

Advance Care Planning

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Principles of Ethics

- Autonomy/Respect for Persons
- Beneficence
- Non- maleficence
- Justice

Autonomy/Respect for Persons

- The clinician ought to provide all the relevant information to the patient in order to empower the patient to make an informed decision
- The patient is the ultimate authority on what is best for his or her well-being, because this is a value judgment

Beneficence

- The clinician ought to do what is medically determined to be in the patient's best interest, balancing benefits and burdens (risks and side-effects)
- Though more traditional, this is a very high standard, as it rules out letting self-interest or third party interests interfere with what is best for the patient

Non-Maleficence

- “First, Do No Harm”
- The clinician must include preventing or relieving pain and other symptoms in the care-giving equation
- Quality of Life is an important value to protect, not just length of life

Justice

- Clinicians ought to provide necessary treatment for all members of society regardless of ability to pay (including the poor, the disabled, and the uninsured)
- Clinicians ought to contribute to a fair distribution of healthcare resources, including preventing waste and fraud



Informed Consent

- A legal doctrine that requires that doctors share information with patients and get their permission before any treatment or procedure
- Its purpose is to help patients make decisions according to their own personal values
- Failure to do this properly is malpractice₇

Informed Consent

- What the doctor recommends
 - Benefits and risks (harms)
- What the alternatives are
 - Benefits and risks (harms)
- What is likely to happen if nothing is done
- Ideally – free from coercion by health care providers, family or others

ACP is informed consent in advance



Our Laws Support ACP

- US Supreme Court 1990
- Patient Self-determination Act, 1997
- FL Statute 765
 - Living Will
 - Health Care Surrogate
 - Durable Power of Attorney for Health Care
 - DNRO “Yellow Form” (FL Statute 409)

Not Just for Older Folks



Karen Quinlan

Nancy Cruzan

Terri Schiavo



Reasons to Plan Ahead

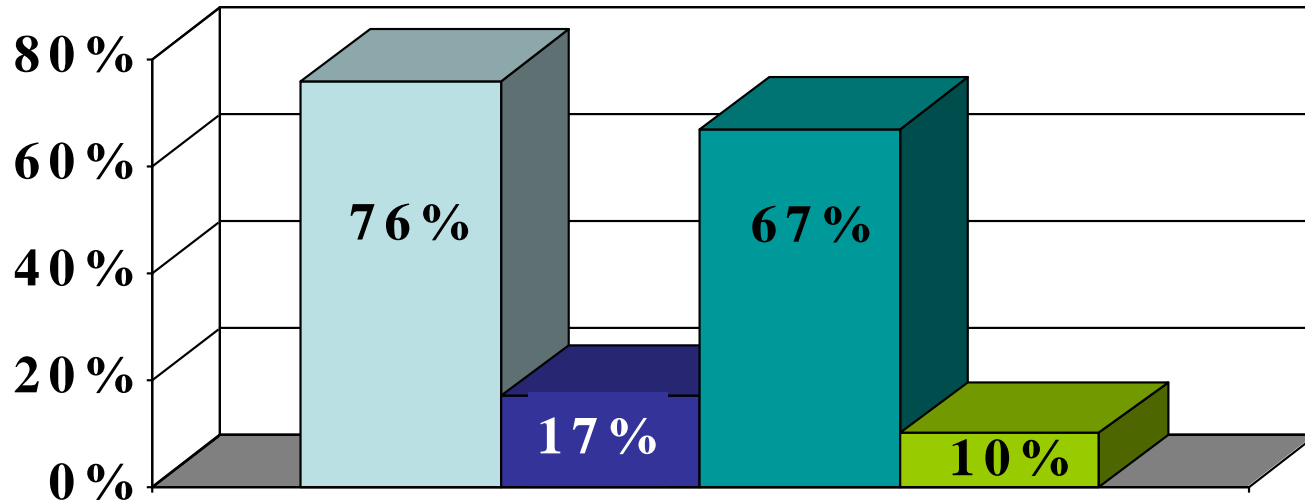
- The future is known – we will die
- Things happen while dying that people do not like
 - May not get treatment wanted
- You have a say in what happens in the future
- These decisions are something everybody should talk more about

Advance Care Planning

- ❑ A process over time
- ❑ Discussing desires and wishes for future medical care
- ❑ May be used when you can't make your own decisions
- ❑ Should be a routine part of medical care

