

“YOUR VOICE, YOUR VALUES”: THE CONVERSATION PROJECT @ ECMC

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This Presentation Will:

- Describe the current state of dying in America
- Introduce the benefit of early, value-based conversations
- Explain the need to consider advance care planning for people with a behavioral health diagnosis a separate, significant issue

“ACCORDING TO MOST STUDIES,

People's number one
fear is public speaking.
Number two is death.
Death is number two.
Does that sound right?”



History of Dying



Forty Years of Work on End-of-Life Care Reform

- **1976-1994**

- Karen Ann Quinlan-Right of choice to refuse life-sustaining treatment and authority of surrogate decision-makers
- Nancy Cruzan-Patient Self-Determination Act spurred efforts to promote advance directives

- **1995-2009**

- Robert Wood Johnson Foundation multimillion-dollar study findings showed that documented treatment preferences failed to change clinical practice.

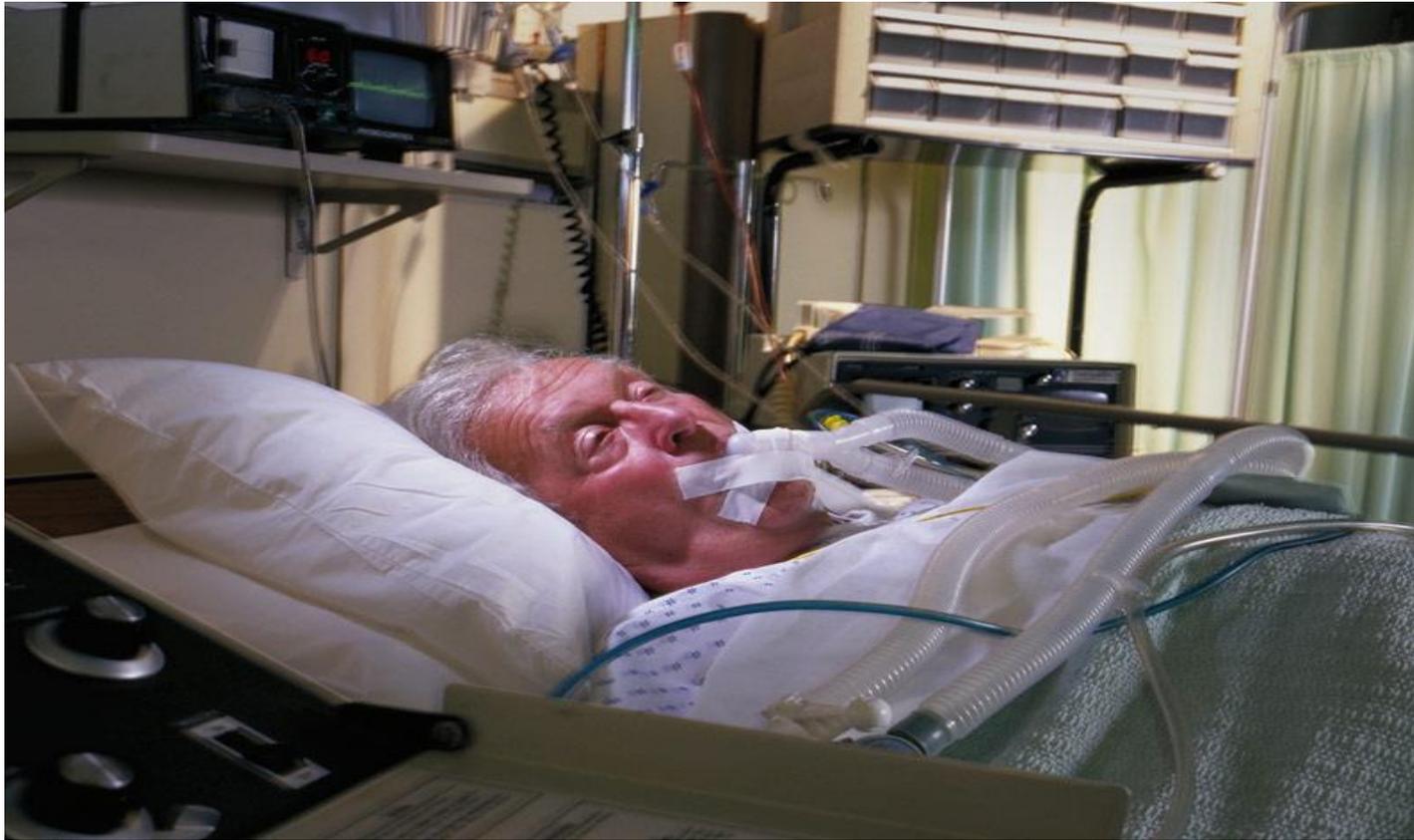
- **2010- Present**

- Affordable Care Act, IOM *Dying in America* Report

What We Say We Want...



Vs. What We Get



<https://www.youtube.com/watch?v=igZvuCJv4VQ>

“Advance care planning is about planning for the ‘what ifs’ that may occur across the entire lifespan.” — Joanne Lynn, MD

the conversation project

"It's a conversation about
what matters to you, not
what's the matter with you."

Ellen Goodman

Co-Founder of The Conversation Project



TCP's Strategy for Creating Cultural Change

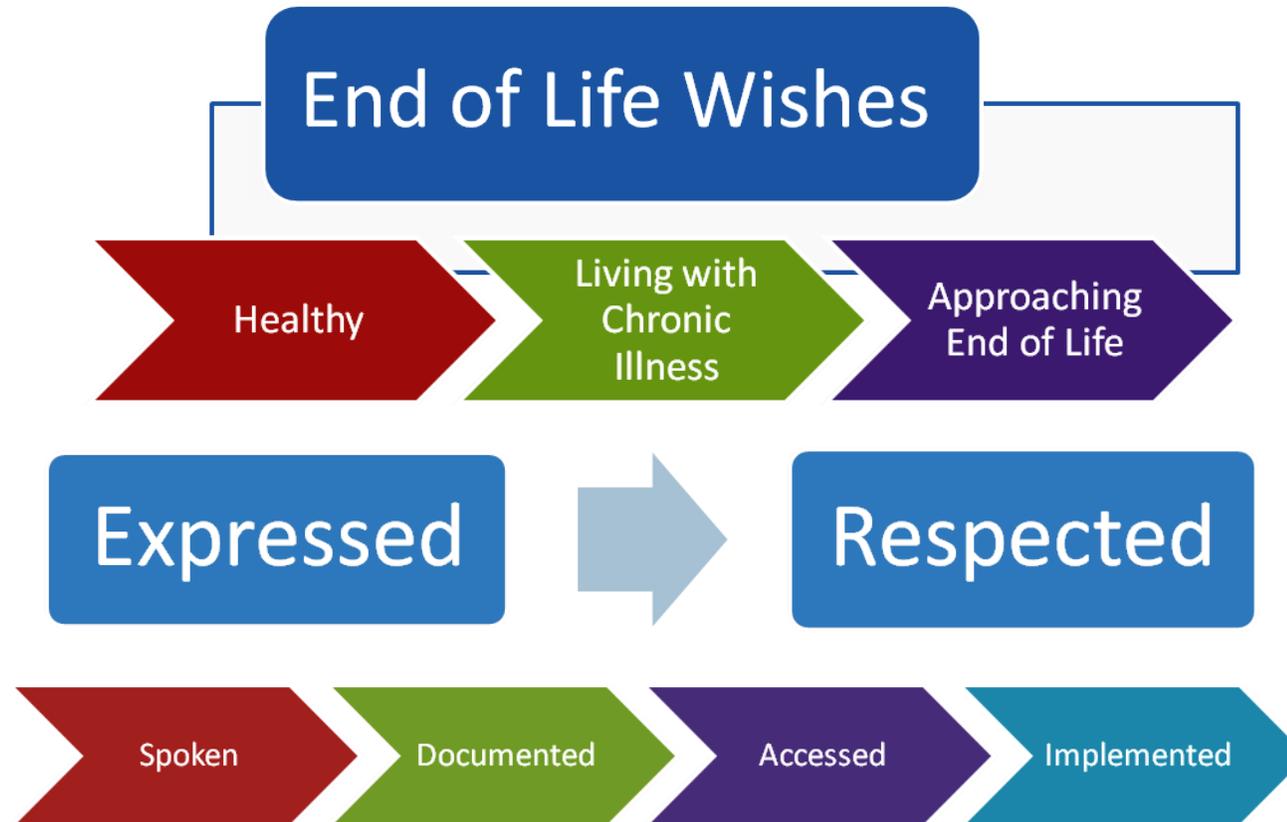
- **Awareness:** National social media campaign and community engagement events
- **Accessible:** Tools to help people get started
- **Available:** Bringing TCP to people where they work, where they live, and where they pray

