



CMS 2012 Tri-Regional PACE CONFERENCE

Programs of All-Inclusive Care for the Elderly

Philadelphia | March 2012



TRANSCRIPT

End of Life Care in a Rural PACE Setting

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Thank you very much. We're from Chambersburg, Pennsylvania, and we're one of two rural PACE programs, called Life Programs in Pennsylvania. And we're really rural. There's a cornfield right outside my window. And a tractor that goes by there pretty often.

Kim and I kind of got stuck with this job kind of like a substitute teacher gets a phone call at 8:00 in the morning. Our beloved program director, Mary Burdette, who lots of you folks probably know, has moved on to be a grandma up in Vermont, and she's going to run a – a program up there as well. And we were informed that, oh, by the way, we're presenting at the CMS conference. So we're like the substitute teacher. And we had toyed with the idea of giving you folks a study hall, and telling you you can just put your little heads down and take a nap after lunch, but we figured that wasn't going to be acceptable, so our plan is to talk about the challenges we have in dealing with end of life care in a rural PACE setting.

Since we're small, involving 70 couple participants, we pretty much meet and talk about – or have the ability to meet and talk about everybody every day. Our challenge has been that because we're supported by Lutheran Social Services and they have a hospice program, we – we are supposed to use them for hospice level services, but we're not allowed to use the hospice program itself. The way it works is if somebody's at end of life, and you go through the process of determining that, it goes to our team, and if we invoke what we call hospice services, we would contract for the skilled nursing piece. Just that piece. And our challenge is because we provide durable medical equipment and because we provide in-home support and we provide social workers and chaplains, then we're already doing almost everything that hospice does except the skilled nurse. So our challenge is to get our team to come up to a hospice level of care without feeling like we've already been there, done that, or – you see where I'm headed with that comment. We're already doing almost everything the hospice does, so what do we need to change. But as you know, in order to meet a family and a participant's needs at end of life, you really need to put a hospice hat on, or put a hospice smock on, you have to do something to generate the feeling that goes along with that.

So in an effort to show how we do that, and demonstrate how we do that, we're going to give you a case presentation. Let's see if I got all this stuff figured out here. The first case is about a little man that we call Artie, and his name's been changed to give you the idea of the experience but to protect us from the HIPPA demeritors. Artie's a 56-year old fellow with end-stage renal disease, in fact at stage five, and

he's refused dialysis. He lives in an apartment, first floor apartment, with his life, and he's got a lot of other problems, too. He's got bad skin. He's got some mental retardation. Some dementia. And his little wife, God bless her, she has mental retardation and she's complete illiterate. The other diagnoses I was talking about includes some COPD, diabetes Type II with tertiary complications, cardiomyopathy, neuropathy, all the opathies that go along with diabetes, he had them all. In early November of this last year he became bedfast and Donna, his wife, called me up and said hey, Artie's not good, and so I went down to see him, and sure enough, he had a new ischemic leg and he was in the throes of end stage renal disease. I discussed with Donna, as well as her friend who is pretty much a constant advisor, that it looked like Artie was truly at end of life and might not get in good enough shape to even get out of bed again. So at that point, they should expect for him to further deteriorate. And we went to our team with that, and we discussed \INAUDIBLE\ for her services. At this point I'll turn it over to Kim, and she can talk about how that process works.

Hi everybody. It's a little tall. Hey, I can see now.

Just so you know our team is very bonded. We're a very small team. We meet on a daily basis, and like Dr. Jim said, about most of our participants. When we say team, that includes an in-home support team that comes in from outside. That includes our PCAs, our drivers – yes, the bus drivers, because they're the ones who see them, pick them up, bring them in to us. Social work, activities, therapy, as well as nurses from the clinic. We decided at that point to transition him into a hospice level of care, and there are several things being rural to our advantage or disadvantage. As a rural R.N., I am not allowed to go into the home care. I am licensed for in center, supply and service only. So we have to contract with an outside nurse, which puts a stranger in the home to the family. So we really work with the team to develop that relationship with our hospice before we send them out there. And for the most part, we have a very consistent group of people that work with us. We decided that he needed a new bed. We gave him some bedside equipment. We also did a lot of education for med-wise, so that the participant's family was prepared because, as Dr. Hammond said, the family was illiterate, so we had to identify bottle colors and different things to help them provide this care in home.

Let's skip. Like I said, we reviewed his med list, we did a comfort pack, and for us, we have standing orders that we can set that up for any of our participants. It's something that we developed as a center. We have liquid concentrated morphine in there, Phenergan, Haldol, Ativan and Atropine drops, and then any non-essential meds that they weren't using at that point, we just discontinued. The other staff also went into the home to make visits, so we actually make probably more in-home visits at that point than we actually see them in the center. And he was actually able to expire at home, ten days later with his family at his bedside, which is what he desired and wanted. For us it's very important to make sure we listen to what the participant says.

Our big challenge is getting our center to look like a hospice but not be a hospice, and I think a lot of centers will fall into that because we are an adult daycare but we have a unique opportunity to have a clinic attached to us. Our hospice nurse works very close with us, and like I said, we go through the process with the team every day. In our facility there is no "I" decision made, it is always a team and "we" decision made. So if a participant brings us a request, we work through that together.

Each one of our cases is unique and presents with a challenge, and every day we have the new challenging people. Our oldest participant was 109 this past month, and never spent a day in the center because – her words, not mine – my boney butt can't take the bus ride. But managed to stay at home, and with less than, what, a month of skilled nursing service expired. So we've had great success in

managing our people outside of the traditional framework. And like I said, we involve the contracted staff when we get to the point where it's critical at that point for us.

