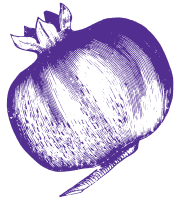


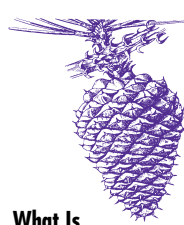
# BRANCHES



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## CHANGING OUR EXPECTATIONS OF CARE AT THE END-OF-LIFE

The healthcare system too often fails families and patients at end-of-life. Once topics to avoid, life-threatening illness, death and bereavement have become mainstream topics of conversation. End-of-life care presents emotional, physical and financial burdens for patients and their loved ones. This is what we have come to expect at end-of-life, but other realities are possible.

True, end-of-life is difficult, sometimes painful. Yet it can also enhance family connection, healing, and affection. Pittsburgh innovators are leading the cultural and structural revolution necessary to serve as a model for others.

Over the past year, the Jewish Healthcare Foundation (JHF) launched an education, planning and outreach effort around end-of-life called *Closure*. Chaired by trustee Tom Hollander, *Closure* was designed to be a learning, community-organizing and planning forum for meaningful change. Participants included doctors, nurses, caregivers, hospice workers, clergy and long-term-care professionals.

Along their journey, they shared tales of how low expectations of care were confirmed by the end-of-life experience. They identified key gaps – such as poor pain management, financing policies that promote cure over care, and disjointed systems. Deficits were turned into opportunities – like palliative care, caregiver training and support, and advanced care planning. The *Closure* participants encountered caring and engaged individuals and forward-thinking institutions prepared to lead change.

*Closure is about community conversations.* Talk precedes action. But, dying is a topic people do not like to talk about in relation to themselves, their family and friends. It is the stuff of nightmares, novels and poetry. It is something that is removed from us and our everyday lives. We can resist fear and evasion; we can make it comfortable to discuss and experience the inevitable end-of-life.

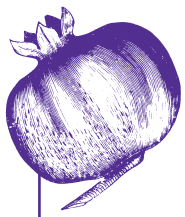
*“There never has been a social movement that succeeds with only professional support. We have an opportunity to define quality end-of-life for our community – respecting values and decreasing the burden of illness. Birthing goes well – we expect that. However, death does not go so well for everyone. But that seems to meet our expectations. It is therefore the expectations that must change. A groundswell of demand from consumers can and will change that. The voices of the public will be heard and then it will be the job of the professionals to promote the issue.”*

**Robert (Bob) Arnold, MD**

Leo H. Crip Chair in Patient Care  
Chief, Section of Palliative Care & Medical Ethics  
University of Pittsburgh

### HIGH INTENSITY OF END-OF-LIFE CARE IN LAST 6 MONTHS OF LIFE (2005)

	PITTSBURGH	USA	PORTLAND
% of hospitalized Medicare deaths	29%	29%	22%
Hospital days	11.96	10.81	6.05
In-patient Medicare reimbursements	\$14,107	\$13,805	\$10,024
% admitted to intensive care during final hospitalization	18%	17%	12%
% admitted to intensive care	43%	39%	25%
% spending seven or more days in intensive care	15%	14%	5%
Data extracted from: The Dartmouth Atlas of Health Care, Center for the Evaluative Clinical Sciences at Dartmouth Medical School, <a href="http://www.Dartmouthatlas.org">www.Dartmouthatlas.org</a> ; Population-based rates for geographic regions			
Hospice days per decedent during the last 6 months of life (2001-2005)	9.26	11.55	13.19
Data extracted from: The Dartmouth Atlas of Health Care, Center for the Evaluative Clinical Sciences at Dartmouth Medical School, <a href="http://www.Dartmouthatlas.org">www.Dartmouthatlas.org</a> ; Provider-based rates for geographic regions			



# THE CURRENT EXPERIENCE

**P**atients and families are suffering at end-of-life. Surveys say that patients and families in general are disappointed with the dying process. In the 2006 Pennsylvania End-of-Life Background Report, families reported great dissatisfaction with the dying process of their loved ones, particularly in the areas of pain management, social and financial burdens, and limited access to palliative and hospice services. Families aren't adequately guided to care options at end-of-life.

**Palliative care is a proven tool for improving the end-of-life experience.** It is a comprehensive approach to patient and family care and symptom management that deals with the physical, the mental, emotional and spiritual needs of patients and their loved ones throughout the end-of-life experience. Delivered simultaneously with all other appropriate medical treatment, such care is designed to prevent and relieve suffering and support the best quality of life regardless of the stage of the disease or other therapies. Palliative medicine views death as a natural part of life, not a failure of medicine. It is delivered by teams that usually consist of specialist physicians and nurse practitioners, a social worker, a pastoral care provider, and possibly complementary therapists, community volunteers, pharmacists and other ancillary providers.

**The general public is unaware of, misinformed about, and underutilizes palliative care and other end-of-life planning and care resources.** When it comes to making medical care decisions, most people have a false understanding about their rights, responsibilities, and use of legal documentation. Surveys show that families who have used palliative care and hospice care services have indicated high rates of satisfaction. These surveys also show that most were not previously aware of the service or they believed that the services would not meet their needs. Only about 20% of those who die in this region have been enrolled in hospice and/or palliative care – and for many of those who have, their length of stay under a hospice service can be measured in days or weeks, instead of months.

Some patients experience relatively quick and predictable trajectories of decline as they approach death, as described by the traditional trajectory for colon cancer in the figure below. In these cases, patients and families are often given clear signals on when to adjust medical care and prepare themselves emotionally for death. However, for most patients, the end-of-life experience is characterized by indefinite chronic illness with unpredictable medical episodes and little ability to anticipate the likely extent of recovery from these episodes. An example is congestive heart failure (CHF).

