

the conversation project

Have You Had The Conversation?

The Conversation Project (TCP) is a national public engagement campaign to ensure that each person's wishes for end-of-life care are both expressed and respected. TCP has its roots in the growing understanding that too many people are dying in ways they would not choose and that too many loved ones are left feeling guilty and uncertain about whether they did the right thing. We are dedicated to changing that reality.

Dying is a universal experience. Nearly everyone has a story about a good death or a hard death among those they love. The difference between these experiences often rests on whether we have shared our wishes for how we want to live at the end.

TCP's goal is ambitious: to change the cultural norm from **not having** these conversations to **having** them. To change that norm, we need to impress people with the importance of *the conversation*, provide them with tools to make it easier to have conversations, and encourage these critical talks to take place at the kitchen table before there is a crisis. By doing this, we will not only help our loved ones; we will also enable the health care system to respond appropriately in critical situations by knowing our wishes and respecting them.

We have developed a three-pronged strategy to change our culture.

One: Raise public awareness of the need for timely conversations about how we want to live at the end of our lives

The Conversation Project has launched a successful national media campaign through our website accompanied by outreach to both traditional and social media. TCP has been featured in *The New York Times*, *The Wall Street Journal*, *O Magazine*, *Women's Day*, the *Harvard Business Review*, *NPR's Here and Now* and *All Things Considered* and scores of other diverse publications and broadcasts, including segments on *ABC World News with Diane Sawyer* and *NBC News with Nancy Snyderman*. TCP has also established an active presence on Facebook and Twitter and is linked to numerous other social media platforms.

At the heart of our strategy is storytelling. Historically, social change most often begins when people from different walks of life share their stories and discover how deeply their words resonate with others. We are most influenced to change our beliefs and behaviors when we hear powerful stories. In today's world, stories can be heard and shared not only through traditional media but also online and via social media, thereby amplifying their impact each time they are passed on in a posting, tweet, blog, or video.

"The conversation" is entering the public vocabulary as people become increasingly aware of the importance of addressing and talking about these issues. The Institute of Medicine (IOM) recently released a 500 page report, entitled ***Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life***. The IOM Report makes frequent mention of the importance of

having *the conversation* with loved ones and healthcare providers, calling it a critical component of quality end-of-life care. Dr. Atul Gawande, noted Harvard Medical School Professor and a TCP Adviser, recently authored a book entitled ***Being Mortal: In Search of a Better Way to Die***, which has become an immediate best seller. In his book, Dr. Gawande emphasizes the need to have *the conversation* early and often with loved ones and clinicians. Recently, TEDx invited TCP's founder, Ellen Goodman, to present TCP's mission and message to a packed audience at Boston's Faneuil Hall as part of a program entitled "Revolutionary Ideas Revisited: The Conversation Project." Each of these recent happenings suggest that the idea of having *the conversation* is becoming broadly recognized as an important issue for public awareness and action.

But this is just a beginning. To increase our effectiveness in raising public awareness, TCP needs to enhance our media outreach and range. By expanding our presence in social media and by enhancing our online capacities to gather, record, and share stories, we hope to enable these stories to echo across the country and beyond. We are presently engaged in creating a public health media campaign intended to resonate with and move people to action. The campaign will be piloted in Massachusetts with the intention of a national spread thereafter.

Since storytelling also takes place in movies, television, and programs produced for the web, we are working with the entertainment industry to include *the conversation* in the storylines of television shows and films appealing to broad audiences. We have met with the Hollywood Writer's Guild of the West Coast as well as the Writer's Guild of the East Coast with the hope of injecting the message of *the conversation* into this important stream of cultural influence.

Two: Provide the tools to help everyone have The Conversation

TCP has created an innovative website where individuals can turn for ideas and techniques to have *the conversation* with their loved ones and their clinicians. Visitors to the site are encouraged to describe how they want to live at the end and to share their stories. The website offers a complementary user-friendly Conversation Starter Kit providing encouragement and step-by-step guidance for how to have *the conversation*. In addition to the Starter Kit, TCP's website offers a parallel kit on how to talk to one's doctor or care provider. Both kits are also available in Spanish, French, Mandarin and Hebrew. At the request of clinicians and parents, TCP has just published a Starter Kit for Parents of Critically Ill Children. The kit was designed to help parents begin a conversation with their critically ill child. This was a task undertaken with deep humility and in collaboration with both clinicians and parents. More than two-thirds of visitors to TCP's website have chosen to download at least one of our starter kits – an exceptionally strong reflection of the felt need for tools to help people get started with *the conversation*.

TCP has also received numerous requests from doctors to assist them to have *the conversation* with their patients in order to actualize their patients' wishes. As a result, TCP has created an online curriculum, also available on a complementary basis, to help health professionals have *the conversation* in both their personal and professional lives. The curriculum fosters skills that may well not have been part of the training or prior experience of these professionals.