It is **NOT** about completing forms

Talking About End-of-life Treatment Decisions



- Patient thought about what they want
- Patient talked to doctor about their wishes
- Doctors thought about treatment for those patients
- Doctors talked to patient about it

Survey:
75 year-old
patients and
their physicians



Advance Care Plans

- Health Care Surrogate
- Advance Directive
 - Living will, or
 - 5 Wishes, or
 - Advance Care Planning Document
- Drs. Orders

Ultimate goal: support the your autonomy¹⁴



Health Care Surrogate

- ❑ Name someone you can trust
- ❑ Someone who can live without you
- ❑ Someone available
- ❑ Tell them what you want
- ❑ Ask them if they can do it

See FL Surrogate form 15

Florida Definitions

- **Health care surrogate** - someone expressly named to make health care decisions for you
- **Proxy** - someone who has not been expressly named
- Durable power of attorney for health care -essentially the same as a surrogate

Who's the Proxy?

1. Legal guardian
2. Spouse
3. Adult child
4. Parent
5. Adult sibling
6. Adult relative
7. Close friend
8. Clinical SW

Living Will

- A expression of wish to die naturally if:
 - Terminal condition
 - End-stage condition
 - Persistent vegetative state
- No reasonable hope for recovery
- Problems:
 - Vague terms
 - Two physicians must document state

See FL Living Will form¹⁸



FL Statute Definitions

□ Terminal Illness

- A condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death.



FL Statute Definitions

- End-stage Condition
 - An irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective.

FL Statute Definitions

- Persistent Vegetative State
 - A permanent and irreversible condition of unconsciousness in which there is:
 - The absence of voluntary action or cognitive behavior of any kind.
 - An inability to communicate or interact purposefully with the environment

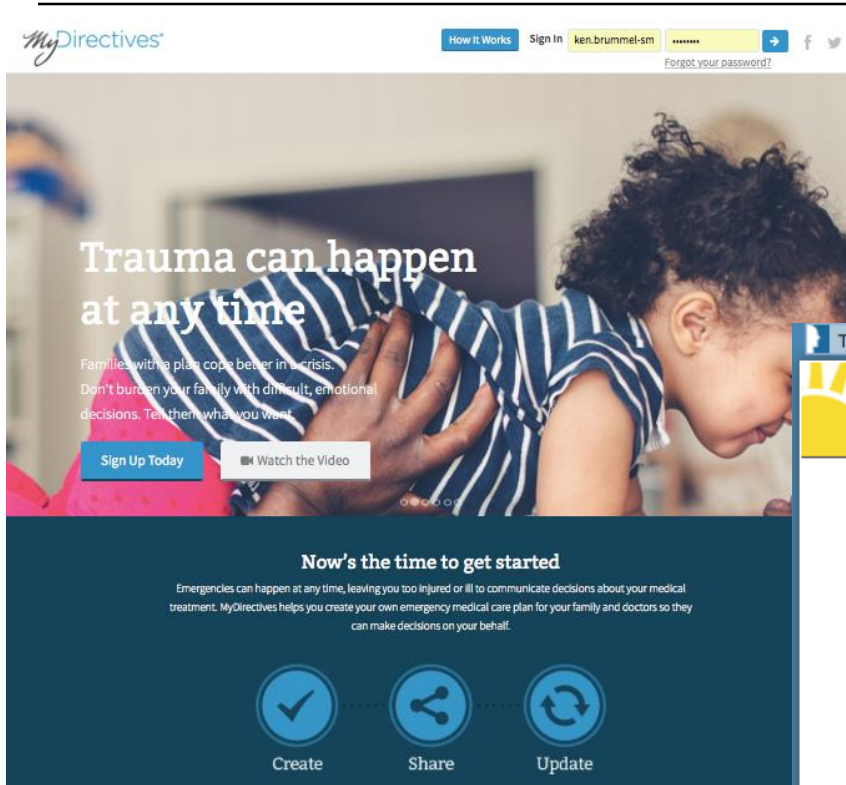
5 Wishes

- Combines forms
 - Name a surrogate
 - Medical directives
 - Values history/end-of-life wishes
- Problems
 - Cost (\$5)
 - Witness restrictions more strict than FL law
 - Medical directives vague

Advance Care Plan Document

- Name a surrogate
- Specific choices on medical treatments
 - CPR
 - Life support
 - Surgery, antibiotics
 - “Tube feeding”
- Problems:
 - Vague terms
 - Only conditions listed

