Caring Conversations®
Death is not Optional: Peace of Mind Is…

Age Positive Conference 2017
Why Caring Conversations®?

Aging population—As of 2011, every day in America, 10,000 baby boomers turn 65 (2,200 a month in KC Metro Area) and that will continue to happen for 20 years—Lots of people with changes in physical and sometimes mental capacity—Clarifying values, naming someone to speak for us, talking about it, can help
Why the Center for Practical Bioethics?

• National leader in bioethics
• Freestanding
• Not for Profit
• Trains hospital ethics committees
• Founded in 1984
• “Guidance at the crossroads of decision”
• Independent resource
What is Caring Conversations®?

For those dealing with advanced illness or responsible for loved ones:

• Consultation/coaching
• Advocacy if needed
Caring Conversations®

• **Relevant information** about resources to help you sort out complex situations

• **Educational programs** about advance care planning—getting clear on your goals and values and making sure your healthcare preferences are known and honored
Caring Conversations®

Having an opportunity to reflect *before there is a crisis* can make the difference:

– A family that is torn apart by disagreements over “what Mom would have wanted”

**OR**

– The peaceful, dignified end that we all want for ourselves and those we love.
Reasons for Caring Conversations®

1:1

2.5 million people die each year (U.S.)
Reasons for Caring Conversations®

- 85% will die without capacity to make decisions/on life support—it can get complex
Reasons for Caring Conversations®

- Legalistic forms are limited in what they can anticipate and how well they guide agents.
Reasons for Caring Conversations®

- How we die is changing

Most of us will die...
  - of complications from chronic illnesses
  - with slow and uncertain disease paths
  - affected by dementia
Pictures of Illness

- The four basic ways a person might experience an illness or serious health condition.
When we die:
What we want vs. What we get

Die at home
Surrounded by loved ones

Die in the ICU
Isolated from family (waiting room)
What we want vs. what we get...

- Pain free (symptoms managed) vs. hooked up to tubes and machines (often in pain)
- Wishes known and honored vs. family and care-provider disputes
- Psycho-social needs of family met vs. isolation
Reasons for Caring Conversations®

• When we die is changing
  – Advancing Age
    Fastest growing population
    • >85
    • In 10 years: >100
  – Caregiver dependent
Reasons for Caring Conversations®

- Family and friends are often unwilling and/or uncertain agents.
Reasons for Caring Conversations®

- Physicians are often without knowledge of patient’s goals and values
- Hospitalists the norm now
Number of Hospitalists in the United States

Data are from the annual survey of the American Hospital Association.
• Health care systems are concerned about possible legal exposure
Limitations of Living Wills

• Legalistic approach alone is not enough

• Talking with loved ones is crucial—ahead of the crisis
"Sorry I'm late, but they had me on a life-support system for two months."

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Barriers to Overcome

• Not many models for how to have this conversation—nobody’s first choice!
Mistaken Beliefs

1. I’ll always be able to make my own decisions.
Mistaken Beliefs

2. My family already knows my wishes.
3. My doctor will know what’s right.
Mistaken Beliefs

4. I’ve written it down so I don’t need to talk.
Tools to Help Start the Conversation

Workbook

Conversation Aid

Bracelet
Caring Conversations® Workbook (overview)

Reflect
Talk
Appoint
Act
Caring Conversations® Workbook (overview)

- Reflect on your own values, beliefs, concerns
• Think about what is important to you about the care you receive at the end of life.
–What does it mean to die well?

–What does “a good death” look like to you?
Caring Conversations®
Workbook (overview)

• **Talk** with loved ones about your wishes

• **Appoint** the person you think is most able to act on your behalf
Caring Conversations® Workbook (overview)

• **Act** by documenting your reflections and conversations in this workbook
What about the formal written documents?
Types of Documents

Durable Power of Attorney for Healthcare Decision-making

+ Healthcare Directive/Living Will

= “Advance Directive”
• With whom should I discuss my *Caring Conversations*® workbook?

• “The drive home…” exercise
Tips for having a Caring Conversation

• Use comfortable language
• Take your time
• Encourage others by doing your own work first
Tips (continued)

• Check for understanding
• Talk about death in a natural way -- Forrest Gump’s mom!
• Discuss practical issues
• Share psychosocial, spiritual, and religious concerns
Homework

• Complete your workbook
• Have a *Caring Conversation*
• Tell others about your workbook
Homework

• Talk to those close to you
• Talk to your doctors
• Share your workbook with family, doctors, clergy and attorney
For information about the Center:

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- http://www.practicalbioethics.org
a program of the
Center for Practical Bioethics

Caring conversations
making your wishes known for end-of-life care