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TRANSCRIPT

Palliative Care: A Journey Through PACE

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Good afternoon. Hope everybody enjoyed lunch. I was just telling Dr. Hammett that I have to say I only kind of caught the tail end of their presentation and some of their questions, but they're actually sort of doing a lot of what we had hoped to do, so by the time I get to my last couple of slides, I'll just say "like they said." Because we haven't quite gotten there yet.

So what I'm going to talk about this afternoon is about how we sort of put together a palliative care initiative. Our site was opened originally in 1999, but the use of hospice and actually having some sort of formal end of life program really didn't start until about three to five years ago. So prior to about 2007, there wasn't any kind of either formal or informal training for the staff in end of life issues at all. There were several--I mean, we are right here in the center of Philadelphia, so we have the benefit of having multiple hospice organizations in the area that we could utilize in various ways, but again, prior to 2007, it was not a service that was really utilized, either for outpatient care, or for inpatient care. We have an area that is a closed unit, and even in the older centers, we've always had it, that we call the Circle of Care, because it originally was a circular area that people could sort of mill about in, but they couldn't get out to anywhere. And while we still have this area, it's for folks who have a higher level of dementia and a little bit of wanderlust, I like to call it.

In any rate, in that particular area, back around 2007, there was a little bit of preparation for the family in terms of the--what was going on with some of the members, as they were getting closer to dying, but throughout the center as a whole, there really wasn't a whole lot. The nurse practitioners and the physicians that were there were really very supportive of doing something along the lines of palliative care, but there was just kind of no direction and no real way to get it started at that time.

So right around then, there was an influx of some new staff who had a very strong hospice background, and they sort of looked around and realized that this was something that was lacking, and started working with the administration at that time to try to get some training, either both for themselves, and for the staff that was in the center. So back in 2007, they were sent to an ELNC training course. ELNC stands for the End of Life Nursing Consortium, and it's a series of training modules and programs that actually teaches the persons who are getting the training how to teach other people to provide good end of life care, predominantly in a long-term care setting.

So after this, it came back and started kind of in earnest, in trying to change the whole culture that was within the center. They spoke with multiple different hospices, just to see what they were like and what they were doing, to get an idea of services that they could utilize from hospice, or even just to learn from them some of the techniques that they use to communicate with families, and with the members as they were entering the last stages of life.

They also started looking at the members that were actually in the program, and to try and kind of figure out which ones would benefit from hospice, who were not necessarily hospice appropriate, but could certainly benefit from a more palliative type of plan of care. They started with education, a lot of educational efforts for the staff, both in a formal way, by in-services and seminars, and even a little bit more informally, where just having conversations one-on-one about specific member issues, or specific family issues, or specific events that could be utilized to start the whole conversation.

The facing death with dignity, I'm going to come back to that in a minute. So in 2009, after all of the groundwork was kind of laid, the palliative care committee came together, and that's sort of the beginning of our formal program of palliative care at (inaudible) Penn. The committee was very, very multi-disciplinary. It was open to anybody in the center that had any sort of an interest either in palliative care, or wanted to learn about it, or just wanted to know what the hubbub was about. So this group, and it still exists today, was made up of social workers, occupational therapists, the chaplain, we had nurses, nurse practitioners, physicians, rec therapists, clerical staff, caregivers, folks off of administration and people in the marketing department that all kind of came together to work on this. Our mission is there in front of you, and the first thing that we had to sort of tackle was this concept of allowing our members to have a good death.

So the first sort of hurdle I guess that we had to get over was we had some cultural--we had to cross some cultural barriers to get the idea that maybe what our members think of as a good death is not necessarily the same thing that the staff would think was a good death. We had multiple conversations about exactly what that phrase means, and had to--like I said, we had to sort of do some cultural searching, to figure out how we're going to find from the members what they want, as opposed to kind of try and impose on them what we think is the idea of a good death. Our other mission was to make sure that the environment for staff, for members, for family, was comfortable enough for people to feel free to talk about these issues, and address whatever things may come up.

