When Treatment Fails, Should Medical Caring Stop?
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TUESDAY, June 20 (HealthDay News) -- Karen Donley-Hayes' best friend, Ashley, died of metastatic breast cancer at just 36 years of age.

For months, a dedicated team of oncologists, surgeons and nurses had worked night and day to beat the runaway cells that were slowly robbing Ashley of life. Then, one October day, the team effectively admitted defeat and turned the young woman over to hospice and end-of-life care.

Donley-Hayes, of West Farmington, Ohio, remembers sitting with her dying friend in the oncologist's office. He had left the room.

Ashley then asked her, "Well, I want to live till Christmas -- do you think that's possible?"

Donley-Hayes, whom Ashley had given medical power of attorney, was left without a reply.

"I remember sitting there, thinking 'What do we do now -- we don't have anybody to ask these questions of -- who do I approach to know where we stand now?' " she says.

Ashley died a few weeks later, her devoted husband, parents and best friend -- the group her Texas father had dubbed "Ashley's posse" -- at her side till the end.

And yet, in an essay published in the June 21 issue of the Journal of the American Medical Association, Donley-Hayes wonders why Ashley's medical team couldn't have done just a little more in the few weeks she had left.

"For the year and a half of her illness, these people had become, in a way, a part of her family," Donley-Hayes wrote. Ashley saw her doctors, nurses, and other hospital staff daily. However, Donley-Hayes added in the essay titled At Face Value, "when no more chemotherapy or radiation would be administered, they were gone. Looking back, I see this as a sad departure, almost an abandonment. They were there to help her try to live, but they were not there to help her die."

This abrupt, confusing and sometimes hurtful division between treatment-oriented care and end-of-life care troubles Donley-Hayes still. She recalls no discussion between Ashley and the oncologist or nursing staff as to what to expect in her final phase of life, or how Ashley and her support team might handle it.

"There's a gap there in medicine," Donley-Hayes says. "It seems like it should be more integrated, a better transition."

One advocate for a more blended transition from active treatment to palliative care says Ashley's story is sadly familiar.

"Clearly, this is not an unusual experience -- it's still far too common, it's awful, and it shouldn't be like this," adds Dr. Karen Ogle, a professor of palliative medicine at Michigan State University.

Somewhere in the slow decline that can occur for patients who lose their battle against illness, Ogle says, medicine too often draws "this sharp line where the patient makes this abrupt transition to hospice." A loved, trusted team makes its exit, and unfamiliar faces suddenly take over.

Ogle and others in the fast-growing field of palliative medicine are pushing for a much more shaded, gradual changing of the guard. Ideally, issues of quality of life and pain management should be discussed very early during the treatment process, Ogle says, and if a patient's prognosis worsens, the search for a cure can slowly
give way to a focus on palliative care.

Medical teams that patients leaned on during treatment can still be a vital part of this final stage of care, Ogle says. "In fact, I thought as I was reading this essay, of a recent, similar case that I was involved in -- a 39-year-old woman with breast cancer whose oncologist was very actively involved, right up until the patient died in a hospice."

This type of more integrated palliative care is making inroads in medical centers across the country, she adds. One recent study found that more than half of all U.S. hospitals with more than 100 beds now have palliative-medicine services in place, and more than 2,000 physicians are now board-certified to practice palliative medicine. The American Board of Medical Specialties is also poised to award palliative medicine "official specialty" status, Ogle says.

For her part, Donley-Hayes, a former paramedic and now a medical editor, agrees that traditional "treatment-focused" doctors and nurses have much to gain from helping patients through the dying process when living is no longer an option.

"It's a disservice to professionals in medicine to be removed from this part of a disease, because it's part of it -- and the most difficult part," she says.

Donley-Hayes stresses that she has no qualms with the "extraordinary" level of care Ashley's medical team had given her as she struggled against breast cancer. But, after they left, she adds, "we just didn't know where we stood, what to do or how to proceed. And if we felt that rudderless, what does the typical person who is ill, or their support network, feel? How do they deal with this?"

Resources are out there, of course -- myriad books, organizations and Web sites aimed at guiding patients and loved ones through this final challenge.

Ogle also urges patients to seek out hospitals that offer palliative-medicine services as part of their programs. And she says that those patients who can, should try to talk openly about the possibility of death -- even as they fight their disease.

"Talking about that worst-case scenario early on actually gives you power," she says.

That's a lesson Donley-Hayes says she learned from Ashley.

"She's the real hero of this story," Donley-Hayes adds. Clear-eyed, honest and able to laugh even on her last day, Ashley had an "undaunted openness about dying" that made helping her that much easier on her "posse," her friend recalls.

"Death isn't like you see in the movies, you know -- that's not how it works," Donley-Hayes adds. But Ashley's life force met it head-on, she says.

"That's why I chose this title for the piece -- to look at death at face value, and to take it for what it is."

More information

For information and guidance on end-of-life issues, head to Michigan State University's Completing A Life.