CENTERS FOR
ADVANCE
QUALITY
CARE

EMS arrives at home of pt.

- Living will clearly states no life prolonging measures desired
- HCPOA is present and says 'do not resuscitate' – desire to die at home
- No pulse, not breathing, no DNR form
- Yellow DNR is prominently posted
- What if....they're breathing and have a pulse? What then?

Section B: MEDICAL INTERVENTIONS



- Full Scope of Treatment
- Limited Additional Interventions
- Comfort Measures
- Guidance about the intensity of care and the patient's goals
- Patient is not experiencing cardiopulmonary arrest (No indication for CPR)

Prioritize Goals of Care

- 1) Longevity
- 2) Function (maintain/restore)
- 3) Comfort

J Am Geriatr Soc 1999;47(2):227-230

Full Scope of Treatment

- Intubation/mechanical ventilation
- Cardioversion
- ICU admission
- Transport to the hospital if indicated
- All other appropriate treatments
- Patients electing "Full Scope" usually express longevity as the primary goal of care

Limited Additional Interventions

- No intubation/mechanical ventilation
- No cardioversion
- Would likely not be admitted to the ICU
- Transport to the hospital if indicated
- "Other instructions" can be used for clarifications
- Goals of Care
 - Usually do not prioritize longevity as their major goal
 - May express other goals like maintaining or restoring function
 - May opt for therapeutic trials and withdraw therapies if they are ineffective or become burdensome

Comfort Measures

- These patients prioritize comfort as their most important goal of care
- Care is focused exclusively on relieving distressing symptoms
- No intubation/mechanical ventilation
- No cardioversion
- No ICU admissions
- Transport to the hospital ONLY if comfort needs can not be met in the current location

Effectiveness Data

POLST USE IN SNF 1996

- 0/180 NH residents with POLST orders of DNR/comfort measures only received CPR/ICU
- 5% died in acute care hospital



Source: JAGS 46:1097-1102, 1998

SECTION B

POLST USERS WITH COMFORT MEASURES ONLY

67% less likely to receive life sustaining medical interventions compared to POLST full treatment.

P<0.004




Consistency of Orders

- Full Scope of Treatment order should follow an order to Attempt Resuscitation (CPR)
 - CPR often results in intubation (ABC protocol)
- DNR (no CPR) with Full Scope of Treatment
 - Some patients may still desire ICU care for serious illness or elective intubation for respiratory failure without cardiac arrest
- DNR (no CPR) with Limited Additional Interventions
 - Provide all other medical treatments as indicated, but no resuscitation attempts or intubation in the event of cardiac or respiratory arrest
- DNR (no CPR) with Comfort Measures
 - Comfort measures should be provided for all patients


Interpreting Section B

- Doesn't cover all possible treatments
- Provides additional guidance beyond CPR or DNR orders
- Clear directions to EMS about intubation, cardioversion, and hospital transportation
- Other treatment decisions are clarified in sections C and D

Section C: ANTIOTIBIOTICS

- 
- To receive antibiotics if life can be prolonged
 - To determine use or limitation of antibiotics when infection occurs
 - No antibiotics, in which case other measures would be used to relieve symptoms

Section D: MEDICALLY ADMINSTERED FLUIDS AND NUTRITION

- 
- IV fluids options:
 - To receive if indicated
 - To receive for a defined trial period
 - No IV fluids
 - Feeding tube options:
 - To receive if indicated
 - To receive for a defined trial period
 - No feeding tube

"If you can't get an enchilada down that thing, it ain't food."

(Where was the 'feeding tube' invented and for what patient population?)

