HAVE YOU HAD THE CONVERSATION?

Learn How to Talk with Your Loved Ones about Your Healthcare Wishes

March 12, 2018 • Warwick, RI

The first in a series of the Institute for Healthcare Improvement’s “The Conversation Project” Presentations in RI

Patient Engagement with Advance Care Planning Initiative funded by State Innovation Model (SIM) Grant
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Standing room only at Tamarisk Assisted Living Residence on March 12, 2018.

Following the event:

**Desire to talk with their family**

95% of participants wanted to talk with their family about their healthcare wishes

**Desire to talk with their healthcare providers**

88% of participants wanted to talk with healthcare providers about their healthcare wishes
Executive Summary of SIM Initiative

The patient engagement with advance care planning initiative, funded by a State Innovation Model (SIM) grant, seeks to empower Rhode Islanders with knowledge of advance care planning and the skills to engage patients with advance care planning. Under the leadership of Healthcentric Advisors, the Improving Care Coalition, (a project of Rhode Island State Nurses Association), VNA of Care New England, Care New England, Progreso Latino, and RI State Council of Churches are conducting campaigns to empower consumers to discuss end-of-life health care wishes with loved ones and health care providers.

The consumer campaign consists of two elements: public awareness campaign and events. The consumer engagement component is a group effort of the partner organizations under the direction of the Improving End of Life Care Coalition, Progreso Latino in Latino communities, and the RI Council of Churches guiding engagement with faith communities.

The public awareness campaign aims to empower the general public about advance care planning and how to share your healthcare wishes with family and healthcare providers. We are currently disseminating information through digital and printed materials, press relations, and community outreach.

Our events focus on discussing the importance of having a plan including discussing health care wishes and hands-on assistance that includes how to complete a documented plan. The community campaign events offer many learning opportunities. Our 30-minute presentations introduce the advance care topic. A 60-minute advance care planning workshop has an emphasis on how to talk about health care wishes. Our 90-minute workshops by the Institute for Healthcare Improvement’s “The Conversation Project” are interactive forums to increase an individual’s comfort level with advance care planning. Our “Train the Trainer” workshops focus on teaching others how to present advance care planning workshops, including having conversations about healthcare wishes. Additionally, we’re offering small group presentations about advance care planning and the Institute for Healthcare Improvement’s “The Conversation Project” workshop in Spanish.

The group medical visit pilot is an effort of Care New England to prepare patients in the Rhode Island Primary Care Physicians Corporation and Care New England Medical Group practices to discuss health care wishes with their provider. Health care providers make referrals for advance care planning education, held in the physician office and focuses on patient and medical provider discussion around advance care planning. This effort offers patients and their families education and tools so they can actively participate in these discussions during medical visits.
Executive Summary: March 21, 2018 Event

Healthcentric Advisors, in partnership with the Improving Care Coalition (a project of Rhode Island State Nurses Association), VNA of Care New England, Progreso Latino, and the RI Council of Churches sponsored the first in a series of the Institute for Healthcare Improvement’s “The Conversation Project” events. These interactive workshops are guided conversations designed to facilitate discussions about end-of-life-plans between with loved ones. The event was held March 12, 2018, in Warwick at Tamarisk Assisted Living Residence and had standing room only.

The speaking program represented a diverse set of perspectives and expertise. Maureen Glynn from the Rhode Island Improving Care Coalition opened the event followed by moving words from Senator Sheldon Whitehouse. Reverend David Ricard from St. Gregory the Great Church provided his perspective as a faith leader and Harriet Warshaw, Executive Director of “The Conversation Project,” facilitated the bulk of the presentation including walking participants through materials to help them tackle the end-of-life topic with loved ones.

Perhaps most notable was the audience participation. Event participants were eager to learn from the expert panel, and share their own experiences. Healthcare experts were on hand to guide participants through their “Conversation Starter Kits.”
Summary of Comments: Reverend David Ricard

Reverend David Ricard, started his remarks with saying that having an advance directive document is only a part of the process. Rev. Ricard emphasized that much is lost if there is only a document and no ongoing conversation about health care wishes at each stage of life. As the chaplain at Kent Hospital, he comforts families facing the anguish of trying to make health care decisions for their loved one without necessarily knowing their wishes. So often families are in conflict having to make difficult decisions for their loved ones who are in critical condition. These families struggle because they do not know what their sick loved one would have wanted, and are suddenly faced with having to figure it out on their own. Rev. Ricard encouraged everyone to broach the discussion of what matters most with who you trust. He noted that having the conversation about health care wishes extends beyond senior citizens and reaches all.