the conversation project

Your Voice, Your Values

the conversation project

The Conversation Continuum



Your Voice, Your Values

- <http://www.ecmc.edu/medical-minute-heather-hoffmann-conversation-project/>

Early Conversations About Goals of Care Benefit Patients And Families

- Enhanced goal-concordant care
- Time to make informed decisions and fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- More and earlier hospice care
- Fewer hospitalizations
- Better patient and family coping
- Eased burden of decision-making for families
- Improved bereavement outcomes

~Mack JCO 2010; Wright JAMA 2008; Caiarciar AATS 2015; Detering BMJ 2010; Zhang Annals 2009

Conversation Ready Principles

- **Engage** with patients and families to understand what matter most to them at the end of life.
- **Stewart** this information as reliably as you would allergy information.
- **Respect** people's wishes for care at the end of life by partnering to a patient-centered plan of care.
- **Exemplify** this work in your own lives so that we fully understand the benefits and challenges.
- **Connect** with patients and families in a culturally and individually respectful manner.

Key Messages about Advance Care Planning



Stigma-False Assumptions

- Having a mental illness means a person is not capable of understanding Advance Care Planning (ACP) and is too unwell to make his/her own decisions. It is better that someone else decides for them.
- People with mental illness cannot cope with talking about serious physical health issues and will become so upset their mental health will suffer.
- People with mental illness will make poor choices. They need protection from making decisions that are not good for their health. They may use ACP as a way to harm themselves.
- People with mental illness do not have any legal rights to make choices about their medical care.

Barriers to ACP

- Tools have not been tested with people living with behavioral health diagnoses
- Advance care planning is complicated by;
 - Capacity assessment issues
 - Legal guardian issues
- Shortage of persons to designate a Health care proxies

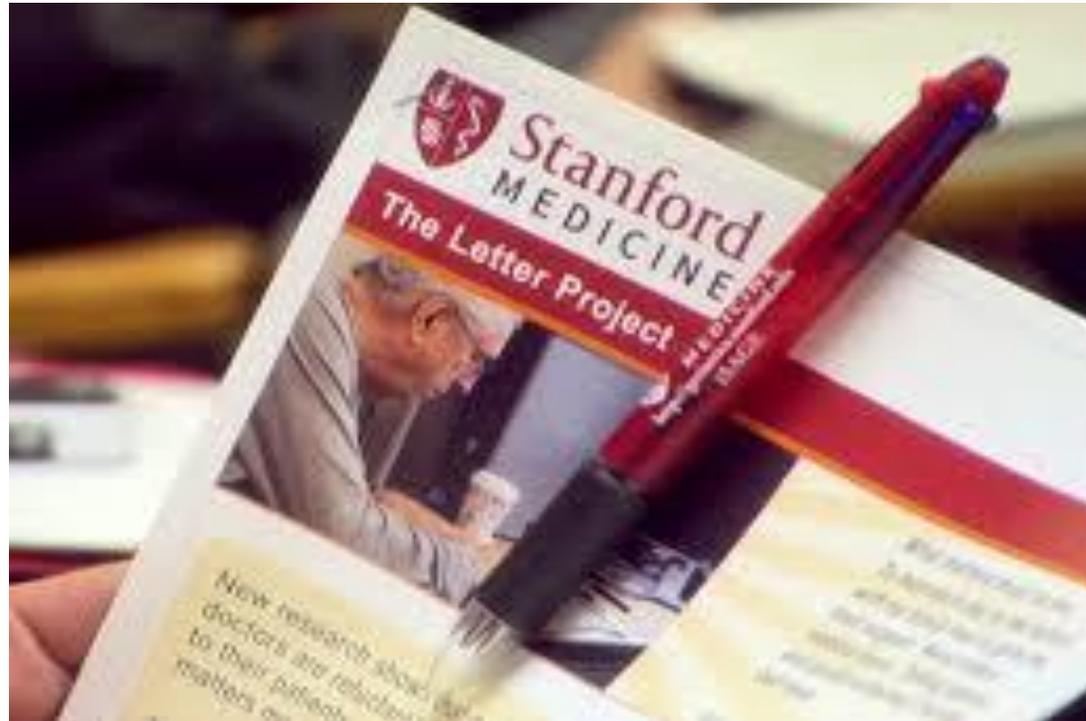
Consumers speak...

- “I worry about what kind of death I’ll have.”
- “Will people know if I’m psychotic or just think I’m delirious?”
- “Who will know when I need my medications?”

Dignity, Respect, & Choice

- “Family” may be other clients, staff, members of the mental health service provision team
- Needs to occur “at home”

The Stanford Letter Writing Project



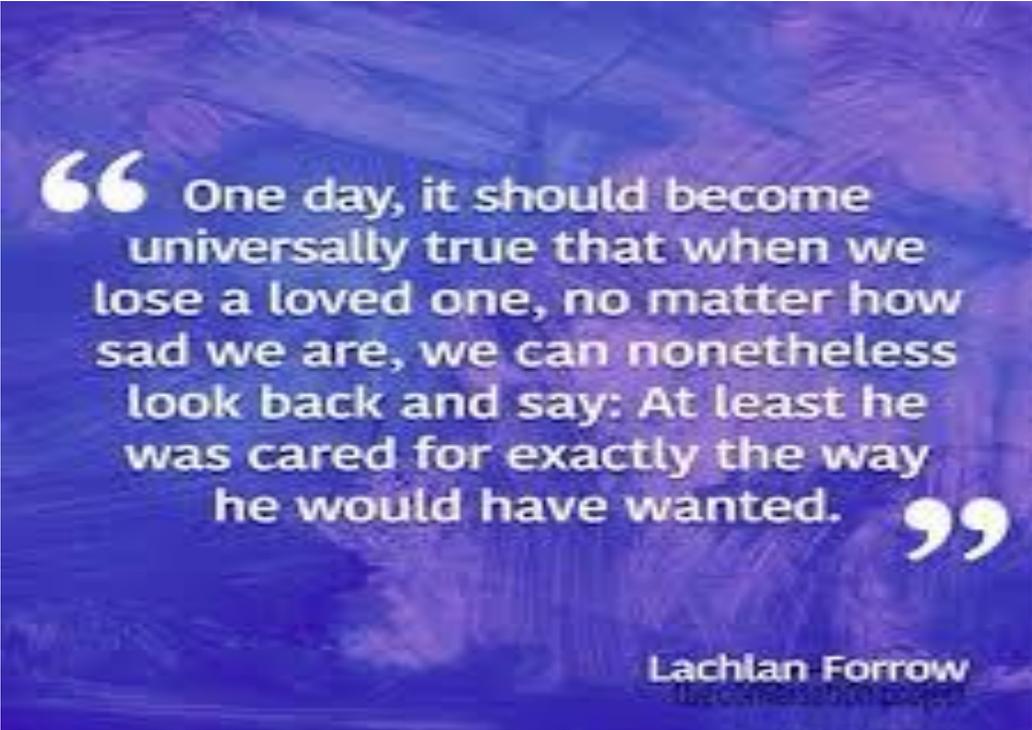
Our goal: To help, empower and support all adults to prepare for their future and take the initiative to talk to their doctors and their friends and family about what matters most to them at life's end.

Community Education

- <https://vimeo.com/36052824>

Don't Panic





“ One day, it should become
universally true that when we
lose a loved one, no matter how
sad we are, we can nonetheless
look back and say: At least he
was cared for exactly the way
he would have wanted. ”

Lachlan Forrow