

Changing Expectations for Care at the End of Life

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The culture and system of care at the end of life present unnecessary emotional, physical, and financial burdens for patients and their loved ones. Although this is what we have come to expect, other realities are possible.

The phrase “**What we’ve got here is (a) failure to communicate**” is a famous line from the 1967 film *Cool Hand Luke*. In the movie, Luke, a prisoner played by Paul Newman, is confronted by the warden who utters this line as he admonishes Luke for failing to understand the one-way nature of the communication and the absence of his right to independent action due to his present circumstance.

It is **a failure to communicate** that underscores much of the improvement needed when it comes to care at the end of life. Providers lack adequate training and practice in one-way and especially two-way communications skills. Physicians and health care providers are often unwilling or unable to tell patients and their families “bad news” or even use the language of death and dying, which leads to difficulty communicating frankly about the disease. As a result, patients are missing out on true shared decisionmaking.

A failure to communicate is the often heard complaint from patients facing serious illness or their family members: “No one told me my options,” “No one talked to me; they talked around me,” and “No one asked my opinion or what I wanted.” The end result: families do not hear about valuable options like hospice or palliative care until much later than they should – if at all. And many are unable to share their care wishes – or have them respected. We recognize that as a consequence, billions of dollars are spent on terminally ill patients – much of that on patients who may not want or fully understand the treatments being offered. This is frustrating since patients who have made a different choice – opting for palliative and hospice care as part of their end-of-life planning – often experience a higher quality of life and lower costs in their final days. Some even see their lives prolonged.

So it is **a failure to communicate**, which has shaped much of the Jewish Healthcare Foundation’s (JHF) current five-year *Closure* initiative. Our goal is to get people thinking, talking

about, and planning for the course of their life, treatment options for serious illness, and, ultimately, reflecting on how they want to die.

CLOSURE CONVERSATIONS AND SELF-DIRECTED EDUCATION

The *Closure* initiative is an education, planning, policy, and outreach initiative with a goal of redefining quality care for people with serious illness by raising expectations and empowering them to seek a different health care experience at the end of life – one that aligns with their values, beliefs, and wishes, as well as their health status.

CLOSURE VISION

- Patients and loved ones are informed about the choices and challenges they are likely to face and provided with the resources available to help them.
- The resources and systems needed to support quality end-of-life outcomes are widely accessible in institutional, home, and community-based settings; understood by physicians, patients, and families; and appropriately funded to meet the needs of patients and loved ones.
- Educational curricula, planning tools, and community support are widely available for professionals and community members.
- End-of-life issues are openly discussed, with the experience being viewed by society not as a period of decline, but as meaningful and uplifting whenever possible.

Through *Closure Community Conversations*, JHF helps bring together approximately 30 individuals (physicians, nurses, pharmacists, long-term care professionals, social workers,

palliative care professionals, attorneys, clergy, and patients and their family members) for six facilitated conversation sessions. These include an initial overview of palliative care and issues at the end of life; a clergy-led discussion of the influence of religion on end-of-life decisions; an exploration of local tools and resources for advance planning; individuals' good and bad experiences at the end of life; and a final session to develop a community strategy/action plan. Successful sessions have already been held by various religious groups and with the African-American community. Others are in planning stages in various neighborhoods and ethnic communities. The lessons and techniques of *Closure* are being packaged into a guide, which will make the *Closure* model fully portable and allow communities with diverse viewpoints and traditions to approach the conversation and learning their way. JHF has already received over 50 inquiries for the guide.

At www.closure.org, JHF provides *Closure 101*, a dozen web-based educational modules (for professionals and consumers) exploring serious illness and advance planning from diagnosis to grief and bereavement. The lessons were written by experts in language appropriate for both consumers and professionals. Site visitors can complete an on-line assessment that directs them to modules that will be the most helpful to them. Locally, organizations may schedule a lesson or a series of face-to-face presentations/lessons through the *Closure* speakers' bureau of over 30 trained professional volunteers.

GETTING THE MESSAGE OUT – ANY WAY WE CAN

JHF is also promoting conversations around palliative care and the end of life through television, books, the internet, and statewide convenings.

With JHF funding, our local PBS station, WQED, produced *The Last Chapter*, a new one-hour documentary that explores the significant medical, cultural, spiritual, and ethical implications surrounding the end of life. The documentary takes viewers inside the hospitals, homes, and lives of palliative and hospice care recipients and providers. It is based on the premise that everyone has a story – a life that can be broken into chapters. For patients with a terminal illness the question becomes: Who will write the last chapter? It features stories about real people facing serious illness and how they and their families live, look ahead, and plan. It models behavior and inspires viewers to have those difficult conversations with their families and their providers so they may control their journey and achieve a more peaceful last chapter.

Twelve Breaths a Minute is a special JHF-funded edition of *Creative Nonfiction* released in 2011. The anthology contains over 20 firsthand accounts from around the country – as told by physicians, nurses, patients, families, and clergy – on end-of-life care. Each story helps readers understand what worked, what did not, and what was learned.

The Coalition for Quality at End of Life (a stakeholder group that JHF helped fund, found, and now leads) is working with policymakers and players across the care continuum to assure that education and training, coverage, and quality metrics throughout our state reflect best practice in palliative and end-of-life care. JHF is convening the statewide dissemination and implementation conference *Closure: Developing a Statewide Strategy for End-of-Life Education and Care Delivery* in Harrisburg, Pennsylvania, in spring 2012. The conference will result in implementation strategies to affect change in practice and establish a learning network for further collaboration, policy, and practice change.

STRATEGY: INFUSING A VISION OF CARE THROUGHOUT OUR WORK

We recognize that changing culture will take more than individual grants or programs. It will require infusing a vision of quality care at the end of life throughout our work – beyond initiatives typically thought of as “end-of-life” or “palliative” care. To get there, this is our strategy:

- Emergency Medical Services Champions are developing curriculum to assure that emergency medical technicians are capable of conducting appropriate conversations with families about Do Not Resuscitate orders or Physician Orders for Life Sustaining Treatment when they respond to 911 calls.
- Long-Term Care Champions will consider how to assure that palliative care education and consults are made available for their residents and their families – even those with dementia.
- Our demonstration projects – Community Care Transitions, the Accountable Care Network, Patient Centered Medical Home, Caregiver, and Readmissions Reduction efforts – are each including appropriate strategies for advance care planning and palliative care.
- Fellowship programs for graduate health professions students and interdisciplinary geriatric training models incorporate conversations around care at the end of life.

JHF is committed to implementing a broad agenda that sparks the conversation and the needed culture shift, supports systems that improve the quality of end-of-life care for patients and their families, and decreases unnecessary costs. Above all, we aim to eliminate *the failure to communicate* and its implications for care at the end of life.

VIEWS FROM THE FIELD is offered by GIH as a forum for health grantmakers to share insights and experiences. If you are interested in participating, please contact Faith Mitchell at 202.452.8331 or fmitchell@gih.org.