What I Hate About Advance Directives

A Panel Discussion

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The “Do Everything” Directive

- 73 year old male patient admitted to the hospital with an altered mental status after spouse found him on the floor in the bathroom and called 911.
- Patient diagnosed with Alzheimer's 3 years ago which has progressed rather quickly. Recently has become increasingly unsteady on his feet, numerous falls at home after a stoke last year. Additional medical history significant for COPD, CVD, hypertension, and ESRD.
- Advance directive completed 5 years ago naming his wife as his health care agent. Patient identified his priority is to “do everything to sustain my life” including CPR, intubation, artificial feeding, antibiotics, etc.
- Since arrival three weeks ago his condition has continued to worsen and he is now in the ICU intubated. Care team believes he is in multi-system organ failure and is dying.
- Patient’s wife is adamant that they continue to “do everything”. Will not agree to change in his code status and wants all measures taken to sustain his life. She points to his advance directive and says this is what he wants and we are obligated honor his wishes.
- She has refused to speak to palliative care and will not engage in discussion about hospice. Her husband is a fighter and would never want to “give up”.

Takeaway: Death is Inevitable

Clarify what matters most when death is inevitable

- Reframe what "do everything" looks like in the context of end-of-life care

Truth-telling in difficult conversations

- Creating a soft landing

Expecting a Miracle

- 43 year old mother arrives at hospital after a devastating car accident. No prior medical history. ROSC at the scene by EMS. Patient remains intubated and unresponsive in the ICU.
- Advance directive completed with an attorney several years prior. Document has standard "Living Will" language stating she would not want any "heroics" or "extraordinary measures" at end of life.
- Patient's husband and 2 adult children are all named as co-agents.
- Health care agents in agreement that she will "get better". She is young and healthy and they have faith that God is on her side. They are a religious family and believe that all life is sacred. Miracles can happen and she just needs more time to recover.
- Care team starting to panic. Unclear how long patient was "down" at the scene before EMS arrived, likely this is an unrecoverable anoxic brain injury. "Miracle thinking" is worrisome as team believes continued treatment is becoming abusive while family waits for Divine intervention.

Takeaway: More than one way to die…

Boilerplate Advance Directives

- Directives may be used when the outcome is not fixed

Advance directives for younger patients

- Contemplate extreme situations and/or altered ability

Moral distress for care team vs. needs of family/agents

Demanding “non-agent” decision-makers & Contradictory Goals

- 80 year old man with Parkinson’s Disease, slips and falls at home and now hospitalized. About a year ago, patient started showing signs for Lewy Body Dementia which has been progressing and affecting his cognition. Team feels he lacks capacity to make decisions about treatment or discharge.
- His spouse died about 10 years ago from cancer and his fraternity brother and long-time friend is now his health care agent. Prior to his dementia, he shared with his friend that things were getting harder with his Parkinson’s at home alone and he would be okay going to the hospital, having treatments and going to a rehab facility if deemed necessary.
- Advance directive is from 10 years ago (updated shortly after wife died). Preferences indicate it would never be acceptable for him to have long-term hospitalization, aggressive treatment or to go to a nursing home.
- Patient has adult children, none of whom are listed as agent/alternate agent but who are adamant that the patient would never want to be in a hospital. They want to take the patient home ASAP with hospice support. Agent is conflicted because of earlier conversation with patient and pressure from family to follow the directive. Nursing staff are frustrated that the non-agent family members continue to call and pressure for discharge home. Agent unwilling to discuss DNR and discharge home with hospice b/c patient stated more recently that he was willing to accept treatments and go to long term care if needed.

Takeaway: Things Change

Regular Review of Documents

Relying on the health care agent for more information

Meeting the conflict head-on

- Patient is priority, but family is also directly involved
- Avoiding difficult situations does not create a solution
- Reframing