Our staff at that time was kind of--they didn't like to talk about it. Even if members were to bring up, you know, I'm not going to be here very long--oh sure you are, why say that? Don't be silly. When maybe they weren't going to be there very long. They may know something that we didn't know. So we wanted to create an environment where everybody's views could be expressed and supported, regardless of what those views were, and also to have a very supportive presence, which I guess is the same thing.

We found that a lot of our staff becomes very, very attached to our members. We have some members that have been in the program eight, nine, ten years, and they've become almost like family, so when they finally do die, they would grieve for them the same way they would grieve for a family member. So we wanted to be able to provide support for them, so that they could continue the work that they do, without being derailed by some of the grieving process.

So one of the first things that the committee did was this program that we called Facing Death with Dignity, and it was a week of presentations that we did, a different one every morning, at the end of our

IDT meeting. Only took maybe about ten minutes at the most, but it was each day was a different activity, and we started off saying you can participate, you can not participate, it's completely up to you, but this is what we're doing and we're going to try and start to explore this idea of death and what it means, and how it means different things to different people.

So the first thing that we did, the very first day, it was a week in October, if I remember correctly, and we had taken a large branch that had no leaves anymore, and we put it up like a tree. And on all of the tables, we'd cut out leaves with a little piece of ribbon, and so we said to everybody that on the tables, you can have one leaf, you can have three leaves, you know, however many you want. Put the name of somebody who has died, who left some kind of mark on you that you carry with you now that they're gone. And in a way to honor them, put their name on the leaf, think about who they were and what they meant to you, and just hang it on the tree as you go out.

So we went from having this completely naked branch to then a fully populated, colorful tree. And then we went on with our day, no muss, no fuss. So we did several things like that. Another thing that we did during that week was we had a mural painted and talked about death by a way of a journey, and it had a mountain in the center with a path that went up one end and down the other, and then we set up two backpacks, and we talked a little bit about how with this journey up to and through death, there are things that you take with you, and there are things that you leave behind. So again on the tables, we had post-its, two different color post-its. One color was for what you wanted to take with you, another color for what you wanted to leave behind, and people were asked to think about that, and write them down and then put them in the various--the bag on whichever side of the mountain was appropriate. And again, that's the last thing they did as they went off to kind of start their day.

And it turned out the staff found it very, very moving. They found it very thought-provoking. We had a lot of actually good feedback on the activities like this, and it got people talking, it got people thinking, and it sort of started to turn the Titanic, as I like to say. One of the next things that we worked on was getting an advanced directive. Prior to this, we had sort of a rudimentary, one-page document that either said, yeah, I'll be a do not resuscitate or a full code, and that's pretty much all it encompassed.

So we looked at several different advance directive documents, and finally settled on the five wishes, which I'm not sure if you're real familiar with it. It's about a seven or eight page document, and goes through from multiple different things that a person may want to have done for them, or about them, towards the end of their life. I mean, there's certainly the issues of whether they want to be resuscitated or have a feeding tube or dialysis or fluids and all that kind of thing, but it's also things like, you know, how do you want people to remember you, and what would you like in your service, and what kinds of things--if you can't speak for yourself, what kinds of things do you want people to do for you? Do you want them to play music? Do you want them to braid your hair? Do you want them to do your fingernails? Do you want to make sure you have on heels? You know, what--and it's a lengthy document that gives people a real opportunity to sort of lay it all out, and relieve their family really of all of the decision-making.

So we--and the way that we went about choosing this--like I said, we looked at multiple different ones, and there was--at the same time there was a class of senior nursing students who were taking a palliative care class down at the nursing school, at the University of Pennsylvania, who is our parent, as it were, and they came up as a project to help some of the members, to talk them through the five wishes, just as a class project, so that they get experience on how to guide someone through this document.

And the members that were chosen for this one--what we thought was a one-time class had such a strong reaction, and enjoyed it so much--we kind of had focus groups afterwards to talk to them about it, and they loved it. So we thought, you know, they've done our work for us, so we decided that we would adopt this as our advanced directive. The class still meets. It's every spring, and there's anywhere from four or five to ten students that will come up, and they'll talk with some of our members about the five wishes. Some of them have already done it, so it's easy for them to do. Some of them are new and it's just their first entrée into it, but that's been a real boon.

A lot of times, members will participate in this class project and then come to either somebody on the primary care staff or (inaudible) social worker and say, you know, I was doing this thing with--but I want to do that. Help me fill one out for me, because it makes a lot of sense. So we're now having it actually--having everyone in our center, all 436 of our members have one filled out, is a slightly different challenge. But we're working on it.

Some of the other things that we did--like I said, there were issues with culture, so we had a--we brought together a panel discussion that we called Culture Conversations and Caring. We had a geriatric--an expert in culture who is actually a geriatrician. We had a chaplain, a couple of hospice representatives were on the committee, and this was something that was presented to our entire IDT, to explore kind of the African-American culture and how it interfaces with end of life issues, and so forth.

During our annual in-service, we've had a section where we talk about palliative care. The first year, we had a mock intensive care room set up with a story and it gave sort of a scenario, and gave people time to sort of talk about the issues with having somebody elderly in the ICU, with multiple tubes and whatnot. We continue with staff education based on what we've learned from LNAC, that teaching series. It concludes such things as talking about goals of care, pain management, loss, grief, and bereavement ethics, all those kinds of things.

The sessions that we did on having the difficult conversation was an interactive kind of group. We brought together social workers, RNs, nurse practitioners and physicians, and had them do various role-plays, where you'd have a difficult family dynamic, having to do with some end of life issues, and so people would play different roles. We had social workers being physicians for the day, or RNs being a social worker. Or, being the difficult daughter who just doesn't want to understand that Mom might really be dying.

So we'd do that, and then the whole group would be able to sort of watch the interaction and discuss what kinds of thing were done, what kinds of things were said. How could we do it differently? What's a better way to phrase this, that, or the other thing? And then we put up a bulletin board, because one of the complaints of some of our staff, especially the drivers who were out and about for most of the day, sometimes didn't get the message when one of our members died, until a couple of days later. So we have a bulletin board where we put pictures of the members, and it allows staff to do a couple things. One, it's communication, so that they know right when we know they know. The other thing is that they will then address letters and little notes to each of the individuals, and it's a way for them to finally say goodbye to this member that they may have been caring with for several years.

We had a change in our committee chair, and they're now--we have--oh, I should have started by apologizing. Dr. Way could not be with us today. I was supposed to say that at the beginning, sorry.

She was--we sort of stole her away from one of the hospices here in Philadelphia. She was their medical director for awhile, and is now one of our physicians, and has taken over chairing the palliative care committee, and has done an excellent job. She instituted kind of a formal palliative care literature review, both looking at the history of palliative care, and where it's going, new changes, et cetera, and that sort of serves just to continue to educate the group that's on the committee as a whole, and help them then further educate other people in the center.

We have part of our annual staff in-service devoted to palliative care every year. I think the last year we had a role-play. We try and do something different every year, so that to try and keep people's interest. We have it as part of our new staff orientation, where there's someone from the committee comes to discuss what our views of palliative care are, and how we approach our members. We're also now using the POLST form, which stands for physician's order for life sustaining therapy, which is relatively new in Pennsylvania. Some states have it, some don't. Ours is on this disgusting pink paper, but we use it as our DNR, formal DNR form, and we use that in conjunction with the five wishes, so that we have them signed and available to go out to--either to the homes or to the nursing homes that need it, or to the emergency room, if somebody has to go out to the hospital.

We also have a list of--we keep a running list of our members who are on hospice care, as part of our morning meeting agenda, so that every day we're aware of who's getting these extra services.

