FAST FACT AND CONCEPT #162
ADVANCE CARE PLANNING IN CHRONIC ILLNESS

Sara N Davison, MD

A cornerstone of excellent medical care is helping patients decide how future medical interventions match their personal goals and values for care near the end-of-life. This Fast Fact reviews key concepts of the Advance Care Planning process.

Advance Care Planning (ACP): is a ***process of communication*** between the patient, the family/health care proxy, and staff for the purpose of prospectively identifying a surrogate, clarifying treatment preferences, and developing individualized goals of care near the end of life. **Advance Directives:** (e.g. living wills, durable powers of attorney for health care) are ***legal*** documents with capabilities and requirements that vary between jurisdictions.

Primary Goals of ACP

- Enhance patient and family education about their illness, including prognosis and likely outcomes of alternative care plans.
- Define the key priorities in end-of-life care and develop a care plan that addresses these issues.
- Shape future clinical care to fit the patient's preferences and values.

Other Potential Benefits of the ACP process

- Help patients find hope and meaning in life, and help them achieve a sense of spiritual peace.
- Strengthen relationships with loved ones.

NOTE: At a minimum, ACP should be considered whenever the health care provider *would not be surprised if that patient died within the next 12 months.*

Facilitating ACP

- **Take the lead in starting the discussion.** Many patients are reluctant to initiate an ACP discussion; physicians and nurses can "open the door" to such discussions by asking, h*ow do feel things are going or, have you given any thought to how you wish to be cared for should your illness worse?*
- **Explain the rationale for ACP.** Patients identify ACP as an important part of medical care if they have a clear idea of how the process will benefit them: *I'd like to spend some time talking to you about the future course of your illness so that I have a clear understanding of your wishes.*
- **Use good communication skills:** Do not use medical jargon (e.g. ventilator) and language should be positive ("I want to ensure you receive the kind of treatment you want"). Use empathetic listening skills (using words, posture and appropriate touch to convey sense of caring) to help build a trusting relationship. Ensure privacy and allow sufficient time for the discussion.
- **Provide information:** Patients require realistic information on prognosis and treatment options with an emphasis on how you expect their illness will impact their daily function.
- **Identify a surrogate:** Patients should be encouraged to both identify a surrogate decision-maker and most importantly, to discuss their wishes with this individual. The power of the ACP discussion is the sharing of information between patient and the patient's surrogate decision maker and other family members, and the health care team. The surrogate should have the greatest knowledge of the patient's preferences and values. If desired, offer to facilitate a discussion between the patient and their surrogate or other family members.
- **Identify how future decision-making will occur.** A patient may have specific desires for how information is shared among family members—this needs to be explicitly discussed.
- **Determine goals of care:** If decisions need to be made at the same time as an ACP discussion, this is an appropriate venue to establish the goals of care (see FF #16, 65).

Cautions

- The ACP process must be sensitive to disease, gender, age, social and cultural contexts.
- Providing opportunities to discuss end-of-life issues does not mean everyone will want or be able to do so at that moment. ACP is an evolving process that requires varying amounts of time to be effective. Patients often need time to reflect on information and how it impacts their lives.

References

1. Martin DK, Thiel EC, Singer PA. A New Model of Advance Care Planning. Observations From People With HIV. Arch Intern Med. 159: 86-92, 1999
2. Briggs L. Shifting the Focus of Advance Care Planning: Using an in-depth Interview to Build and Strengthen Relationships. *Innovations in End-of-Life Care*, March-April 2003, Vol 5 (2) www.edc.org/lastacts
3. Johnstone SC, Pfeifer MP, McNutt R. The Discussion About Advance Directives. Arch Intern Med. 155:1025-1030, 1995

Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mail.mcw.edu. The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu