

# Let's Talk: Community Promotes the Conversation About End-of-Life Care Wishes

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*"When my mother was in the ICU, intubated, and with sepsis, it came to that moment of removing the tube and allowing her to die. But my sister wasn't ready and so we continued the interventions. My mother is now in a nursing home, mentally alert but with no physical capability — exactly what she would not have wanted."*

*"I'm an only child, and my mother had already passed away when my father became very ill. I'll never know if he thought the decisions I was making about his care were what he wanted, because we had never talked about it."*

STORIES LIKE THESE — REVEALING THE uncertainty many people face when having to make medical decisions for a loved one — were on the table April 11 when 40 health care and community stakeholders came together to advance The Conversation Project in Contra Costa County. The Conversation Project is a national initiative created to encourage and make it easy for people to talk with their families as well as with their doctors about the care they want if they become seriously ill.

Attending were representatives from health care, civic, and faith-based groups in the county, as well as organizations with a special interest in end-of-life care. (See list, page 5.) Speakers included leaders from the Institute for Healthcare Improvement in Boston and the Coalition for Compassionate Care of California. During the day-long workshop, participants learned and exchanged strategies for reaching their own constituencies and beyond. The ultimate aim of the workshop, said The Conversation Project's Lindsay Hunt, is "to change our culture from not

talking about end of life to talking about it — starting with Contra Costa County."

## What People Want

Kate O'Malley, a senior program officer at the California HealthCare Foundation, explained the impetus behind the gathering. Medical care at the end of life often is burdensome on patients and families, she said, in addition to being extremely costly. Unfortunately, she said, many people are not getting the kind of care that they would want. O'Malley described the findings of a CHCF survey of Californians' attitudes and experiences toward death and dying. The top four most important factors at the end of life were:

- Making sure family are not burdened financially by my care
- Being comfortable and without pain
- Being at peace spiritually
- Making sure family is not burdened by tough decisions about my care

O'Malley noted that only 36% thought "Living as long as possible" was extremely important.

Although people have strong opinions about having their wishes followed, O'Malley said, relatively few have talked to their doctors or their loved ones or written their wishes down. For example, while 60% of survey respondents said that making sure family is not burdened by decisions about care was extremely important, 56% also said they have not talked with loved ones about the kind of medical treatment they would want. When asked why they have not had this conversation with a loved one, the top reasons were:

- I have too many other things to worry about right now
- I don't want to think about death or dying
- My loved one doesn't want to talk about death or dying
- I'm too young / death is a long ways off
- I haven't thought about it
- I have no one to talk to

Fully 82% of respondents said it was "very important" or "somewhat important" to put their wishes in writing, but only 23% actually had done so, continued O'Malley. Similarly, 79% of respondents said they would "definitely" or "probably" want to talk with their doctor about what medical treatment they would want at the end of life; but when asked if a doctor had ever asked them about their wishes for such treatment, 92% said "no."

O'Malley said the data inspired CHCF to look for ways to make the health care system more responsive and patient-centered in providing care for seriously ill patients, and at the same time lessen the burden of health care costs in the future. "It's expensive to provide unwanted care," she said. For about five years, CHCF has been working to support Physician Orders for Life-Sustaining

Treatment (POLST), a document that records patient wishes and that follows them from one care setting to another.

"Now we began thinking about going more upstream and seeing if we can encourage people to have the conversation earlier on, and to help this become more embedded in the health care system."

O'Malley knows this is a real possibility. "I am a geriatric nurse practitioner," she said, "and for 20 years I worked in a community organization in San Francisco called On Lok. We worked with frail elders, most of them Chinese, and it was a very routine part of our practice to have the conversation with our patients. This was 1980s, and having an updated record of patient wishes in every chart was part of the culture of our care. So I know, from my experience, that it's possible to have good robust conversations, to have people feel included and participatory. And we know from the literature that people feel better after they have had these conversations and documented their wishes, and families feel relieved as well."

### Why Now, Why Contra Costa?

"We have over-medicalized death, but it's really a part of life — in fact very much like birth," said Martha Hayward, IHI's chief of public engagement. Work to improve end-of-life care has been going on for years within the health care system, she said, "but what effect was it having out in the public realm? The Conversation Project, which partners with IHI, launched in August 2012 to address this gap.

This is a national campaign to bring end-of-life conversations into the culture by activating whole communities — starting in Contra Costa County where there is strong leadership by the local medical association, interest by area hospitals and hospice organizations, active community and faith groups, and experience using the POLST process.

The conversations happen anywhere that people are, she said — at kitchen tables, in coffee shops. It's not about sharing woes, she said. It's about envisioning a better way. And then, reaching more and more people — “engaging person to person, and group to group.”

Several local leaders spoke of their support of The Conversation Project. Speaking to the physician point of view, Donald Waters, executive director of the Alameda-Contra Costa Medical Association (ACCMA), said “doctors are very proud of the advances in health care, but they recognize that there are times when all those wonderful things they can do aren't necessarily in the best interest of the patient and might not be what the patient wants.” He emphasized the importance of caregivers and families and patients all communicating, “and that leads you to the conversation,” he said.

“We're an aging population,” said Linda Best, president of the Contra Costa Council, which focuses on economic vitality and quality of life for residents. “We need to be sure that seniors have the opportunity to have the conversation, to make an advance directive, and to make sure that they be heard,” she said. The Council believes that helping people to prepare for a good death is a quality-of-life issue for all families.