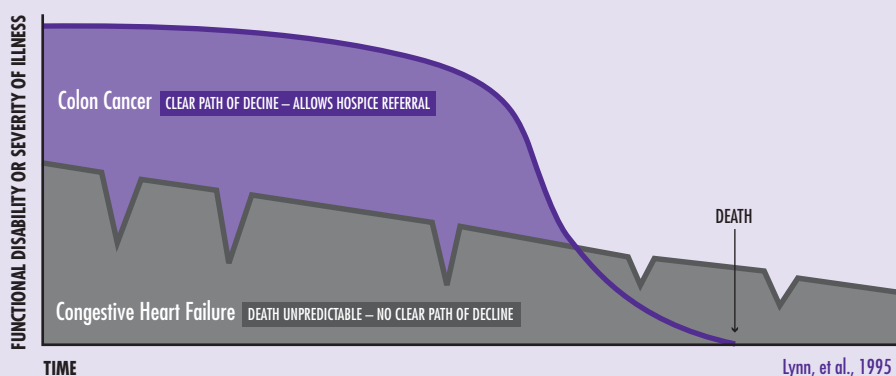
## From Gates of Repentance

If some messenger were to come to us with an offer that death should be overthrown, but with one inseparable condition that birth should also cease; if the existing generation were given the chance to live forever, but on the clear understanding that never again would there be a child, or a youth, or first love, never again would new persons with new hopes, new ideas, new achievements; ourselves for always and never any others – could the answer be in doubt?

*We shall not fear the summons of death; we shall remember those who have gone before us, and those who will come after us!*

Dr. Robert Arnold, Chief of Palliative Care and Medical Ethics at UPMC, reports that one study reviewed cases of patients with such “unpredictable” conditions as CHF, chronic obstructive pulmonary disease, and cirrhosis found that these patients were considered to have had a 50% chance of living six months or more in the week before they died. As a result, it can be very difficult to pinpoint clear transitions between stages of decline at which to re-evaluate and refocus medical care and prepare emotionally for death. Patients and families may not be fully prepared for end-of-life until very close to the end. However, this extended period is necessary to proactively prepare for inevitable death in a thoughtful, willful manner.

## Examples of Clear and Unpredictable Paths of Decline at End-of-life



**Healthcare systems do not support the use of palliative services.** Traditional medical systems are designed to address acute symptoms – that is, help patients recover from individual medical episodes – not to provide chronic care or support end-of-life preparations. Many providers lack the training and communication skills to direct patients to palliative care options. Current reimbursement does not promote palliative care or compensate for the care management necessary for appropriate advanced care planning or decision support. Palliative care and

hospice care have traditionally been thought of as appropriate for end-stage cancer patients, but are not widely offered to those with other chronic conditions. For example, CHF affects more than one in ten people over the age of 70 and the five-year mortality rate is 80% – worse than that of most cancers. Yet the rate of palliative and hospice care use among CHF patients is significantly lower than for cancer.

**Meaningful change is possible.** Medical systems are capable of rapid change, as exhibited in the birthing experience in the 1960's. Smaller-scale projects locally, and larger-scale investments in other communities, have improved end-of-life experiences. In Oregon, the rates of hospitalization, ICU stays and associated costs are at least 50% lower than the national average. In those communities, providers counsel families on whether ICU stays or additional interventions are likely to be value-added for the patient.

## A “GOOD” END-OF-LIFE EXPERIENCE

In the fall of 2007, JHF asked David Servan-Schreiber, MD, PhD, former chief of Psychiatry at UPMC Shadyside and current professor, author and lecturer, to speak to a small group of community leaders about his experiences with end-of-life care. Dr. Servan-Schreiber engaged participants from his unique perspective as a healthcare professional and cancer survivor on how emotion complicates practical considerations and results in varying levels of preparation for and satisfaction with the end-of-life process. Recounting his experiences with patients and physicians, Dr. Servan-Schreiber shared his intimate thoughts on what makes a “good” end-of-life experience for this lecture, helping to confirm the appetite for change in the community, and invigorated key *Closure* stakeholders. Highlights of Dr. Servan-Schreiber's remarks included three recommendations:

- Physicians call on their personal experiences and feelings to help patients deal with their anxiety around death

- Patients who are concerned about being a burden on their family have an open dialogue with their loved ones

- Patients let their death be a model to their loved ones on how to confront the experience

He suggested that “those who preceded us – our relatives and mentors and loved ones – live on in us. So too do we live in others.”



David Servan-Schreiber, MD, PhD

## A LESSON FROM MALKA BARAN

When 80-year-old Malka Baran died at Forbes Hospice on May 7, 2007, she was prepared and in control. This is a far cry from 65 years ago, when, as a prisoner at a Nazi forced labor camp, others had sought to hasten the timing and determine the nature of her death. After the war, as an early-childhood educator, Malka continued to educate her family and the community throughout her lifetime and even in death.

Upon receiving the diagnosis of terminal uterine cancer, she thanked her doctor for the respect he showed her by being honest as to her illness. She made her own decision to take advantage of hospice home care services, later moving to inpatient hospice for her last four weeks of life. She chose to avoid treatments which would have proven futile given the disease's stage and progression, and hospice workers who came to her home each day helped to manage her symptoms, including pain. And, as she had always done throughout her life through previous bouts of cancer and Parkinson's Disease, she continued to play an active role in her own care planning, learning about each medication, its role and side effects.

Malka, [a name which means 'Queen' in Hebrew] was the center of her family's life. She used her remaining months productively, spending them with family and friends of all ages; continuing to learn and to prepare her family for a life without her physical presence, taking the time to talk one-on-one with her husband, Moshe, each of her children, their spouses and her grandchildren. Surrounded by music, laughter, the community, family and friends at her 80th birthday party just months before her death, Malka looked around, smiled and said, “I could die tonight.” Her daughter Avi, also an educator, said when she died, “she had prepared us so beautifully.” When asked about her bereavement process, Avi added, “It's a passage, but I'm fine. I keep thinking I shouldn't be.”



