Community 201 Call:
Lessons on Messaging from the Massachusetts Coalition for Serious Illness Care

The Conversation Project

July 17, 2019
Welcome to today’s session!

Please use Chat to “All Participants” for questions.

For technology issues only, please Chat to “Host”

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)
Ice Breaker Question

Type into the chat box your response to the following question:

*How did you learn about this call?*

Make sure you send your message to “All Participants.”
Where are you located on the map?
The Conversation Project Field Team

Kate DeBartolo
Director

Christopher Joshi
Project Coordinator
# Upcoming Community Calls

The next Conversation Project Community Call will take place on:

**Wednesday, August 21st, 3:00-4:00 PM EDT**

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td>Wednesday, August 21st, 3:00 – 4:00 pm ET</td>
<td><strong>Special Interest:</strong> Planning for Conversation Sabbath</td>
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<td>Community 201: TBD</td>
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TCP Community Updates

What’s New:


- One-Pager: Integrating End-of-life Care Conversations into Professional Services Work: Getting Started

- Case study: Fidelity’s Journey and One Leader’s Mission to Integrate End-of-Life Conversations into Financial Advisors’ Workflow/Practice

- Proxy Kit → Health Care Agent version
TCP Community REMINDER

Quarterly **Community Activity Survey** is open until Friday, July 26th!

https://www.surveymonkey.com/r/CYWJ7HK
Virtual Expedition and Podcast

- Conversation Ready: Engaging Patients in Advance Care Planning
  - Becoming Conversation Ready is an effort to provide more patient-centered care by gaining an understanding of what matters most to patients when it comes to end-of-life care. This virtual training teaches the five principles of being Conversation Ready.
  - Kicked off Tuesday, July 16, 1:00-2:00 PM ET—twice a month from July to September https://bit.ly/2KoDQHn

Let’s get started!

- Background
- Anna Gosline from Massachusetts Serious Illness Coalition: Research Results and Learning
- Q&A and Discussion

What do you hope to learn on today’s call?
Getting Started Questions

- Who do you want to reach? And by when?
- What do you want to support them to accomplish?
- How do you want to reach them?
  - What is the context of this topic for population you’re trying to reach?
  - Who else is already doing this work in your community? Who else could you be working with?
  - Who are respected leaders or organizations that could help you advocate for the importance of this work?
  - Who will be responsible for actually doing this work in your community?
  - How will you measure successes and challenges?
  - How do you plan to reach diverse groups of people in your community?
  - What can you do by next Tuesday?
How do you want to reach them?

What are ways you can reach your target audience where they:

- Work
- Live
- Pray

What activities might help you engage your target population? For example:

- Writing op-eds in the local newspaper
- Speaking at conferences or educational events
- Creating PSA Campaign to raise awareness

What messaging and messenger should you consider?
Anna Gosline
Senior Director of Health Policy and Strategic Initiatives
Blue Cross Blue Shield of Massachusetts
Advancing the language of advance care planning: a messaging research project

Anna Gosline, Massachusetts Coalition for Serious Illness Care

July 17, 2019
Research Objectives and Overview

• Through a combination of quantitative and qualitative research, develop unifying set of messages that motivate consumers to have meaningful conversations about their preferences, values, and goals at all stages of life and health
  
  — Shift conceptual focus away from life-sustaining treatments and care at the very end of life to quality of life, serious illness care, and shared decision making.

• Research overview:
  
  — Through robust, nationally representative quantitative survey research, identify and understand key target audience segments based on their experiences and attitudes with advanced care planning and other relevant variables
  — Through structured, qualitative research with consumers representing each segment, gain in-depth understanding of what language and messages motivate all consumers to engage in advance care planning and provide additional, strategic segment-specific insights.
Segmentation
Why Segment?