AHN Benefits and Burdens

- Often religious and cultural beliefs guide a patient's decision
- Discussed in the context of goals of medical care
- IV fluids may not promote comfort at the end of life
 - Swelling
 - Shortness of breath
 - Need for frequent urination.
 - Excessive secretions
- Feeding Tube decisions are complex
 - Promotes longevity in some cases (ie. brain injury)
 - No clear survival benefit in advanced dementia
- Comfort care measures: ice chips and mouth care

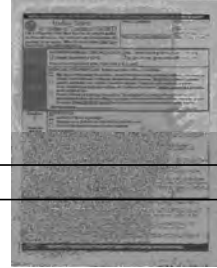
Trial Periods



- Not starting and stopping are equivalent
- Emotionally, stopping is often more difficult
- When goal is not achieved, shift focus
- Sometimes difficult to define duration

Section E:

DISCUSSED WITH AND AGREED TO BY:



Section E: Informed Consent

- Alert patient with capacity to decide
- Parent of a minor
- Health Care Agent
- Legal guardian
- Attorney-in-fact with power to make health care decisions
- Spouse
- Majority of pt's 'reasonably available' parents & adult children
- Majority of pt's 'reasonably available' adult siblings
- Someone with known relationship with pt who is acting in good faith and can reliably convey pt's wishes

How is this physician order different from any other you've seen?

When should it be reviewed?

MOST: Signatures

- Medical Order: signature of the authorizing physician (MD/DO), physician assistant, or nurse practitioner
- Signature of the patient or the patient representative
- Effective date of form (page 1): all signatures completed
- If a patient representative cannot be present
 - Copy of completed form sent to the patient representative electronically
 - Representative signs copy, sends it back
 - Include the notation "on file" in the signature field on the original MOST

When is MOST Appropriate?



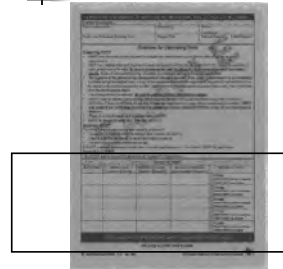
- Serious, terminal illness
- Prognosis is death within a year
- Debilitating chronic progressive illness
- Not for healthy, disabled or stable patients with longer life expectancy
- Or anyone wanting to convey their preferences using MOST

Goals of Medical Care

- Prioritized goals provide context for medical decision making
 - 1) Longevity
 - 2) Function (maintain/restore)
 - 3) Comfort
- Rarely, can all three goals be maximized simultaneously
- As clinical circumstances change, goals are reprioritized

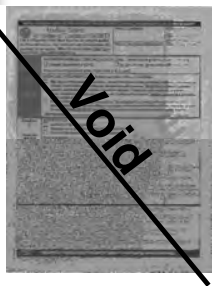
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MOST Validity and Review



- Original pink form (no copies)
- Signed by physician, NP, or PA issuing the order
- Signature of patient or authorized representative
- MOST must be reviewed *at least annually*, or when
 - 1) Patient admitted and/or discharged from a health care facility
 - 2) Substantial change in the patient's health status
 - 3) Patient's treatment preferences change.

Revocation of MOST



- MOST no longer reflects patient's preferences
- Put line through the front page and write "void"
- "Form VOIDED" in the Review section on back of MOST
 - New form completed
 - No new form

MOST is . . .

- Optional
 - Won't work for everyone
 - Another instrument to help honor patient wishes
- Identifiable
 - Bright pink color
- Flexible
 - Accept or reject medical treatments
 - More than resuscitation preferences
- Portable
 - Travels with the patient
 - Directs care in a variety of settings
- Medical Order
 - Immediately directs care
- Reviewed Regularly
 - Annually
 - Changes in health status
 - Admissions/discharges

MOST is NOT...

- A replacement for an advance directive
- Intended for those with a low risk of dying
 - Rather than progressive decline from chronic disease, healthy patients are at risk for sudden catastrophic events associated with prognostic uncertainty
 - Likely to benefit more from a Health Care Power of Attorney
- Available for patients to download or from their attorney
 - Must be signed as a medical order by a physician, PA, or NP
 - Should be completed after a discussion of goals of care, prognosis, and benefits/burdens of treatments.

