

Session 3

Advance Directives:

Hopes, Expectations & Magical Thinking

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To Pursue in Future Sessions

- Permission to die
- Caregivers and partners, experiences and needs
- What do we mean by a “natural” death?
- Having enjoyed a full life, why continue only to face the problems of aging?
- Feelings around a close relative with dementia

Works Recommended by Participants

- *Walking Each Other Home: Conversations on Loving and Dying*, Ram Dass and Mirabai Bush, 2018
- *My Father's Wake: How the Irish Teach Us to Live, Love and Die*, Kevin Toolis, 2014
- ***The Grief Recovery Handbook: Action Program for Moving beyond Death, Divorce and Other Losses*, John James & Russell Friedman, 1998**

Quick Review of 5 Themes

1. Learning to die is learning to live
2. Problems/Mysteries
3. What is a good death?
4. Spiritual Possibilities
5. We are mutable creatures

1. To Learn to Die is to Learn to Live

- Human flourishing involves learning to die; death gives intensity and meaning to life
- Death is my finis (end), but also my telos (purpose).
- “I not only accept but embrace my finitude.”

2. Problem/Mystery (Marcel)

- Obstacles to dying well, a meaningful death, are problems; we can work toward solutions.
- Death is a mystery; if treated as a problem it makes every dying a crisis

Problem/Mystery

When is death treated as a problem?

1. When it is seen as a medical/scientific failure
2. When it is denied
3. When it becomes a taboo subject
4. When it is feared excessively
5. When it becomes politicized
6. When it is villainized in a dualistic philosophy or theology (death as “the enemy” of God)

3. What is a Good Death?

Some Candidates. . .

1. Death not marked by pain, abandonment, or loss of identity-bearing attributes or capacities
2. Dying in a way that reflects, completes (or improves upon) one's sense of self?
3. Death that does not burden survivors, emotionally or financially?
4. Dying marked by caring: expressions of gratitude, love, reconciliations, hope, appropriate goodbyes?
5. Dying that includes spiritual experiences?

Additional Features, from our October 12 session

- One in which I don't get mean, whine, obsess and am prepared
- One in which I sense there has been **enough** of life
- One in which my survivors can find their way without me
- One that is peaceful
- One in which I am clear-headed

4. Inherent Spiritual Possibilities

Dying opens onto spiritual possibilities

1. Being in presence of, in touch with, what's real--eternal, rather than transient--sacred
2. Sense of goodness, beauty, wholeness, and belonging to that encompassing wholeness
3. Response of awe, wonder, reverence

--Abraham Maslow, *Religions, Values and Peak-Experiences*, 1964

5. We are Mutable, always changing

- As historical creatures we are inevitably altered by all that happens to us, by choices we make, by accidents, luck, fate. . . And incorporating this is part of the human task, and also our special genius
- There is no fixed or static self
- We are at least partially opaque to ourselves

Importance of Advance Care Planning

- In executing an AD and choosing an agent we are embracing a particular narrative from the larger anthology of selves available to us

“I am that person who...”

Tennessee's "Advance Directive for Health Care"

- Revised in 2014; 1 form rather than 2 or 3

Part 1: Naming an agent & an alternate

"my agent must follow my directions below"

Part 2: "Wishes" for Quality of Life

- *Quality of Life* categories: conditions "I would not be willing to live with", e.g., Permanent Unconsciousness, such as PVS
- *Treatment* categories: CPR, ventilation, "tube feeding" perhaps most controversial

Reasons for Advance Directives

- Expressing your Wishes (Values; designating the person you are, or hope to be *in extremis*)
- Guidance for Health Professionals ,Surrogate (Agent) and Family/Friends
- Setting Expectations/Relieving Burdens
 1. Decision-making & possible guilt
 2. Reducing potential for family conflicts
 3. Reducing financial and emotional burdens of extended care
 4. Enhancing opportunities for progeny

Who Should Have Copies/With Whom Conversations?

- Primary Care Professional
- Members of your family
- Your named Surrogate (Agent)

These are also people with whom you should have conversations, and to whom you should explain your reasons.

Nobody should be surprised!

YOU should start the conversation!

Arguments Against Advance Directives

- Incompleteness
- Better a dynamic advocate (agent) than a static document
- Suppose I change my mind?
- Worries that an AD will trigger a premature DNR, or neglect of my medical needs
- Misunderstandings (medical team's, family's, or even my own)
- Low probability of it being used

Language to Avoid, in ADs and elsewhere

- Heroic care
- Unnatural care
- Inappropriate care
- Extraordinary care
- Practically dead, as good as dead
- Brain dead—unless given by a physician as a medical diagnosis
- Hopelessly ill

Health Care Agent

- Few of the objections against Advance Directives apply to designation of an Agent
- Naming an Agent is more important than having rest of Advance Directive filled out
- Pick as your Agent a person who knows you well, willing to follow your instructions rather than their own preferences, and has courage

Surrogacy Designation by Physician

- Tenn. Code Ann. § 68-11-1806 (2010)

“The goal of the law is to find the person in the best position to know the patient’s current health care wishes”

--Kate Payne, Ethics Consultant, Vanderbilt

Surrogacy (Agent) Designation

- Goes into effect only if:
 1. Patient determined to have lost capacity
 2. No agent or guardian has been appointed, or is not “reasonably available”

Then, supervising health care provider may designate a surrogate...