# MOBILIZING THE COMMUNITY: *CLOSURE*

**C**losure brought together a group of about 30 community leaders in late 2007 through early 2008 to share collective experiences, expertise and passion to develop and implement an agenda to advance end-of-life care. *Closure* participants understood first-hand the importance of quality end-of-life care, what works and what is “broken” and how institutions and individuals need to change.

In five sessions, participants outlined specific, pragmatic actions to improve end-of-life planning, decision making, and care. Members represented a wide range of perspectives as adult day care workers, clergy, family caregivers, financial planners, home care, hospice and long-term care, lawyers, physicians and other medical professionals, social workers and other social service providers. They represented a natural network to community stakeholders who can directly improve end-of-life care.

*Closure* participants’ recommendations would increase appropriate hospice and palliative care, decrease unnecessary healthcare expenditures and ICU admittance at end-of-life, and help patients proactively plan for and manage end-of-life experiences.

## Major Takeaways from *Closure* Experience

*Closure* stakeholders were given a chance to learn and teach. Their takeaways included:

- The end-of-life continuum is broad. For the patient and family the end-of-life process begins before diagnosis and continues past death to the grieving process; it includes emotional, legal, medical and ethical aspects.
- Most players in the process see it only from their own narrow professional perspective – oblivious to other confounding issues.
- Death should not be viewed as a medical failure.
- Appropriate resources and supports can help families cope with end-of-life, making it a rewarding period.
- Our community is replete with dedicated

professionals ready to work on making the experience meaningful, comfortable and personal.

- Other communities can learn from our experience.

Tom Hollander concluded that “this is about a movement. This process has instilled in those who participated a feeling of what a better system can be. Now we must get there.”

## Summary of Sessions and Session Leaders

### Opening Lecture:

David Servan-Schreiber, MD, PhD

Dr. David Servan-Schreiber engaged participants with his unique perspective as a psychiatrist, integrated medicine proponent and cancer survivor, on how emotion mingles with practice, producing varying levels of satisfaction with the end-of-life process. He shared his intimate thoughts on what makes a “good” end-of-life experience for both healthcare providers and patients.

### Session 1: Issues at End-of-Life

Robert M. Arnold, MD  
Alan Meisel, JD

Dr. Arnold presented a model of how most Americans live the last 10% of their life, and how their needs are (or aren’t) met by the current medical system. Meisel led the group through a series of ethical questions around medical treatment that present themselves at end-of-life. This session provided participants with a baseline of factual information about the end-of-life experience today, and an opportunity to reflect on their own perspective on end-of-life and how it may differ from others, based on professional or personal experiences or training.

### Session 2: Jewish Perspective

Rabbi Stephen Steindel  
Rabbi Yisroel Miller

Through this clergy-led discussion, members of *Closure* learned about Jewish religious law (halacha) regarding end-of-life, how these laws and their underlying values and resulting customs influence contemporary end-of-life decisions across different streams of Judaism, and discussed how the Jewish community is best suited to come together to support each other through the end-of-life experience. Among the conclusions from this session are that while the end-of-life experience is universal, Judaism has something to say and offer. And that while the concept of “a Jewish death” is hard to precisely define, it should evoke an experience characterized by strong community support and personal closure through the dying and bereavement process, not a set of rules that should be followed.

### Session 3: End-of-Life Resources

Maryanne Fellow, RN, MEd  
Thomas Hollander, JD  
Hillary Kramer, LSW  
Nancy L. Rackoff, JD  
Fred H. Rubin, MD

The group discussed specific resources available to patients and their loved ones to help plan for and deal with the end-of-life experience, and that consumers can’t find these resources when they need them. Three types of resources – hospice, legal planning and geriatric medical practices – were presented.

### Session 4: The Family Experience

Lulu Orr, Director,  
Good Grief Center

This final learning session brought *Closure* back to the personal realm. Members shared their personal experiences, both good and bad, as caregivers and/or medical professionals. Lulu Orr, director of the Good Grief Center, added the perspective of how families deal with bereavement or special circumstances, such as suicide. With the knowledge gained from earlier sessions, participants reflected on their own experiences and offered thoughts on how, with better support, they could design an easier or more rewarding experience.

### Session 5: Action Plan for the Jewish Community

Unlike earlier “learning” experiences, this final session functioned as a planning and organizing meeting. Participants discussed specific strategies to advance the state of end-of-life care, focusing on pragmatic actions that are scalable.



