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# Leaders in the Patient Experience: Diane Meier, Palliative Care

By Barbara Sadick

When Patrick Owen was diagnosed with bile duct cancer in 2007 at age 51, he and his wife Lisa found a surgeon who gave them what Lisa describes as an amazing five additional years of life together. The surgery went well, but the margins were positive, and Patrick was immediately treated with chemotherapy. After a ten-month remission, the cancer came back with a vengeance and he began a chemotherapy protocol that would last for most of the rest of his life. Patrick's chemotherapy routine was increasingly stepped up, radioactive wire was run through his bile duct, he had a heart attack, and by the end of January 2012 the cancer was ravaging his body. Soon after, the couple was introduced to palliative care at Mt. Sinai Hospital in New York.

Patrick felt immediately at home. He was relieved of the debilitating effects of chemotherapy. Care focused on treating symptoms to alleviate pain and on improving his quality of life. "He kept telling me he was tired of being sick," says Lisa. "And the palliative care team worked hard to give him relief. I was amazed at what good communicators they were." She was awed by their positive outlook and ability to make the time she had left with her husband joyful.

Diane Meier, a pioneer in the field of palliative medicine, has spent years trying to get the word out about palliative care. She says most people think it's end-of-life care, and while it sometimes precedes end-of-life care, it's care at any point of life that is focused on treating and alleviating symptoms, pain and stresses, and on improving quality of life as perceived by the patient. Palliative care is needs-driven, rather than driven by the need to cure chronic or incurable illness. It's designed for those whose diseases are serious enough to affect day-to-day life, some of whom live with chronic conditions such as multiple sclerosis or rheumatoid arthritis for their entire life.

"When I went to medical school, I thought my work would be to help people," says Meier. "But I found that the system was more focused on sustaining itself." She began to doubt herself, because most of her colleagues seemed to be following a different path, and she considered giving up medicine.

Meier is a trained geriatrician. She says that was the closest she could get in medicine to a holistic practice, but even that focused mainly on treating diseases and prognoses. She continued to search until the Robert Wood Johnson Foundation and George Soros' Open Society Foundation began to invest hundreds of millions of dollars to improve access to high quality palliative care. "That was when my concerns were legitimized." says Meier. "It was the catalyst that connected me to others who had similar perspectives, and I finally felt a sense of having a peer group of professionals with whom to work."

The Center to Advance Palliative Care, established in 1999 and directed by Meier, is a non-profit national organization devoted to providing health care professionals with the assistance needed to start and sustain palliative care programs in hospitals and other health care settings throughout the country. The organization is working toward training more doctors, requiring that it be available in hospitals, nursing homes and the community, setting standards, and investing in research. Recognized as a board-certified specialty in 2007, the field still has no national standards and little more than a week of required training in most medical schools. Specialties such as pediatrics, internal medicine, family medicine, neurology and surgery are now pursuing the field, and in the last ten years, palliative care teams in hospitals have doubled. But there's still a lot of work to be done. "There are 4,000 board certified physicians in palliative care," says Meier, "but we need about 25,000." She adds that for every 1,200 people living with serious illness, only one palliative care physician is available.

"Recent studies show that palliative care patients live longer than other patients," says Meier. "If practiced correctly, it's practiced as a team with a physician, a fellow, a nurse practitioner, a social worker, massage, art, and yoga therapists, and a chaplain." The team approach creates a different problem. Insurance companies normally pay in full for only an MD and a nurse. Meier's hope, though, is that eventually enough people will come to understand the positive benefits of palliative care and be able to separate truth from scare tactics, resulting in a demand that will create a shift in the marketplace.

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Until that time, philanthropic contributions help sustain the field.

In the United States, where health care costs reached $2.9 trillion in 2010, representing a whopping 17 percent of the gross domestic product, medicine has been traditionally geared toward saving lives at any cost, which, when compared with the cost savings of palliative care, is a very expensive proposition. With less than 10 percent of patients accounting for two-thirds of health care costs, and its percentage of the GDP expected to reach 20 percent in the next few years, health care spending has become the number one threat to the U.S. economy. Half the population spends little or nothing on health care, five percent spends almost 50 percent, and those over the age of 65 spend in excess of 36 percent. An exploding aging population, those 65 years and older, is expected to account for 20 percent of the total population by 2030, with those over the age of 85 likely to double to 8.5 million. Many elderly patients are well-suited for palliative care, whether they're living with Alzheimer disease, Parkinson's disease or cardiovascular disease. Traditional treatments cost more, but don't necessarily benefit the patient. When comparing the costs and quality of life of disease specific treatment to those of palliative care treatment, it becomes apparent that continuing to increase spending without change is putting unsustainable stress on the economy without delivering better results.

