Centers for Medicare & Medicaid Services
COVID-19 Call: Home Health, Palliative Care, and Hospice
Moderator: Alina Czekai
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OPERATOR: This is Conference # 1854778

Alina Czekai: Good afternoon, thank you for joining our April 28 CMS COVID-19 weekly call with home health, palliative care, and hospice. We appreciate you taking time out of your busy schedules to join us today. This is Alina Czekai leading stakeholder engagement on COVID-19 in the office of CMS administrator, Seema Verma.

Today, we are joined by CMS leadership and subject matter experts as well as providers in the field who have offered to share their best practices with you all today. I'd first like to turn it over to Jean Moody-Williams, acting director at the Center for Clinical Standards and Quality at CMS. Jean will be providing a brief update on the agency's latest guidance in response to COVID-19. Jean, over to you.

Jean Moody-Williams: Hello, and good afternoon everyone, great to be on the call with you today. And we have some wonderful guest speakers that will be sharing their insights from the field that have been really very illuminating over the past couple of weeks. Before I do that again, just to thank you for the work that you're doing with patients and families and caregivers and all of the people that you're working with.

A reminder to check our website frequently. We have new information almost every day and I think certainly this week we are expecting to be able to post some new information and so please check that frequently. Last week we updated our guidance on infection control and prevention concerning coronavirus 2019 in home health agencies and it really included religious, non-medical health care institutions.And since (inaudible) as you recall provide non-medical services in a residential care setting, CMS is

recommending that the staff follow very similar procedures to those outlined in home health agencies – due to the possible community transmission.

CMS expects that religious non-medical nursing personnel and non-medical personnel who are experienced in caring for patients to identify those at risk for having COVID-19 and follow the same principles as we've outlined in the home heath agency guidance. And ,again, that guidance can be found on our website. So, we receive a number of questions that we generally try to answer during office calls. There's one that we've received on more than one occasion so I thought I would address that here and then – but still encourage you to tune in to our office calls.

But the question that we get frequently is about home health staff being restricted from accessing patients in assisted living and independent living facilities and which you're attempting to go in to provide the services that you have to render. And the question is whether CMS can intervene in some manner. And so, we recognize obviously that the services that you are providing are important role and those facilities are in essence that persons home and so, the health care services are being rendered in that particular assisted living and independent living facility.

However, CMS does not regulate assisted and independent living facilities. These are rarely subject to state jurisdiction, so it's probably one of those things where you have to work with each state agency to let them know if you are experiencing difficulties there and also obviously, we encourage you to continue to work with those assisted living and independent living facilities, so that they can understand that you're going to come in and you're going to follow the CDC guidelines, etcetera. But again, that really is something you'll have to work out with the state.

So, we are really fortunate today to have three guest speakers and the first I'll turn over to Dr. Balou Natrajan and the chief medical officer for Seasons Health care management incorporated in Rosemont, Illinois. So, let me turn it to you, thank you.

Balou Natrajan: Thank you very much. Our compass in terms of the care that we're providing is it's around the person. We know that hospice is an interdisciplinary benefit and so we're very grateful to CMS for the very wise waivers that the entire industry has been given so we can continue to serve everyone of the people under our care. In terms of best practices at my hospice, Seasons Hospices in 31 locations across 19 states, and so we've basically had four principles that we've tried to follow in terms of continuing to care even in the middle of a pandemic.

And so, the four basic tenants are number one, get there, two, when we can't get there we should virtually be there, number three, we should remember the interdisciplinary spirit of hospice which has been a basic fundamental of hospice since the benefit was created in 1983 and then number four, remember the bereavement responsibilities of hospice. So, not only is there a dying person but those that go on living after they die. And so, we've done everything that we possibly can to get that to that bedside every 14 to 21 days, it's consistent with the regulations.

But also, it is helping because these folks are isolated and even if they're in homes or facilities, they're not getting a lot of contact with people. But when we're not able to get there we're doing everything possible to virtually be there and so we've spent a lot of energy training our staff on how they can make virtual visits using an audio-visual format of some kind. We've even in some of our facilities and in our general in-patient settings sent tablets that can be then brought to the bedside by, for example, facility staff or hospital staff and then those can be used to take – with cleanings in between, from patient to patient, and that allows us to connect not only our staff to those patients but sometimes their families. And it may have been a month since their family was ever able to even make contact with them – eye contact or facial contact.