## OUTCOMES OF CULTURE CHANGE AT END-OF-LIFE

OUTCOMES OF CULTURE CHANGE AT END-OF-LIFE			
Pre-Event	Illness / Event	Near Death	After Death and Bereavement
<b>Families (patient and loved ones)</b>			
<ul style="list-style-type: none"> <li>• Understand the choices and challenges they might face</li> <li>• Participate in conversations among themselves, with their lawyers, clergy and health professionals</li> <li>• Receive and are educated in the use of planning tools for decision-making (including Living Wills, information about organ donation)</li> </ul>	<ul style="list-style-type: none"> <li>• Have basic and updated knowledge of choices (palliative care and hospice, pain management, choice of locations) given changing medical circumstances</li> <li>• Have their decisions supported by health providers and family; e.g., ask for and receive services such as palliative care and hospice, as appropriate</li> <li>• Feel supported by medical, social services and general community</li> </ul>		<ul style="list-style-type: none"> <li>• Are supported by community (have access to support groups, grief services)</li> <li>• Are satisfied that the patient's choices were respected</li> </ul>
<b>Community Groups (including religious and culturally distinct communities)</b>			
<ul style="list-style-type: none"> <li>• Foster widespread understanding of issues, conversations and planning</li> <li>• Provide appropriate educational opportunities, programming and leadership for issues discussions</li> <li>• Make information and planning tools widely available through websites, periodicals, offices</li> </ul>	<ul style="list-style-type: none"> <li>• Provide access to high-quality, needed resources and systems (including palliative care, hospice and respite)</li> <li>• Provide access to reliable, culturally appropriate, accurate information to support patient and family decision-making</li> <li>• Provide access to respite care for families</li> </ul>		<ul style="list-style-type: none"> <li>• Ensure that support services and grief counseling are widely available and accessed appropriately</li> </ul>
<b>Healthcare Professionals (physicians, nurses, social workers, pharmacists)</b>			
<ul style="list-style-type: none"> <li>• Receive quality education about palliative care, hospice and long-term care resources and the distinct needs of various cultural groups</li> <li>• Receive training on how to hold conversations with families and patients</li> <li>• Initiate/are receptive to talking to families about options given medical circumstances</li> </ul>	<ul style="list-style-type: none"> <li>• Have comfortable and forthright discussions about options among healthcare teams and with patients and families</li> <li>• Call in palliative care consults, when appropriate, and make appropriate referrals to hospice, respite and primary care</li> <li>• Honor patient's and family's wishes (about care vs. cure)</li> </ul>		<ul style="list-style-type: none"> <li>• Learn from experiences to inform communication and support of future patients and families</li> <li>• Make referrals to resources (bereavement services)</li> </ul>
<b>Other Providers (long-term, hospice, palliative and social services)</b>			
<ul style="list-style-type: none"> <li>• Have access to information about palliative care, hospice and respite, and appropriate indications for their use and restrictions</li> </ul>	<ul style="list-style-type: none"> <li>• Are called in appropriately by health providers and families and are able to work collaboratively with them to meet patient's needs</li> </ul>		<ul style="list-style-type: none"> <li>• Provide community-based support for surviving family members</li> </ul>

## STARTING THE CONVERSATION

### LESSONS LEARNED FROM WORKING HEARTS® COALITION MODEL

The Jewish Healthcare Foundation started the Working Hearts® Coalition in 2000. Then, few were focused on women's heart health though 500,000 women were dying of heart disease in this country each year. A collective of women's organizations and health-related groups banded together to empower women to make behavioral changes to reduce their risk of heart disease, and to prepare them to talk with their healthcare provider. It helped begin a movement.

*The model capitalized on the natural women's networks that crisscross our*

*community.* It encouraged women to help women, healthcare systems to partner for the greater good, experts to share their knowledge and build outreach strategies, and community-based organizations and their volunteers to carry the message to their constituents. The model captured the spirit of Pittsburgh – people collaborating for a good cause.

Working Hearts® provided a model on which to address a new priority in our community and to start a conversation

about maximizing the quality of life at the end-of-life. Working Hearts® demonstrated the value of reaching out to community-based organizations, healthcare systems, clergy, legal experts, care providers and caregivers alike to begin such conversations.



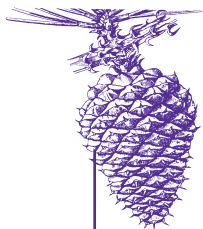
A social movement can be contagious. With the right conditions we want to inspire people to improve their own care and engage others. *It all starts with a conversation.*

# THE PREPARE MODEL: OVERALL STRATEGY

**T**he Jewish Healthcare Foundation is proposing a comprehensive seven-part strategy aimed at changing culture at end-of-life in partnership with community organizations and experts.

The PREPARE Model			
What is needed	Stakeholders	Activities	Organizational Lead Role
<b><u>POLICY</u></b>	Government, payer and institutional policy makers	Forum for community organizing around end-of-life issues to improve policy	Coalition on Quality at End-of-Life (CQEL)
<b><u>RESEARCH EDUCATION PRACTICE</u></b>	Healthcare providers	Academic and field expertise, demonstration and impact projects	Institute to Enhance Palliative Care (IEPC)
<b><u>AWARENESS RESOURCES ENGAGEMENT</u></b>	Community, patients and families	Conduct community focus groups and engage caregivers and professionals in the development of education resources, tools, and website; convene community groups and sectors in <i>Closure</i> -type activities; develop collateral materials	Jewish Healthcare Foundation

<b>P</b>	Advocate for <b>POLICY</b> change to align reimbursement, professional education, and professional behavior at the local and national level to clear the path for culture change around end-of-life issues.
<b>R</b>	Conduct <b>RESEARCH</b> with various professional and lay constituent groups to validate their views, preferences and barriers around best practice and planning for end-of-life care; testing new models of education and care at end-of-life (e.g., use of palliative care for non-cancer patients).
<b>E</b>	<b>EDUCATE</b> providers about their role in end-of-life issues. Expand professional education programs to reach new and practicing professionals (physicians, nurses, social workers, pharmacists, and lawyers) and train them to better understand the needs of patients and families at end-of-life, their role and position of authority to support families through this period, and resources available to both professionals and families to help them.
<b>P</b>	Expand the <b>PRACTICE</b> of palliative care and other end-of-life supports to ensure that members of the community have quality services available to them, when they need them.
<b>A</b>	Raise <b>AWARENESS</b> about end-of-life issues so that families understand the importance of preparing for the experience, know how to access the resources they need to help them at every stage, and learn how they can help others.
<b>R</b>	Develop and disseminate planning tools and <b>RESOURCES</b> through sophisticated and targeted distribution channels to ensure that families and patients have access to accurate and useful information.
<b>E</b>	<b>ENGAGE</b> community leaders and volunteers to use their talents and positions in the community, heighten awareness of issues and better support their community members through end-of-life experiences. <i>Closure</i> was an example of a concerted effort towards community engagement within the Jewish community that will be replicated in other communities.



