Transforming EOL Care
It All Begins with a Conversation

By Billie Kester & Harriet Warshaw

December 6, 2015
1:00-4:30pm

Session Objectives

- Demonstrate the importance of having the conversation from the personal, professional and system perspectives
- Develop an action plan that includes both a personal and professional conversation
- Identify the barriers to having end-of-life care conversations and the strategies to promote action
Welcome

“When you talk about dealing with people who are nearing the end of their life and their family members, the work that we do stays with them forever.

It's the same way that people tell stories about the birth of their children, they also tell stories about the death of a loved one.

And I just feel like you have one chance to do it right.”

- Julie Knopp, NP, Palliative Care, Beth Israel Deaconess Medical Center
The Problem is Clear

"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being... Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same:

What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"

- Atul Gawande, Being Mortal

"We have so medicalized death. We have to make sure we sit down with a patient as a human being and understand what’s important to them as a human being and then make sure that's at the center of every decision."

— Lachlan Farrow, Dir. of Ethics Support Services, BIDMC

Stern family circa 1962
Introductions

- Name
- Organization
- Share a time when you experienced a “good” or “hard” death - either personally or professionally

5 minutes

A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.

the conversation project
WANT TO DIE AT HOME.

ACTUALLY DIE IN THE HOSPITAL.
WANT TO DIE AT HOME.

70% WANTS TO TALK WITH THEIR DOCTORS.

HAVE HAD A CONVERSATION WITH THEIR DOCTORS.
WANT TO TALK WITH THEIR DOCTORS.

80%
90%

THINK IT'S IMPORTANT TO HAVE THESE CONVERSATIONS.

What Matters to Me
AS WELL AS
What's the Matter with Me

Public Awareness/Community Engagement
Health Systems Transformation
Strategy for Creating Cultural Change

- **Awareness**: National 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
Awareness: Death Over Dinner

Some things should not go unsaid.

When it comes to end-of-life care, talking matters.
Sharing your wishes for end-of-life care can bring you closer to the people you love. Visit TheConversationProject.org for inspiration, personal stories, and a step-by-step guide to get you started.
You always have something to say.

When it comes to end-of-life care, talking matters.
Sharing your wishes for end-of-life care can bring you closer to the people you love. Visit TheConversationProject.org for inspiration, personal stories, and a step-by-step guide to get you started.

You tell each other everything.

When it comes to end-of-life care, talking matters.
Sharing your wishes for end of life care can bring you closer to the people you love. Visit TheConversationProject.org for inspiration, personal stories, and a step-by-step guide to get you started.
Conversation Sabbath

- November 6-15th
- 30 Houses of Worship in Greater Boston
  “Teaching and Preaching” about TCP

Getting the Conversation Started

- Conversation Starter Kit (Translations + EMR summary)
- How to Talk to Your Doctor Starter Kit
- Starter Kit for Parents of Seriously Ill Children
- Dementia/Alzheimer’s Disease Starter Kit
The Conversation Starts with You

Setting the Table

Example Ground Rules

• Privacy. Please do not share others’ personal stories.
• Listen quietly. This is not a time to offer advice or solve problems.
• Turn off cell phones.
• Everyone is here as a person, not a “role” or “title.”
• What else is important to people in the group?
The Starter Kit

Step 2 Get Set

What’s most important to you as you think about how you want to live at the end of your life? What do you value most? Thinking about this will help you get ready to have the conversation.

Now finish this sentence: What matters to me at the end of life is...
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

What Matters to Me...

“I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90’s music, and go.”

“A tingling sensation of sadness combined with gratitude and overflowing love for what I leave behind.”

“Paced (and with enough space and comfort so that I can make it a ‘quality chapter’ in my life,) I want time and help to finish things.”

“Without suffering and without reproach.”

“Peaceful, pain-free, with nothing left unsaid.”

“In the hospital, with excellent nursing care.”
The Starter Kit: Go

MARK ALL THAT APPLY:

1. **WHO do you want to talk to?**
   - [ ] Mom
   - [ ] Dad
   - [ ] Child/Children
   - [ ] Partner/Spouse
   - [ ] Sister/Brother
   - [ ] Faith leader (Minister, Priest, Rabbi, Imam, etc.)
   - [ ] Friend
   - [ ] Doctor
   - [ ] Caregiver
   - [ ] Other: ____________________________

2. **WHEN would be a good time to talk?**
   - [ ] The next holiday
   - [ ] Before my child goes to college
   - [ ] Before my next trip
   - [ ] Before I get sick again
   - [ ] Before the baby arrives
   - [ ] The next time I visit my parents/ adult children
   - [ ] At the next family gathering
   - [ ] Other: ____________________________

What Did You Learn?

