5.3 Advance Care Planning

Key Points

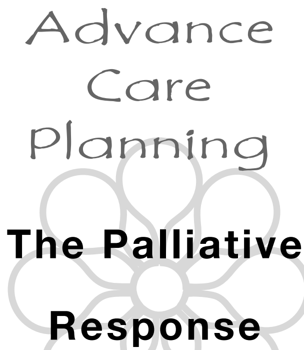
1. The advance directive (AD) is a valuable clinical and personal tool.
   The AD helps the physician build trust, assist the patient to plan future care, designate a proxy decision-maker, and explore values and fears relating to health care. It allows patients to reduce uncertainty, avoid family conflicts, and achieve peace of mind.

2. Discussion of advance directives should be a routine part of care.
   Physicians should discuss AD as routinely as any other health promotion or prevention issue. Barriers to successful use include physician discomfort and time pressure, poor timing of discussion, and the cumbersome legal language of some documents.

3. Physicians should carefully plan discussion about advance directives.
   An AD discussion should include:
   - Designation of surrogate
   - Documentation of healthcare preferences
   - Review of the AD document
   - Encouragement to discuss AD with family
   - Scheduling future time to review completed document and address questions
   - A plan for distribution of document to surrogate, family members, physicians, and faith community representative

4. Physicians should periodically review advance directive with patient.
   Indications for future review and modification of AD include a major change in patient's health status and/or a change in the health status or availability of the designated surrogate.

5. Advance directives are not equivalent to DNAR orders.
   AD may specify various degrees of aggressiveness of treatment.



Advance Directives
Frequency of Use

- The Federal Patient Self Determination Act mandates that all hospital admissions include information on Advance Directives (AD)
- Still, relatively few persons have completed an AD
- Studies show that the physician is frequently unaware of an AD, if it exists

Advance Directive as a Clinical Tool

- Plan and document preferences for future medical care
- Designate proxy decision-maker
- Explore values, fears, and other concerns
- Foster trust with provider

Advance Directive as a Personal Tool

- Build trust
- Define and document goals
- Reduce uncertainty
- Avoid family conflicts
- Permit peace of mind

Advance Care Planning
Barriers to Success

- Physician reluctance
  Personal discomfort
  Time pressure
- Poor timing
  Crisis situation vs. during clinic visit or at hospital discharge
- Cumbersome language

Advance Care Planning
Component of Basic Care

- Include AD as part of clinical routine
  "I encourage all of my patients to complete an Advance Directive"
- Patient is less likely to be alarmed or to fear that provider anticipates imminent death if Advance Planning is routine

Advance Care Planning
Getting Started

- Introduce topic in least stressful setting

  Clinic visit

  Hospital discharge planning
- Use natural language and approach

  "You were pretty sick when you came to the hospital. If you got so sick that you couldn't speak for yourself…

  • Who would you want to speak for you?

  • What would you want them to know?"

Advance Care Planning
Discuss Naturally and Calmly

- Discuss Advance Planning as you would any health promotion or prevention issue

  Similar to tobacco cessation intervention
- Be observant about patient's comfort level
- Extend conversation into future visits

  Follow up, give homework, encourage, praise success

The Planning Document
Introduce as Advance Directive rather than Living Will

- Patient less likely to be familiar with AD
- Allows physician to define instrument
- Distinguishes from Living Will

  "Have you heard about advance directives?

  Let me tell you a little bit about them"

Designation of Surrogate

- Patient's preferred decision-maker
- Good opening question
- Less threatening than healthcare decisions
- Documentation especially important if patient prefers a surrogate outside the usual legal progression (e.g., patient names domestic partner or friend rather than spouse or children)

Healthcare Preferences
Discussing and Documenting

"If something happened and you could not speak for yourself… your surrogate might have to make difficult decisions."

"It is helpful to discuss the kinds of treatment you might want or not want…and to write down some things to guide that person."

Review and Complete

- Review an advance directive document (e.g., *The Five Wishes*)
- Demonstrate briefly how to complete
- Encourage discussion of AD with family
- Plan to meet again to review the document and answer questions

Documentation

- Copy completed AD for patient's chart

  Write Advance Directive note to alert others

  If you do not document, it did not happen!
- Suggest that patient/family keep copies
- Remind patient/family to inform providers of AD at ER visits/ hospital admissions

Indication for Review

Change in Status of Patient

- Major change in patient's health
- Change in treatment preference
- "I wanted to go on the vent for my COPD if necessary, but since I have learned about the cancer, I feel different."

Indication for Review

Change in Status of Surrogate

- Death
- Relocation
- Cognitive impairment
- "My wife has had a stroke; I don't think she could be my surrogate anymore."

Advance Directives

Utilization

- Assure that physicians are aware of the existence of Advance Directive
- Read and discuss the AD with surrogate
- Consider an Ethics Committee consult if problems arise about interpreting AD
- Carry out the plan of the AD

AD versus DNAR

- An AD is not equivalent to a Do Not Attempt to Resuscitate (DNAR) order
- The AD may specify a variety of different degrees of aggressiveness of therapy

Encourage Non-Medical Planning

- Location of care
- Autopsy
- Funeral plans
- Guardianship for children or other dependents
- Plans for pets
- Financial arrangements
- Gifts
- Disposition of personal belongings

Selected Readings

Physician Experience

Derse, A. R. "Decision-Making Capacity: Determination and Consequences." *Supportive Oncology Updates* 2 (1), 1999.

Tulsky, J. A., G. S. Fischer, M. R. Rose, and R. M. Arnold. "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441–449.

Patient Experience

Kuczewski, M. "Cancer Patients Say the Darnedest Things: Commentary on "Paradoxes in Cancer Patients' Advance Care Planning." *Journal of Palliative Medicine* 3 (2000): 23–35.

Evolution of Palliative Medicine

Baumrucker, S. "AND versus DNR." *American Journal of Hospice and Palliative Care* 18 (2001): 370–371.

Ditillo, B. A. "Should There Be a Choice for Cardiopulmonary Resuscitation when Death Is Expected? Revisiting an Old Idea whose Time Is Yet to Come." *Journal of Palliative Medicine* 5 (2002): 107–116.

Tolle, S. W. and V. P. Tilden. "Changing End-of-life Planning: The Oregon Experience." *Journal of Palliative Medicine* 5 (2002): 311–317.