

Small Group Presentation Without Videos

JTA, May, 2015

Intro

What is TCP?

How we got interested in this -- brief history of the initiative, hx of Goodman – “It’s always too soon before it’s too late.”

Dying in US –

- More necessary due to advances in med. technology
- Some changes (hospice numbers in CO, ICU)
- IOM report: more than half of people will not be able to participate when decisions have to be made near the end of their life
- Concept of “adult orphans” – potentially 1/3 of people over 65years.
- Katie Butler and grey zone between life and death (Knocking on Heaven’s Door)
- Stats from Starter Kit

Our background (everybody different):

- At the bedside; ethics consults
- Families in stress in the ICU or ED:
 - Don’t know wishes, can’t find ADs; families who disagree
- Unpredicted or unpredictable situation

Conceptual Framework: “Estate Planning for the Heart”

What:	Conversation	Written ADs	MOST Form
With whom:	Family, agent, friends	Internet CO forms, navigator, lawyer	Physician/provider
Why:	Express values	Document agent, ?procedures, funeral and other wishes	Orders as death approaches

- All need updating, continued review

Quick survey of YOU as a person with family, relationships and who is going to die

- How many of you in this room have a **written** advance directive?
- How many of you have an **agent** authorized through an MDPOA document?

- If you have an agent designated with a MDPOA (a very good idea!), **does that person know they are designated** and have you two had a conversation about your values and wishes?
- Does your family or do your loved ones know **where your paperwork** is?
- And how many of you have had a **meaningful** conversation about your wishes with **all** members of your family who would be sharing in the conversation about where to go for you if you can't participate?
- Quick quiz: Who decides for you if you don't have a designated "agent"? (State-specific)

Our comments:

- Documents (p. 9) are helpful, important, but conversation is critical – reasons (from Sudore):
 - Prediction: we aren't good (what are you going to want for dinner next week?)
 - Adaptation: People surprise themselves by accommodating disabilities more than they might predict
 - Extrapolation: If you check "no CPR" or "No intubation" – what does that mean about amputating a leg for gangrene, or another round of chemo?
- Disclaimer: Ellen's goal and ours is NOT to limit care, but to have people express wishes and **values** about the amount and type of care that they may want at the end of their lives, so these wishes can be honored!!
- Goal of TCP: **Right care, right time, right place.**
- Most people concerned about whether they may get either too much, too little care

Starter Kit

Covers:

- What matters to me
- Role in decision-making process
- Kind of care
- Role of loved ones
- 3 most important things
- Who, when, where re conversation

Chance to try out the Kit - look at p. 3

- "What's most important to me? What do I value most?" or "What matters to me at the end of life?" Take a few minutes to think about, then share with person next to you (or table)
- Group sharing

Likert scales – think about how you would answer-- use bottom of p. 3, p. 4 or 5 – just one scale to demonstrate – (i.e. 5 is not more right than 1)

- Group sharing

The Big Challenge: breaking the ice.... (Leave good amount of time for this).

- How many of you have loved ones who might not be on the same page about how the end of your life should be? Have seen families torn apart
- Casey Kasem – the most recent and egregious example of family fighting....
- Joan Rivers – a good death where she had discussed with daughter Melissa

FAQs:

- P. 7 – the challenge of breaking the ice on a difficult conversation:
 - How many of you have loved ones who might not be on the same page about how the end of your life should be?
 - How do I get my kids/parents to talk? They don't want to do this!
 - I don't have kids, or a partner...

Questions from Audience: & Look at p. 9

Agent, POLST-type forms, other written documents, State-specific information

Audience questions, feedback

Closing – (10 min.)

Homework for follow up session:

- Take this home and think about your answers, “play” with this yourself.
- Look at p. 6, answer questions (who, when, where)
- Share with someone – perhaps practice with a friend, then share with loved ones?
- Resources, Death Cafes, Conversations on Death, websites, etc.

Thanks for your thoughtful attention and for sharing.

This is a difficult subject for all of us, but important – for you AND those you love. This is “estate planning for the heart.”

You can help your family and loved ones by modeling how to discuss death in a less “electric” way.

We aren't always in control, but.....

It can make a difference in terms of how gently and peacefully your exit or those of people you love can be.

One of the purposes of TCP is to make it less difficult and easier for all of us.

We have coaches, role of friends, communities (of faith, of friends)....

Some Ellen Goodman Quotes (or close to them!) from April, 2013

These conversations are always too soon, until they're too late."

I was the "designated daughter." (when her mom was dying)

I went from working mother to working daughter.

We need to know what to do when there is no plug to pull.....

"The needle is not moving" on physician or hospital-based initiatives to get people to complete Advance Directives or express end-of-life wishes. (Therefore her grassroots effort to get people to talk and then share with their doctors.)

We have two fears: That we will not get the care we need, and that we will get care we don't want.

Starter kit is designed to answer the need to have something with a low bar for entry into conversations that are tough.

We have had culture changes that come from the grass roots -- from not being able to talk about "cancer" to discussing erectile dysfunction.

....also about hospice, natural birth, etc. So there is precedence for moving healthcare conversations from the "bottom" up.

The emotional costs of difficult and uncertain dying are far greater than the financial costs.

One goal of the project is "trust restoration" with the healthcare system.

Seagull kids: the ones that fly in from the coast and (dump their shit) on families gathered near the end of life.

From Sudore, Rebecca

