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Life's tough choices

With more facing difficult end-of-life decisions, awareness and enhancements in palliative and hospice care have grown tremendously

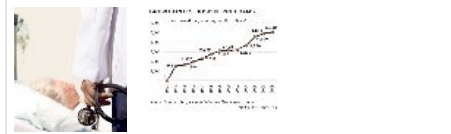
By Vicki Viotti

POSTED: 01:30 a.m. HST, Oct 30, 2011

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PHOTO ILLUSTRATION BY BRYANT FUKUTOMI / BFUKUTOMI@STARADVERTISER.COM



Hospice can be considered a dreaded word by many families caring for someone nearing the end of life. It suggests turning the page on the chapter about finding a cure and entering a phase everyone's been avoiding.

Kenneth Zeri hopes all that may be changing, and he points to advances in public policy and in ways the private sector is approaching the end-of-life question. He's in a position that affords a pretty clear view. He's president both of Hospice Hawaii and of the board of directors at Kokua Mau Inc., a statewide hospice and palliative care organization.

A 2010 study of terminal cancer patients, published in the New England Journal of Medicine, showed patients receiving early palliative treatments (pain-relieving and comfort care) had better quality of life and mood -- and lived 2 1/2 months longer.

"If you relieve the burdens of the disease," Zeri said, citing the study, "if you engage people in conversations about what's important in their life and their values, if you provide that support and counseling that they need and you give good symptom management, then their quality of life will be better, their families' quality of life will be better ... and they did seem to live longer."

Jeannette Kojane, executive director of Kokua Mau, agrees wholeheartedly. While acknowledging that Hawaii still has a way to go in getting the message out on end-of-life care, she said patients are now more frequently seeking hospice and palliative services at an earlier stage and staying with it longer.

The ultimate message that needs to get out to families,

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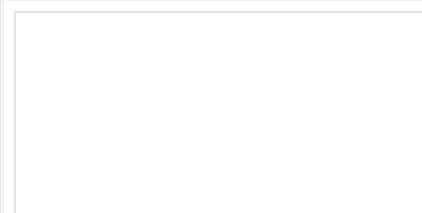
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Kojane said: Seeking help and planning do not equate with "giving up hope."

"We need to change what it means to be a good caregiver," she added. "It shouldn't be, 'I gotta do everything in order to take care of my loved one.'"

"Hope is not a plan. Hope is OK, but that doesn't help improve quality of life for our loved one."

AMONG those who've received that message is Sophie Ann Aoki. Long known for her community activism in past years, she had focused more recently on the care of her father, a noted retired pastor and University of Hawaii religion professor who had himself become a counselor helping people to prepare for their life's end. Mitsuo Aoki died in August 2010 and, his daughter said, Hospice Hawaii had provided the support and guidance the family needed.

"He was fine with that, and I'm so grateful that he was," she said. "

"It was just such a gift to us ... just to have their presence and someone to call if you need to."

Families hesitate to call hospice early on, with what are, at present, good reasons. Until this year, health care plans would not cover hospice care while life-extending treatments are still going on, and families did not want to give up trying to hold off the disease, to have more time.

In March, however, University Health Alliance, a Hawaii medical-plan provider, became the first in the nation to offer insurance coverage for concurrent end-of-life care — curative treatments as well as the comfort hospice care provides.

In addition, the Affordable Health Care Act of 2010 enabled, starting this year, for children with a terminal disease diagnosis to be covered both for ongoing medical treatment as well as the comfort of hospice.

A patient can get coverage for hospice care only with a prognosis indicating he or she is likely to die within six months. That's what distinguishes hospice from palliative care, which can be administered earlier in the disease process — for example, for a cancer patient who is still seeking a cure but has significant pain and needs relief.

Ordinarily, Zeri said, these treatments are given in hospitals, but there are now some palliative clinics. Even more attractive to some families, Kaiser Permanente in Hawaii has a palliative care program that is typically delivered in the patient's home and is accompanied by support services more common in hospice settings: counseling by chaplains, for example, or social-worker visits.