And for our staff, we've created direct lines to our leadership with the centralized hub for information and there's a lot on there that is up to the minute. So, we're monitoring what's put up for example by CMS or CDC websites along with protocols, so our staff is constantly aware of what's going on. In terms of remembering the interdisciplinary spirit of hospice, we've

been holding our interdisciplinary virtually, so using either Zoom or Microsoft Teams.

So, we're bringing our team members together weekly still even through the mandate is every two-weeks. And then we've been making sure for our patients that even if our nurses are getting there according to the expectations, our music therapists, our chaplains, our social workers, our doctors, etcetera are at least able to Skype in so that the interdisciplinary group – the breadth of that team is getting to that patient and family. And then the last aspect is remembering the bereavement responsibilities of hospice, there was a really solid article in the New England Journal of Medicine a few weeks back, where basically people are dying in acute care and nobody – their loved one can't even say goodbye.

And so, we are explaining the value to our facility partners about that 12 months of bereavement that's offered. And what happens if a family doesn't get closure at the bedside. We are very likely as a country going to see a lot of post-traumatic stress among people who didn't get to say goodbye, and our counseling and grief services will be there. So, if at least we can serve as a conduit it would probably help a lot. Some of the fears and barriers that we face as a hospice, lockdown is a big barrier.

Guidance has been given to facilities that they should not have visitors and we're getting lumped in with visitors and so we feel terrible sometimes that we can't even get there and we can't discharge our duty. And we feel bad that people will die alone with no eye contact whatsoever. And then the last couple of things are you know, there's not been a lot of guidance about what will future audit expectations look like.

So, we're working in good faith, we're trying everything to do things virtually, we're trying to get the best possible physical exam and through the screen, but are we going to be Monday morning quarterbacked when a third party audits us later. That is something that is very scary to us. The very last thing is around cap and so, we are committed as a hospice to serving the entire community, patients in homes, in facilities and patients who are going to die in a day or two in the hospital.

But sometimes, the hospitals just won't let us in and so, that means patients are going to die in acute care, they're going to stay longer in acute care and that impacts us as a hospice with our case mix and cap concerns. So, we are worried that our inability to serve all of those who we typically serve is going to wind up creating trouble for us later on.

Again, I'd like to thank very much CMS for being thinking forward for the waivers and being wise and understanding the virtual IDG and virtual visits can really make a difference. Now we need CMS' help in making all of that idea a reality and understanding that we can't help all those in need and can't help with the ventilator crisis if we're not allowed into hospitals and facilities a lot more than we already are. Thank you.

Jean Moody-Williams: Thank you so much for that. And one of the benefits of these calls is really set out to share information with colleagues and peers in the field but it also provides CMS with a unique perspective into the day-to-day challenges that you are faced with and finding solutions to when possible.

So, that as we move forward in a time post-pandemic and we are now trying to go back to some of the routines we can remember these experiences in these calls, so we appreciate that. And that will in fact shape our thinking on how we develop policy. So, with that I'd like to move to Dr. Katie Lance, the national director of the national hospice and palliative care organization.

Katie Lance: Hi, this is Katie Lance, it's a pleasure to be here. I am a hospice and palliative provider and a clinical executive and recently served as Aspire Health chief clinical officer and then I'm also on the board at NHPCO and really glad to be here. And in the last year I found a company called TopSite and I'm bringing this up because in preparation for this call today, I did some interviewing and put together some insights about what we're really seeing out there across the country.

And one of the things I did in those interviews is appraise the best practice literature and resources that companies are really appreciating and then I also interviewed some of the largest and smallest operators from palliative care

and just wanted to know what was top of mind. And I'm going to start with the latter – and that's the top of mind problem that most hospice and palliative care providers I talk to are saying. And the resonating sentiment was we want to get in, but we can't get in.

As Balou mentioned previously, there are a lot of regulations around infection control and the PPE shortages and sharing with outsiders and policies that don't trigger the right types of individuals getting to the right patients. And I wish that this was just a now problem, a COVID problem. But as someone who's been in the industry 20-years, it just isn't. We've always kind of been challenged, it's just exasperated and highlighted today.

And in one of the interviews, one of the CEOs encouraged me to talk to one of their employees and his name was Todd. Todd's an exquisite palliative care nurse practitioner who performs visits in patients' homes and this is what he shared with me. Todd is a geriatric NP and he has been in this role for 10-years, he's a father of two small kids and he works in a local hospice, but he does the palliative care side of the work upstream from the hospice benefits.

Over the last five years, he's built a successful practice in his community and served approximately 300 patients on average. The quality outcomes he has are both great, they say that the fact that he's out there saving the local health system money and helping the insurers is great, but the patient's love what he does. Both he and his team are providing them great services as their condition decreases and changes day by day. The work he does is fee for service and barely covers his salary in a normal day pre-COVID and it's always been OK because the mission of the organization and the partnerships within his local in-patient practices preserve his role.

But Todd got a call from his CEO last week saying that since COVID has hit, his (inaudible) has decrease by 50 percent and they were going to have to furlough him. He offered to retrain himself and stay onboard as an RN or doing some of the hospice visits or CNA, doing baths for patients, reading to patients or even a palliative educator going out and teaching other providers how to have conversations. But the hospice and palliative care organization could not support his role. As I talked to him, he cried and he described the

feeling of being more equipped than most to help deal with what's unfolding in his community and the fact that he can't get to the patients who need him.

He is one of hundreds, probably thousands who are sitting dormant right now and will probably need to move to another specialty to get through this time for his family or you know, just kind of hold off on working for a while. And one can only hope that he'll come back to this important work, because we know this silver tsunami of aging is coming in America. So, in this what it said to me is there's never been a more public and professional awareness for the needs of skilled palliative care – both in terms of supporting patients and families through crisis and suffering and also supporting other providers in delivering and debriefing on the traumatic situations they're dealing with.

No one disagrees, this is bipartisan support, American support, stakeholder, patient support. But no one disagrees with the fact that people shouldn't die alone without good sense of management. Patients should be able to say "Goodbye and I love you" and families should be able to communicate with their loved ones. But right now, as Balou pointed out, it's just not what we're seeing and in fact, we're losing the work force. So, this isn't just a COVID-19 issue that's kind of coming up, it's a palliative care access crisis and it has unintended consequences on the national workforce.

So, you know, despite the fact that palliative care's a flexible swat team who understand moral distress and how to manage any symptom and how to diagnose and treat and test and will go wherever the patient is, we just can't get to people and the systems who need us. And that's what I'm hearing today as the fear. So, some solutions that are coming about as I interview people is what I'm hearing is that people are – they're really utilizing tele-health more and more and they're seeing that some this is helping in some situations – especially for the providers in those buildings and helping them have conversations and connect loved ones.

They're also seeing and this is – the ERs are allowing some palliative providers to get onto the front line and have conversations up front, which can actually help with volume and get people to the right level of care and feeling like they have a say in where they can receive that care. There are some states

starting to think about nursing facility partnerships with local palliative practice and high quality centre management, daily support for those that are dealing – especially the facilities who are having the outbreaks and that I would strongly encourage and hope to see continue and in fact pro-active conversations with those facilities would be great. And then health systems are beginning to require 24/7 access to palliative training and resources.

So, a hotline for their internal staff members to help support those nurses, doctors, social workers, etcetera in the building, dealing day in and day out with people who are crashing and burning and needing to have careful conversations and just empathetic presence. And so, I think that what we're seeing is an up-tick in that from about 20 to 50 percent in the companies that I talked with. So, I think the last thing is that we're seeing and hoping for the industry experts coming together like we're doing right now to work with CMS to design the new future and the new normal and the definitions of palliative and how they've been set.

So, we have a ton of great resources and we have a ton of great leaders, but getting them all in the same room in a unified way around new benefit design and collaborative unified voices is just going to be, you know, critical. So, I just wanted to share briefly as well, in addition to some ideas around, you know, what we're seeing in terms of the shortage and the furloughing of really great providers, is letting people know that we are poised and ready to train other people and to think about creative ways to get and utilize what feels like down time to begin atypical relationships with community stakeholders and begin training them.

Some of the resources that really stuck out to be and that I think everybody should know about is – one is Prepare for your care. It's a consumer driven step by step program with video stories to help people who have a voice in their medical care talk with doctors, give their family peace of mind. So, it's a consumer driven component that you can give to patients to help walk them through the decisions and choices that they might have to make in the event that they get ill or if they've been diagnosed they might get sicker. I want to applaud too CAPC, the Center to Advance Palliative Care, for their symptom

management tool kit protocol, both around medications, in-patient and out-patient settings and protocols for those settings.