Reverend David Ricard is a priest in the Roman Catholic Diocese of Providence. He serves as the chaplain at a Kent Hospital, a Care New England Hospital in Warwick, RI and staff ministry at St. Gregory the Great Church. He served as pastor of St. Gregory the Great Church.
Summary of Comments: Honorable Sheldon Whitehouse

Senator Whitehouse greeted the attendees and congratulated them for taking the time to learn how to have the advance care planning conversation. He noted that it can be a difficult conversation for families but a needed one.

Senator Whitehouse shared his personal end-of-life care story with his family. He compared his father’s passing with his wife’s grandmother’s passing. His father died in a way he wanted—-with peace and dignity. His wife’s grandmother, however, lived out-of-state. She had a fall and had to be hospitalized. She died in the ICU with a tube down her throat and connected to wires through her arms. She didn’t get to say goodbye to her family, the way she would have liked.

He noted that Rhode Islanders can choose to memorialize our end-of-life care wishes. Regardless of age, discussions about advance care planning needs to be had among all members of our families. Let your loved ones know what choices are important to you when it comes to end-of-life care. He highlighted how personal the topic is and how valuable the conversation can be for families to have prior to a medical crisis. It can look very different if the family hasn’t had the conversation. You don’t want the dying person’s wishes to be unknown or overridden. It is important that nurses, doctors, and families are allowed and encouraged to have these conversations.

Senator Whitehouse acknowledged the efforts made by regional leadership to raise awareness around the topic having end-of-life discussions, including C-TAC (Coalition to Transform Advanced Care,) Healthcentric Advisors, Improving End of Life Care Coalition, a project of the Rhode Island State Nurses Association, Care New England Health System, Rhode Island Hospital (Lifespan), Progreso Latino, and the RI Council of Churches. He thanked the Roman Catholic Diocese of Providence for its efforts in helping people know about the advance care planning conversation, including a booklet for “End of Life Decisions – A Catholic Perspective.” He acknowledged Marti Rosenberg, the Director of the State Innovation Model Program for supervising the administration of the SIM grant.

Senator Whitehouse stated that he will continue to work in Congress to improve end-of-life care decision making so that federal regulations don’t get in the way of these choices. He welcomed ideas related to this topic to aid his conversations in Washington, DC.

Honorable Sheldon Whitehouse is a United State Senator for Rhode Island. He is committed to the improving advance care planning. In 2000 he held the first Summit to assess the state of end-of-life care in Rhode Island when he was Rhode Island Attorney General. He mobilized a Task Force to Improve End-of-Life Care to act upon the findings and recommendations of the Summit. His improving end-of-life care initiative continues today through the Improving Care Coalition, a project of Rhode Island State Nurses Association. Senator Whitehouse serves on the Budget Committee; the Environment and Public Works Committee (EPW); the Judiciary Committee; and the Finance Committee.
Summary of Comments: Harriet Warshaw

Harriet Warshaw facilitated the interactive workshop dedicated to helping people talk about their wishes for end-of-life care. She used a multifaceted approach consisting of presentation, videos, and discussions among attendees.

She opened with a story of Ellen Goodman, a former Boston Globe editor, Pulitzer Prize winner, chronicler of the women’s movement, and co-founder of “The Conversation Project” initiative. When Ellen’s mother passed, she spoke to Hebrew SeniorLife about how the organization handles end of life experience. She then spoke to Don Berwick of the Institute of Healthcare Improvement. Ms. Berman concluded that how end of life care is handled things will change when people demand the rules are changed. From this idea, a public campaign occurred that people’s wishes are respected.

Ms. Warshaw noted that “everyone has a story” about end of life and they want to talk about it. She asked the audience to share an experience about a “good death” and “difficult death.” In small table setting, attendees shared experiences with any “good death’ or “bad death.”

After reconvening the entire group, Ms. Warshaw explained that having a conversation about end-of-life wishes is a conversation worth having. She noted that she had the conversation with her young adult children. One cried and the other assured her that he would help. Consider when you should sit down and talk with your kids about this. The impact of these conversations is the feeling that you know you did your best to honor the wishes of your loved one.

Ms. Warshaw explained that research shows that 90% of people in the U.S. think it is important to have this conversation. Yet, only about 30% are actually having the conversation. The conversation should be happening at home, in the physician office, in the faith-based organizations – prior to a tragic situation.

She noted that “the Conversation Project” has starter kits to help people learn how to have the conversation with family. It also has educational materials in many languages and trains a variety of audiences on how to have the conversation with groups of people. There is a starter kit for parents of critically ill children, families with loved ones with dementia, and for faith leaders about bringing the conversation to their congregations.

She showed a video¹ with journalist Diane Sawyer, who is a vocal advocate for the Conversation Project and highlighted a story about a family from Nebraska. The family had the conversation with their elderly father/grandfather which prompted the three generations to talk together about their wishes.

