# Creating an Effective Advance Care Plan for ESRD Patients

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## Outline of Talk

- Define advance care planning and advance directives
- Review outcomes of CPR and ways to discuss DNR
- Summary – discuss advance care planning as part of the overall plan of care

## Advance Care Planning (ACP)

- process of communication among patients, health care providers, families and other important individuals about the kind of care considered appropriate when the patient cannot make decisions
  - Teno, 1994

## Advance Directives -- Definitions

- AD = written documents completed by a capable person
  - stipulates decision-maker (proxy directive)
  - stipulates decisions to be made (instruction directive or POLST)

## The Failure of Advance Directives

- <30% of patients have AD
- Goals and preferences may change over time and AD are rarely re-visited
- Proxy decision-makers often don't understand patients' wishes
- AD often unavailable or not followed
- All contingencies cannot be anticipated

## Concepts of ACP: Traditional vs Contemporary
(from Singer, AJKD 1999;33:980)

| | traditional | contemporary |
|---|---|---|
| purpose: | prepare for incapacity | prepare for death<br>achieve control<br>relieve burdens<br>strengthen relat. |
| focus: | written AD | AD only 1 aspect |
| context: | physician-patient | patient-family |

## Contemporary Advance Care Planning

- To prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions Sudore, Fried Ann Int Med 2010;153:256
- A relational patient-centered process that focuses on broader goals of care for a particular patient and serves as a guide to help health care professionals explore ACP discussions with patients and their families Davison, Torgunrud AJKD 2007;49:27

## Topics in End of Life Discussions

- Goals of Treatment
  - Values
    - -- life prolongation
    - -- quality of life

## Representative Questions for End-of-Life Discussions

- Advance directives
  - If you are unable to speak for yourself in the future, who would be best able to represent your views and values ? Proxy
  - Have you given any thought to what kinds of treatment you would want or not want if you become unable to speak for yourself in the future? Living will

## Representative Questions for End-of-Life Discussions

- Goals –
  - Given the severity of your illness, what is most important for you to achieve?
  - What are your biggest fears?
  - What are your most important hopes?
  - Is it more important to you to live as long as possible, despite some suffering, or to live without suffering but for a shorter time?

# Representative Questions for End-of-Life Discussions

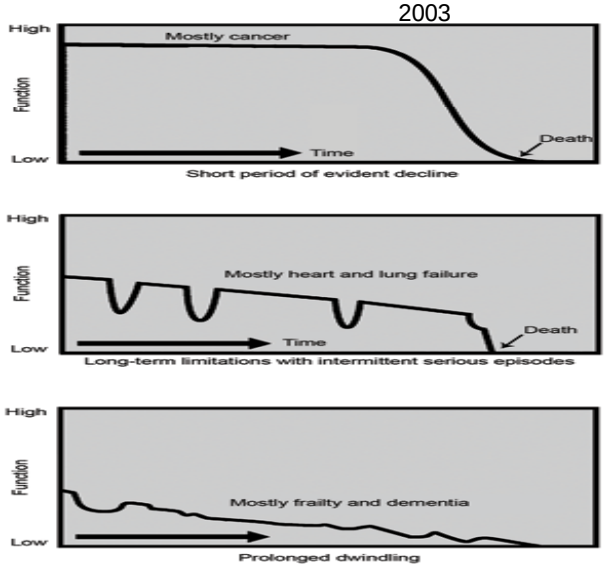
- Values
  - What makes life most worth living for you?
  - Are there any circumstances under which you would not find life worth living?
  - What do you consider your quality of life to be like now?
  - Have you seen or been with someone who had a particularly good (or difficult) death?

## WHAT DO PATIENTS WANT?
## 20 Focus groups, 137 subjects
## (Arch Int Med 26 March, 2001)

- Talk in an honest and straightforward way
- Be willing to talk about dying
- Give bad news in a sensitive way
- Listen
- Encourage questions
- Know when it is the right time to discuss death and dying (when is the patient ready)
- Balance - leave room for hope

## Illness Trajectories

Adapted from Lynn & Abramson 2003




## Clinical Indications for Discussing End-of-Life Care --Routine

- Discussing prognosis
- Discussing treatment with low probability of success
- Discussing hopes and fears
- Physician would not be surprised if the patient died in 6-12 months

## Patient Participation is central to ACP and requires

Davison, Torgunrud, AJKD 2007

- patient's ability to be involved
- patient's interest in participating
- perception of level of control and power
- perceived benefits of participation
- resources to participate
- identification of individuals the patient wants to be included in the process

## Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

RPA

Renal Physicians Association

**Contains guidelines for withholding and withdrawing dialysis**

rpa@renalmd.org
301.468.3515

## Guideline Recommendation # 4

- Advance Care Planning
  - Conditions for coverage mandate
  - Advance directives only one part of ACP
  - 5 key components of ACP:
    - Facilitated ACP
    - Document process and patient's preferences
    - Timing of discussion
    - Involve optimal systems and processes
    - Assess process through quality improvement

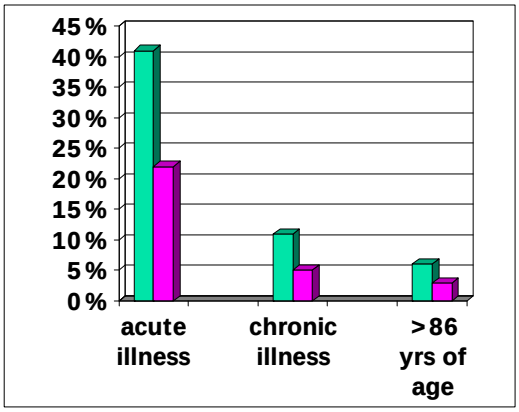
## Useful Advance Directives

- DNAR or DNR
- POLST or POST (Physician Orders for Life-Sustaining Treatment)


## Outcomes of CPR

- On television: 75% survived CPR, 67% to hospital discharge (Diem et al NEJM 334:1578, 1996)
- Medical literature: 30-40% survived CPR, 15% to hospital discharge
  - Pulseless electrical activity 1-4% survival to discharge
  - Asystole near 0% survival to discharge

## Influence of probability of survival on pts' preferences for CPR Murphey, NEJM 330:545, 1994




287 pts >60 yr

Probability of survival 10-17% acute, 0-5% chronic

## CPR Information for Informed Consent

- Chest compressions, electroshock, intubation
- Possible outcomes: survival, prolonged mechanical ventilation, persistent unconsciousness, death
- Complications: rib and sternal fractures, pneumonia, permanent neurologic damage

## Deciding on Resuscitation Status from Moss and MacKay Sem Dial 7:347, 1994

- Decide status in advance
- Educate about outcomes – recommend DNR if appropriate
- Re-visit decisions if condition worsens, status changes
- Do not offer CPR in cases in which it is predicted to be ineffective

## Representative Questions for End-of-Life Discussions

- DNR Orders
  - If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using CPR. Are you familiar with CPR? Have you given any thought as to whether you would want it?

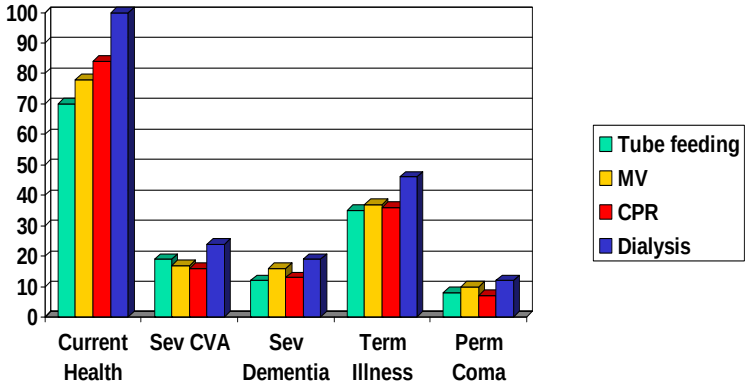
Quill

## Representative Questions for End-of-Life Discussions

- DNR Orders
  - Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?