I just – we wanted to talk about – we wanted to ask if you had any questions, number one, and then we have two different people we'd like to talk about, things that just recently happened for us. We have some very challenging families, as I'm sure most of you do. I say that politely. I have grown very close to the participants in our center, and I think as a nurse that's very tough to separate sometimes, but we have learned to have what we call the tough conversations with our participants on enrollment time. We want to know what their end of life wishes is right up front. They may be with us ten or 15 years, but it's very important that they understand that we will honor their wishes when it comes to that time and that we will do everything in our power to honor that wish, but we – we are very limited in what we can do in some instances. For example, we have a very unique family that has six adopted people in their family, including two geriatric residents and four mentally disabled adults. And I don't believe she has any children of her own, they are all adopted. And she actually took one of our participants and adopted her – like went through the legal proceedings. And the lady had a massive coronary in our clinic about three weeks ago. And everyone was like, oh, we have to send her to the hospital, and I literally came screeching through the clinic and said, stop, stop, stop. This is not what this lady wanted, because at that point she was struggling just to get to the clinic. And the family came in, and Dr. Hammett graciously rode home with the participant in an ambulance so that if the participant died on the way they wouldn't go to the hospital, and within an hour of her getting home I stopped by and she expired right there. So that kind of story is what we try to do every day, like immediately we made those decisions and switched gears for what they needed for her.

But we have some standard things that we do. Like I said, we have the comfort care medications that we handle on a routine basis. In our pharmacy, we're very fortunate. They have them set up and stocked and ready to go for us at any point. And we make a house call, to the house. Either the physician or myself or a nurse or our PCAs, and we go over those medicines until the family's comfortable. And if they're not comfortable, then we send the skilled nurse in, again, to go over it until they are comfortable. And we are on call 24 hours a day for our programs. I'm not sure whether you all are or not, but we have 24 hour coverage for our programs. And there are only three nurses in our clinic, so we know the participants pretty intimately because we are small.

Those are the kind of things that we do, and I thought it would be nice if you heard that from me because it means a lot for me to be able to honor those wishes, because I'm finishing my education to be a nurse practitioner and intend to practice advanced \INAUDIBLE\ palliative care. And also we're getting ready to expand our practice. We just got permission to open a new 110-bed center, so we will have two centers in our area, and within two years, a third center. So the need is out there for our area, because like you said, we have a cornfield in our front yard and the tractor drives by every once in a while.

But, do you have questions that you'd like to ask or things that you might like to know that we do? Cause I can't see you guys. It's like being at the Oscars or Emmys.

That's better. I can see.

Now we can see. Thanks.

I was just wondering if you could clarify when you were sharing the story of the gentleman that passed why the team wasn't able to go into the home. I just didn't get all the pieces there.

Our –
\INAUDIBLE\.

We're a dual eligible program, but our skilled nursing services are not home eligible. We cannot take a skilled nurse out of the community. Our community health does that for us. Our PCAs, which are our Personal Care Aides, can do that as well as our physician, but it's a licensure issue for liability that we are not allowed to go out into the community. That's – we work for a large organization that does have a home health agency, so we can use their services. We can go in, but we cannot physically put our hands on the participant or do any care, as a nurse. And that makes it very difficult for us to cross that boundary, and we're very careful with that. But our participants are very open, and when they're ill, they come into our clinic because they want us to see them. And their families will drive them, even if they can't ride the bus because we provide all their transportation, which is nice.

Do you – your hospice nurse, you contract with her?

Yes.

And does she provide education to your staff, the PACE staff, on hospice-like care?

We work as a conglomerate. We – we actually work for Lutheran Life Services, so we also have a home care agency and a hospice agency that are under our parental company. And they do do a lot of education together. We're very blended when it comes to that, as well as them learning about our program as well so that we can help them make a referral into the program instead of a participant struggling at home with in-home support, so we do both, education with them and they do with us. Does your home care nurses, through your home care agency, provide after hours and one call coverage for you?

They do if we need them. They will – we call them and then contract the visits that we need. It's just like a regular contractual doctor's office service; we contract per visit with them, based on the participant need.

How do you keep them, I guess, abreast of your participants and, you know, the care?

In our team meeting in the morning, a support staff from their campus comes over to participate so that they are on the horizon with us if something's happening for one of our participants, so they actually know. Plus our in-home support services team is blended between their home health aides and our personal care aides that go out to provide the care, so we work as a team with the two agencies.

Thank you.

Did you con – contract with the hospice a special rate just for the skilled nursing portion or do you pay the entire per diem that they usually charge?

We pay just for the portion.

Okay.

You're asking a nurse finances.

\INAUDIBLE\.

We average about 75. Like I said, we're tiny. Cornfield. And our participants average about 15 to 20 minutes minimum bus ride in, with some as far as 45 minutes to come in. We're very rural. Like our participants will call on a snowy day and say don't send the driver because you're not getting up here, even though we're open and they're willing to go get them. They're very – I think our participants are very unique like that. I think they worry about us as much as we do them.

When you contract with the skilled nursing service to provide the end of life care, do you use your own forms? You don't use the hospice agency's forms, do you?

We have a blended electronic documentation system, which is very unique to us that we can open our case side-by-side with the home hospice nurse opening their case, and we can see what they've documented as well as they can see what we've documented, which is a very nice feature in our system. And, like I said, we authorize their services as needed. But it's nice because our care planning is electronic, so they can see what our participant has been doing all along and what services we've been providing for them.

So you're participating in the care with them?

Absolutely.

Okay.

We – for – I don't know how to say this. We're the bus driver, always, with the participant. The – the participant is always driving the agreement, and then we are the provider of the services coordinated with them. So they work for us at that point based on what the participant needs.

Thank you.

You're welcome.