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Tagline

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Through Online Media, The Conversation Project Provides an Easier Path to End-of-Life Care Discussions

The Conversation Project wants to know: Have you had the conversation?

Since its founding in 2010, this grassroots campaign has been encouraging people across the country to start conversations about dying. Through initiating these conversations, the campaign hopes to prevent the feelings of guilt and uncertainty that often accompany rushed or uninformed end-of-life care decisions.

“We know that everyone has a story of a good death or a bad death,” states co-founder Ellen Goodman on the campaign’s website, “and we know that the difference between those two stories is often whether or not they have the conversation.”

The Conversation Project emphasizes the importance of having discussions about end-of-life care with family, friends, and caregivers before any major decisions are necessary. These



discussions may include wishes about avoiding overly aggressive medical care, being cared for in a nursing facility, funeral or memorial service arrangements, and when to focus on being comfortable over being cured. This ensures that the wishes of the dying are honored and that they are given the best death possible.

Recognizing that “hearing about other people’s experiences can be a good way to get your own conversation started,” the web-based format of The Conversation Project provides a unique opportunity for members’ experiences with end-of-life discussions to be shared worldwide. The website encourages its users to share their own stories about having conversations about the end of life, and many of the featured stories describe feelings of relief and security from knowing their wishes, or the wishes of loved ones, are clearly outlined.

“We know that no guide and no single conversation can cover all the decisions that you and your family may face,” the website assures. “What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.”

For more information, and to read stories shared by others about death and end-of-life care, visit theconversationproject.org.

How Do We Begin the Conversation?

The Conversation Project provides a free starter kit that can guide you through the process of end-of-life care planning. Here are some suggested steps:

- **Get Ready:** Think about who you might have the conversation with, and when and where can it may occur.
- **Get Set:** What are the most important things that you want your friends or family to know about your goals for end-of-life care?
- **Go:** Break the ice and let the conversation happen. Don’t force it.
- **Keep Going:** Continue to talk, and put your wishes down on paper.

End-of-Life Care News Briefs for Patients and Families

Getting Rid of the Phrase ‘Do Everything’

When a loved one is seriously ill, it may be tempting for friends and family members to say to the doctors, “We want you to do everything.” But what does the phrase “do everything” really mean?

The authors of an article published in the *Archives of Pediatrics & Adolescent Medicine* point out that “medical care can go in many different directions, but not all at the same time,” and that the phrase “do everything” does not indicate a specific path for care.

Patients, loved ones, and doctors must be open to discussing what different options for patient care might look like, instead of hiding behind the false comfort of “do everything.” What if “everything” includes treatments that do not have any long-term benefit for the patient? Should doctors always attempt to resuscitate an elderly patient, even at the risk of cracked ribs or further injury? When should nature take its course? Answers come more easily when communication about patient care is clear and direct. This approach also allows families and physicians to make genuine connections and establish trust. Families and friends can be reassured that doctors will remain “committed and engaged with their loved one,” which provides comfort during a time of difficult decisions.

On the other hand, the authors also describe the dangers of saying “There’s nothing more we can do.” Even when patient recovery is no longer possible, and further treatments may only cause additional pain for patients, families can still focus on managing pain and discomfort for their loved ones. Doctors, families, and patients can establish goals of care at all stages of treatment, even through the transition to comfort-only care. “Just as we cannot do everything,” explain the authors, “we can always do something.”

How Hospice Care Can Benefit Dementia Patients

Hospice is traditionally used as an end-of-life option for cancer patients because of the better quality of life it provides for those who are terminally ill. What many do not consider, however, is the benefit that hospice care can also have for those suffering from dementia or similar illnesses.

A study reported in the *American Journal of Hospice & Palliative Medicine* started out with one question: Do patients with dementia have a better quality of life when they are enrolled in hospice?

The study results indicate that yes, they do. While many dementia patients were not able to participate in the study themselves, the majority of caregivers and family members expressed

that hospice care provided a level of comfort at the end of life that would be missing otherwise. Not only did family satisfaction increase, but dementia patients enrolled in hospice had a “better overall dying experience” than patients with the same disease who did not use hospice care.

Hospices are able to provide a better dying experience for dementia patients by ensuring that they have fewer unmet needs at the end of life, and by keeping patients on a schedule for pain management. Dementia patients in hospice were more likely to die in their location of choice, something important to many patients and their families.

With more and more Americans dying of dementia-related illnesses, report the study authors, “this research indicates that hospice care can make a difference in [their] dying experience.”

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