The Whys and Wherefores of Advance Care Planning

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Definition: Advance Care Planning (ACP)

A process of planning for future medical decisions. This process, to be effective, needs to meet similar standards as the process of informed consent, i.e., the person planning needs to…

- Understand selected possible future situations and choices;
- Reason and reflect about what is best; and
- Discuss these choices and plans with those who might need to make the final decisions.

What are the desired outcomes of Advance Care Planning?

Ideally to "know" and to "honor" a patient's informed plans, by…

1. Creating an effective plan, including:
   a) selecting a well prepared health care agent or proxy when possible, and
   b) creating specific instructions that reflect informed decisions that are geared to the person's state of health.
2. Having these plans available to the treating physician.
3. Incorporating plans into medical decisions when needed.

Why is Advance Care Planning Needed?

- In a medical crisis, especially when the patient cannot make decisions, health professional must assume that all treatment that might prolong life is reasonable.
- We also know that at a certain point a patient, especially when his/her health is failing, decide that some forms of treatment no longer make sense or simply have little or no chance of success.
- Unfortunately, there is no obvious way to know who these patients are or when a patient would change the goals of treatment unless we plan.

What matters to ill patients?

"Our results suggest that an understanding of patients' preferences depends on an assessment of how they view the burden of treatment in relation to its possible outcomes and their likelihood."

Fried TR, Bradley EH, Towle VR et al. Understanding the treatment preferences of seriously ill patients. *NEJM* 2002;346:1061-6.

Why is ACP an ethical responsibility?

- If patient's have a right to make their own medical decisions, including the right to refuse medical treatment, then the only way someone can really decide about future, emergent medical care is by doing it before the acute event…in advance.
- If we deny a patient the ability to create an advance care plan, we are fundamentally deciding that they cannot exercise his or her right to make his or her own medical decisions.

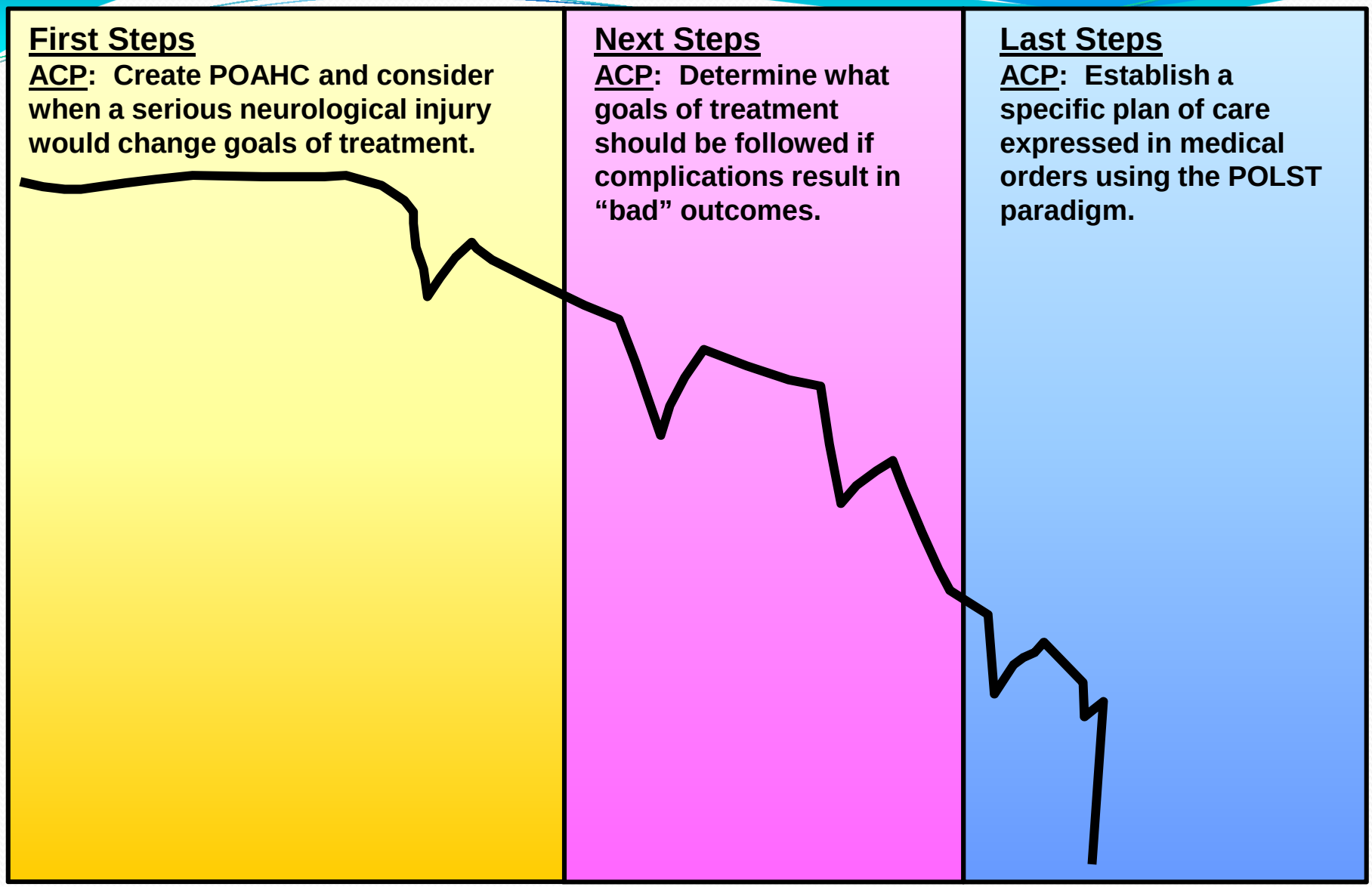
Can elderly, chronically ill persons make informed care plans?

