

the conversation project

Have You Had the Conversation?

The Conversation Project is a national public engagement campaign to ensure that all people's wishes for end of life care are both expressed and respected. The campaign has its roots in the growing understanding that too many people are dying in ways that they would not choose and that too many loved ones are left guilty, depressed and uncertain about whether they did the right thing.

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

The Conversation Project's goal is ambitious: to change the cultural norm from **not having** these conversations to **having** them. To change that norm, we have to change when people have end of life conversations. We need to move the conversation from a time of medical crisis in the ICU or emergency room back to the kitchen table. We can best change how the health care system responds to the end of life from the outside in.

To reach our goal, we have developed a three-part strategy for cultural change.

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

The Conversation Project (TCP) has already launched a successful national media campaign through our own website and outreach to both traditional and social media. The project has been featured in *The New York Times*, *O Magazine*, NPR, *The Wall Street Journal* and in dozens of other publications and broadcasts, including an ABC World News feature with Diane Sawyer. TCP has also established an active presence on Facebook and Twitter, and we are linked to numerous other social media platforms.

Our innovative website was visited more than 100,000 times in its first eight months. We welcome people to tell us how they want to live at the end and to share their stories with us, and many have already done so. We offer families a user-friendly Conversation Starter Kit that has been downloaded almost 50,000 times and has been reproduced and circulated thousands of times thereafter by interested organizations and individuals. We have also developed a kit on how to talk to your doctor or care provider.

Two: Everyone has a Story

At the heart of our strategy is story telling. Social change begins when people from all walks of life share their stories and discover how deeply their words resonate with others. We are most influenced to change our beliefs and behavior by hearing such powerful stories. Stories can be shared on-line in a dedicated bank of true narratives from a vast array of people from all cultural and demographic groups. Stories can also be shared through social media, amplifying their impact each time they are passed on in a posting, tweet or blog.

The Conversation Project looks to greatly increase story telling and sharing on every available platform and in every community. With a designated story manager working on social media platforms from Twitter to YouTube, and by reaching out to media partners, we hope motivate people to talk with their loved ones before it is too late. By audio and videotaping them, we expect to make their conversations echo across the country.

Storytelling also takes place in movies, television, and webisodes. We hope to work with the entertainment industry to include the conversation in shows appealing to a broad demographic audience around the country. We also plan to create an engaging video for community presentations that links Hollywood moments of moving, familiar, absurd, unrealistic, and telling scenes of dying—*How Hollywood Does Death*—to real life and the message that we need to start talking right now.

Three: Bringing the Conversation Project to people where they live, work and pray

As we enhance our media presence, we are keenly aware that that we must also bring The Conversation Project directly to people where they are everyday: in their town halls, congregations, and companies. The Project lives and thrives both in the air and at the grass roots.

The genuine sense that we are at a tipping point has come from the remarkable number of unsolicited invitations TCP has received from communities stretching from Providence to Honolulu to bring them into the conversation. In the last six months, we have been invited to and featured at 22 events and workshops. We will also be starting to work shortly with Corporate America-- in particular with two major companies which have invited us to share our resources and coach up their own professionals to be prepared to speak to the importance of The Conversation with their own employees and retirees upon request.

The Conversation Project now plans to create a pioneer group of **Conversation Ready Communities**. We see these communities like an archipelago, points of cultural change spanning the country and serving to influence those around them. In these communities, the Project will work to engage everyone from faith leaders to local officials, from human resource and employee assistance professionals in businesses to medical educators and professionals, from book groups to other civic and community groups, from leaders in hospice to volunteers

who can coach others to have the conversation. We have both the understanding and –through our work to date—the experience, to launch this as a national model resulting in true local change.

Multiple ways to achieve a single ambitious goal

The intricate braiding of these three strategies—a national media campaign, an agenda to promote individual storytelling and sharing across multiple platforms, and a grassroots strategy to reach out to communities across the country—can and will fuel the most significant change in the end of life experience in decades. We are not looking for small changes. We expect nothing less than wholesale cultural shift.

Our simple transformative goal is that we will be able to ask, "***Have You Had the Conversation?***" and hear, in response, a resounding "***Yes.***"

Brief Background and History

The Conversation Project grew out of the experience of Ellen Goodman with her mother’s journey through the healthcare system. It was a journey that Ellen was not prepared for, filled with many decisions about the kind of care her mother should receive once she was no longer able to make those decisions for herself. Ellen was very close with her mother; they talked about everything. But the one conversation they never had was how her mother wanted to live at the end of her life.

After Ellen experienced her mother’s “hard death,” she was filled with uncertainty about what her mom might have wanted. Ellen began telling her story to her friends and to her surprise learned that others had similar experiences with their loved ones. Ellen looked for a way to take her learning and improve the way others experienced the death of their loved ones.

Ellen reached out to a group of colleagues, media, clergy and medical professionals and invited them to gather and to share stories of “good deaths” and “hard deaths” within their own circle of loved ones. The consensus of this diverse group was that although some progress had been made over the past thirty years in terms of end-of-life care, major changes would not occur until there was pressure from the outside pushing the healthcare system to solicit and honor peoples’ wishes. What was necessary, in short, was a grassroots national public engagement

campaign to change the cultural norm from not having timely end-of-life conversations to having conversations starting around the kitchen table.

In the Fall of 2011, The Conversation Project was invited by the Institute for Healthcare Improvement (IHI) to co-locate in its Cambridge, Massachusetts offices and to collaborate with its professionals in developing the campaign. IHI is a highly respected not-for-profit organization that helps lead improvement of health care throughout the world. Several months thereafter, The Conversation Project incorporated itself as a not-for-profit organization and filed its application for federal tax-exempt status. While its application is pending, IHI also serves as TCP's fiscal sponsor.

The collaboration with IHI has been instrumental in the launch and rapid expansion of TCP's campaign. So has the generosity of a number of other funders around the country led by the Cambia Health Foundation of Portland, Oregon which is a founding funder of TCP and which has shared its own vision, resources and wisdom to help propel the campaign forward and expand its reach. Also essential to TCP's development has been an outstanding Board of Advisers composed of highly accomplished professionals from a variety of disciplines whose experience and insights have been helpful in shaping TCP's direction and strategy.

To learn more about the work of The Conversation Project, please visit our website at www.theconversationproject.org