- Segmenting populations into distinct groups of consumers based on their experiences, attitudes, beliefs, and personalities helps us gain a deeper understanding of the issue of advance care planning and provides an invaluable foundation for developing messaging:
  - Provides nuanced segment-specific understanding into reasons why – or why not – consumers have engaged in advance care planning
  - Helps ensures that any messaging truly works across for consumers – identifies “common ground” across all segments as well as language or concepts to avoid that may not surface if just looking at overall averages
# Methodological Overview - Quantitative

<table>
<thead>
<tr>
<th>Who?</th>
<th>Representative national sample of 2,514 adults age 18 and over. Additional Massachusetts oversample of 500 adults over 18 years of age.</th>
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<tbody>
<tr>
<td>When?</td>
<td>January 3 – January 18, 2019</td>
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<td>How?</td>
<td>Online and telephone interviews. For the national sample 2,114 surveys were completed online, with 400 phone surveys conducted with people over 60. For the Massachusetts oversample 500 surveys were completed online.</td>
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<tr>
<td>Segmentation?</td>
<td>Segmentation cluster analysis conducted on national sample and discrete analysis on Massachusetts sample.</td>
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</table>
Five Consumer Segments

Worried Action Takers 10%
Self-Assured Action Takers 24%
Disengaged Worriers 34%
Defiant Independents 18%
Self-Reliant Skeptics 14%

Action Takers
100% have both a written document naming their health care decision maker and a document that describes their wishes for care; about 90% have also spoken to loved ones about their wishes and many (50-85%) have talked to their doctors, too.

Non Action Takers
Very few have completed written documents (4 – 16%); about half have had conversations with loved ones about their wishes; few (~20%) have talked to their doctors.
Self-Assured Action Takers and Defiant Independents are considerably less worried that their wishes for serious illness care will not be followed.

Worries Regarding Serious Illness Care – % Very/Somewhat Worried

- Your wishes for the last months or years of your life won’t be followed

- Worried Action-Takers
- Self-Assured Action Takers
- Disengaged Worriers

n = 258-615-850-446-345
Q10. How worried are you that if you were to become seriously ill…?
Self-Assured Action Takers and Defiant Independents are considerably more likely to say their dying loved one’s wishes were followed very well, while Disengaged Worriers reflect more negatively on this experience.

Q14. To what extent would you say that your loved one’s wishes were followed and honored by health care providers at the end of their life?

- Worried Action-Takers: 45%
- Self-Assured Action Takers: 67%
- Disengaged Worriers: 60%
- Defiant Independents: 49%
- Self-Reliant Skeptics: 36%

n = 199-385-488-251-219 (Lost a loved one within the past five years)
Expecting loved ones to know their wishes is a common reason for inaction across all segments. Disengaged Worriers cite many other reasons for their lack of action.

<table>
<thead>
<tr>
<th>Reasons for Not Documenting ACP</th>
<th>% Major Reason</th>
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</thead>
</table>
| Loved ones / decision-maker will know what I want | Disengaged Worriers: 33%  
Defiant Independents: 38%  
Self-Reliant Skeptics: 31% |
| Don't want to think about sickness and death | Disengaged Worriers: 44%  
Defiant Independents: 17%  
Self-Reliant Skeptics: 13% |
| Don't know where or how to begin | Disengaged Worriers: 44%  
Defiant Independents: 6%  
Self-Reliant Skeptics: 19% |
| Don't have loved ones | Disengaged Worriers: 26%  
Defiant Independents: 5%  
Self-Reliant Skeptics: 3% |

n = 850-446-345
Q11. There are different reasons why people may not [have their wishes for medical care written down and/or completed a document that names someone to make decisions about their medical care.] For each of the following, is this a major reason, a minor reason or not a reason for you?
Five Consumer Segments

**Worried Action Takers**
10%
Younger, diverse, most educated.
Highest trust and regard for the health care system. Recent caregiving for incapacitated loved one.

**Self-Assured Action Takers**
24%
Oldest, most likely to be white.
Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

**Disengaged Worriers**
34%
Youngest, most diverse, lowest education and income; poorest health and health care navigation and management skills. Seen loved one’s wishes not honored. Many worries about their health and future serious illness.

