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## Tagline

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## Hospice and Palliative Care Help Change the Cultural Idea of What Makes a ‘Good Death’

**M**any professionals in end-of-life care will often explain the goal of hospice or palliative care as “creating a good death,” and recently a pair of researchers took on the task of finding out what “good death” really means.

“Studies show that too often patients die in hospitals with poor quality of life,” they explain in their article, but the circumstances that make a death “good” are often harder to pinpoint.

The authors’ efforts to find out what makes a “good death” led them back to different places in time. “Throughout history, humans have always tried to answer questions about death and dying,” they note. Early ideas of “good death” often focused on community and the passage to the next life. But around the 20th century, “the concept of good death transitioned to *managed death* which included...participation of health care professionals in the event of dying through managing different aspects of the dying process,” the authors explain. “Death was no longer viewed as part of the journey of life but rather as a medical failure.” The beginnings of the hospice and palliative care movement in the 1960s, however, created a new framework for treating death as a journey.

Hospice introduced a team approach to address the needs of patients and families, and emphasized the importance of treating the patient’s

full range of needs — physical, mental, social, and spiritual — instead of managing only physical pain. The hospice movement also stressed that a patient should die on his or her own terms.

This idea of “good death” is still prevalent in the current medical world. After interviewing nurses, physicians, patients, and families, the researchers found that “common attributes to a good death [included] relief from pain and suffering, being aware of dying, accepting the timing of one’s death, acceptance and autonomy, keeping hope alive, preparing for departure, and making the decision about where to die.” They emphasize that good communication between patient, family, and care team — whether in hospice or palliative care — is crucial to understanding and finding a “good death” for the modern patient.

### What Made a “Good Death” During Different Points in History?

- **Prehistoric (2,500,000 - 4,000 BCE):** Since death was often sudden, the focus for a good passing was centered on the journey the individual would experience in the next life.
- **Premodern (3,500 BCE - 15th century):** Gradual death by disease gave individuals the opportunity to have families and communities assist in preparing for death. Death was often a community event and occurred at home.
- **Modern (16th - 20th century):** Death became more managed, and individuals often died in hospitals under the watch of a health care team. The introduction of hospice and palliative care in the mid-20th century helped to give patients more independence to die on their own terms.



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

## Advance Directives Should Take Center Stage, Say Doctors

According to a recent study published in the *American Journal of Public Health*, a large portion of the population is unaware of how important having an advance directive is, and how easy it is to fill one out. The authors of the article answer some common questions about this essential part of end-of-life planning:

### What is an advance directive?

“Advance directives are free, legal, and straightforward forms that can be completed in a few minutes,” state the authors. These forms ensure a patient’s wishes are respected, even when the patient can no longer make decisions for himself.

### What does an advance directive cover?

- Amount and kind of care received under certain medical circumstances, like coma or heart failure
- Who will be the health care agent to make medical decisions when the patient is no longer able
- Organ/body donation
- Funeral and burial arrangements
- Recordings for posterity
- Assisted dying (in certain states)

### Why is an advance directive important?

“Though we Americans strive to control nearly every aspect of our lives, many of us abandon control of life’s final passage,” the authors note. “We believe [end-of-life care] should be primarily determined by individuals, and not by government, insurance companies, or hospitals.” Advance directives give us a voice in “how, when, and where we die.”

Additionally, the authors urge that advance directives are not only for the elderly or terminally ill — **every person can and should take the time to fill out an advance directive** and discuss his or her choices with doctors, friends, and family. “The more normal the topic is,” the authors remind, “the less scary it will become.”

## Step Two of The Conversation Project: Talking to Your Doctor

The Conversation Project is a public engagement campaign launched in 2012 to help patients become more comfortable determining and discussing their end-of-life care wishes. The first phase, focused on how to bring up the subject with loved ones, has now been followed by phase two: talking to the doctor.

The downloadable booklet, available for free on The Conversation Project’s website, includes worksheets, practice scenarios, and scripts to help patients feel more confident in knowing what to say to doctors or care team members.

“Don’t wait for a medical crisis,” the booklet suggests. “Talking with your doctor or nurse now makes it easier to make medical decisions when the time comes.... Remember, you’re the expert about what matters most to you.”

Though it provides simple explanations for complex medical terms, the booklet reassures that a patient should not be concerned with knowing all possible medical interventions or treatments. Instead, the patient should focus on what’s important to him or her as an individual.

The booklet also guides patients through how to set up an appointment to discuss care options, what questions to ask the doctor, what to do if medical opinions conflict, and when to have follow-up conversations.

“You’ll probably have several conversations with your doctor,” the booklet notes. “But every conversation will help your health care team understand what matters to you.”

To download the free booklet, and to get more information on The Conversation Project, visit [theconversationproject.org](http://theconversationproject.org).

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