

Part 2 of HFA's interview with the founders of one of the largest hospice companies in the United States continues below.

Esther Colliflower and Hugh Westbrook founded Hospice, Inc., which later became Vitas. Westbrook and Colliflower started Hospice, Inc. with a single patient in Miami, Florida, and grew it into Vitas, a national program that now serves tens of thousands of patients and families each year. They are no longer involved with Vitas but oversee the [Foundation for End-of-Life Care](#) charity, which provides for special needs of hospice patients and families that fall outside of the hospice benefit.

In the [first installment](#) of their interview with HFA CEO Amy Tucci, the two hospice pioneers spoke about getting Hospice, Inc. up and running when the concept of hospice care was in its infancy in the United States. In Part 2 they discuss the negotiations around the Hospice Medicare Benefit and the evolution of hospice care.

(HFA): Can you talk a little about the attitude toward hospice care in the early days and how it has changed or not changed over the years?

(EC): We had people whose jobs were to meet with physicians and champion hospice care for their patients. It caught on, from my point of view, very quickly with a lot of positive support. We finally introduced the whole marketing component to every one of the hospices so that we could sell the idea to physicians and get them to participate in providing better care for their patients who were terminally ill.

(HFA): In today's hospice world, you hear clinicians who work in hospice care say that, not all physicians but many physicians, continue to refer patients way too late to hospice.

(EC): It's unfortunate, but certainly we're smart enough to be able to figure out how to staff for that. We figured out how to give continuous care when we found out that patients [occasionally] needed round-the-clock care when they were at home, and how to develop inpatient units when we discovered that that was another component of hospice care that would be appropriate for the development of end-of-life care for terminally ill patients.

So why people groan about [late referrals] rather than devise a way to [deal with them], I don't understand. They might even have a team for late referrals. I don't know. I'd like to talk about it.

(HW): But the fact is, the economic incentives that are set up in our health care system today are driving treatment and procedures, and we don't do things to help people face the fact that, at some point, somehow, some time, they are going to die and it may be of some disease or something else and they need to have a plan for that.

It was politicized a few years ago when the idea of death panels was the talk of politics, which was very, very unfortunate. But I think today you'll find that most physicians want to do the right thing for their patient at the right time. And at the same time, you need to be realistic and recognize that physicians are there to try to heal and save life, and prolong life, and it is an ongoing discussion. You can never stop having that discussion. Hospice can never back away from its mission to educate people about what the hospice mission is.

(EC): What I have a problem with is that Medicare regulations so stifle creativity. Hospice isn't just about dying. Hospice is about providing quality of life to people at the end of their lives, so the things that I used to consider goals and exciting, like the [Dr. Richard] Lamerton experience or the Cicely Saunders' experience (see Part 1 of this interview), or many, many, many that we had in hospice care, the attempt to provide those kinds of experiences are now not able to be fulfilled because of Medicare regulations.

(HW): Exactly. Right now, if you were to take a patient out to a movie, Medicare will come back and review that day and say, "If they were well enough to go out and go to a movie, they were not terminally ill and we're going to deny payment for that day."

(EC): And meanwhile, the [hospice] team would be rejoicing that the patient was able to go to the movies.

(HFA): Should the six-month limit for entry into hospice continue?

(HW): No, it should not continue. When we wrote the [hospice] law in Florida, terminal illness was defined as one year or less. That was also proposed for Medicare and it is one of the things that the Republicans at the time on the House Ways and Means Committee refused to accept, and they cut it back from one year to six months. I think six months is too short. I think that we ought to open up hospice and make it available for a longer period of time and pay hospices [so] at least their costs are covered.

(HFA): How did you approach Capitol Hill about the benefit?

(HW): We organized the National Hospice Education Project and we met [then] Congressman Leon Panetta of California, whose parents had recently died and were cared for in a volunteer hospice in California, then Senators Lawton Chiles of Florida, and Bob Dole of Kansas, and we worked with Congressman Claude Pepper of Florida, who assigned one of his people working on the House Permanent Select Committee on Aging to help us draft a Medicare law which looked exactly like the Florida law in the way it defined hospice.

That created a lot of controversy around the country because we were imposing a certain view of how hospice ought to operate. We required an emphasis on dying at home, on providing bereavement care, and also required that you provide inpatient care, which at the time, none of us was able to do except for very few hospices that were doing only inpatient care in their hospital but did not do home care.

In 1982, the Medicare law passed and hospice became a uniform provider of end-of-life care.

But I want to say one thing because this is important to what happened along the way to a couple of our ideals when we were working in the Congress. We thought that it was important to have a chaplain as part of the hospice team, and strangely enough, we met resistance on that score from a couple of congressmen, Democrats and Republicans mainly from the south who said, "Look, we have preachers and pastors and priests and rabbis who will provide that kind of care, and we can't mandate any religious or spiritual care be provided."

We just didn't win that one, and we didn't win it mainly because one of the things that we felt was important was bereavement care. There was a particularly important congressman from Tennessee who said, "Look, when somebody dies in my community, our pastor takes care of them and I'm not going to

have the government paying to take care of somebody after the death of the Medicare recipient because we don't take care of people who aren't Medicare recipients, and once the patient has died, there's no longer a Medicare recipient — there are only survivors. And [he said], "I'll agree that we can require the hospice to provide bereavement care, but we won't pay for it and we won't necessitate the requirement of a chaplain."

The compromise was that they require bereavement care, but it doesn't get paid for by Medicare, and instead of having a chaplain, you have to provide a counselor as a member of the team. Now, as it turns out, that counselor could be a social worker or a certified counselor, clinician of some sort... or a chaplain.

And in those days, many hospices were started by churches, ministers, and by folks that had religious affiliation to various organizations. And so nearly all hospices had a chaplain as "our counselor" and involved the chaplain in organizing bereavement programs in the communities around this. We didn't win 100 percent of that argument but we got part of it.

(EC): You know, I still have some debate about that. I think we both agreed that a chaplain is a necessary part of the team and we also have to recognize that not every family needs a chaplain, but it should be available. Also, families go through bereavement in different ways, but it's impossible to give good hospice care without having bereavement services available - not imposed but available. I just had a personal experience within the last year and became more understanding about what my needs were, and concluded that (a chaplain) wasn't necessary. It was very necessary for my neighbor. So, we need to be available in whatever way the family gets support.

Back while all that legislating was going on that was so important to our survival, it meant that in the field where care was really being provided, we had to establish criteria for the provision of care medically and in all the psychosocial areas and so forth that we had agreed were necessary.

So, it meant finding staff and training staff to look at the care in another way than that which they had been accustomed – adopting a whole new way of working with the team. It was a lot of work. It was interesting. It was challenging. But it was really fantastically exciting.

(HFA): What about future changes to the benefit? Should the government reimburse hospice providers for concurrent care?

(HW): I think it's very controversial and very dangerous, but at the same time, I don't believe that anywhere, politically, would you win an argument that would say to somebody that they don't have the right to try one more thing to cure themselves, particularly when we are in an environment in which many of the commercials on television are talking about new drugs that are going to cure you from things that were once thought to be incurable.

At the same time, I think we have to be logical and realistic and that's where I believe that the payment system has to be looked at carefully, about how hospice can be there to provide the support for the family and the preparation for the eventual death of the patient even if they are trying some concurrent kind of care. But what you don't want to see is what it looks like now when a person is in a clinical trial, for example, and they are going back and forth to the hospital all the time or to this physician and then that one, in this treatment then that one. You've got to be able to make a decision at some point that

maybe that person's not really ready for hospice, and that they need to try what they want to try, and then come in.

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