**Defiant Independents**
18%
Older (mostly 45+), average education and racial composition. Fewer experiences with dying loved ones. Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

**Self-Reliant Skeptics**
14%
Middle-aged, lower income and education.
Lowest trust of doctors and the health care system. Poor health care self-management and navigation skills.
**Side note: where is X population?**

- Reviewers of this work often ask where a particular population fits among the segments, especially different racial or ethnic minorities, and those with health issues, such as disabilities, behavioral health diagnoses or other serious illnesses.

- Across all segments, there were more similarities than differences when it came to these kinds of demographic indicators, though some characteristics did stick out – for example, the Self-Assured Action Takers were disproportionately white and Anxious Action-Takers included a large number of those who self-identified with a disability (*also see the complementary report with the full national survey results*).

- However, those demographic characteristics generally did not *drive* the segments – when it comes to advance care planning, an African American who is in the Anxious Action Taker segment is more similar to other Anxious Action Takers than other African Americans in different segments.
Messaging and Campaign Development and Testing
ACP Social Norms Marketing Pillars

**Product**
Behavior change/attitude shift

**Price**
Cost of adopting behavior

**Place**
How to reach target audiences

**Promotion**
Messaging & creative

**Advance Care Planning**
Meaningful conversations
Complete health care proxy
Document wishes

**Inertia**
Loved ones will know
Too many things to worry about
Don’t want to talk about death

**Coalition Members**
Various sectors and disciplines

**Messaging**
Umbrella
Segment-specific
Message Map

**Umbrella Message**
universal, aspirational value and vision

**Supporting Messages**
reasons/motivations

**Proof Points**
1) reinforce reasons
2) reinforce reasons
Two Online Communities – 150 Participants
Umbrella Campaign
Three Shared Values Were Explored

- **[self-determination]**
  “I want to have power to make my own life choices”

- **[quality of life]**
  “I want to live a good quality of life, my whole life”

- **[self-advocacy]**
  “I want care that treats me as a whole person, not just a disease”
Three Key Insights

1) While “quality of life” resonated most, having “control” and “power” over decisions impacting one’s life and care is the way to attain and preserve the quality of life they envision.

2) People reacted positively to talking about “what matters to them” and what having a “good day” meant, shifting focus away from treatment options, DNRs, etc.

3) The idea of family and loved ones can be a loaded topic for some and an excuse for others.
Three umbrella campaign concepts were tested.

• The umbrella campaign serves as the unifying creative and messaging, i.e. thematic glue for awareness building.

• Umbrella campaign concepts are the translation of the shared values and message research.

• Campaign concepts were developed based on what resonated with most consumers, across all segments, to encourage ACP thought and action.
Posters shown here for illustrative purposes only and reflect work in progress.
Posters shown here for illustrative purposes only and reflect work in progress.
More and more people are speaking up about the care their loved ones need, and how personal decisions can become burdensome.

The more personal decisions we make, the better you pre-planned they can be. Let the people who matter know what matters most to you.

GET IN THE CONVERSATION

Posters shown here for illustrative purposes only and reflect work in progress.
“Good Days Start with Good Talk” was the most preferred across all segments

• Warm, cheerful
• Conveys togetherness
• Relatable
• Easy to understand, clear, simple
• Easy-to-remember tagline
• Straightforward
• For a few it felt “pushy”
“What’s best for me” ranked in second place

• Vague
• Disconnect between images and text

“Get in the conversation” ranked in third place

• Absence of other people in the photo
• Health care decisions shouldn’t be made solo
Note on Qualitative Data: Ns are small (total across both communities is 150; per segment can be as small as 30). Data observations from these communities are viewed as directional.
Messages & Language
### Five Supporting Messages/“Reasons” Were Tested