They also parted with VitalTalk to build scripts for conversations around COVID, both in person and via tele-medicine and I like what they've published around moral distress and crisis leadership too. So, check that out. The National Hospice and Palliative Care Organization, they won a prize for their amazing webinars in office hours, from each webinar they produced slides and recordings and some good ones were around successful tele-heath implementation.

All of these that I'm mentioning are free to the public and they do a good job at really diversifying their work to also RN, CNA, social workers and shared decision makers. So, check that out, I could go on and on and I'm not even touching on the slew of resources out there, but these are the what I saw where really helpful and also helping people today. Areabni lab put out different types of COVID-19 conversation guides to help with video examples too and implementation tool kits, so their website all of that's free.

And the Coalition Transformative Care, they work closely with HelpSpirion and they have a lot of excellent resources that touch on decision making. I specifically like the ones that they have around their CPR and vent support and approaching different levels of illness and excellent work that they've done. The Home Centre Care Institute and the American Academy of Home Care medicine have tons of primary care package resources and best primary practice for primary palliative care and symptom management, but also just general symptom management in home.

And lastly, the Hospice and Palliative Nurses Association and American Academy of Hospice and Palliative Medicine have resources for primary palliative care and how to – I love what they did on working from home during the pandemic and specifically self-care for providers in this industry. So, those that is your coffee talk version of what I believe to be the best resources out there and again, they're doing so much great work. But thank you for giving me an opportunity to share a little bit about what I'm hearing from the field and great experience.

Jean Moody-Williams: Yes. Absolutely, thank you so much for joining us. And you're so right in that the coronavirus pandemic is really exacerbating long-standing issues, things that have existed in health care long before this pandemic. So, I always say we don't want to necessarily go back and you referenced the new normal. We want to move forward, addressing issues and so, thank you for looking for those solutions and seeing what's working.

So, I'd like to move to Susan Pondestantle, the president and CEO of community hospice and palliative care to bring us some words and she'll be our last speaker and then we'll take a few questions. Thank you.

Susan Pondestantle: Thank you very much. And I really appreciate the invitation and I echo the thanks to CMS for all their support with being flexible with us and how we deliver care during this unprecedented time. My organization is in North Florida, a large community based non-profit, 1,300 hospice patients, 1,100 palliative and we have 17 locations including 9 hospice in-patient units. So, we kind of broad (inaudible) across North Florida.

And what I'm going to share is not only best practices but some insights and what we've learned, the first thing may sound like a captain obvious comment, but we've learned that hospice is very important in our medical care system, more so than ever. This did draw a focus to the fact that we are really an essential element in ways that perhaps would not have been so otherwise. For the consumers of our care, we definitely are seeing those that are choosing hospice wanting us to get there quickly because they are concerned about care giving alone.

Patients are concerned about dying alone if they go into the hospital and they're really looking for us to be that way that they don't have to do those things that are so abhorrent to their process of how they would like to be with their loved one or how they would like to leave this world. And then our hospital partners and our medical system turned to us immediately and they asked us to focus very acutely on our speed to care on making sure that when they identified a patient who was eligible for hospice that we very quickly could move them to a different location of care and the right level of care.

So, that's been something that we have really put a lot of resources toward. Although, I will say the disruption to our medical system because of the moratorium our Governor put on any elective or non-emergency surgeries, the volume of patients who are in the system now is very low and that has impacted the number of referrals that we've been getting. We know there are lots of folks who need the care but maybe are not in the system and we assume that once the moratorium is lifted, that we'll be seeing a pent up demand and need for hospice care.

We have 14 COVID patients in our care and one of the things that our hospitals asked us to do in anticipation of a surge, which thankfully did not come in North Florida, is to create a unit for COVID patients so that they could move those that were not going to have a good outcome to a unit. And because we have three free-standing facilities that are one floor we picked one of those so that we could still allow window visitation because we had heard that one of the toughest pieces of this for anyone whose loved one was in the hospital is just no contact at all and we wanted to avoid that. And right now, we only have two patients thankfully who have needed that unit, all the others are being cared for at home, which is where a lot of patients want to be right now.

