

END-OF-LIFE CONVERSATIONS: HAVING THE TALK

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DIVERSE PERSPECTIVES
ETHICS CONSULTATION

▶ I have nothing to disclose

DISCLOSURES

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University of California
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DEVELOPMENTAL DISABILITIES: Update for Health Professionals

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SPECIAL THANKS

“I didn’t know I had a choice!”

CLARITA’S STORY

- ▶ Rapid advances in technology
- ▶ Incentives to use new knowledge
- ▶ Beliefs we can forestall death
- ▶ Belief that because we have it available we should use it
- ▶ Your doctor at the hospital is not your primary care physician
- ▶ Forgotten death as a sacred moment

MEDICALIZATION OF DEATH

- ▶ New incentives
 - ▶ Limit length of stay
 - ▶ Readmissions
 - ▶ Home Care
 - ▶ Hospice

COST OF HEALTHCARE

WHO WILL DECIDE?

- ▶ Living wills (with little legal grounding)
- ▶ Patient Self Determination Act 1990
- ▶ 20 Years later, only 15% have completed
- ▶ Little new data

HISTORY OF ADVANCE CARE PLANNING

- ▶ Little or no data available
- ▶ Very little written about end-of-life issues for this population
- ▶ There **are** some wonderful resources available

PREVALENCE AMONG PERSONS WITH DEVELOPMENTAL DISABILITIES

EVERYONE IS TALKING ABOUT IT

News Papers

Movies and Television

Social Media (“everything’s a twitter”)

News Papers

- ▶ Ken Murray's "How Doctors Die"
- ▶ The New York Times



Television/ Movies

- ▶ Diane Sawyer
- ▶ The View
- ▶ Amour
- ▶ George Clooney's "Descendants"
- ▶ TED X Stanford with Tom Brokaw

WHAT IS IN THE NEWS

NEW ORGANIZATIONS

SOCIAL MEDIA



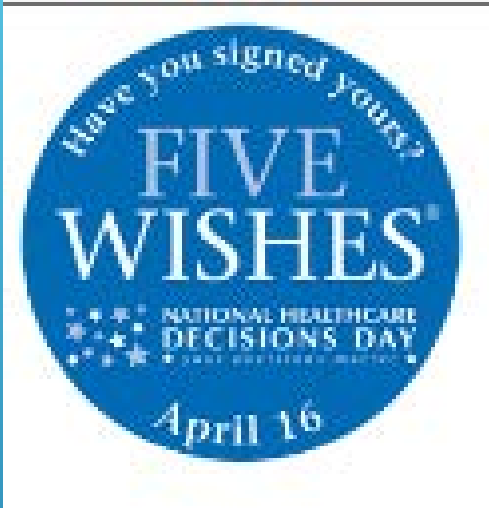
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NATIONAL HEALTHCARE
DECISIONS DAY
★ *your decisions matter* ★

the conversation project





Under-treatment

- ▶ Perceptions about quality of life
- ▶ Lack of knowledge about person
- ▶ Family unavailable or uninvolved
- ▶ Family become decision makers
 - ▶ Know little about the person
- ▶ Old assumptions about perception of pain

Over-treatment

- ▶ Fear we will be accused of discrimination
- ▶ Family and care giver guilt

PERSONS WITH DEVELOPMENTAL DISABILITIES

- ▶ Life expectancy of individuals with Developmental Disabilities is within 5 years of the general population
- ▶ Significant numbers are in some way dependent
 - ▶ ADLs
 - ▶ Basic communication
- ▶ Medical knowledge is still often held by individual's pediatrician
- ▶ Confusing regulations
- ▶ "Futile – death delaying" may be normal life sustaining
 - ▶ Feed tubes – ventilators

(from Last Passages Project)

BARRIERS FOR CONVERSATION AND QUALITY END-OF-LIFE CARE

- ▶ Minnesota – Honoring Choices, Video

WHAT IS THE VALUE?

- ▶ Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of ability of such individuals to participate in, and contribute to, society.
- ▶ ADA of 1990, 43 U.S.C. § 12101(a)(7).

CAN IT BE THAT WITHIN HEALTHCARE
SO LITTLE HAS CHANGED

Barriers

- ▶ Beliefs that persons with Developmental Disabilities
 - ▶ Do not understand death
 - ▶ Should be protected from even attending funerals
 - ▶ Lack of understanding of complex medical issues
 - ▶ Non Verbal = can't communicate

Need To Use

- ▶ IPC
- ▶ Self Advocacy
- ▶ Communication, understanding come in various ways and forms
- ▶ We must take the time

COMMUNICATION ABOUT END-OF-LIFE

▶ The Special Hope Project: THINKING AHEAD

- ▶ Determined that “a Trusted Helper” should be used help have the conversation and complete the form
- ▶ “A Trusted Helper” should be a close friend
 - ▶ Is this realistic?
- ▶ Counselors are willing and able to do IPCs
 - ▶ Those usually do not include this most important conversation



WE DO KNOW THAT PEOPLE ARE NOT COMFORTABLE HAVING THESE CONVERSATIONS

- ▶ Use every opportunity
 - ▶ Personal experiences
 - ▶ News Stories
 - ▶ Movies
- ▶ Death is part of life: Conversations about it need not be “morbid”

NORMALIZE THE CONVERSATION

- ▶ Who would make your decisions if you were unable?
- ▶ Is this who you want to make your decisions?
- ▶ Does the person you want to make your decision know that?
- ▶ Have you told that person what your preferences are about treatment during serious illness and/or the end of your life?

WE NEED TO HAVE THE
CONVERSATION

- ▶ Medical Language is complex
- ▶ Clarify what words mean
 - ▶ Intubation, Ventilator, CPR, Asystole, Life support

CLARIFY MEANINGS

▶ Complete Advance Directives

- ▶ Document our choice of decision makers and alternates
- ▶ Document our wishes about end of life care
- ▶ Get witnesses (Attorney or notary not needed)

▶ Give copies to

- ▶ Your chosen decision maker
- ▶ Your doctor
- ▶ Your care providers

WE NEED TO DOCUMENT OUR
CONVERSATIONS

- ▶ The physician treating may not know you at all
- ▶ Emergency Room MDs, Hospitalists, Intensivists, Hospice MDs)
- ▶ We Must
 - ▶ Increase their awareness of the very individual special needs of persons with developmental disabilities
 - ▶ Increase their awareness of disparities in treatment
 - ▶ Emphasize and develop a sense of cultural humility and an attitude of openness and respect for person's with Developmental Disabilities

(Community Partnerships for Older Adults)

" ATTENTION MUST BE PAID "

(DEATH OF A SALESMAN – ARTHUR MILLER)

- ▶ Minnesota – Honoring Choices, Video

UP TO YOU

▶ We need to:

- ▶ Have the conversation for ourselves
- ▶ Respect the opinions, voices and requests of all people
- ▶ use any opportunity to open up the conversation
- ▶ Document the conversation

WE REALLY NEED TO DO THIS!

Minnesota – Honoring Choices, Video

DUST TO DUST

TALK ABOUT IT
AND
PUT IT IN WRITING!

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THANK YOU!