# WHAT IS PALLIATIVE CARE?

**P**alliative care (from the Latin, palliare, to cloak) concentrates on reducing the severity of disease symptoms rather than striving to halt, delay or reverse progression of the disease itself, or provide a cure. The goal is to prevent and relieve suffering and to improve the quality of life for people facing serious, complex illness.

Palliative care grew out of the hospice movement. Its goals are: relief from suffering, treatment of pain and other distressing symptoms, psychological and spiritual care, support services to help the individual live as actively as they choose, and to sustain and rehabilitate the individual's family.

In the United States today, 55% of hospitals with over 100 beds offer a palliative care program and nearly one-fifth of community hospitals have palliative care programs. A relatively recent development is the concept of a dedicated team that is entirely geared toward palliative treatment.

The most important distinction between hospice and palliative care programs in the United States is that hospice is a Medicare Part A benefit. Non-hospice palliative care is appropriate for anyone with a serious, complex illness, whether they are expected to recover fully, to live with chronic illness for an extended time, or to experience rapid disease progression.

## INSTITUTE TO ENHANCE PALLIATIVE CARE

The Institute to Enhance Palliative Care is a collaboration of the schools of health sciences at the University of Pittsburgh with one of the region's largest community hospice providers. Within the Institute, scholars and health professionals from diverse fields join together to improve access to and quality of care for people who are seriously ill and dying in western Pennsylvania. Leading the Institute's work is Director David Barnard, PhD with Project Manager Paige Hepple. Areas of focus include:

- Education of health professionals in the principles, practices, and ethics of palliative care
- Research that develops new knowledge about the needs of people who are seriously ill or near the end-of-life
- Public awareness of the need for palliative and hospice care
- Consultation and support to area healthcare institutions and providers
- Public policy advocacy

Visit [www.dgim.pitt.edu/iepc](http://www.dgim.pitt.edu/iepc) to learn more about the Institute's activities in the community.

## PALLIATIVE CARE ACTIVIST: BOB ARNOLD, MD

**L**ong before people were talking about palliative care, Dr. Bob Arnold had been listening...listening to the wishes of people who were living with AIDS, listening to their caregivers, and realizing that care providers had a lot to learn about the quality of life for people facing the end-of-life.

Dr. Arnold is the Leo H. Crippe Chair in Patient Care; professor of medicine in the Division of General Internal Medicine; chief, Section of Palliative Care and Medical Ethics; and assistant director for education, University of Pittsburgh Center for Bioethics and Health Law. He also serves as the

assistant medical director of palliative care for the Institute for Quality Improvement at UPMC. Dr. Arnold was a Faculty Scholar for the Project on Death in America and part of the team that developed the national EPEC curriculum, for which he is a trainer, facilitator and speaker.



Bob Arnold, MD

Dr. Arnold has served as an advisor to JHF for many initiatives on end-of-life and successful aging and is a mainstay of the Patient Safety Fellowship for students in graduate health programs. He is intent on changing the culture of practice among physicians and nurses while trying to ensure that patients with

life-limiting and life-threatening illnesses receive the care they want and need.

So, how can we begin to make a culture change in society around the end-of-life? Bob suggests that healthcare providers promote palliative care. "The power to mainstream such change will lie with the public and the caregivers, not the patient. The 'boomers' are unlikely to allow the healthcare system to remain so chaotic. We are too controlling."

Bob explains, annually in this country, two million babies are born and two million people die. The expectation is that the birthing experience will go well – doctors will listen, settings will be appropriate, preferences and values will be honored and respected. Contrast that to what most people experience at end-of-life.

*“The public needs to become aware of what palliative care is and can offer. Health systems need to compete on how well they reduce the burden of illness; every health professional should be exposed to a mandatory basic curriculum on end-of-life; health systems need to have integrated transitions; insurers need to support palliative care in nursing homes and hospices. These criteria are achievable.”*

— Closure participant

#### PALLIATIVE CARE ACTIVIST CONTINUED

People have low expectations and consider themselves lucky if things go well. Most people in this country want a ‘good death’ – but they don’t want it a moment too soon.

The medical community is not good at predicting death, underscoring the need to assure that supportive services like palliative care are available to all with life-limiting illnesses. Of the thirteen symptoms common at end-of-life, most providers can only recognize less than half. It is not the fault of doctors and nurses as they receive little training in this field. We can do better. The good news is that Pittsburgh has done better over the past five years. We have gone from having no palliative care units in this region to

having units in each flagship hospital in this region in 2008.

I am pleased to see that the top 20 hospitals listed in U.S. News and World Report all have a palliative care service now. That inclusion of a palliative care department is among the criteria to be named a top U.S. hospital. Palliative care has finally landed. It has taken nearly 20 years. With palliative care now integrated into academics at major medical centers, there is the opportunity to improve the care plans of clinicians, the trainings for house staff, open up new opportunities for research funding, and influence the decision-making of administrators. But the thing we take the most pride in is that in the end, palliative care makes a difference in peoples’ lives.

## WHAT IS HOSPICE?

**H**ospice is a special concept of care designed to provide comfort and support to patients and their families. Patients are referred to hospice when life expectancy is approximately six months or less. Hospice is not a place. Most hospice care takes place within the dying person’s home, the home of a family member or friend, or a nursing or assisted living facility. Hospice care can also be provided in a residential hospice facility or a hospice unit within a hospital. Hospice care neither prolongs life nor hastens death. Hospice staff and volunteers offer a specialized knowledge of medical care, including pain management. The goal of hospice care is to improve the quality of a patient’s last weeks, days and hours by offering comfort and dignity.

## BARBARA K. SHORE: A VISIONARY

**F**orty years ago, another Pittsburgh visionary had the foresight to “start the conversation” about end-of-life issues. When you ask Barbara Shore what motivated her to offer a class on death and dying through the University of Pittsburgh, School of Social Work, she will tell you “it was highly personal.”

