The Conversation Project: 5-Year Review

The Conversation Project (TCP) is a public engagement campaign with a goal that is both simple and transformative: to have every person’s wishes for end-of-life care expressed and respected. Too many people die in a manner they would not choose, and too many of their loved ones are left feeling guilty, depressed, and uncertain about whether they have done the right thing. TCP is dedicated to changing that reality.

The Conversation Project began when Ellen Goodman and a group of concerned media, clergy, and medical professionals gathered to share stories of “good deaths” and “hard deaths” within their own circle of loved ones. They realized that the difference between the two experiences often hinged on whether or not they had the conversation.

TCP was launched in August 2012 in collaboration with the Institute for Healthcare Improvement (IHI). From TCP’s early beginnings, IHI has generously provided space, expertise, funding, and invaluable credibility in support of TCP’s mission.

TCP has developed a three-pronged strategy to change our national cultural norm. What follows are some of TCP’s key undertakings and accomplishments during the past five years to implement its strategy, advance its mission, and enhance the cultural spread of The Conversation.

Our Strategy

STRATEGY ONE:
Raise public awareness of the need for timely conversations about our wishes regarding end-of-life care.

STRATEGY TWO:
Provide the tools to help everyone have The Conversation.

STRATEGY THREE:
Bring The Conversation to people where they live, work, and pray.
STRATEGY ONE:
Raise public awareness of the need for timely conversations about our wishes regarding end-of-life care.

People are moved by what they read, hear, and see. The more often people hear TCP’s mission and message, the more likely they are to consider having The Conversation. During the past five years, TCP has become a trusted source for journalists and a voice to the public through the media regarding the importance of talking about end-of-life care. As a result, TCP has generated significant media exposure.

TCP “Talking Matters” Blog

- 90 blog posts
- 42,500+ total blog views

Social Media

Facebook: 6,800 likes
Twitter: 3,750 followers
#TalkingMatters

Through grants from The Nordblom Foundation, TCP’s social media and public messaging efforts are focused on using storytelling to spread our message and tools. As part of this initiative, TCP curated and shared over 50 personal stories on Facebook, Twitter, and Instagram to grow our community and reach diverse audiences.

Conversation Project in the News


500+ pieces of news coverage

Public Messaging Campaigns

With funding from The Nordblom Foundation, TCP created a series of five Public Service Announcements that were displayed on the MBTA’s T, buses, and bus terminals. TCP also received ad space at Logan Airport’s Terminal B thanks to the generous support of the Women Against Alzheimer’s Association.
STRATEGY TWO:
Provide the tools to help everyone have The Conversation.

The Conversation Project offers the tools, guidance, and resources needed to begin talking with loved ones about their wishes and preferences, before a medical crisis and not in the intensive care unit. The Conversation Starter Kit is designed to be used by families, or by individuals, as a way to help them think about and communicate their wishes regarding end-of-life care. These tools have been the heart of The Conversation Project’s mission, helping over a million families across the country and beyond to open up and have the courage and confidence to have The Conversation.

835,000+ Total unique website visitors

10 Translations: English, Spanish, Portuguese, French, Chinese, Hebrew, Korean, Russian, Vietnamese, and Hindi

314,000+ Conversation Starter Kit downloads

7,000+ Alzheimer’s Starter Kit downloads

5,000+ Health Care Proxy Kit downloads

3,000+ Pediatric Starter Kit downloads

9,000+ How To Talk To Your Doctor Kit downloads

National Survey by Kelton

90% of people say that talking with their loved ones about end-of-life care is important.

Yet only 27% have actually done so.

Source: New survey from The Conversation Project, www.thecommunicationproject.org

In 2013, TCP partnered with Kelton – a global public affairs company – to conduct a national survey on end-of-life conversations. The survey produced robust and interesting findings.

Training Clinicians

IHI Open School Course: “Having the Conversation: Basic Skills for Conversations about End-of-Life Care”

Launched in 2014, the IHI Open School online course was developed by TCP in conjunction with the Boston University School of Medicine. The course has been taken over 26,000 times.

TCP created resources to help clinicians better understand implementation of the CMS reimbursement policy that went into effect in 2016. TCP developed online course content and written materials, and incorporated this teaching into all health system programming.
STRATEGY THREE: Bring The Conversation to people where they live, work, pray.

The Conversation Project has created a wide array of relationships across the country to help spread its work and foster cultural change. These relationships range from community collaborations, to inter-organizational cooperation, to private business initiatives, to local, state, and national government involvement and impact.

Deeper Collaborations Made Possible by Foundation Funding

John A. Hartford Foundation Grant
With support from the John A. Hartford Foundation, TCP is accelerating our spread strategy by working intensely with local leadership and willing partners in 12 communities across the nation.

Massachusetts End-of-Life Collaborative
A grant from the Gordon and Betty Moore Foundation allowed for 22 diverse health care organizations from across Massachusetts to participate in the Conversation Ready Massachusetts Collaborative. This Collaborative is a part of a statewide project aimed to increase the number of people whose end-of-life wishes are documented and respected. TCP is also engaging with faith communities and professional organizations from financial services to law firms within Massachusetts.