Benefits of Pink MOST Form

- Identifiable: consistent pink color
- Flexible: allows accepting or refusing treatments
- Actionable: medical orders
- Up-to-date: reviewed regularly
- Portable: transfer across health care settings

Benefits of MOST

- Facilitates appropriate EMS tx
- Facilitates HIPAA compliant transfer of records between healthcare settings
- Centralizes info; facilitates record keeping
- Enhances link among LTC, EMS, ED, ICU, Palliative Care Services, Hospice



An invitation to talk

- Elicit and prioritize goals of care
- Discuss prognosis and expectations
- Present treatments relevant to an underlying disease
- Discuss benefits and burdens of treatment options
- Assess knowledge and educate
- Connect treatment decisions with goals of care
- Recommendations from health care professional

Barriers

- Not enough time
- Not enough education
- Low comfort level
- Low skill level
- Change is hard
- Avoidance

- Benefits are not recognized
- Doesn't travel with patient
- Availability of family or surrogate
- What about after hours? By phone?
- Choice of words

So, what to do???

- "go-to" person
- Facilitated conversation up to signature line
- Mortality committees want fewer deaths in hospitals; hospices want earlier referrals???
- Routinize education for MD, NP, PA, RN, SW
- Policy
- Procedures
- Protocols
- Paradigm shift in systems – raise expectations

Follow the Leaders LADS II... '07-'08 (N=400)

- 67% of decedents had a POLST document.
- 98.5% of POLST forms were in the medical record of the health organization where the person died.
- The most recent POLST form was completed 4.5 months prior to death.
- 96% of all decedents had either an AD or a POLST form at the time of death.







Susan Tolle, MD
 Director, Center for Ethics in Health Care
 Chair, Cornelia Hayes Stevens
 Professor of Medicine, Division of General Internal
 Medicine and Geriatrics, OHSU




Bud Hammes, PhD
 Director, Medical Humanities
 Gundersen Lutheran Medical Foundation
 Chair, National POLST Paradigm Task Force

Data from CA, OR & WI indicate:

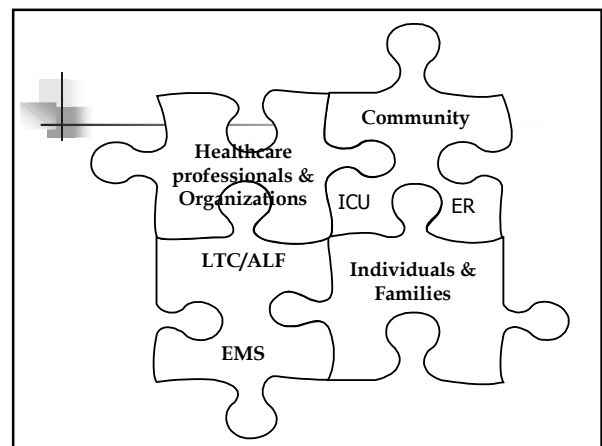
1. Palliative medicine leaders play key roles in health system implementations of POLST Paradigm
2. POLST is associated with reduced unwanted hospitalizations
3. Electronic registry's can improve access




Think....
Talk....
Document....
Think....
Talk....
Document

Who needs to be involved?

- ✓Patients and families
- ✓Trained facilitators!!
- ✓Administrators, nurses, social workers
- ✓Physicians & attorneys
- ✓Clergy & friends



Creating successful systems

- Community
- Workplaces
- Medical Centers
- Retirement communities
- Long-term care facilities
- Physicians' practices

Win-Win for ???

- | | |
|-------------------|-------------------------|
| ■ Patients | ■ ICU staff |
| ■ Physicians | ■ Primary Care MDs |
| ■ Families | ■ Hospice med staff |
| ■ Nurses | ■ Palliative care staff |
| ■ ER personnel | ■ Social workers |
| ■ EMS personnel | ■ CFOs |
| ■ Risk managers | ■ Ethics committees |
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Questions?

Contact information

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