<table>
<thead>
<tr>
<th>Message</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Love/Gift</strong></td>
<td><img src="image" alt="Image" /> If any of us became seriously ill, those closest to us may have to make important decisions about our care. Asking and sharing what would matter most to each other in that event is an act of love and kindness that can make future decisions easier—a gift we can give to those who matter most.</td>
</tr>
<tr>
<td><strong>Peace of mind</strong></td>
<td><img src="image" alt="Image" /> The future is full of unknowns. But open conversations can pave the way to clarity, no matter what happens with our health. Having conversations about serious illness and the kind of care that’s right for us gives us a shared understanding that fosters peace of mind.</td>
</tr>
<tr>
<td><strong>Right/Demand</strong></td>
<td><img src="image" alt="Image" /> Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we’d want if we couldn’t make decisions for ourselves.</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td><img src="image" alt="Image" /> We can’t plan for everything. But we can help manage life’s unknowns by talking openly about what matters to us and what we’d want most if we became seriously ill. Conversations about things we can’t control can actually help to give us a sense of control.</td>
</tr>
<tr>
<td><strong>Honor loved ones’ wishes</strong></td>
<td><img src="image" alt="Image" /> There may be a time when we have to help the people closest to us—our friends, our spouses, our parents or grandparents—get the care that’s right for them. Delivering on the promise means understanding what is most important to them in the face of serious illness.</td>
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</table>
I want you to carefully read through the content and use a highlighting tool to share what resonates and what doesn’t. You’ll see the option to use GREEN to indicate words/phrases that resonate in some way, RED to indicate words/phrases that do not resonate in some way and BLUE to indicate words/phrases for which you are indifferent.

Reason #3: We can have a say in our care.

Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we’d want if we couldn’t make decisions for ourselves.

We can have a say in our care. What does this mean?

We’re part of the equation. We deserve to be heard. Health care can help us live our best life, every day. But only if we speak up about what a good life means to us.

You know you. We’re not doctors, but we’re the experts on what’s right for us and our lives. When we share our values, preferences and wishes with our doctors, we’re part of the team that makes sure we get the right care for us.
Participants read the content and did a highlighting exercise.

Example of visual output from “We can have a say in our care”

**Words that resonate**

Getting the healthcare we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we’d want if we couldn’t make decisions for ourselves. **We can have a say in our care.** What does this mean? **We’re part of the equation.** We deserve to be heard. Health care can help us live our best life, every day. But only if we speak up about what a good life means to us.

**Words that don’t resonate**

Getting the healthcare we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we’d want if we couldn’t make decisions for ourselves. **We can have a say in our care.** What does this mean? **We’re part of the equation.** We deserve to be heard. Health care can help us live our best life, every day. But only if we speak up about what a good life means to us.

**You know you. We’re not doctors, but we’re the experts on what’s right for us and our lives.** When we share our values, preferences and wishes with our doctors, we’re part of the team that makes sure we get the right care for us. **Help them help you.** Our care is ours. For doctors to do their best job and provide care that’s right for each of us, they need to understand our lives and what matters to us. And that understanding comes from speaking up. **Having a say means living our best lives, every day of our lives.** Serious illness care can involve choices that impact our quality of life. That’s why conversations with our doctors and those we care about are so important, so they understand what we need to live our best lives, our whole lives. **The more we speak up, the better care can be.** More conversations with our doctors and caregivers make it more likely we’ll receive the kind of care that works for us.
#1 People appreciate simplicity in the language

• Instances when the **language felt more conversational**, such as “you know you,” “conversations about things we can’t control can actually help to give us a sense of control,” and “if we don’t say it, they won’t know,” resonated most with participants.

• Participants were **put off by language that felt more marketing-like**: “ease the burden,” “have that good talk today,” “we’re part of the equation.”
#2 Word choices matter

- Some reacted negatively to the word “right” – it puts them in a defensive mindset.

- “Conversations” can sound daunting, while “a good talk” is more approachable.