- What plans did you make?
- Questions
- Concerns
- Surprises
- Trends
The Conversation Continuum

Resources

- IHI Open School Course – free CEUs
- TCP YouTube channel
- TCP website (stories, translations, materials)
- Monthly community calls
  - Third Wednesday of each month, 3-4 pm ET
- Quarterly speaker trainings
  - Next call is January 13, 3 pm ET
- Stat Call Series on Convo for Clinicians – January 2016
Upcoming Programs

End of Life Conversations:
Preparing Your Team for Success and CMS Reimbursement

What You'll Learn:
- What has changed with the CMS reimbursements and what it means
- How to bill to CMS
- Effective strategies for where to start
- How to train and engage staff
- Tools and principles for having the conversation with patients

Who should attend:
- Physicians
- Nurses
- Nurse Managers
- Social Workers
- Physician's Assistants
- Geriatric Specialists

How Reid Health is Influencing the Conversation

By Billie Kester

This presenter has nothing to disclose
Why do we need to have the conversation in healthcare?

- It is our duty
  - Patient Self-Determination Act
  - Conditions of Participation for Patients’ Rights
- We are liable
  - Judgements awarded in multiple states for neglecting to honor patients wishes
- It is financially responsible
  - 25% of Medicare spending goes towards the 5% of beneficiaries who die each year
  - Costs for those in their last year of life is six times that of other beneficiaries
  - Aggressive treatment at the end of life has been increasing over time and is showing no signs of slowing down


How did Reid Health become more involved in facilitating the conversation?

Joined IHI Conversation Ready Healthcare Community

1. Dedicated a multidisciplinary team to these efforts
2. Determined a subpopulation to focus on
3. Developed an aim statement
4. Performed a chart audit of the last 20 patients that died in the facility

Engage Steward Respect Exemplify Connect
Death audit findings

Of the last 20 deaths in the facility:
- 70% of the patients did not have an advanced directive on file
- 50% of the patients did not receive heroic measures, but of those that did:
  - 70% were intubated and placed on a ventilator (35% of the overall total)
- There was an average of 2.3 hospitalizations within the last 6 months per patient

The road to change requires a map

**ENGAGE** with our patients and families to understand what matters most to them at the end of life

- Partner with Community Agencies
- Bring the Conversation to the Public
- Bring the Public to Reid to Have the Conversation
- Engage the Identified Population in the Conversation

**STEWARD** this information as reliably as we do allergy information

- Investigate Options for Sharing Across the Continuum

**RESPECT** people's wishes for care at the end of life by partnering to develop shared goals of care

- Create a Culture of Honoring Dignity
- Make the Information Easily Accessible in the System

**EXEMPLARY** this work in our own lives so that we understand the benefits and challenges

- Share the Stories of Reid Staff Members

**CONNECT** in a manner that is culturally and individually respectful of each patient and their family

- Make the Reid Team Culturally Competent and Confident with the Conversation
How do you know if a change is an improvement?

- You measure it!
  - ENGAGE
    - % of patients who are asked if they have a legal surrogate
    - % of patients without a legal surrogate who engaged to identify a legal surrogate
    - % of patients who are asked what matters
    - % of patients who engaged to determine what matters to them
  - RESPECT
    - % of charts with what matters documented
  - STEWARD
    - % of patients with identified legal surrogate in system
    - % of patients with what matters available in system

How are we doing at engagement?

- Chart Audits
  - Found that people were not being asked questions related to advanced directives and healthcare representative
  - Changes made in EMR to make questions mandatory and easier to access
- Forms
  - The advance directive form was very limited
  - Lots of confusion about the various types of advance directives
  - Changed the form to include additional components
  - Created the tool kits
- Staff were not good at initiating conversation
Engagement

% of Pts Asked if They Have a Legal Surrogate

% of Patients Asked if They Have a Legal Surrogate

Linear (% of Patients Asked if They Have a Legal Surrogate)

How are we doing at stewardship?

- Chart Audits
  - Found that patients would often have advance directives present, but charting would state that patient did not have documents
  - Documents on record would often conflict with nursing documentation
- Need to educate staff on the importance of collecting that information as part of the admission history
Example

2010 advance directive on file

I do not wish to receive artificially supplied nutrition and hydration, if the effort to sustain life is futile or excessively burdensome to me.

