

Palliative Care Innovation in the Pacific Northwest

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Sometimes it's not the medicine, but the wisdom of those who practice it that makes all the difference. Dr. John Forsyth learned this early in his career when, in the middle of the night, he hurried to the emergency room. It was the early 1970's and his patient's adult daughter was struggling to say good-bye to her mother in her final hours. Dr. Forsyth couldn't calm her down, and her cries of fear and loss were agonizing. So, he called an older, more experienced, doctor to come help. The seasoned doctor quietly placed

the daughter's hand on top of her mother's and his own hand on top of theirs. The emotions of fear and loss were no less than before, but through his quiet touch the cries slowly melted into a moment of calm and peace before her death.

Palliative care: a developing field

It's this type of care and compassion that have become the trademarks of palliative and end-of-life care. While certain elements of palliative care - like the power of touch - have been around for many years, as a medical specialty it's still a new field that's often underutilized - and misunderstood.

Simply put, palliative care is a type of medical care that focuses on reducing the pain and suffering associated with serious disease or a terminal illness. Palliative care provides patients and families with an extra layer of support, addressing physical, intellectual, emotional, social and spiritual needs, while facilitating patient autonomy, access to information and choice. Anyone with a life-threatening or life-limiting medical issue can receive palliative care, and it can be combined with curative treatment. It is an im-

portant method for honoring patient choices and understanding personal definitions of quality, rather than merely focusing on the clinical aspects of terminal illness.

Cambia Health Foundation, a non-profit grantmaking foundation with headquarters in Portland, Oregon, is working to improve understanding and awareness of palliative care, while increasing access. Through grantmaking and collaborative partnerships in the health care community, the Foundation is committed to improving access to and quality of palliative care, recognizing and advancing leadership and innovation, and facilitating an open dialog about end-of-life issues.

Research illustrates a willingness to discuss end of life, but barriers exist

Research conducted by Cambia Health Foundation and the National Journal, a national news organization, illustrates that end-of-life care is a key issue for many Americans. An overwhelming majority (78%) believe there should be a more open public dialogue about the issues and options surrounding end-of-life and palliative care. In the Northwest,

more than 80 percent (85% in OR, 83% in WA) say that enhancing quality of life - not simply extending it - should be a priority.

Despite a genuine openness to discussing end-of-life care options, especially in the Northwest, the research also indicated that there are significant roadblocks to understanding - and accessing - palliative care. Only about a third of Pacific Northwest citizens are familiar with the term "palliative care." Once they understand the meaning of the term they support it, but nearly half believe it is only available to people who know where to look or have the right resources.

Uncertainties about palliative care aren't unique to patients and families. Those concerns also extend to physicians, who report that they sometimes struggle with how to engage in end-of-life conversations with their patients. Many say their patients are not well-informed about their options, and about a quarter say they're reluctant to recommend palliative care because patients might believe they're not doing everything possible to extend their lives.

Palliative care pioneers in the Northwest

In addition to grantmaking, Cambia Health Foundation is promoting access to, and advancing qual-

ity in palliative and end-of-life care by honoring exemplary leaders in the field. The Sojourns Awards recognize leadership and innovation, while providing recipients with a \$50,000 grant to invest in their future work. At an upcoming Sojourns Awards and palliative care summit in Seattle, five award recipients, including three individuals from Oregon and Washington, will be honored for their passion and commitment to advancing the field.

2012 Oregon and Washington Sojourns awardees:

- *John Forsyth, M.D. (Medford, Oregon):* The young physician from the beginning of this article is now a retired cardiologist and medical ethicist. A pioneer in the field of palliative care and the founder of a coalition called Choosing Options, Honoring Options, Dr. Forsyth has spent the last four decades encouraging Southern Oregonians to talk about their wishes and preferences for end-of-life care.
- *Darrell Owens, Ph.D., R.N. (Seattle, Washington):* After observing serious gaps in care, Owens, the director of outpatient palliative care at UW Medicine's Harborview Medical Center, developed the outpatient Primary Palliative and Supportive Care Clinic. He launched one of the

first clinics in the nation to combine primary and palliative care for vulnerable patient populations facing health disparities.

- *Kathy Perko, P.N.P. (Portland, Oregon):* For the director of OHSU Doernbecher Children's Hospital's pediatric palliative care program, caring for seriously ill children is her calling. Perko partners with hospices around Oregon to help them better care for seriously ill children in their communities, and she is nationally recognized for her work. To advance access, she's in the process of starting a pediatric palliative care telehealth program.

Although we are still a long way from a health care system where conversations about care preferences at the end of life commonly occur, the Pacific Northwest is a leader in the innovation and advancement of palliative care. The dedication, commitment and compassion of the individuals who are driving this effort are both inspiring and humbling. As a community, we should applaud their efforts to ensure that access is available to all who want - and need - palliative care.

Angela Hult is the executive director of the Cambia Health Foundation. Learn more at www.cambiahealthfoundation.org or @CambiaHealthFdn on Twitter.

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