Knowing someone’s end-of-life care wishes is critical to helping caregivers honor goals for care. Ms. Warsaw shared more details about her mother’s story. After multiple previous cancers, her mother was diagnosed with lung cancer. By this time, her mother felt as if she’d had enough treatment and didn’t want to have any more chemotherapy. It turned out though that she did

¹ [https://youtu.be/J1r0Xbh0UVo](https://youtu.be/J1r0Xbh0UVo)
want to be able to attend her grandson’s bar mitzvah. Therefore, they went back to the oncologist to talk about the current need.

The attendees broke into groups to discuss what was important to them and how to communicate them to family. Some examples of important considerations are:

- To be pain free;
- Free of life-saving machines; and,
- To have the family around me.

Ms. Warshaw discussed the importance of picking someone to make health care decisions for you when you cannot communicate your wishes yourself. She suggested selecting someone you feel can carry out your wishes and advocate for you. She stated that you do not have to select a family member to be your health care proxy. However, it is important for you to talk to whoever you ask to get a sense of their ability to understand and honor your wishes.

She stated now is the time to choose your health care proxy. There is no time like the present. Have the conversation and appoint a proxy today.

Ms. Warshaw suggested that you review your health care choices every five years or when a big event comes up (e.g. marriage, vacation, childbirth, illness etc.). Make sure to review your health care choice with your loved ones and your health care provider.

Ms. Warshaw recognized the difficulty of beginning the conversation about end-of-life care wishes but noted its importance. She played a humorous video about practicing how to initiate the conversation. ² She encouraged attendees to practice their best approach for discussing end-of-life care with each other.

Ms. Warshaw concluded by summarizing her presentation and encourage the attendees to share their healthcare decisions with loved ones.

**Harriet Warshaw is the Executive Director of “The Conversation Project,” at the Institute for Healthcare Improvement. Harriet Warshaw has over thirty-five years of management experience in both the public and private sectors including senior positions at The Boston Hospital for Women, New England Baptist Hospital, Genzyme Corporation and the New England Healthcare Institute.**

² “Practice Makes Perfect Video,” [https://youtu.be/pyMXtVprN74](https://youtu.be/pyMXtVprN74)
Lessons Learned

- Ninety percent (90%) of participants would recommend the event to family and friends.

- After attending the event, attendees were more willing to discuss health care wishes with their family and health care provider.
  
  - Before the event, 82% of participants wanted to talk with their family about their health care wishes. This increased to 95% of participants after the event.
  
  - Before the event, 79% of participants wanted to talk with their healthcare provider about their healthcare wishes. This increased to 88% of participants after the event.

- Fifty-one percent (51%) of participants report having an advance care plan which is higher than the national average of 36.7% of people with some form of an advance directive plan.¹

- Forty percent (40%) of participants’ report having a written advance care plan. This is slightly more than the national average of 38.2% of people with a chronic illness have advanced directives compared to 32.7% of healthy people, a difference that wasn’t statistically meaningful.²

- Forty-eight percent (48%) of participants report having discussed healthcare wishes with family which is less than the national average of 56% discussing end-of-life care wishes with family.³

- Less than 1% of participants’ report having the healthcare wishes conversation with a healthcare provider.

- Our event survey suggests that attendees were more willing to discuss healthcare wishes with family and friends rather than healthcare providers.

- Less than 1% of attendees report having the healthcare wishes conversation with a healthcare provider which is consistent with studies that suggest that physicians’ have concerns about holding advance care planning discussions with patients.⁴ A 2016 Hartford Foundation survey suggests that nearly half (46%) physicians reported that they frequently or sometimes feel unsure of what to say.⁵

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² Id.

³ Survey, Center for Disease Control (2005.)

⁴ Survey, The John A. Hartford Foundation, California Health Care Foundation and Cambia Health Foundation (April 2016.)

⁵ Id.
After experiencing the recent loss of two loved ones: one with and one without an advance care plan, Linda Loxley, an elder care case manager, was inspired to do her own.

“It really is the best gift you can give your loved one because they are going to be going through so much stress after losing you that they’re really not going to be able to make sound decisions.”

Colleen DeGroot was a hospice nurse in the past but now works in caregiver homes and has personal experiences with being with loved ones in their final days.

“I’ve seen so many families at end-of-life and it’s disruptive. Now that I have this actual pamphlet to give then I think it will be very beneficial.”
Thank you to the following organizations for making this event a success:

Alliance for Better Long Term Care, Inc.

- AARP RI

- Blue Cross and Blue Shield of Rhode Island

- Brown University

- Caregiver Homes

- Executive Office of Health & Human Services

- Hope Health

- Rhode Island College, School of Nursing

- Rhode Island Department of Health

- Rhode Island Medical Society

- Rhode Island State Nurses Association

- Tamarisk Assisted Living