- Yes, if mentally capable and they receive help from a trained person…
  - They can select another person who might make decisions when they are incapable
  - They can determine what health goals are most important to them (*I don't want to die hooked up to machines*.)
  - They can indicate when certain treatments may no longer have enough benefit or may create too much burden. (*My lung disease is so severe I know that a breathing machine will only prolong my dying and make me miserable*.)

What is ACP facilitation?

- Assisting patients and their family about future care plans is time consuming. Training non-physician health professionals to work with physicians to undertake this work is both realistic and effective.
- The goal of facilitation is to 1st understand the patient's ability to make decisions and to determine their general goals of care. Patients are the only true experts at their own goals. We then can work with patients to determine if certain medical treatments will or will not be acceptable means of attempting to achieve these goals or can achieve these goals at all.
- Plans are seldom either/or…do everything or do nothing. In most cases with elderly patients with advanced illness plans are a combination of attempting some type of treatments, but not attempting others.

Stages of Advance Care Planning Over the Life Time of Adults



Physician Orders
for Life-Sustaining Treatment (POLST)

This is a Physician Order Sheet. It is based on patient/resident medical condition and wishes. It summarizes any Advance Directive.

ANY SECTION NOT COMPLETED INDICATES FULL TREATMENT FOR THAT SECTION. WHEN THE NEED OCCURS, FIRST FOLLOW THESE ORDERS, THEN CONTACT PHYSICIAN.

Last Name of Patient/ Resident	
First Name/ Middle Initial of Patient/ Resident	
Patient/ Resident Date of Birth ___/___/___	Gender M F
Clinic #	Clinic

ORIGINAL FORM MUST ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED.

Section A (Check One Box Only)

Treatment options when the patient/resident is not breathing and has no pulse.

☐ Resuscitate ☐ Do Not attempt or continue any Resuscitation **(DNR)**

Section B (Check One Box Only)

Treatment options when the Patient/Resident has pulse and/or is breathing.

☐ **Comfort Measures Only.** The patient/resident is treated with dignity, respect and kept clean, warm and dry. Reasonable measures are made to offer food and fluids by mouth, and attention is paid to hygiene. Medication, positioning, wound care, and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction may be used as needed for comfort. These measures are to be used where the patient/resident lives. If comfort measures fail, contact physician. For hospitalization transfer to:_____

☐ **Limited Additional Interventions:** Includes care above. May include cardiac monitor and oral/IV medications. Transfer to hospital if indicated, but no endotracheal intubation or long term life support measures. Usually no intensive care.

☐ **Aggressive Treatment:** Includes care above plus endotracheal intubation, advanced airway, and cardioversion/automatic defibrillation.