Sort of what we're doing--what we look to do towards in the future, we have what we call a palliative care consult team, which we call our little resident experts who are available to help with family--difficult family meetings. Some families are a little more amenable to these conversations than others. Some people still in our--despite all the education, some of the staff members, even in the primary care department, are not as well-versed at having the conversations as others. So we put together a team of people who will kind of help guide them through the process. They can either run the meeting completely, or just sort of be there to make sure that they guide it in a certain direction. It sort of helps to model conversational techniques in front of other people and be kind of an informal education as well.

We try to track what happens after someone does die. We have a survey that's supposed to go out to the family, basically it goes out six months later, to ask were their wishes followed, was there anything that happened that you wish had been done differently, did you have discussions about various things ahead of time, did you feel that this was explained sufficiently--things along that nature.

One of our challenges--well two of our big challenges--is to kind of keep up with our completion of the advanced directives. The other challenge is where we have some members with significant cognitive impairment, who really can't make the decisions on their own. They may not have a POA, they may not have a guardian, and they may not have family that actually want to make the decision for them. We have no solution for that yet, but I see you're nodding. But we're working on it. Education is an ongoing thing, both formally and informally in every way that we can. We try to do a lot of different things, so that people don't kind of get kind of bogged down, and we sort of try and take the pulse of the staff in the center, and sometimes we've had complaints, it's like, why are you always talking about somebody dying? Can't we talk about something else for awhile? And so it's okay, so maybe it's time for us to pull back for a little while, and then we'll ease off and start up at a later time.

We have bereavement support. We've always had a regular memorial service for members. We have it every six months, for members that die, but we've also started having support groups for the staff, and

for family of the members, to try and help them through their grief as well. We do utilize outside hospice. We originally thought, when we sort of embarked on this, that since PACE is so interdisciplinary, and as Dr. Hammett was talking about before, we do so much of the same things that hospice does in terms of supplying meds and doing home care and DME, that there was really no reason that we couldn't just do this all ourselves.

And after we sort of started really looking at it, we realized that was just a little too lofty, that there was no way that we were going to be able to provide that level of service to probably several hundred members, at the same time. So we do utilize an outside hospice and we look for specific events--not events, but specific settings--I'll get it out. Some families that may be somewhat complicated, or that we know are going to need an extra amount of hand-holding, we'll certainly contract with hospice for them.

If we know that there may be the potential for symptom management that's required on off-hours, at night, in the middle of the afternoon on a Saturday, or they may have the potential to need inpatient care, none of which we can really provide, and it's in those instances that we really kind of turn to hospice for their expertise.

Okay, so we went through a little bit about the similarities between PACE and hospice, and there are certain differences. Usually, at least with the hospices that we contract with, their bereavement services will run for a year after the person has died. They have a crew of volunteers that are at their beck and call. They also have the ability to do on-call visits after hours, at night, on a weekend, which we kind of cannot do. And then there's the inpatient unit. The differences between Pace and other insurers, Blue Cross Blue Shield, Aetna, it's pretty obvious to this group here.

So what we would like to do, and it's still a work in progress, is to explore using hospice in a unique way, to interface with the pay sites, very similar to what Dr. Hammett was talking about, where you actually just contract for the services that you need, and if you don't need home health aides, or you don't need the DME, you don't need the meds, don't necessarily contract for them.

Now, we've actually sort of been in discussions just to sort of see if this is possible, with our hospices here, and we're discussing. So it may be something that doesn't work as easily in an urban setting as it does in a rural setting. I don't know, more later film at 11. But it certainly makes sense, that if we're able to do--we can do the part that we can do and utilize hospice for some of the things that they can do, that we can't. And it is--it's a win-win all the way around, I would think, and a lot of times what we've run into, hospice--at least hospice here, I should say, is used to sort of turning the whole person over, and they'll just sort of take it and run with it. And they do everything. They go out to the home, they're going to take out our bed, put in their bed, give meds, do this, and we've had to sort of try and reign them back in a little bit, and say, wait, you know, time out. This part's already done, this is what we need for you to do, and we need you to work with us, and it's been a little bit of a challenge in getting them to really realize that we are as involved with these people as we are, because it's not what they're used to.