- “Honest conversation” can feel judgmental, while “open conversation” does not introduce judgment.
#3 Control and Power messages were preferred by most

<table>
<thead>
<tr>
<th></th>
<th>Conversations clarify</th>
<th>We can have a say in our care</th>
<th>Caring means learning about them</th>
<th>There is no need to wonder</th>
<th>Love means speaking up</th>
</tr>
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<tr>
<td>Worried Action Taker</td>
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<td>Disengaged Worrier</td>
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<td>Defiant Independent</td>
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<tr>
<td>Self-Reliant Skeptic</td>
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</table>
**What resonated?**

<table>
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<th>“We can have a say in our care.”</th>
<th>“Caring means learning what matters to them.”</th>
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<tbody>
<tr>
<td>- Information is power</td>
<td>- Emphasis on self-advocacy</td>
<td>- Simple reminder</td>
</tr>
<tr>
<td>- Another way to speak up</td>
<td>- Importance of speaking up</td>
<td>- Bring families together</td>
</tr>
<tr>
<td>- Guiding principles speak to importance of planning and preparation</td>
<td>- Connection between quality of life and engaging health care team</td>
<td>- Learn something new about a loved one, no matter how hard the conversation can be</td>
</tr>
</tbody>
</table>
Why have ACP conversations?

A good day tomorrow starts with a good talk today. If you became seriously ill, would the people who matter most really know what matters most to you? Share the kind of care that’s right for you, and what your good days look like—no matter what happens tomorrow.

Why should we believe?

Conversations clarify. We can have a say in our care.

Not convinced?

➢ Information is power.
➢ If we don’t say it, they won’t know.
➢ You know you.
➢ Having a say means getting the most out of every day.
Activity #1

• How does the messaging resonate with you?

• How do you feel about the segments and personas? Do you recognize these groupings among your own constituents?

• Which segment do you personally fall into?
Advance Care Planning

Ensuring your care is aligned with your values, goals and preferences at all ages and stages of life

Making sure we get the care we want, especially when facing a major injury or serious, advancing illness, starts with conversations - with loved ones, doctors, or other important people in your life. The process of reflecting on what's important to us and then documenting those preferences, values, and goals is called advance care planning. Having an advance care plan is important for all of us, because we never know when we might not be able to speak for ourselves.

Having a plan also removes the burden on our loved ones of having to guess what we would want and gives important guidance to our doctors based on our wishes. As part of our Healthy Blue program, we are pleased to offer the following trainings and resources for associates who want to start or refresh their advance care plan.

Meet the Healthy Blue Advance Care Planning Coaches!

We are excited to introduce our first class of Healthy Blue Advance Care Planning Coaches. Our coaches, who went through a 3-hour training with experts from The Conversation Project and Honoring Choices Massachusetts, are now our in-house resources on all things Advance Care Planning. Throughout the year, coaches will be offering
If you became seriously ill, would the people who matter most really know what matters most to you? Share the kind of care that’s right for you, and what your good days look like—no matter what happens tomorrow.

We can’t plan for everything. But we can help manage life’s unknowns by talking openly about what matters to us and what we’d want most if we became seriously ill. Conversations about things we can’t control can actually help to give us a sense of control.
Appendix: Detailed Language
**UMBRELLA MESSAGE**

**A good day tomorrow starts with a good talk today.** If you became seriously ill, would the people who matter most really know what matters most to you? Share the kind of care that’s right for you, and what your good days look like—no matter what happens tomorrow.

**SUPPORTING MESSAGES/REASONS WHY**

**Conversations clarify.** We can’t plan for everything. But we can help manage life’s unknowns by talking openly about what matters to us and what we’d want most if we became seriously ill. Conversations about things we can’t control can actually help to give us a sense of control.

**We can have a say in our care.** Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us, and ask doctors to recognize what matters to us. Asking for what we want from our care also means telling those closest to us what we’d want if we couldn’t make decisions for ourselves.

