

Helping Parents Talk to Terminally Ill Children about End of Life

CAMBRIDGE, Mass. | A Pediatric Starter Kit launched by The Conversation Project will help parents facilitate the critical and necessary conversation about end-of-life with their terminally ill children.

[Research](#) has shown that parents who talk about death with their children do not regret it – while many of those who do not talk about it, regret not having done so. Medical literature and stories from the field show that children often sense that they are dying well before their care teams and families. Children don't talk about it because they don't want to upset, and feel an urge to protect, their parents.

Helping families overcome the communication barrier is the goal of The Conversation Project, a public engagement campaign with the mission to have everyone's end-of-life care wishes expressed and respected.

At the heart of the project is the [Conversation Starter Kit](#), a free downloadable step-by-step guide that helps adults have "the conversation" about their preferences for end-of-life care. Once the Starter Kit became widely used by adults, parents and pediatricians began contacting The Conversation Project to express the need for a guide specifically designed to help parents have the conversation with their seriously ill children, often not just once, but over time as the disease progresses.

"For most adults, planning their own end-of-life care is difficult enough, let alone planning for the loss of a child. It's never easy, but we know how important this conversation is," says Ellen Goodman, founder of The Conversation Project. "We collaborated with parents, palliative care experts, and nurses to bring forth a guide to help ease parents into this delicate topic. There is no prescriptive, one-size-fits-all methodology, but rather multiple ways to begin and continue this conversation."

The new [Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child](#) is now available for download. The Pediatric Starter Kit offers advice and provides stories from parents and palliative care specialists who have been there. It provides questions that can help parents navigate the approach to the conversation based on the personality and cognitive level of the child.

"No one wants children to die, but they still do," says Dianne Gray, president of Elisabeth Kubler-Ross Foundation and a contributor of the Pediatric Starter Kit. "I understand it can seem unkind or cruel to talk to children about their own death, but it is not." In 2005 Gray experienced the loss of her son, Austin, age 14, as a result of a neurodegenerative disorder.

"Though he was nonverbal the last five years of his life, we had developed a method of communication that worked for us," says Gray. "Having those conversations with him was one of the most difficult, yet grandest acts of love that I could do for him. Knowing that he was a

part of the decision making helps me feel such peace.” She now shares this message globally, as an advocate for pediatric palliative care via the International Children’s Palliative Care Network and the American Academy of Pediatrics Section of Hospice and Palliative Medicine. The Pediatric Starter Kit provides suggestions and ways to navigate the conversation if a child or baby cannot speak.

“How parents and loved ones handle the end-of-life of a child can truly define that family going forward. Talking it through makes the impossible slightly less impossible,” says Blyth Lord, founder of the Courageous Parents Network and contributor to the Pediatric Starter Kit. “When your child has a terminal illness it becomes a part of the family’s narrative. Being prepared and having a plan can write the story of their child’s life so they can be at peace with the way it ended.”

Lord never got to have that conversation with her two-year-old daughter, Cameron, who died from Tay-Sachs, a degenerative disease. However, she credits her palliative care team for guiding her family through some of the most difficult decisions they’ve ever made.

“My husband and I had these conversations, practiced them with each other, and thought through every option with our pediatrician,” Lord says. “We would hear of families making these emergency decisions in the hospital, without time to think, and felt horrible for them. It’s hard to make a thoughtful decision in a crisis when you haven’t done the work.”

About The Conversation Project:

The Conversation Project, co-founded by Pulitzer Prize-winner Ellen Goodman and launched in collaboration with the Institute for Healthcare Improvement (IHI), 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.

###