They're used to--I mean, I was in private practice before I joined Pace, and a lot of times, I would have somebody that went into hospice and I'd get a call every now and again, oh by the way, Mrs. So-and-so is doing X, Y, and Z. Okay, fine, and another six weeks might go by, and I'd get another phone call, and that's what they're used to doing, just sort of like absorbing the person and doing everything, whereas

we still want to be in control. This is still our member, we just need you to do X, Y, and Z. So that part is still a work in progress. But that's--so that's pretty much it, I guess.

Any--I think--yeah. I don't know. Thank you.

Does your Pace program have a specific policy for end of life, or is the process absorbed into other policies and procedures?

We don't have a specific end of life policy, no, we don't. It's really something that sort of comes out of just the usual care. Do you have a specific policy? I'm just curious. Oh, okay.

Does any other Pace programs in this room have a specific end of life policy?

Center Pace does.

What does that look like?

A page with words.

Oh, okay, thank you.

No seriously, I'm presenting tomorrow--no, I don't have that, but if you want a copy of it, I'll be happy to forward it to you. But it really is (inaudible). No, but seriously, it sort of outlines how we look at someone who has had a change in condition, what are some of the triggers that might have somebody going into hospice, and then what are the services we provide, what are the goals, so to speak--I don't want to say goal, but what are the expectations we want to achieve when that person goes into hospice care?

We do have a specific end of life policy which I can share with folks. I brought a couple copies with me, but you'd be better off to e-mail them to you, I guess. I also have--I can give you a copy of our end of life comfort kit prescription that we made up, which is I keep theirs at home, and if somebody goes into hospice level care on a weekend, I can sign that and fax it to the pharmacy so you have that, too. Anybody wants those things, just fix me up with your e-mail address, and I'll forward that stuff to you.

In case anybody is interested, there's a Web site called CompassionAndSupport.org, that's put out by Excelis in Rochester, and Dr. Pat Bomba is kind of the queen of that (inaudible) pink ugly form, but they do some really great education. And if you go to www.compassionandsupoprt.org, there's great education, videos, policies and procedures, everything that you could possibly ask for, for training your staff and all that kind of stuff. CompassionAndSupport.org.

Thank you, Dr. Nichols. Can you just comment on the (inaudible) with the medications with hospice?

What we've been doing--mainly, we've been providing the medications when we contract with hospice, we pretty much provide the medications and don't have them provide any at all. Because sort of--that's what we did. Well they do--we do--we provide the medications. If we've already put DME in, then we retain it. We don't--because a lot of times, if hospice will come in, and there's already a bed there, they will say, well we'll take yours and put in ours, which makes no sense. Because if it's there, why swap it

out? We also tend to supply the home health aide services, because we have a little bit more time available to do that than they do. Like I said, they have volunteers that they supply at times.

They certainly--we do rely on them for after-hours care and inpatient services, if we need that inpatient in their unit. The two hospices that we use have their own inpatient unit, so we utilize them for that as well. We still are the physician of record, we have them--we try to have their hospice nurse participate in our team meetings. We try to participate in their team meetings. Sometimes it's a phone connection, sometimes not. Sometimes we may not make every one, it make be an every/other thing. It's been--I have to say, it has been a little bit challenging, meshing the two teams together, just because they're so large. But we're working it through.

They've been--it's been two years now, almost, almost more, and so we're sort of getting used to each other. And they know what we expect from them, and they sort of know what we expect from them as well, and we're real easy to pick up the phone and say, listen, you know, this didn't work out right. We've been trying to contact you about, and what's the problem here? And so they're usually very responsive.