**PROOF POINTS**

**Information is power.** We can help answer tomorrow’s questions today by sharing our values and preferences with the people who matter most. We may not be able to predict every choice we’ll have to make, but we can give those we love the guiding principles to confidently make decisions for us.

**You know you.** We’re not doctors, but we’re the experts on what’s right for us and our lives. When we share our values, preferences and wishes with our doctors, we’re part of the team that helps us get the right care for us.

**If we don’t say it, they won’t know.** Our caregivers may need to make decisions for us, whether we’ve told them what we want or not. We can’t simply assume they know.

**Having a say means getting the most out of every day.** Serious illness care can involve choices that impact our quality of life. The more we speak up, the better care can be, and the more we’ll have the chance to receive the kind of care that works for us.
**Caring means learning what matters to them.** There may be a time when we have to help the people closest to us—our friends, our spouses, our parents or grandparents—get the care that’s right for them. Delivering on the promise means understanding what is most important to them in the face of serious illness.

**#1**

It’s worth it. To ensure our loved ones get the care that’s right for them, we have to understand their values, preferences and needs by making conversations a priority. The more we talk about the kind of care our loved ones want and expect, the more comfortable it becomes for all of us.

**#2**

Talking can strengthen relationships. The trust involved in conversations about care, and what matters most, can serve to bring us closer. Asking those closest to us about what they would want in the face of a serious illness is a way to show them we care. And it helps prepare us to be the best support we can be.
Love means speaking up. If any of us became seriously ill, those closest to us may have to make important decisions about our care. Asking and sharing what would matter most to each other in that event is an act of love and kindness that can make future decisions easier—a gift we can give to those who matter most.

#1

Conversations guide us. Planning for a day when we might become seriously ill or unable to make health decisions for ourselves is a kindness to loved ones who may need to make those decisions for us. An expression of our values and preferences will make the decision-making process easier for those we care about.

#2

Conversations align us toward a common goal. Sharing what matters provides a sense of confidence—that we will be prepared to cope with a serious illness and honor each other’s wishes together, whether we are a patient or a caregiver.
TCP Get Involved Page:
Community Engagement Resources

- Get started
  - Community organizing guide and resources (identifying partners and sample work plans)
  - *Case studies*
  - Template for tracking progress, suggested metrics

- Promote your message
  - Sample promotional materials (PSAs, ads)
  - Social media toolkit

- Host an event (planning, publicizing, facilitating, evaluating)
  - Invitations and agendas for events
  - Press release and flyer templates
  - Slide deck, videos, materials to bring
  - Evaluation forms

- Bonus content
  https://theconversationproject.org/get-involved
TCP Conversation Champions Map

Search, connect/network and learn together

Conversation Champions Map

- Connect with others doing similar work in your area.
  - You can search by location, organization, name, and filter by setting: faith, health care, or community. Feel free to reach out directly to members on the map via their listed contact information.
- Apply here to be listed on the map if you are actively sharing TCP resources and/or messaging.

The Conversation Project (TCP) relies on the Conversation Champions, like the ones listed on the map below, to help spread the importance of end-of-life care conversations in their communities. These groups plan their own programming using TCP resources or messaging (in addition to their own). As a reminder, TCP has no preference for what someone’s opinions on end-of-life care should be—we just want folks to start talking about it. Please read more about our principles HERE.

Add your pin!

https://theconversationproject.org/get-involved
Write a Letter to Your Loved One

- Write a letter to your loved one(s) about what matters most to you and email your letter to conversationproject@ihi.org

“And for God’s sake, have mercy and trim my chin and upper lip hairs.”

“No heroics. Listen to your mother.”
## Monthly Community Calls

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We want your feedback!

After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today’s topic, what would you like to learn more about?
- Any other comments on today's session?
Stay Connected!

- Twitter: @convoproject
- Facebook: The Conversation Project
- Instagram: convoproject
- Newsletter:
  - General Newsletter
  - Community Engagement Newsletter
Thanks and appreciation

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