In 2010, health care costs were the second most common cause of bankruptcy in the U.S., and 30 percent of families are losing most or all of their savings caring for family members with serious illness. Spending clearly doesn't correlate with patient outcomes, satisfaction or experience. When compared to other industrialized countries, efficiency and quality rank lower, and more than half of hospitalized Americans report a negative experience.

Meier is also a professor and vice chair of Hertzberg Palliative Care Institute at Mount Sinai School of Medicine, where she's been on the faculty since 1983. She says data shows that palliative care improves quality of care and length of life, and lowers costs by reducing the need for hospitalization, emergency room visits and by eliminating pain. A report published by the Institute of Medicine concluded that if palliative care teams were fully integrated into the nation's hospitals, total saving would be in excess of $6 billion per year. "When patients and families understand the options, they usually make conservative choices," says Meier.

For example, chemotherapy is often the preferred and most effective treatment for a cancer patient, but there are situations in which cancers are so aggressive and lethal that it's obvious that even with chemotherapy, lives can't be saved and quality of life can become miserable. But to indicate that nothing can be done is not acceptable to palliative care teams who believe there is always more to do to help people live well during their illness or in their last years of life. They say this is when many doctors disappear. "Palliative care forces uncomfortable conversation, but a patient is entitled to options," says Meier. "And once a patient and family have experienced this kind of care, they have amazing things to say about it." Many who've been in the health care system for long enough come to palliative care and are surprised to see patients who aren't hooked up to monitors or being poked and prodded.

Meier trains and works with numerous physicians such as Betty Lim, a geriatrician and palliative care fellow who says Meier has done amazing work. "Diane has helped change the culture at Mount Sinai by building relationships and assuring doctors that palliative care isn't there to take away their patients," says Lim. The primary care doctor is, in fact, the client of the palliative care team, and due to Meier's relationship building efforts, Mount Sinai physicians are now asking for help from the palliative care team when working with patients whose illnesses are complicated and time sensitive.

"We don't take over the care of the patient," says Lim. "Instead, we support them and serve as the eyes and ears and hands of physicians who work all day in their own practices, but have patients who are very sick and in the hospital." That means helping them coordinate care and often conducting repeated lengthy family meetings to help patients and families discuss their concerns and arrive at important care decisions. "Diane has built a great reputation for our service," says Lim. "She's taught us that we have to take care of our colleagues because they are caring for very sick patients, and we need to support them as much as we support patients and families."

Meier's hope is that in the future, all incoming patients will be screened for eligibility for palliative care, because she believes if they are sick enough to be in the emergency department or in the hospital, palliative care should be a treatment option. She hopes to see more physicians embracing this kind of care as an adjunct to their own care. "If we don't let ourselves see that a patient is suffering, then there is nothing we can do about it," says Meier.

Reflecting on her experience, Lisa Owen praises the skill and humanity of Patrick's palliative care team. "This approach to treating illness allowed Patrick to say goodbye and to articulate to me that he was at peace and wanted me to be there with him," says Lisa. "He was aglow with acceptance and wonder at the world. He had no pain, no chemo, and he knew he only had to love me and not be strong for me anymore." He told Lisa that death is part of the circle of life and that they were traveling on that circle. And one Saturday, he gathered everyone together to say his official goodbye so that he and Lisa could be alone together to prepare for their separation.

Patrick died in March following a short stay in hospice care. Lisa says he often mused on how we spend too much of our lives running from death, and if we could just come to accept it as part of our journey, we can have an amazing experience. Palliative care allowed him to be free of pain and aglow with acceptance and wonder at the world. "My husband loved life and didn't want to leave it," says Lisa. "But at a certain point, it became a blessing that he did."

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This is the third article in this series, written by Barbara Sadick, Association member and freelance health writer. Based in New York City, Barbara's clients include U.S. News & World Report, Healthline.com, The Commonwealth Fund and Health Behavior News Service. In 2003, after the death of her brother from lymphoma, she began working as a freelance health advocate, researcher, and writer. Her personal experience has been supplemented with an MA in Health Advocacy from Sarah Lawrence College and an MS in Health and Behavior Studies from Columbia University. Available for freelance writing and research, Barbara can be reached at barbara.sadick@gmail.com.

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