Online Advance Directives



MyDirectives.com website header and main content. The header includes navigation links: How It Works, Sign In (ken.brummel-sm), and a password field with a 'Forgot your password?' link. The main content features a video player with the text: "Trauma can happen at any time. Families with a plan cope better in a crisis. Don't burden your family with difficult, emotional decisions. Tell them what you want." Below the video are buttons for "Sign Up Today" and "Watch the Video". At the bottom, there is a section titled "Now's the time to get started" with the text: "Emergencies can happen at any time, leaving you too injured or ill to communicate decisions about your medical treatment. MyDirectives helps you create your own emergency medical care plan for your family and doctors so they can make decisions on your behalf." Below this text are three icons: a checkmark for "Create", a share icon for "Share", and a refresh icon for "Update".

MyDirectives.com

PrepareForYourCare.org



PrepareForYourCare.org website header and main content. The header includes navigation links: Talking is OFF. Click here to turn on., HELP, CHANGE LANGUAGE, and SIGN IN. The main content features a yellow banner with a sun icon and the word "PREPARE". Below the banner is a section titled "Welcome to PREPARE! ¡Bienvenido a PREPARE!". Below this text are two buttons: "Click here for English" and "Haga clic aquí para español". To the right of the buttons is a stick figure holding a sign that says "PREPARE". At the bottom right, there is a yellow box with the text: "Click a language above to move on. Haga clic en un idioma arriba para seguir adelante."



Limitations of Advance Directives

- ❑ Usually not available in clinical settings
- ❑ Do not provide clear guidance to EMS personnel
- ❑ Only 25% - 30% of people have them
- ❑ Variations in forms
- ❑ Terms may be unclear to clinicians
- ❑ Don't work well – SUPPORT study

Angela Fagerlin and Carl E. Schneider, “Enough: The Failure²⁵ of the Living Will,” *Hastings Center Report* 34, no. 2 (2004): 30-42.



Physician Orders

- Different than Advance Directives
 - In force NOW
 - Will direct the care provided by emergency personnel and other health care providers
- Should be limited to people with advanced life-limiting illness or advanced frailty

Physician Orders

- Do Not Resuscitate Order ¹
 - “DNRO form”
 - the “Yellow Form”
 - Used in FL
- Physician Orders for Life-Sustaining Treatment ²
 - “POLST form”
 - the “Pink Form”
 - Used in 16 states, 30 more evaluating

POLST is NOT an Advance Directive

Advance Directive

- Hypothetical / future condition
- Instructions to use as guide for decision-making
- Created by patients