So, the other insights that we gained is that perfect is really the enemy of good. To us, high touch service is perfectly delivered in person, but we knew that first of all families were requesting that not a lot of people come and go in their homes and we also knew that because of our facilities not allowing us to come in as we used to that we would have to deploy tele-health. It's been an interesting learning experience, we've found that actually for bereavement, for patient care, tele-health is better than not being there at all. And we decided that not being there at all was unacceptable, our bereavement groups are telling us that it's not as good as being around a table, but they don't feel isolated.

And that's the important take-away is that tele-health is a tool and I can see that in some settings – especially rural areas, it's enabled us to be there immediately for patients and families because we do also serve rural areas.

But we have seen that it's also something where there are no – there's no substitution for in person, particularly with nursing care. One of the challenges we're seeing is that that is a lot of what patients and facilities want, is only the nurse.

So, the other members of the interdisciplinary care team are getting a lot of no's, no visits, not even wanting to see them virtually. And that is a challenge, but again, it's not about us and what we think, it's about what families want at this point of time. With facilities, one of the best practices that we have done is to use dedicated staff for the larger facilities so that patients – families, excuse me, so that staff are not coming and going from different facilities because that's been a real concern. And rather than having a separate admissions team, which is what we normally do, to just switch to a generalist model so that if there are referrals there that staff member can do the admission as well as provide the care – and that has helped somewhat, but we're seeing a lot of facilities including assisted living say that they're doing it themselves now.

And one of the concerns we have is that it took so long to convince our long term care and assisted living facilities that hospice was an essential part of the continuum of care, we hope that this habit does not endure because it certainly is a challenge when you see some of what isn't happening. The other thing we've learned is that communication is essential, nature abhors a vacuum and it will fill it, so your staff have to be able to feel comfortable and be present and know that you have PPE for them and that if they have concerns they're hearing from you what's going on. That's one of the things that we've all spend a tremendous amount of time doing, including counter-acting the isolation that's happened because our offices are closed now by the order of our Governor and Mayor.

So, some campaigns like, where are you working and letting teams post things on Twitter and on Facebook and on our internet in their protected gear to see what's going on and having a lot of interchange that way has been a best practice. And it's "Where are you working?" with a capital Y-O-U, just to let people feel that their team mates are still out there. Also, rather than furlough employees because of our census decrease we have developed a resource pool

where employees can say I'm available and we've deployed them in other areas of the business where there has been more demand and need and so far that's allowed us not to have to furlough. We have seen much more demand for advanced care planning, this has put a focus on the need for that and made it less abstract and more concrete than ever.

We used the respecting choices paradigm and we have done facilitations and are doing them by FaceTime and if your families involved, we're doing them by GoToMeeting and that's been surprisingly effective. One of the things we also have seen are the gaps in palliative care, we're seeing a lot of folks who really need more goals of care discussion, but we're not able to get to them in the hospital and they're really not necessarily happening within the hospital.

So, we are getting a lot of calls from the community for grief support because their loved ones died without hospice being involved and without a good goal of care discussion and we're doing a lot of webinars and grief counseling via FaceTime and a couple of other apps. So, just in summary, the best things we've learned is that there are a lot of opportunities to deliver the care, you have to sort of decide if you're in the horse and buggy business or the transportation business.

And we've decided that this isn't normally the way we do, but if we can still reach people, we're definitely learning that tele-health has some really good applications. One of the other lessons learned that I mentioned earlier is that we're going to need to work that much harder to get our facility based partners to return to using hospice as one of their valued partners and caring for those with very serious end-stage illness.

And we are just grateful that we still are a resource for our community and that all of our staff want to continue to work even those who are going in and serving our COVID patients. Thank you for giving me the opportunity to speak today.

Jean Moody-Williams: Thank you so much for sharing, and I think we've certainly heard some consistent themes this afternoon. As well as some new ways of thinking through how we deliver care both to meet the needs of the patient, but also I

heard you mentioned some things that really were geared towards decreasing transmission and infection control. So, those are the things we want to share in particular as well. So, think we are at time and I really appreciate everyone joining in, I'll turn it to Alina to sign us out.

Alina Czekai: Sure thing. Thank you Jean, thank you to our guest speakers and to everyone joining our call today. Though we don't have time for Q and A, I hope that you'll consider joining our office hours later today at 5 p.m. Eastern where all of our CMS experts will be on the line to answer your questions and in the mean time you can continue to direct any questions to COVID-19@cms.hhs.gov. Again, we appreciate all that you're doing for families and patients around the country as address COVID-19 as a nation. This concludes today's call.

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