In 1969 her dear friend and colleague Lois Jaffe, who had been diagnosed with leukemia, asked her to serve as her back-up for the class that she was offering. Neither medical nor nursing schools offered such a class; however, nursing students enrolled in large numbers in this class at the School of Social Work.

As Lois’ energy level waned due to her medical treatment, the class’s popularity soared; so Barbara and Lois began to co-instruct the class. Barbara went on to lead the class in each of three terms per year until 1975. Training eventually moved into hospitals through in-services and was spread through organizations like Contact Pittsburgh, the local crisis hotline.

“This was just the beginning of the hospice movement,” said Barbara, “and soon afterward Forbes Hospice was the first to open its doors. I am excited by JHF’s planned efforts. [Acceptance of] palliative and hospice care are not as far down the road as they need to be.” Fortunately for the Foundation and our region, forty years later, Barbara is ready once again to lend her expertise to enhance the community conversation as an advisor.



Barbara K. Shore, PhD, MPH, Distinguished Service Professor Emerita, University of Pittsburgh School of Social Work



# ADVANCE HEALTHCARE DIRECTIVE

**A**n advance healthcare directive lets physicians, family and friends know a patient's healthcare preferences, including the types of special treatment they want or don't want at the end-of-life, their desire for diagnostic testing, surgical procedures, cardiopulmonary resuscitation and organ donation. By considering options early, patients can ensure the quality of life that is important to them and avoid having their family "guess" their wishes or make critical medical care decisions under stress.

## Checklist for Developing an Advance Care Directive

- Gather information for decision-making.
- Discuss your end-of-life decisions with key people – family, physician and others who are close to you. Some questions to consider for discussion:
  - What is important to you when you are dying?
  - Are there specific medical treatments you especially want or do not want?
  - When you are dying, do you want to be in a hospital, nursing home, residential hospice, or at home with or without hospice care?

- What are the local options in palliative care/pain management and hospice care?
- Where is your advance care directive form?
- Designate a person to carry out your wishes.
- Inform key people of your preferences.

There are many other forms for use at end-of-life: durable medical power of attorney, living will, etc. We encourage people to talk to their healthcare and legal professional and with their families to make sure that their specific needs and end-of-life plans are identified and documented.

## DR. EUGENE HIRSCH: PHYSICIAN, POET, VOLUNTEER

### To the end of her life\*

Two flights up,  
she cradled her swollen belly  
in memorabilia,  
in the bowels of her bed.  
Her sallow face told me  
how near death she must be.

She paused and stared into space,  
asking not for medicine, but for prayers.  
I led her to find those she knew.  
I'd learned some, not others.

In my confusion,  
I searched for a "likeness" of her God  
(shaped with the palms of my hands)  
to sit there beside her and smile. I asked her  
to tell Him what she wanted Him to know –  
to take away her terrible pain,  
to forgive,  
to bless.  
She wanted never  
to be alone again, never  
to die each day, never  
to really die.

I asked her to tell God  
what she'd want Him to say.

– Eugene Z. Hirsch, MD

Dr. Hirsch is a poet and former volunteer Director of Physician Education at Forbes Hospice in Pittsburgh.

He has devoted much of his career in clinical medicine to helping medical professionals "understand the ways in which suffering people and their loved ones try to comprehend their misfortunes and strive to overcome."<sup>1</sup> Dr. Hirsch teaches that "dying" and "end-of-life" are not interchangeable ideas. Dying is the physical process of decline. End-of-life is about the life we live "until we say goodbye."<sup>2</sup> This life can bring insights, endearment and new meaning. He counsels professionals by empowering them so they can, in turn, empower patients and their loved ones. Empowerment brings out personal capabilities for living and can help rescue suffering people from lapsing into helplessness.



Dr. Eugene Hirsch

## POLST – PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT

A POLST Paradigm form is a brightly colored, medical order form used to write orders indicating life-sustaining treatment wishes for seriously ill patients. The form accomplishes two major purposes: it turns treatment wishes of an individual into actionable medical orders; and it is portable from one care setting to another.

It is based on effective communication of patient wishes, documentation of medical orders and a promise by healthcare professionals to honor these wishes. While the POLST is voluntary on the patient's part, it was developed initially for seriously ill patients receiving medical treatments not consistent with their wishes. A healthcare professional (usually a physician, nurse practitioner, physician assistant or social worker) completes the form after understanding the patient's values and goals of care.

Many states have adopted the POLST Paradigm, mandating its universal use; Pennsylvania has yet to do so (although a Governor's Task Force is currently working on that issue). Western Pennsylvania is developing a program for seven counties as evidence of the growing acceptance of POLST as a valuable tool at end-of-life.

\* Published in The Pharos, journal of Alpha Omega Alpha Honor Medical Society, Winter 2007

<sup>1</sup> <http://netwestwriters.blogspot.com/2008/07/dr-gene-hirsch-poetry-class-at-jccfs.html>