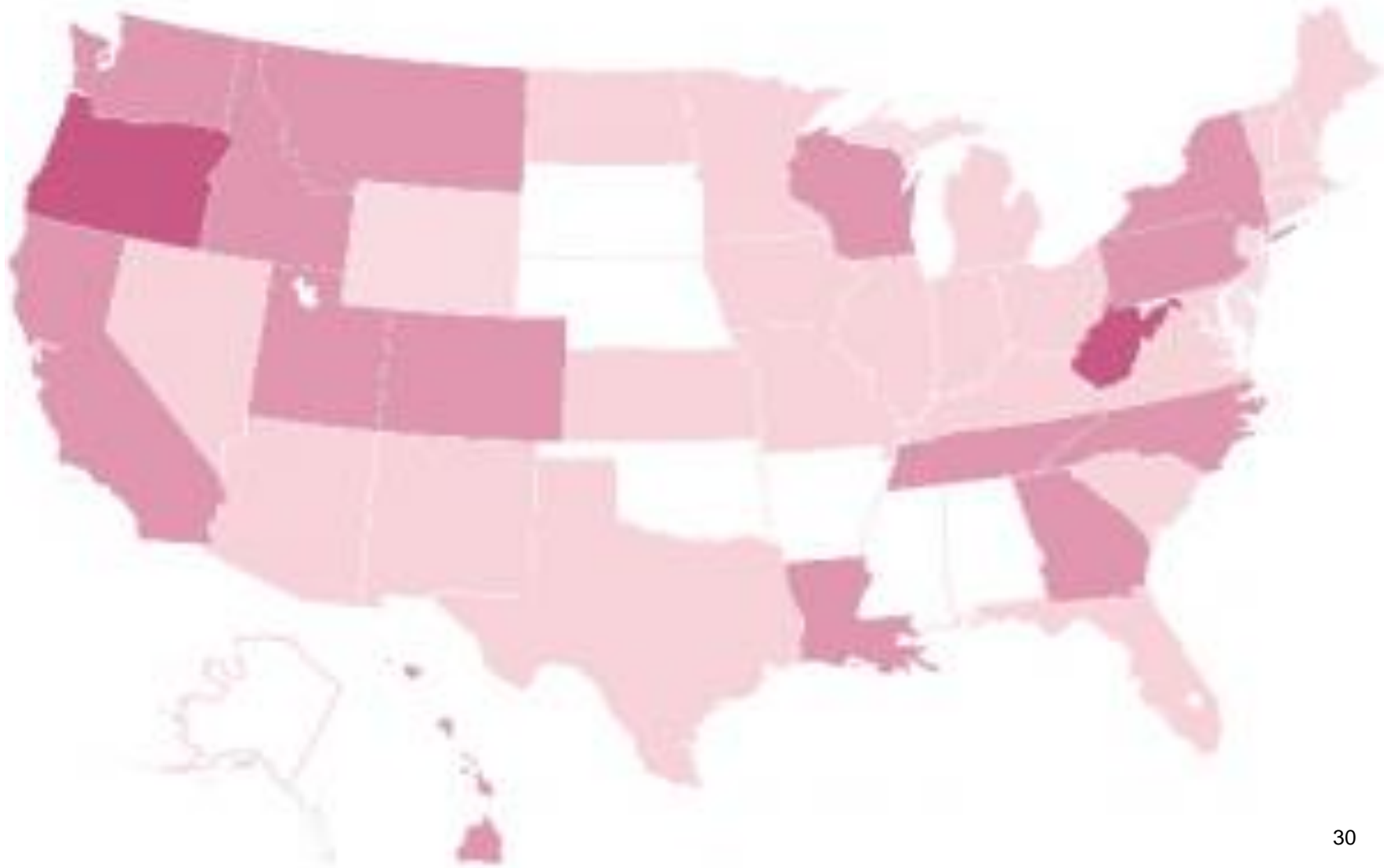
POLST

- Current condition
- Actionable orders integrated in care plan
- Created by physicians and health professionals