2015 nursing documentation

<table>
<thead>
<tr>
<th>Advance Directives</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Possible to Sustain Life?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Has no Advance Directive, but wants to share wishes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Patient agrees with Advance Directive information</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Stewardship

% of Patients with Legal Surrogate Information in System

- % of Patients with Legal Surrogate Information in System
- Linear (% of Patients with Legal Surrogate Information in System)
### Stewardship & Respect

**% of Patients with What Matters in System**

- **% of Patients with What Matters in System**
- **Linear (% of Patients with What Matters in System)**

### Example

**2007 advance directive on file**

```plaintext
I do not wish to receive artificially supplied nutrition and hydration, if the effort to sustain life is futile or excessively burdensome to me.
```

**2014 POST form completed**

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#27FORUM
Example

2015 nursing documentation

<table>
<thead>
<tr>
<th>Advanced Directive</th>
<th>Yes</th>
<th>Do you want information about Advance Directives?</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has no Advance Directive, but wants to share wishes?</td>
<td>Yes</td>
<td>All Possible to Sustain Life?</td>
<td>No</td>
</tr>
<tr>
<td>Ventilation?</td>
<td>No</td>
<td>Antibiotics?</td>
<td>Yes</td>
</tr>
<tr>
<td>CPR?</td>
<td>Yes</td>
<td>Pain Medication?</td>
<td>Yes</td>
</tr>
<tr>
<td>Feeding Tube?</td>
<td>No</td>
<td>IV?</td>
<td>Yes</td>
</tr>
<tr>
<td>Appointed Healthcare Representative?</td>
<td>No</td>
<td>Healthcare Rep Present?</td>
<td>Yes</td>
</tr>
<tr>
<td>Advance Directives Decisions</td>
<td>Yes</td>
<td>Contact Name</td>
<td>contact</td>
</tr>
<tr>
<td>Contact Phone #</td>
<td>contact #</td>
<td>HCR</td>
<td>HCR #</td>
</tr>
</tbody>
</table>

Real Hospital does have a copy of my Advance Directive/Living Will but the following are my wishes.

Yes | I do not have an Advance Directive/Living Will but the following are my wishes.
No |
If you are terminally ill with no hope of recovery, do you want all means used to sustain your life?
No |
Do you want to be kept on a ventilator or mechanical device in order to keep you alive?
Yes |
Do you want to be kept on antibiotics or medications used to fight infections?
Yes |
Do you want CPR (Chest/Resuscitation/Revival)? Emergency medical procedures to resuscitate the heart and/or to provide artificial breathing, if you have no longer been breathing?
Yes |
Do you want to be taken off of life support/medication/medication to relieve your pain even if it may lead to reduced consciousness and/or shorten your life?
No |
If you cannot eat or drink, do you want to be fed by tube/ IV placed into your stomach?
Yes |
If you cannot breathe or do you want to be put on a respirator put into your lungs?
No |
I have already appointed a healthcare representative will?
No |
The healthcare representative is present at the time this form is being filled out?
Yes |
If not, is there someone that you want to make decisions and speak for you if you are not able to speak for yourself?
None |
HCR |
Signature |
Phone |
HCR # |
Date |

I understand and agree that this document will serve as a recording of the substance of my existing Advance Directive/Living Will until (rename a copy of the Advance Directive/Living Will) (I do not have an existing Advance Directive/Living Will). The document serves as a recording of my wishes as this time. NOTE: IF YOU CHANGE YOUR MIND, PLEASE TELL THE STAFF IMMEDIATELY. WE CAN ASSIST YOU IN MAKING THESE CHANGES.

I understand that this document does not serve as a DNR(Do Not Resuscitate) order. I must discuss my wishes with the physician/podiatrist/patient care.

Signature of Patient/Contact: ___________________________ Date: ____________
Deciding Over Dinner Activity

Rules for Game Play:
1. Players can feel free to pass if they do not want to answer the question.
2. There are no wrong answers.
3. Players can change their answers at anytime.
Planning Time

Developing Your Action Plan

Change takes place when people decide to take action. *What action do you want to take?*

- Who do you need to talk to when you get back?
Developing Your Action Plan

Change takes place when people decide to take action.  *What action do you want to take?*

- Who do you need to talk to when you get back?
- What information will you still need?

Developing Your Action Plan

Change takes place when people decide to take action.  *What action do you want to take?*

- Who do you need to talk to when you get back?
- What information will you still need?
- In one year, if you were to have wild success, what will have been the factors of this success?
Developing Your Action Plan

Change takes place when people decide to take action. *What action do you want to take?*

- Who do you need to talk to when you get back?
- What information will you still need?
- In one year, if you were to have wild success, what will have been the factors of this success?
- What can you do by Next Tue., Feb. 1, June 1?

Developing Your Action Plan

Change takes place when people decide to take action. *What action do you want to take?*

- Who do you need to talk to when you get back?
- What information will you still need?
- In one year, if you were to have wild success, what will have been the factors of this success?
- In one year, if this project was a flop, what will have been the factors of this failure?
- What will you try by next Tuesday, in six months, in one year?
A Successful Session

• Complete the Starter Kit
• Have the Conversation
• Appoint a Health Care Proxy
• Bring What Matters to Me to your Organization

Thank you!