Other Instructions: _____

Section C (Check One Box Only)

Antibiotics

☐ No antibiotics except if needed for comfort (e.g. dental infection)

☐ No Invasive **(IM/IV)** antibiotics

☐ Aggressive Treatment

Other Instructions: _____

Section D (Check One Box Only)

Artificially Administered Fluids and Nutrition **Comfort measures are always provided.**

☐ No feeding tube/IV fluids

☐ Defined trial period of feeding tube/IV fluids

☐ Long term feeding tube/IV fluids

Other Instructions: _____

Section E

Discussed with: ☐ Patient/Resident ☐ Health Care Agent ☐ Court-appointed Guardian ☐ Other (specify):

Name of agent/guardian:_____ Phone #:_____

THE BASIS FOR THESE ORDERS IS:

Signature of Physician/Nurse Practitioner (mandatory)	Physician/NP Name (type or print)	Time and Date Signed

ORIGINAL FORM MUST ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED.

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Outcome data on ACP in La Crosse, Wisconsin

La Crosse County Health System

- Population in La Crosse County: 110,000 people (about 45% of German ancestry).
- Two integrated health systems.

  Each system has:
  - A tertiary hospital plus other community hospitals
  - Large physician practice (approx 650 physicians total)
  - A home hospice
- 7 independent nursing homes (in La Crosse County)
- The two systems serve a population of approximately 450,000 people in 19 counties

Prevalence, Availability, and Consistency of Advance Directives in La Crosse County after the creation of an ACP system in '91-'93

	LADS I * Data collected in '95/'96 N=540	LADS II** Data collected in '07/'08 N=400	P value
Decedents with ADs, No (%)	459 (85.0)	360 (90.0)	.023
ADs found in the medical record where the person died	437 (95.2)	358 (99.4)	<.001
Treatment decisions found consistent with instructions	98%	99.5%	0.13

*Hammes BJ, Rooney BL. Death and end-of-life planning in one Midwestern community. *Arch Intern Med.* 1998;158:383-390.

**Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and utility of advance care planning in a county that implemented an advance care planning microsystem. *JAGS*. 2010;58:1249-1255.

Additional Data Regarding 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.

Comparison of POLST vs AD Only

POLST (N= 268)

- Older: Mean age 83
- More likely to die of chronic or terminal illness (97%)
- More likely to die in LTC or at home (84%)
- 30% of POLST forms were completed by health care agents

AD only (N= 116)

- Younger: Mean age 77
- More deaths from sudden or traumatic causes (18%)
- More likely to die in the hospital (59%) or inpatient hospice (23%)

Does POLST work in La Crosse?

- POLST has great flexibility: Of 268 deaths where patient had a POLST, there were 35 different combinations of orders from the 4 POLST sections.
- POLST is highly prevalent: 67% of all deaths from all setting has a POLST.
- POLST is available: The POLST form was available to the health professional where the patient died.
- POLST is honored: If patients wanted treatment they always received it. If they did not want it, they almost never received it. There were only 2 cases where patients desire not to be hospitalized was not honored.

In the USA, has the political discussion of "death panels" harmed ACP?

- Yes…to some degree. It has made it difficult, on a national level, to approve policies to support ACP work by providing a payment for it.
- No…at a local level patients and health professionals understand that good ACP results in better care of patients and families.
  - There has been absolutely NO pressure in La Crosse from anyone to stop what we are doing!
  - Large metropolitan areas like Minneapolis/St. Paul (2.7 million people) are aggressively moving forward to implement effective ACP systems similar to those in La Crosse.
  - The POLST program continues to wide gain support a crossed the USA and be approved by more and more state governments.

If ACP saves money, is it because of rationing care?

- Typically all interventions (Palliative Care/ACP) that engage patients, who have end-stage illness, in informed decision-making about treatments lower the cost of care.
- The patients who participate in these intervention also live as long or longer (as a group) than patients who don't have these services!!!
- Basically interventions that help patients make informed decisions about treatment save money because patients are smart enough to know when treatment offers little benefit (little survival benefit) and will more than likely prolong and increase their suffering.
- This decision to limit treatment by patients or their surrogates is clearly NOT rationing and certainly NOT a death panel.

Conclusion

Creating effective care plans for patients, especially those who are both older and suffer advanced illness is both possible and respectful.

To accomplish this outcome requires an organized approach that includes trained health professionals, working together as a team, who share common practices like documentation tools and related standards of care.