<sup>2</sup> Dr. Elizabeth Kubler-Ross

# NATIONAL TRAINING FOR PROVIDERS

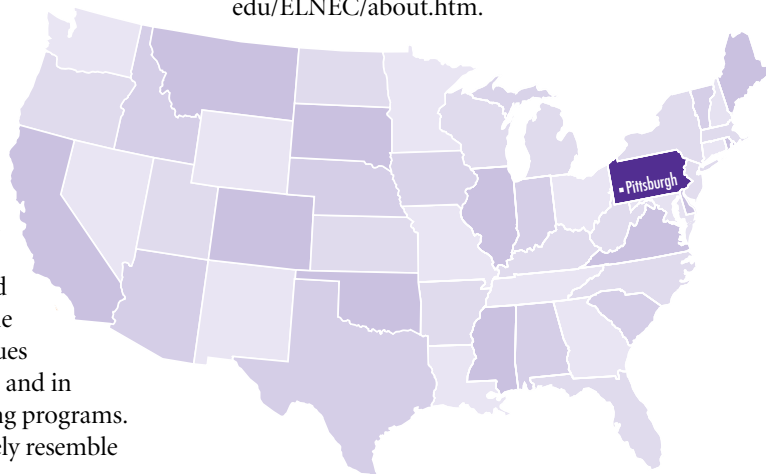
## EPEC & ELNEC

To overcome the gaps between what healthcare providers know about palliative and end-of-life care and what they need to know, Northwestern University's Buehler Institute on Aging, Health, and Society spearheads the Education in Palliative and End-of-Life Care (EPEC) project. EPEC addresses palliative care and end-of-life topics, including pain management, discussing prognosis, negotiating goals of care, and confronting issues surrounding the last few hours of life. Additional courses are available with a specific focus on oncology, geriatrics, emergency medicine, and the unique challenges that face each of these specialties in dealing with individuals who are dying. Most importantly, EPEC trains and certifies new trainers, both to refresh its own pool of educators and to enable others to take the curriculum out into their home institutions. Visit the EPEC

Project at [www.epec.net/EPEC/Webpages/index.cfm](http://www.epec.net/EPEC/Webpages/index.cfm).

End-of-Life Nursing Education Consortium (ELNEC) is administered through the American Association of Colleges of Nursing (AACN). This curriculum grew out of a 1998 AACN report entitled *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*. Since its inception in 2001, thousands of nurses have been trained in ELNEC and have gone on to train their colleagues in every state of the U.S. and in graduate nursing training programs. The topics covered closely resemble

those in EPEC but with a special focus on the roles played by nurses. As with EPEC, ELNEC has addressed the various specialties by developing courses specific to oncology, pediatric and adult critical care, and geriatrics. To download the ELNEC Fact Sheet visit [www.aacn.nche.edu/ELNEC/about.htm](http://www.aacn.nche.edu/ELNEC/about.htm).



## STATE STRATEGY: IMPROVING END-OF-LIFE EXPERIENCES FOR PENNSYLVANIANS

In 2006, PA Governor Edward G. Rendell created the Task Force for Quality at the End-of-Life and allocated resources to facilitate this effort. The primary goal of the task force is to mobilize stakeholders to create momentum for change in policy, systems, and grassroots community activity to reform and improve palliative and end-of-life care. The report entitled "Improving End-of-Life Experiences for Pennsylvanians," published in 2006, outlined the following key concerns that must be addressed:

- Improved, more supportive policies governing advance directives and greater awareness of the advance care planning process through the education of healthcare professionals and the broader community
- Improved standards for palliative care, better coordination of care, and more highly-trained professional palliative and end-of-life education personnel in healthcare facilities
- Public awareness of palliative care and new healthcare delivery and financial structures
- Improved attention to special needs populations
- Improved public understanding of palliative care and the end-of-life experience; improved communication about death and dying; support for the lay caregivers; and improved accuracy of information about hospice and palliative care relative to pain and symptom management
- Research, analysis, measurement, and tracking of efforts in palliative and end-of-life care

## LOCAL RESOURCES

### The Coalition for Quality at the End-of-life

The Coalition for Quality at the End-of-Life (CQEL) is a consortium of leading health systems, providers, insurers, citizen groups, governmental agencies and philanthropic, faith-based and other organizations concerned about the quality of care that is available in western Pennsylvania. CQEL's mission is to improve end-of-life care in the region by identifying and collaborating with key stakeholder groups. CQEL works to achieve its mission by engaging the community to build demand for better end-of-life care, building capacity among local healthcare institutions for the delivery of skilled and compassionate care, focusing attention on the regulatory and financial barriers to quality end-of-life care, and by promulgating appropriate standards and measures. For more information visit [www.dgim.pitt.edu/iepc/cqel.html](http://www.dgim.pitt.edu/iepc/cqel.html).

## GOOD GRIEF CENTER

*Grief is not a process of forgetting.  
It is a process of learning to cope while  
we remember.*

**G**rief is a multitude of emotions and a natural, although intense, reaction when someone dies. The staff and volunteers of the Good Grief Center are trained to understand grief and serve as educators, listeners, advocates, and coaches who generously offer empathic understanding and presence to the people they serve.

Executive Director Lulu Orr states “each of us will experience grief at some time in our lives. While it is a universal experience, it is also a unique one. There is no specific process, no healing formula, and, no ‘right way’ to manage grief. However, there are healthy, effective ways to cope.”

The Center is located in Squirrel Hill where people may walk in or schedule appointments for services that include:

- one-to-one support, in person or over the phone
- support groups on site and a comprehensive listing of other bereavement support groups
- an extensive library of grief-related books, brochures, magazines, audio tapes, video tapes, CDs and DVDs
- grief in the workplace sessions
- compassionate calling
- Good Grief packages

To learn more about the Good Grief Center, visit [www.goodgriefcenter.com](http://www.goodgriefcenter.com) or phone 412-461-1776.