“Speak(easy) Howard” End-of-Life Collaborative
The Horizon Foundation launched Speak(easy) Howard, a campaign that aims to change the way people in Howard County, MD, a suburban community of Baltimore, talk about and plan for the health care they want to receive in the future. The focus of this Collaborative is to increase the number of individuals residing in Howard County who have end-of-life care conversations, increase the number of individuals with a documented health care agent, and impact institutions where end-of-life care wishes are honored so that actions to respect these wishes are a more consistent standard of care.

Berkman Family Foundation
TCP was the recipient of a generous grant from the Berkman Family Foundation to test strategies that had the potential to accelerate the spread of our work across the state of Florida. We have established significant connections with local leaders, creating a strong foundation for future work across Florida. Floridians who visited the TCP website took advantage of our available resources. We reached over 2,250 individuals and leaders and have more events scheduled for 2017.

Cambia Health Foundation
Beginning in 2012, the Cambia Health Foundation was TCP’s founding grant funder and has generously supported its work for the past five years. Because of their support, TCP has been able to bring TCP to communities across the country through the development of tools such as the Conversation Starter Kits and the Coaching the Conversation Guide, through virtual speaker training programs that are held quarterly and community calls that are held monthly. The Foundation has supported the development of our web-based Community Resource Guide, which brings together best practices from across the country, and they are underwriting a Gathering of TCP’s Community Leaders to build grass-roots leadership and begin visioning for the next five years.

Fidelity
Fidelity has provided TCP with funding to help build content capacity. Through this partnership TCP has been a featured speaker at seven National Financial Advisors meetings across the country, including Boston, New York, Chicago, San Francisco, Los Angeles, Gainesville, and Atlanta. TCP’s tools have been placed on Fidelity’s customer-facing website and Associates are being trained to utilize these tools with the clients. The goal is to bring TCP’s resources to all of Fidelity’s customers, financial advisors, and employees.
Massachusetts Department of Public Health
As part of the state's educational efforts, the Massachusetts Department of Public Health included the Conversation Starter Kit in their brochure.

Death Over Dinner
In 2014 and 2015, TCP collaborated with Death Over Dinner to create #SevenTwoOne – seven days, two organizations, one conversation – challenging Americans to host a dinner party and talk about death as a part of their new year’s resolutions.

The initiative drove 31,000 people to TCP’s website, generated over 20,000 downloads of the Conversation Starter Kit, and tracked 1,594 “dinner date” events.

National Healthcare Decisions Day
TCP has committed to lead National Healthcare Decisions Day to promote advance care planning conversations across the country.

Over 2 million individuals were reached through public events, social media, and employer participation.

In celebration of 10 years of NHDD, TCP partnered with other organizations in 2017 to host a congressional briefing and panel discussion in Washington, DC.

American Academy of Family Physicians (AAFP)
TCP has partnered with the American Academy of Family Physicians (AAFP) to promote conversations about end-of-life care to AAFP members.

“I experienced the burden of unspoken end-of-life wishes with my mother’s illness and subsequent passing, as well as in my professional life as an owner of a senior focused homecare agency. It has been extraordinarily gratifying to make people aware of, facilitate and encourage people to initiate this very uncomfortable conversation for themselves and their loved ones. The Conversation Project makes this dreaded yet necessary task achievable.”
- Laurie Miller, Dallas Area Gerontological Society

TCP delivered more than 500 presentations across the country to community-based organizations, civic leaders, houses of worship, professional associations, medical schools, hospitals, insurers, and foundations regarding the importance of The Conversation.

- National Academies of Science, Engineering, and Medicine (formerly the Institute of Medicine): Integrating the Patient and Caregiver Voice into Serious Illness Care: A Workshop (May 2016) and Assessing Progress in End-of-Life and Serious Illness Care (December 2016)
- 7 national speaking engagements for Fidelity’s InsideTrack Series
- Quarterly speaker training for people to hold their own Conversation Project Workshops
- AAMC (2013)

Massachusetts Coalition on Serious Illness Care
Organized by The Conversation Project, Blue Cross Blue Shield of Massachusetts, and AriadneLabs, the coalition is working to ensure that health care for everyone in Massachusetts is in accordance with their goals, values, and preferences at all stages of life and in all steps of their care.

Speaking Engagement Highlights

- National Institute of Nursing Research (2016)
- BCBSA Western Leadership Conference (2016)
- AAFP Family Medicine Experience (2016)
- Post-Acute Care Center for Research Evolution Summit (2016)
### Policy

- In June 2013, TCP testified before the US Senate sub-committee on aging.
- In November 2013, TCP testified before Mass Public Health council on regulatory changes on advance care planning.
- In January 2014, Met with US Undersecretary of DHHS to discuss collaboration to spread TCP.

### Faith

- In 2016, TCP had 50 congregations participate in preaching the conversation, including Christian, Jewish, and Buddhist communities.
- TCP has a strong connection within Greater Boston’s Interfaith Organization (GBIO) and other prominent community-based organizations.

### Work

- Tufts Health Plan integrated TCP into their work with employees, subscribers, and clinical staff.
- TCP is working with Blue Cross Blue Shield of MA to educate their employees and their subscribers about the importance of EOL care conversations.

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*With Deep Appreciation to Funders Past and Present*

- Berkman Family Foundation
- Cambia Health Foundation
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- Harman Foundation
- Institute for Healthcare Improvement
- Jane’s Trust
- John A. Hartford Foundation
- Schwartz Center for Compassionate Care
- Virginia G Piper Charitable Trust
- Women Against Alzheimer’s Foundation