

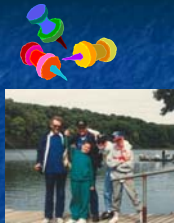
Personal definition:

Going beyond traditional (legal) advance directives, advance care planning means making decisions way ahead of time about all the stuff associated with the continuum of aging and the rest of my life so I can get on with the meaningful and fun things I still want to do.



The Point

- Sense of control of the future
- Values & wishes respected
- Peace of mind
- Less burden on family
- Fewer conflicts & stress
- Less confusion
- Fewer "disconnects"
- Savings in time, energy & money
- Continuum of care



It's Not That Complicated



What Advance Care Planning ISN'T

- Legal documents only
- "Once and Done" forms
- Discussions in ICU
- Talking during a crisis
- Hospital admission question
- Senior citizens' issue
- Medical outcomes centric

What Advance Care Planning IS

- Ongoing conversation
- Holistic rather than medical focus
- Fluid & flexible decisions
- Lifelong process
- IDT involvement
- "Family" discussions
- Learning about diagnoses & treatments
- Shared understanding about what matters
- Life goal focused

Multi-generational

She Did It For US!

What I learned:
POA
Medical POA
Personal Wishes
Post Death Discussion



So I Did It for THEM!

What I did:
Not Convenient to Die
Legal Documents for
Continuity
(passwords!)
DNR, POA's
Life Insurance
Post Death Discussion



Everyone's Baggage

- Culture/Religion
- Age
- Quality of life
- Fear
- Attitudes
- Upbringing
- Past experience/life events
- Denial
- A self fulfilling prophecy?
- Perception: Palliative care=Hospice=death



Professional Barriers

- Media impressions/politics
- Misinformation
- Lack of training
- Poor communication skills/discomfort
- Lack of integration into routine care
- Perceived patient loss of hope/giving up
- "Everyone else responsible" syndrome
- Failure or "saving patients is what we do"



Patient & Family Barriers

- It will upset my loved one
- He/she will think they are dying
- There's time to talk about that later
- I am not even sick
- That's for old people
- "I heard that..." (aka misconceptions)



Overcoming Professional Barriers

- Initiate early, recurring discussions
- Start slowly and innocuously
- Incorporate into routine care
- Talk to patients about their life & goals
- Observe family dynamics
- Ask about "bad" healthcare experiences
- Embrace holistic care
- Educate patients in non didactic manner
- Don't assume patient knowledge
- "Walk the walk"

Barriers to Document Acceptance of POA, MPOA Professional VS Family



Proper Wording
Acceptance
Ignorance of the Law



Family Guilt
Patient Wishes
Real or Imagined

Practical Talking Tips

- Pick up on cues
- Let conversations just happen
- Use similar situations or current events
- Break the talk into smaller parts
- Add a little humor, if appropriate
- Avoid "pat" answers
- "Ask, tell, ask"



Patient & Family Action Plan

- Talk early and talk often
- Share your values and ideas about life
- Discuss what matters most to you
- Use life events as a springboard
- Write it down (meaningful scribbles)
- Share ideas in a non-morbid way >>>>
- Take advantage of similar situations (movies, articles...)
- Think about the quality of life that is acceptable to you
- Make a bucket list (& whittle away at it)
- Do the paper work, then share it & review it regularly
- Get details out of the way early (passwords, insurance...)
- Challenge your healthcare providers
- Educate yourself about care options
- Realize you talk about it, even if you think you don't



"Rights" of Advance Care Planning Talks

- Have the right **conversation**
- Covering the right **information/topics**
- With the right **people**
- At the right **time**
- In the right **place**
- In the right **way**
- Completing the right **documentation**



Development of the "Rights"

- Adaptation of "Rights of Medication Administration": giving the right medication, to the right person, in the right dose, at the right time, by the right route
- Use of definition of quality by Carolyn Clancy, MD, Director of AHRQ: "the right care, for the right person, at the right time"
- Inclusion of SPIKES protocol and RPA's suggested format for advance care planning

Resources

- The Conversation Project
www.theconversationproject.org
- My Gift of Grace www.mygiftofgrace.com
- Project Talk www.projecttalk@hmc.psu.edu
- Talking it Over: Coalition for Compassionate Care of CA
- *Farewell My Friend* by Beatrice Toney Bailey
www.farewellmyfriend.net
- *Medical Care of the Soul* by Bruce Bartlow, MD

Resources



www.kidneysupportivecare.org



"It's always seems too early to talk until it's too late."

Let's get our "ducks in a row"
Don't be afraid to talk



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