Lulu Orr

# JHF'S LONGSTANDING COMMITMENT TO SUCCESSFUL AGING

**T**he Foundation has long been a champion for successful aging and care at end-of-life. In our 17-year history, JHF has invested approximately \$45 million – nearly half of all grantmaking – in a range of strategies and initiatives targeting frail, vulnerable and well seniors and their caregivers. A sampling of our successful efforts, which included dedicated staff, as well as funding, includes:

**Planning & Policy Change Sample Grants:** Coalition on Quality at End of Life (CQEL), the first-ever statewide Summit on End-of-Life Issues and its report, Governor's Task Force for Quality at End-of-Life and its POLST subcommittee, and *Closure* (see feature)

**Changing Practice Sample Grants:** University of Pittsburgh School of Medicine and Winter Institute for Simulation Education Research (WISER) to train medical students, practicing physicians and other medical care providers in provider-patient relations and the use of end-of-life resources, as well as demonstrations to improve pain management for nursing home residents in western Pennsylvania

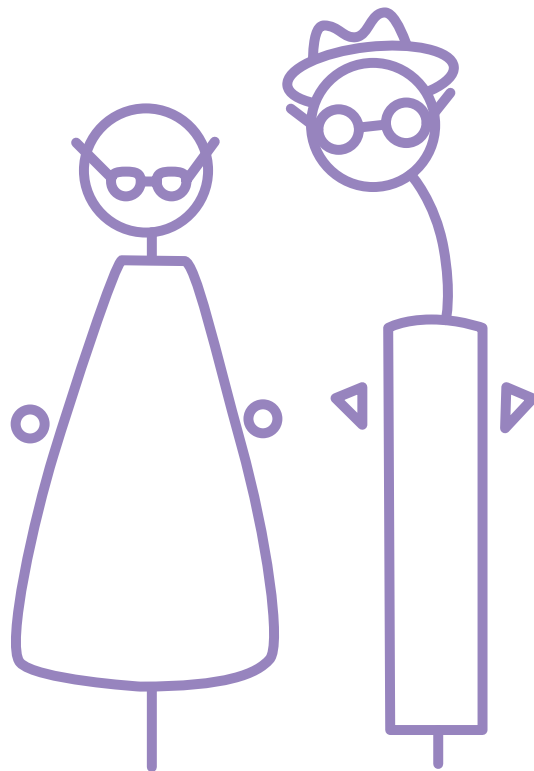
**Prevention Sample Grants:** depression in primary care settings with the MacArthur and Hartford Foundations, falls prevention and Tai Chi, reducing the co-morbidity of hospitalization

### Caregiver Education and Volunteerism Sample Grants:

paid caregivers' education and training program, Caregivers' Manual, Senior Volunteer Summit, PBS series on Caregiving. JHF served as the home and “incubator” for this community's Interfaith Volunteer Caregivers

**Maximizing Lifelong Engagement and Learning Sample Grants:** Elderhostel Pittsburgh, Carnegie Museum on the Move

**Aging Workforce Training and Skills Enhancement Sample Grants:** I-WISE (Incumbent Worker Training and Train the Facilitator Training); Health Workforce Summit, Perfecting Patient Care<sup>SM</sup> in Long-Term-Care



# “ON OUR OWN TERMS”

The 2000 landmark PBS series, “On Our Own Terms” featuring Bill Moyers, brought the American public first-hand accounts from patients, caregivers and providers from across the country. Including stories from hospitals to hospices to homes, the series captured intimate stories and candid conversations around death and dying choices. The four-part, six-hour series included:

## Program 1: Living with Dying

The premiere of “On Our Own Terms” examines the ways patients and caregivers are trying to overcome American culture’s denial of death.

## Program 2: A Different Kind of Care

Part two reports on the evolution of palliative or “comfort” care and its emphasis on patients’ psychological, emotional and spiritual well-being.

## Program 3: A Death of One’s Own

“A Death of One’s Own” explores the choices surrounding dying, including physician-assisted suicide, terminal sedation, the withdrawal of nutrients and hydration, and the implications for families, institutions and communities.

## Program 4: A Time to Change

The finale of “On Our Own Terms” profiles crusading individuals who offer palliative care to the working poor and the uninsured.

The series was accompanied by discussion guides and generated activity in chat rooms, community forums and homes throughout the U.S. and beyond. For additional information on the series, visit [www.pbs.org/wnet/onourown/terms/index.html](http://www.pbs.org/wnet/onourown/terms/index.html).

## What People Want At End-of-Life

- Respect my uniqueness as an individual
- Provide me with peace and comfort
- Address my spiritual issues
- Recognize my cultural heritage
- Communicate with me
- Help me with my pain
- Don’t prolong my dying
- Give me a sense of control
- Relieve the burden on my loved ones

## Vision for Changing Our Expectations of Care at the End-of-Life

Patients and loved ones are informed about the choices and challenges they will face and provided with the resources to help them. The resources are widely accessible in institutional, home and community-based settings, understood by physicians, patients and families, and appropriately funded. Educational curricula, planning tools, and community support are widely available for professionals and community members. End-of-life issues are openly discussed and viewed not as inevitably tragic and painful, but also as meaningful and uplifting.

## RESOURCES

The following are select institutional partners in CQEL. For a complete list visit [www.dgim.pitt.edu](http://www.dgim.pitt.edu)

**Allegheny County Medical Society**  
[www.acms.org](http://www.acms.org)

**Commonwealth of Pennsylvania  
Department of Aging**  
[www.aging.state.pa.us](http://www.aging.state.pa.us)

**Highmark Caring Place  
Southwest PA – Downtown Pittsburgh**  
[www.highmarkcaringplace.com](http://www.highmarkcaringplace.com)

**Hospice and Palliative Nurses’ Association**  
[www.hpna.org](http://www.hpna.org)

**Hospital Council of Western Pennsylvania**  
[www.hcwp.org](http://www.hcwp.org)

**University of Pittsburgh Institute on Aging**  
[www.aging.pitt.edu](http://www.aging.pitt.edu)

**Oncology Nursing Society**  
[www.ons.org](http://www.ons.org)

**Pittsburgh Pediatric Palliative Care Coalition**  
[www.pppcc.net](http://www.pppcc.net)

**Take Charge of Your Life Partnership**  
[www.takechargeonline.org](http://www.takechargeonline.org)

**United Way of Allegheny County**  
[www.unitedwaypittsburgh.org](http://www.unitedwaypittsburgh.org)



*The Jewish Healthcare Foundation (JHF) is a not-for-profit public charity that supports healthcare services, education, and research to encourage medical advancement and protect vulnerable populations.*

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