

## **The last days of our lives: Our health-care system needs to provide better, more thoughtful end-of-life care**

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By Dr. Robert Arnold and Nancy Zionts

Each year, millions of babies are born and millions of people die. Yet, while we expect the beginning of life to go well, when it comes to the dying process we expect, and often settle, for the worst.

In the 1950s most births took place in hospitals. Cesarean sections, epidurals and heavy doses of pain medication were the norm. Expectant fathers paced the halls away from the action. Women then began to feel that they were being denied the true experience of giving birth. Throughout the 1960s and 1970s, they challenged the perception that childbirth needed to be treated as a sickness instead of a miracle. Now, decades later, expectant mothers have choices, and fathers participate in the birthing process.

Today, people suffering from life-threatening illness face a situation similar to what expectant mothers faced in the 1950s. The end-of-life experience seems to spiral out of their control. In the 2006 Pennsylvania End-of-Life Background Report, families reported great dissatisfaction with the dying process, particularly in areas of pain management, social and financial burdens, and access to palliative care and hospice services.

Research shows Pittsburghers are more likely to be hospitalized in the last year of life, spend more time in the ICU during their final hospitalization and spend more money than patients in other cities, even though studies show that there is no correlation between intensity of medical services, length of life, or patient and family satisfaction.

The Jewish Healthcare Foundation is leading a charge to redefine quality care for patients with life-threatening illness by raising expectations and empowering the community to want, and demand, a different health-care experience. The goal is for people to redefine how they think about medicine's role in improving function, so that they can begin asking their doctors to do the "right things," instead of asking them to do "everything." In addition, people's end-of-life focus should shift from the last days of life, to the last period of living.

For this to happen, the health-care system needs to change its "default" settings. Currently, there is a bias toward treatments that cure illness, sometimes without attention to care for those who cannot be cured. Providers focus more on tumor size and lab results, than on decreasing the burden of illness. We spend too much time treating the disease, rather than improving the lives of the patients with the disease. Changing this bias will require a new skill

set for health-care providers, who will need to communicate with patients on a new level, and function both as skilled clinicians and sensitive healers.

To catalyze this change, JHF has introduced Closure, an education, planning and outreach effort focused on end-of-life care. For more than a year, doctors, nurses, caregivers, hospice workers, clergy and long-term-care professionals have been sharing their experiences. The group has developed a series of recommendations:

### **Talk about it**

As uncomfortable as it is and whatever your age, begin discussing dying and diagnoses of serious illness with family members and health-care providers. While it makes sense to hope for the best, you should talk to your family about your goals if medical treatment doesn't help. Consider how you want to live out your life before you are in chaos and critically ill. Think about who will make decisions for you in the event you no longer can. Talk to them about what you want and what you want to avoid if your time becomes limited. The conversation should be ongoing and should eventually lead to the development of a living will, descriptive narrative or health-care proxy to clarify your wishes.

### **More training**

Health-care providers need better training in hospice and palliative care, and these services need to be utilized more often. In our region, only about 20 percent of those who die have been enrolled in hospice or palliative care. Yet research shows people who have used either service have indicated high rates of satisfaction. Palliative care specialists are not currently available in every hospital in Western Pennsylvania. They should be.

Palliative care deals with the physical, mental, emotional and spiritual needs of patients with life-threatening illnesses, and those of their loved ones. Palliative care is consistent with getting other potentially life-prolonging treatments. The cancer community often utilizes palliative care early in a patient's illness, but in other illnesses such as heart failure and Alzheimer's disease these specialists are rarely accessed.

All hospitals need active palliative-care programs that are publicized and accessible to all patients, regardless of diagnosis. In addition, all health-care providers need basic competencies in core palliative-care skills, including treatment of pain, nausea and fatigue; delivery of bad news; discussion of patient goals, and bereavement support.

### **Change policies**

Create a social movement of patients, families and community leaders that demands a focus on care, not just cure. This movement would insist on changes in policy and practice to ensure clear communication about chances of survival, options for care and support for advance planning and decision-making that reflects patient values.

In other cities that have looked carefully at the care of people with life-threatening illness, patients have less hospital and ICU stays and more days spent under hospice care in their last year of life. The cost of their care is lower by several thousand dollars per person. More importantly, patients have a better quality of life and experience no change in life expectancy. By spending smarter, we save money *and* improve care.

The Institute to Enhance Palliative Care and the Coalition for Quality at the End-of-Life have been working to improve end-of-life care in our region. Their efforts prompted the governor's office to create the Task Force for Quality at the End-of-Life. But we need more.

It's time patients with life-threatening illnesses and their families stopped weathering the grief of futile treatments and unrelieved suffering. The last period of living should be a fitting final chapter for patients and a positive experience for loved ones that enhances family connections and healing.

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