Two years ago, state lawmakers passed a law authorizing a document known as POLST (Physician Orders for Life-Sustaining Treatment). It enables the patient to encapsulate information more typically found in an advance directive but kept on hand so that a paramedic in the ambulance can begin immediately in giving the person the care they want.

This is all part of what Zeri sees as an overall trend to make end-of-life options — everything from aggressive curative treatment, to a mix including hospice services — part of planning at an earlier stage. The biggest regret from families afterward, he said, is that they didn't seek help earlier.

A SIGNIFICANT STEP in that direction has been taken by Hawaii Medical Services Association, which has entered into multi-year contracts with hospitals incorporating an additional program for reimbursements based on measures of quality, said Hilton Raethel, HMSA senior vice president. Among the categories, he said, is advance care planning, including training for providers and staff in how to approach patients in discussing end-of-life care options and preferences.

Zeri believes this initiative will further the goal of getting people the help they need much earlier.

"This is not a prescription to say, we have to talk everybody into hospice — not at all," he said. "It's a tool to say, when we are able to identify people in the last year or so of their lives, how do hospitals have the skills to talk to their families about it?"

"Yes, it's good for the hospitals, and it's a good thing for hospices, but mostly it's a good thing for people."

Aoki was only too happy to welcome the assistance of such professionals in making her father's last days comfortable and welcoming to family and friends. There are so many unknowns a family caregiver feels ill-equipped to handle, she said, and without hospice help she could only hope to keep her head above water.

That kind of chaos gave way to a greater calm once hospice came aboard, she said.

HMSA's Raethel said ensuring that end-of-life planning happens helps the patient and gives peace of mind to their families, assuaging their grief when they die.

"The adjustment to that person's passing is so much better — they realize the person had a say in the end of their life," he added.

Aoki agreed.

"Hospice just offers tremendous resources for the person who's dying, a know-how, sensitivity, really assisting the person who needs care," she said. "It helped our family open its doors to a broader community to be part of dad's process — all with his OK."

Forums to air end-of-life issues

Kokuu Mau, a nonprofit organization of hospice and palliative-care providers, is promoting two coming events, both aimed at raising awareness of end-of-life concerns.

It's the host of the first event, an educational summit ("Transformation: Enhancing Care, Containing Cost; Maximizing Satisfaction"), set for 8 a.m. to 5 p.m. Nov. 10 at The Queen's Conference Center. Information: kokuuamau.org/summit.

The aim is to draw individuals and organizations with the goal of reducing suffering for the seriously ill, including everyone from health care executives and doctors to chaplains and family caregivers.

This event will be followed at 8 a.m. Nov. 11 with "Mission Possible V: Operation Palliation," a day-long conference to cover advances in pain management; it will take place at the Richards Street YWCA aimed at physicians, nurses and other health care professionals. Information: 691-7009.

— *Star-Advertiser staff*

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SUBMIT COMMENT

Highinthesierras wrote:

At least we don't have chunks of ice in Hawaii

on October 30,2011 | 05:58AM

REPLY

Changalang wrote:

The best gift one can give to a loved one that is terminally ill is an easy and honorable death. I am not an end of life legislative proponent, per se, but making the inevitable journey we all will take as comfortable as possible is a duty of our humanity. Hawaii is very short on beds and there are supportive companies like Hospice Hawaii that need the public's help to expand desperately needed services statewide.

on October 30,2011 | 09:11AM

REPLY

wiliki wrote:

This is a personal choice. But everyone should have the opportunity for good affordable care when they can no longer take care of themselves.

on October 30,2011 | 09:38AM

REPLY

Leewardboy wrote:

My father was in hospice for several months. It was difficult seeing him slowly slip away but the care given him at St. Francis Hospice was fantastic. Strangely - visiting the hospice every day - took away most of the fear of death which I had before. Hospice eased my father's pain and took a lot of the burden of care off the family. Before and since I've helped care for several relatives and family friends in a home setting and the stress and physical demands nearly killed some of us. Hospice eases such burdens and I am grateful to the dedicated people who work to ease suffering by working in hospice settings.

on October 31,2011 | 09:21AM

REPLY

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