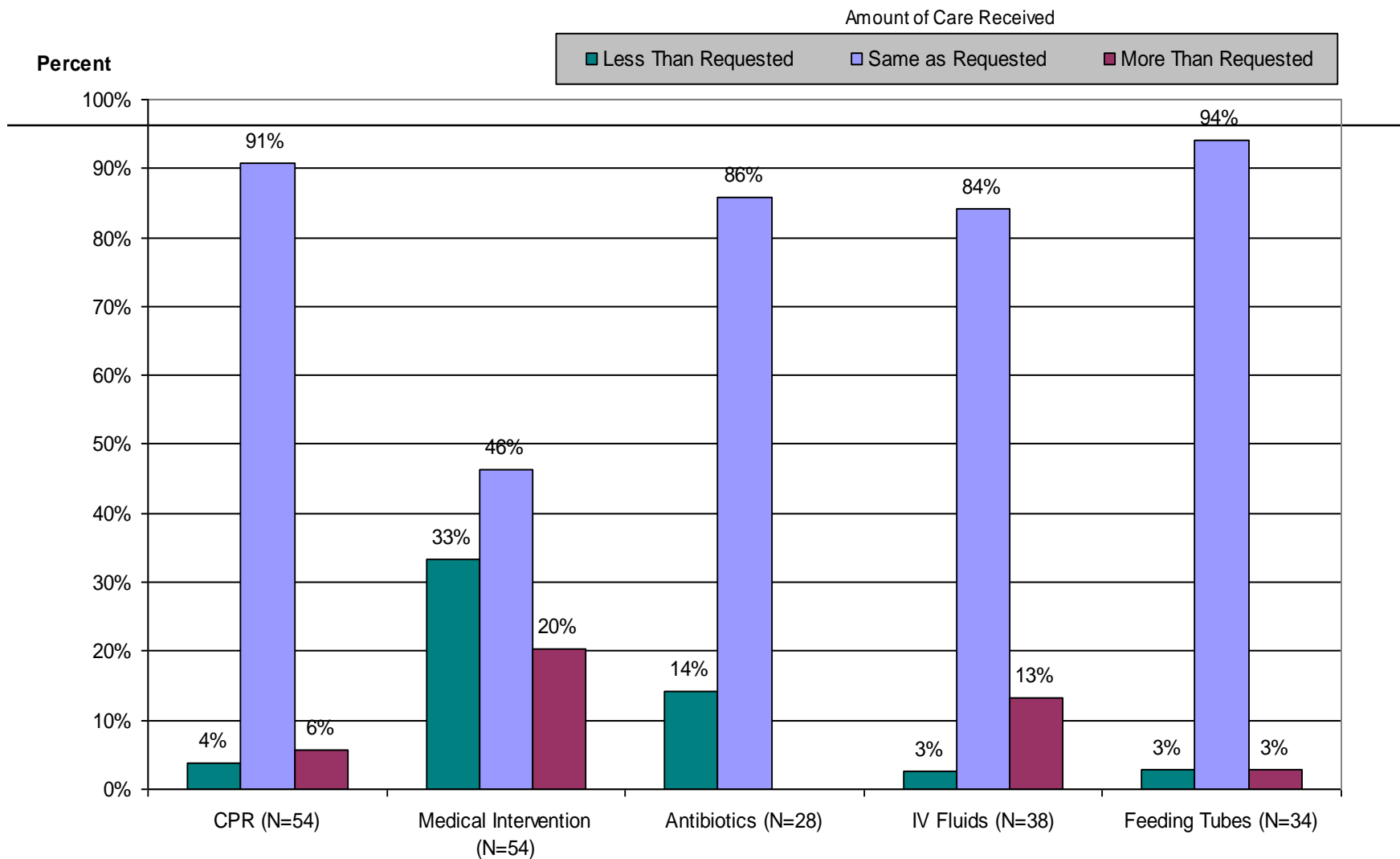
Purpose of POLST

- To ensure that patient preferences are followed
- To provide a mechanism to communicate patient preferences for end of life treatment across treatment settings
 - Home ↔ Hospital ↔ Nursing home

POLST in the US



Percentage of Participants Who Received Less, Same, or More Care than Requested¹.



Areas of Care and Valid Responses

¹ Percentages exclude participants for whom care was not applicable.

Deaths in Hospital

- Nationally about 33% of people die in a hospital ¹
- Oregon – 18,000 deaths (2010-2011)²
 - 6.4% of pts with a POLST and *Comfort Measure Only* died in the hospital
 - 34.2% without a POLST died in the hospital
- POLST is a process not a form

1. <http://www.cdc.gov/nchs/data/databriefs/db118.htm#ref3>

2. Fromme EK, et al, JAGS 2014; 62:1246-1251



POLST Categories

- ❑ Section A: Resuscitation or DNR
- ❑ Section B: Level of medical intervention
- ❑ Section C: Artificial nutrition
- ❑ Section D: Hospice or palliative care
- ❑ Section E: Signatures

Section A: Resuscitation

- Resuscitate
 - Can't be “Comfort Measures Only”
- Do Not Attempt Resuscitate (DNR)
 - Have to have no pulse and/or no breathing
 - Some have suggested changing this term to “AND” – Allow Natural Death but EMS are not ready for that change yet

Section B – Three Levels

- Comfort Measures Only
 - Allow natural death
 - Transfer to hospital only if comfort needs cannot be met
 - Can't be CPR
- Limited Additional Interventions
 - Do not use intubation or artificial ventilation, avoid ICU
- Full Treatment
 - Use intubation & ventilation, pacemaker insertion, ICU
 - Can be DNR



Sections C and D

- Artificial nutrition
 - No artificial nutrition by tube
 - Use for a defined trial period
 - Use long term
- Hospice and palliative care
 - Hospice?
 - Palliative care?
 - Not indicated or requested



Section E

- Physician signature
- Patient (or representative) signature



Future of POLST in FL

- Legislative route likely needed
 - Some states have used regulations
 - S.B. 1052 – Sen Brandes, St. Pete
- Physicians and hospitals want immunity for following a POLST in good faith
- Strong interest in POLST in FL
- Pilots in Miami (UM), Atlantis (JFK), Tampa (Suncoast), and others
- Opposed by the FL Catholic Conference

Resources

- www.empathchoicesforcare.org
- mydirectives.com
- www.prepareforyourcare.org
- www.polst.org
- med.fsu.edu/?page=innovativeCollaboration.POLST