## The Time Is Right

Judy Citko, executive director of the Coalition for Compassionate Care of California, noted trends that are pushing for change in the way people die. Health reform is sharpening the focus on the 5% of the population for whom 50% of the health care dollar is spent, she said. Providing better care, care that is more consistent with patient wishes, will also provide better value. Further, Citko said, because California already has significant experience with managed care and integrated care, it is in a better position than most other states to lead the way in compassionate care toward the end of life.

Another important trend, she said, is the recent increase in public awareness of the importance of end-of-life care. “Society appears more ready to talk about this than in the past.” On the political level in California, Citko noted, there is much more receptivity than there has been before. Under health reform, improving care at the end of life is one of the state's priority areas.

The Coalition's focus is on culture change at multiple levels, working with health care providers, consumers, and regulatory agencies simultaneously. It is currently doing outreach to employers throughout California — large health systems in particular — to get their employees engaged in advance care planning. “It's very different to experience this on a personal level than as a health care provider,” said Citko. “We're working with the health care systems to personalize this for people so that when they show up at the bedside to help patients, they show up differently.”

The Coalition, which has 25 local coalitions throughout the state, is also doing outreach and training with faith communities so that faith leaders know about end-of-life care and can better support their congregants.

The workshop participants, Citko explained, would also serve as leaders in bringing The Conversation Project to their community organization. She showed participants how to “map” their local spheres of influence using sticky notes. The resulting map showed where people lived, worked, worshipped, and socialized. “This is how we get a sense of how this room correlates to the areas of influence in Contra Costa County,” Citko said. The longer-term goal is to have the



Attendees “mapped” their spheres of influence.

ideas that are successful in this pilot community begin to disseminate throughout the state.

### **At the Kitchen Table**

Ellen Goodman, co-founder of The Conversation Project and Pulitzer Prize-winning writer, spoke about the power of stories in cultural change. As a journalist Goodman had covered the civil rights movement, the women's movement, and the LGBT movement — all of which were led by the baby boomer generation, she said. "We are a pro-change generation."

Now, boomers are leading the longevity revolution, she said, as 10,000 people reach age 65 every day and the average lifespan has lengthened by 30 years in the last century. "We have a generation that is poised to overwhelm the health care system," Goodman said, and at the same time, many people "are not dying in the way they would choose." Longevity has brought with it the fear of not getting enough treatment at the end of life, she said, as well as the fear of getting unwanted treatment. Both fears can be addressed if people's wishes are both communicated and followed, she noted, and this requires cultural change.

Most of the social change of the past decades has come about because people have told their stories, Goodman said. Everybody has a story. When these stories are shared, she said, "that's the moment when change happens." Goodman's own story moved her to create The Conversation Project:

"In my 60s I went from being a working mother to a working daughter. I was faced with a huge number of decisions for which I was blindsided and unprepared. So I began to talk to others. We took off our professional hats and just told stories — there were stories about good deaths and hard deaths. We then asked, 'How can we change this? How can we leave our own survivors without guilt and with less uncertainty?'"

The answer, Goodman said, is cultural change outside the health care system as well as inside it. "We believe the starting point is the kitchen table with the people we love," she said. "We can make Contra Costa a national model — the epicenter of a cultural change movement that can simply make the end of life more humane for everyone."

### **Conversation Moving Ahead**

Since the April gathering, a steering committee has formed with representatives from a number of organizations: Contra Costa County Inter-faith Council; John Muir Senior Services; Hope Hospice; Hospice of the East Bay; Alameda-Contra Costa Medical Association; Comfort Homesake; Contra Costa Council, and other community leaders.

Hospice of the East Bay scheduled a Conversation Project workshop to be held at the Pleasant Hill Senior Center in September.

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## **ORGANIZATIONS REPRESENTED AT *THE CONVERSATION PROJECT***

Alameda-Contra Costa Medical Association  
Brighter Beginnings  
Coalition for Compassionate Care of California  
California HealthCare Foundation  
Cambia Health Foundation  
Cambia Health Solutions  
Chevron Corporation  
Contra Costa Council  
Contra Costa Emergency Medical Services Division  
Contra Costa Regional Medical Center  
The Elders Learning Community  
Hope Hospice  
Hospice of the East Bay  
Hospital Council of Northern & Central California  
Institute for Healthcare Improvement  
Interfaith Council of Contra Costa County  
Kaiser Permanente Diablo Area  
Lamorinda Senior Transportation  
Muir Medical Group  
Office of Assemblywoman Susan Bonilla  
Office of Senator Mark DeSaulnier  
Office of Supervisor Federal D. Glover  
Office of Supervisor Karen Mitchoff  
Rossmoor  
San Ramon Senior Center  
SCAN Health Plan  
Stanford University School of Medicine  
Sutter Care at Home  
The Conversation Project  
The Permanente Medical Group  
United Way of the Bay Area  
VITAS  
Volunteer and Emergency Services for Contra Costa  
Youth Homes, Inc.

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## **ABOUT THE FOUNDATION**

The California HealthCare Foundation works as a catalyst to fulfill the promise of better health care for all Californians. We support ideas and innovations that improve quality, increase efficiency, and lower the costs of care. For more information, visit us online at [www.chcf.org](http://www.chcf.org).