TCP's goal is to ensure that whenever and wherever someone is looking for help to have *the conversation* with a loved one, there are tools and resources available to support them: in print, online, or in person.

Three: Bring The Conversation to people where they live, work, and pray – “Conversation-Ready Communities”

As we enhance TCP's media presence, we are keenly aware of other important ways to reach people as they go about their everyday lives – in their hometowns, in their workplaces, and in their places of worship or other public gatherings. In order to maximize our impact, TCP needs to live and spread not only on the air but also at the grass roots.

Immediately following the launch of our website and media campaign, TCP received a remarkable response not only from individuals but also from community organizations around the country. From Akron and Atlanta to Winston Salem and Washington, D.C. and many locations in between, communities all over the country have asked us to bring *the conversation* to local forums that can inspire and engage a broad array of local constituencies. TCP is working actively with over 240 communities across the country to help them spread the message of *the conversation*.

TCP is also working with the American business community. Major companies like Dow, Goodyear and Tufts Health Plan have invited TCP into their worksites to address their leadership, to share our resources, and/or to coach key staff members to be prepared to speak to the importance of *the conversation* with their employees or retirees – an increasing number of whom are also caregivers to loved ones and eager for additional resources to support their loving and difficult roles.

TCP is also collaborating with religious congregations and clergy from each of the major faith traditions. We are piloting this effort in the Boston area to determine how best to inspire and empower clergy and lay leaders to implement *the conversation* within the doctrinal framework of their respective religions. We expect to build upon this pilot and expand our efforts nationally.

In all of these arenas, TCP is seeking not only to stimulate *the conversation*, but also to teach others how to lead Conversation Groups, supporting and encouraging the spread of *the conversation* throughout our culture.

Through the totality of these national and local initiatives, TCP is seeking to catalyze the creation of *Conversation-Ready Communities* across the country. We see these communities as archipelagos – as points of cultural change spanning the country and serving to influence other organizations and towns around them. In these communities, TCP is partnering with capable and energized local organizations and coalitions to engage everyone from faith leaders to local officials, from human resource professionals to medical educators, from health care organizations such as hospice and hospitals to commercial organizations and businesses, and from members of book groups to members of civic organizations. As the number of *Conversation-Ready Communities* has increased, we have created a forum for their local leaders to share ideas with one another, creating their own learning communities built upon each other's experiences.

We have both the passion and – as through our work to date – the experience and knowledge to help create this national model of communities leading cultural change at the grass roots. TCP’s goal now is to garner the resources to make this vision of *Conversation-Ready Communities* a reality.

Multiple Strategies to Achieve a Single Ambitious Goal

The intricate braiding of these three strategies – a broad national media campaign, effective tools that encourage every person to express his or her wishes, and an array of grass-roots community initiatives – can and will fuel broad change in our culture. We believe our society is now at a tipping point in recognizing the importance of addressing end-of-life care issues openly and honestly with our loved ones and with our care providers. TCP is poised to be a powerful force to ignite this critical change.

Our simple yet transformative goal is for each of us to be able to ask any person or audience anywhere, “Have you had *the conversation?*” and to hear in response a resounding “**Yes**”.

To learn more about the work of The Conversation Project, please visit our website at www.theconversationproject.org or contact Harriet Warshaw, Executive Director at hwarshaw@ihi.org or 617-301-4868

The Conversation Project’s 2015 Major Initiatives:

1. **Public Health Messaging Campaign** – lead by Ellen Goodman, Founder, TCP and Argus Communications: Funded by The Nordblom Family Foundation.
2. **Creating Conversation Ready Communities/On-Line Resource Center** – lead by Kate DeBartolo, TCP, National Field Manager: Funded by Cambia Healthcare Foundation.
3. **Integrating The Conversation Project into Communities of Faith** – led by Rev. Rosemary Lloyd, TCP Advisory to Faith Communities: Funded by Hunt Foundation.
4. **TCP in Diverse Communities: A Collaboration with Boston Community Health Centers** – led Harriet Warshaw, TCP Executive Director: Funded by The Jane’s Foundation.
5. **The Conversation Project Collaboration with the Business Community** led by Harvey Freishtat, TCP Board members.
6. **Documenting Success through Measurement Strategies** – led by Harriet Warshaw, TCP Executive Director: Funded by the Cambia Health Foundation.

The Conversation Project, co-founded by Pulitzer Prize-winner Ellen Goodman and launched in collaboration with the Institute for Healthcare Improvement (IHI), and our Founding Funder, The Cambia Health Foundation, 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 bereaved, guilty, and uncertain. The Conversation Project offers people the tools, guidance, and resources they need to begin talking with their loved ones about their wishes and preferences, before a medical crisis – “at the kitchen table,” not in the intensive care unit. For more information, visit theconversationproject.org