Quill, 2001

## Patients' Desires for Treatments in Various Health States (%)



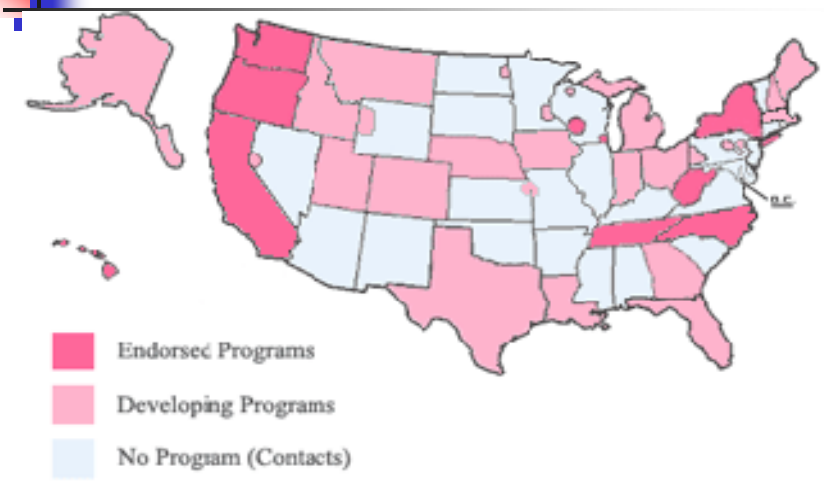

Singer et al. J Am Soc Nephrol 1995;6:1410-1417

## POLST – Physician Orders for Life-Sustaining Treatment (an instruction directive)

- Designed to improve end-of-life care by converting patients' treatment preferences into medical orders that are transferable throughout the health care system
- Developed in Oregon, form released there in 1995
- Now used in all hospices and 95% of nursing homes in Oregon

## Use of POLST (Physician Orders for Life-Sustaining Treatment) Nationally

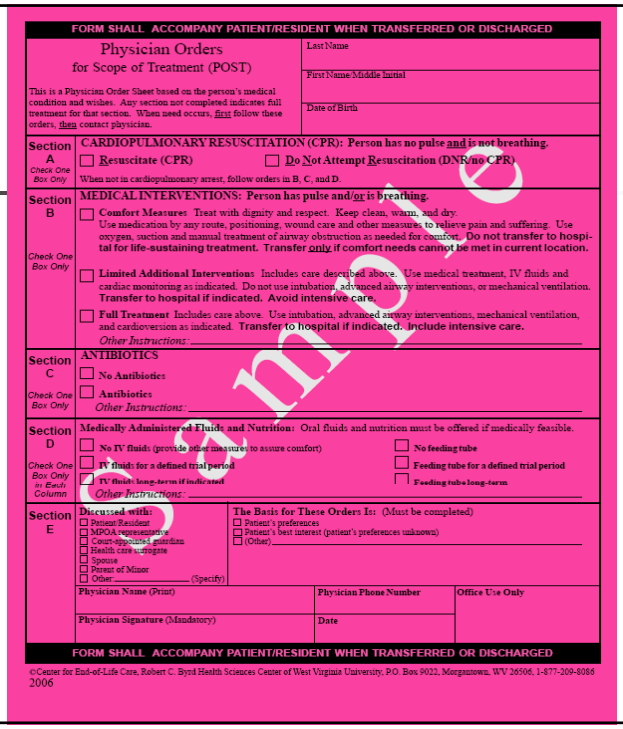
Sept 2010



WV

POST

(Physician Orders for Scope of Treatment)



FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

**Physician Orders for Scope of Treatment (POST)**

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.

Last Name

First Name/Middle Initial

Date of Birth

**Section A** (Check One Box Only)

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ Resuscitate (CPR) ☐ Do Not Attempt Resuscitation (DNR/no CPR)

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

**Section B** (Check One Box Only)

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Comfort Measures** Treat with dignity and respect. Keep clean, warm, and dry. 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. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care.

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

*Other Instructions:* _____

**Section C** (Check One Box Only)

ANTIBIOTICS

☐ No Antibiotics

☐ Antibiotics

*Other Instructions:* _____

**Section D** (Check One Box Only in Each Column)

**Medically Administered Fluids and Nutrition:** Oral fluids and nutrition must be offered if medically feasible.

☐ No IV fluids (provide other measures to assure comfort)
☐ IV fluids for a defined trial period
☐ IV fluids long-term if indicated

☐ No feeding tube
☐ Feeding tube for a defined trial period
☐ Feeding tube long-term

*Other Instructions:* _____

**Section E**

**Discussed with:**
☐ Patient/Resident
☐ MPOA representative
☐ Court-appointed guardian
☐ Health care surrogate
☐ Sponse
☐ Parent of Minor
☐ Other _____ (Specify)

**The Basis for These Orders Is:** (Must be completed)
☐ Patient's preferences
☐ Patient's best interest (patient's preferences unknown)
☐ (Other) _____

| Physician Name (Print) | Physician Phone Number | Office Use Only |
|---|---|---|
| Physician Signature (Mandatory) | Date | |

FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED





## The Case for Useful Care Plans

- Generally limiting aggressive care
- Wanting fully aggressive care with some limits
- Having other (unusual) priorities

## Summary – ACP in ESRD

- Assess decision-making capacity
- Include ACP in the comprehensive care plan for all patients
- Raise ACP issues at initiation of dialysis, with any change in status, at least yearly
- Encourage completion of health-care surrogate, DNR, POLST where possible
- Include ACP process in unit QI activities