**End of Life Discussion: It’s not just about Full Code or DNR anymore**

-in recent years, there has been a growing realization that physicians don’t know what is important to their patients when it comes to end of life decisions

From the AAFP:

“The American Academy of Family Physicians encourages the use of advanced directives including but not limited to living wills and durable powers of attorney for health care, so that the desires of the individual will be followed in the event he or she lacks the capacity to participate in health care decisions.”

Family physicians are in a unique situation to have these conversations early with patients.

Talk about it when people are feeling well and NOT in a crisis situation, document what your patient’s wishes are.

**Why it’s so important, consider the facts:**

-People over 85 are the fastest growing population.

-Recent studies suggest that our healthcare system pays an average $145,000 for each additional ear of life after the age of 65

-Despite medical advances, mortality rate is still 100%

*\*60% of people say that making sure their family is not burdened by tough decisions is “extremely important”*

*56% have not communicated their end-of-life wishes*

Source: Survey of Californians by the California HealthCare Foundation (2012)

*\*70% of people say they prefer to die at home*

*70% die in a hospital, nursing home, or long-term care facility*

Source: Centers for Disease Control (2005)

*\*80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care*

*7% report having had an end-of-life conversation with their doctor*

Source: Survey of Californians by the California HealthCare Foundation (2012)

*\*82% of people say it’s important to put their wishes in writing*

*23% have actually done it*

Source: Survey of Californians by the California HealthCare Foundation (2012)

**Initiating "the conversation"**

-why we don't do it: fear of taking away hope, fear that it may appear we are "giving up", time constraints, uneasiness about what to say or not say, etc. etc

-recent studies suggest that patients who utilize hospice actually live longer

-a new patient based website has excellent “starter kits” to help families and their doctors have this discussion (see the conversation project website below)

**Suggestions on how to have this conversation**

1. Make time

2. Make space

3. Turn off all distracting electronics

4. Find out what the patient wants to know

5. Listen carefully to the patient's response

6. Discover the patients goals

**Websites:**

[www.theconversationproject.org](http://www.theconversationproject.org)

<http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleId=57>

<http://www.aafp.org/online/en/home/policy/policies/e/ethicsadvplan.html#Parsys0004>

**Hospice Care**

Definition:

The word "hospice" stems from the Latin word "hospitium" meaning guesthouse. It was originally used to describe a place of shelter for weary and sick travelers returning from religious pilgrimages. During the 1960's, Dr. Cicely Saunders, a British physician began the modern hospice movement by establishing St. Christopher's Hospice near London. St. Christopher's organized a team approach to professional caregiving, and was the first program to use modern pain management techniques to compassionately care for the dying. The first hospice in the United States was established in New Haven, Connecticut in 1974.

Today, “Hospice is not a place but a concept of care. Eighty percent of hospice care is provided in the patient's home, family member's home and in nursing homes. Inpatient hospice facilities are sometimes available to assist with caregiving.”

**Predicting Life Expectancy**

-it's hard, one study found we overestimate 63% of the time

-try to use more evidence based tools like the Palliative Performance Scale (used for cancer patients), score of < 50% often die within six months

-limit your conversation to weeks, months, years rather than specifics

-clinical criteria also helps: unintentional weight loss of 10% or more TBW, recurrent infections, increasing hospitalizations, serum albumin of < 2.5 and overall functional decline

-clinical judgment: "would I be surprised if this patient died within 6 months" if the answer is "no" --> start thinking about having a conversations with the patient and include hospice early

**Explaining Advance Directives**

-allow patients to document their wishes

-instructive advance directive requires the patient to write down or tell someone what he/she wants (e.g. living will)

-proxy advance directive enables the patient to select someone to make decisions on their behalf if they are unable to do so (e.g. durable power of attorney)

-advance directive can be completed without a lawyer

-see Advance Directive Toolkit from Erin Stratta for more information on how to complete legal documents with the state

***It’s important to remember that if you don’t talk about it, who will?***

**Websites**:

<http://www.hospicefoundation.org/whatishospice>

<http://www.americanhospice.org/>

<http://palliative.info/resource_material/PPSv2.pdf>