Features of a Designated Surrogate

- An adult, who
 1. “exhibited special care and concern”
 2. “familiar with patient’s personal values”
 3. “reasonably available”
 4. “willing to serve”

Suggested Order of Preference

1. The patient's spouse, unless legally separated;
2. The patient's adult child;
3. The patient's parent;
4. The patient's adult sibling;
5. Any other adult relative of the patient; or
6. Any other adult who satisfies the requirements

If No Surrogate can be Found

The patient's designated physician becomes the decision-maker after either:

- "Recommendation of institution's ethics mechanism"
- Or
- "Concurrence of a 2nd physician"

Physician must follow patient's instruction, or if no AD, the "best interests" of the patient

Surrogate can make all decisions, *except*

- “artificial nutrition and hydration may be withheld or withdrawn for a patient upon a decision of the surrogate **only when** the designated physician and a second independent physician certify in the patient's current clinical records that the provision or continuation of artificial nutrition or hydration is merely prolonging the act of dying and the patient is highly unlikely to regain capacity to make medical decisions.”

A Dementia Directive

Barak Gaster MD, Univ. of Washington S of M



Most ADs address PVS; dementia more common--20-30% of us at some point

Dementia AD

Preferences for mild/moderate/severe dementia

- 4 options at each stage:
 1. all efforts to prolong life
 2. treatments but DNR and no ventilator
 3. No hospitalization; receive only care I can receive at home;
 4. Comfort care only; prevent suffering

Reasons for Dementia AD

- Progression from mild to severe can take 8 or more years. . .
- Take burden from family or surrogate
- Relief from my own anxiety, knowing there is a plan in place, and knowing that my historical (authentic) self is less and less available
- www.dementia-directive.org

Why Advance Directives Fail

- Who knew he had one?
- Nobody can find it
- Person who has it not member of family
- It is buried in the medical record at another institution
- Medical bias against ADs
- Equivocal or contested diagnosis
- Family member objects
- Person designated as an Agent doesn't know they are so designated
- Person designated as Agent disagrees with what the AD says, or believes it is invalid, or finds he/she can't really accept responsibility



Case #1: Jeremiah Clark

- What are the next steps?
- What are the lessons?

Jeremiah Clark, Time 1

- Jeremiah Clark, age 74, was hospitalized with increasing weakness, abdominal pain and jaundice. His past medical history is unremarkable except for the placement of a pacemaker 3 years ago. Further testing indicates advanced pancreatic cancer.
- Mr. Clark shows little interest in participating in his care plans. The person accompanying Mr. Clark, who is constantly present in his room, has formed a good working relationship with the professional staff. She is consulted for decisions about his care and often relied upon for communicate with Mr. Clark.

Jeremiah Clark, Time 2

- Palliative care and ethics become involved. After several discussions it becomes apparent that Mr. Clark has an AD, executed some years ago, but he has no interests in discussing it or revealing its contents. Subsequent conversations indicate that the AD is in the possession of his wife. As it happens, the person accompanying Mr. Clark, who has shown consistent care and concern, is not his wife but his girlfriend. The wife, rather than the girlfriend, is named in the AD as the surrogate.

Case #1: Jeremiah Clark

- What are the next steps?
- What are the lessons?

Case #2: Henry Bush

- What are the next steps?
- What are the lessons?

Henry Bush, Time 1

- In April, 2016, Henry Bush, age 80, suffered massive head injuries from an unimpeded fall on his face from a standing position. Prior to his fall, Mr. Bush was in reasonably good health except for increasing problems with balance. He and his wife, Gertie—who suffers from a moderate form of Alzheimer's—are being cared for by their daughter, Sarah, 55, who has recently moved to Nashville from St. Louis to care for her parents. Sarah has retired from a career as a child development specialist. Surgery for Mr. Bush following his fall was unsuccessful, and he is comatose and ventilator dependent.

Henry Bush, Time 2

- Mr. Bush has been in the hospital ICU for 2 weeks. His chances for improvement are described by the neurologist as exceedingly small, “less than 1%.” Mr. Bush has an advance care planning document, duly notarized, which dates from 1996. It says that should he suffer from permanent loss of consciousness that no effort be made to prolong his life. The medical team is ready to shift to palliative/comfort care and remove the ventilator and feeding tube.

Henry Bush, Time 3

- Sarah is reticent to discuss this option, saying it feels like “giving up.” She also questions whether the advance care plan is still valid, since it is 20 years old, and she says she was never informed that he had such a document. She is also emphatic that her father’s religious beliefs, and her own, forbid her from agreeing to removal of life support. She added her father would not have rejected his current quality of life because “he liked being waited on.”

Case #2: Henry Bush

- What are the next steps?
- What are the lessons?

Optional Exercise: For next week, *if you want*, choose one....

- 1. Write your obituary
- 2. Write about a dying episode or death scene that troubles you. It could be factual or fictitious.
- 3. Write a short paragraph that explains the following:

