

- Good morning, Virgin Islands, and again we're back to Ability Radio on Saturday morning with co-host, Iris Bermudez.

- Good morning, Virgin Islands.

- And we have a special guest, Tracy Sanders.

- Good morning.

- I'm Archie Jennings from the Disability Rights Center of the Virgin Islands. And we bring you this Health Literacy Program on Saturday mornings to help you understand your rights as a patient, or a health participant. During this show, we requested no use of names, that there's no third party advertising, no personal attacks, no unfounded allegations, product pictures, no profanity, and we do not give medical advice. So, we won't represent--respond to any questions along those lines. The opinions expressed during this show or the host of Disability Rights Center, and those of the guests. Oh, our topic today is...

- Hospice Care.

- Hospice Care.

- Hospice Care. And our guest speaker today is Tracy Sanders, who will walk us through the processes involved in receiving Hospice Care on Medicare provided service to our beneficiary--beneficiaries, specifically those who are discharged from the hospital. And she has a wealth of information to share with you today. Tracy.

- Uh-hmm. Good morning. Thank you so much for having me, for many of you that know me, hospice has really been a passion of mine. I'm a registered nurse, and I'm almost Croixan. My husband and I have been here 19 years. And we lived on the west end of Frederiksted. And realizing that, for as long as we have been on the Earth, we've been taking care of others. Kind of us we call womb to tomb. But we also realize when we moved here in the '90s, there was nothing for end-of-life care formally. And particularly under the Medicare Part A benefit, there is a program called "Hospice Care". Actually the word "Hospice" is a medieval term that is considered a place for weary travelers at the end of their journey, and this is the journey of life. So, we've been continuously Medicare-certified since 2000. We started here on the big island of Saint Croix, and we expanded over in 2004 to Saint Thomas. We're also on Saint John and Water Island. It is end-of-life care, and none of us really wanna talk about that.

- Yeah.

- We'll spend more time talking about a two week vacation than the most important journey of our life. And the hospice program is one that encompasses, not just the medical attributes, but also the spiritual, the emotional, many call it comfort care. And we have a team, our physician, registered nurses, social workers, chaplains, our bathing nurses, homemakers, and volunteers. And their individual life's plans of care, when individuals are going through this, they've never gone through it before. So, we like to shepherd them through this process of trust-teaching education, expectations, and really comfort care is the best way to describe it.

- Tracy, one of the things that a lot of people probably ask or wanna know about is the staff, are they all certified, are they required by Medicare to be certified?

- Uh-hmm. Absolutely. Medicare does have fairly rigid requirements that are very, very important for the integrity of the program. And the Medicare requirements that we are under here in the Virgin Islands, are the same for any Medicare certified hospice across the country. For human resources, physicians, nurses, our certified nursing assistants, they all require certification, skill competencies, background checks, both on the local and federal level, and it's an ongoing process of skills competency.

- And every other, every two years or a year, on a yearly basis, they are re-certified or it's just a one-time certification?

- The certification for the agency itself is periodic. It is unannounced. Medicare will show up at your door and say "Hello, we're here for your survey." And they look, really from top to bottom, at all aspects of the organization. They look at the administration, the organization, they look at competencies, they look at quality of care. They go out with us on field visits. They wanna observe the staff in the field interacting with patients. They also want to talk to the patients and their families about the care to ensure that the way the Medicare benefit is established, is being delivered.

- Yes. Also, there's gonna be a lot of questions, I'm sure, Tracy, I want to remind the radio audience that you can call in at 713-1079. That's 713-1079. Actually, on a second hand level, Stacy, I've had a couple, Tracy, I've had a couple issues with regard to Hospice Care. It's a very emotional time for the surrounding family. And one time, I even had a friend family call me from Georgia. And they were concerned that they had taken the husband to Hospice, but the Hospice Center was discharging them back to the family. And they were asking me was there anything legal they could do about it. Could you sort of explain the

process for a family who's going to be engaged with Hospice Care, as to what the steps are, and what the position of the Hospice Care Center is.

- What you're talking about is eligibility, under Medicare for Hospice. And most insurance companies follow the same steps as a Medicare Certified Agency. And the eligibility part, if I could start there, is someone has a life-limiting process. Most often in the way Hospice was created 30 some years ago was for, for primarily for cancer patients that maybe receiving treatment. But at some point, whether the physician said, "There's really nothing more that can be done, the disease is winning." Or if the patient and family may have decided, they didn't want to continue treatment. It expanded to other disease entities, congestive heart failure, which is a bad heart. Pulmonary, lung, kidney and renal, a lot of these kinds of things, and also now, Alzheimer's disease that we know affect so many in our, in our company, in our families, and in our communities. There's eligibility guides as far as what is required from a medical standpoint. When Hospice first started, it was simply a physician saying, "Six months or less." And they would come on to the program. With medical science looking, if I take the example of congestive heart failure, they look at something like the Echocardiogram, that is able to tell us how the heart is functioning as a pump, and if the ejection fraction is below 30% or 40%, then we know the heart's not working at its optimal level. And although an individual may look fine, they're able to get out of the house, we know the longevity is not going to be there. We also find, and that's just one example. But to your question about coming off the program, one of the things I have to focus our listening audience on is the issue of hope, and quality of care. Hope changes in a Hospice. It may not be what we're doing in ten years and five years. But what we're doing next week, next month, in the several months, sometimes when an individual comes on to the Hospice Program, everything is looking towards a life-limiting process. But we also find, by the nature of working with families, in a multi-faceted capacity, not just medicines, and nursing, but emotional, nutritional, physical therapy, the emotional part, people may have been so depressed, they don't have a will to live. That through this they start to feel that empowerment, and say, you know, "I feel so much better about this." And their ability is better. They actually do better on the program, medically, physically, emotionally. And so what Medicare says is that they do stabilize, they plateau, we're really looking at a failure to decline. We talk to the families, manage expectations, and we say, "You know, you can go back out into the community again." It doesn't look as foreboding as it was in the very beginning. And so, that's something that can be optimistic for the families. And we never know, none of us have a crystal ball, the human spirit is such a combination of mind, and body, and spirit. And everyone is so different.

- Tracy, you bring up a good point. Because I recall with my own sister, going through this whole process, and she got better, thank God. But I was wondering for the listening audience, if you'd start to do better, are you automatically terminated from Hospice or is there a transition into, for example, home health, and then you're, you know, you're let go. Or how does that work?

- Absolutely. There is a discharge planning process. One of the things about Hospice, it's a very interconnected relationship that we have with our patients, their families, their extended families, and you know, we're working towards what we believe is peaceful life closure. And when we realize these changes, you have this tight relationship that you have to look at severing for a while. And so, we do a discharge process of saying, "Let's review your medications, what equipment do you have in the home? What care do you have in the home?" And we transition them back into the community. Whether, as you say, it might be a referral back to home health care. It might be to custodial care, we work very closely with our government agencies here. Human resources, the department of health, a lot of the agencies that are here for are the beneficiaries and for those in need. So there is a transition period and, once someone comes off Hospice, it doesn't mean that door is shut. Medicare has benefit periods, there's two ninety-day benefit periods, and then, unlimited sixty-day periods. And that keyword unlimited means, you may come off the program, and then come back on the program. We have individuals that we may have discharged a year, two years ago, and we always let them know. Give us a call, we'll come out and evaluate in the home, we'll look back to see eligibility, so this program can continue.

- And now we're going to stop for a minute for a station break, okay?

- Yes, Virgin Islands, welcome back to Ability Radio. And with us this morning, we have Tracy Sanders, talking about Hospice Care. Call-in number is 713-1079, 713-1079. Again, Tracy, this is a very difficult time of life, and over the years, I've had at least one or two calls, and one time, a family called me, he was a very good friend of mine and more so of a mentor, to talk to the person who was going through the final stages to keep him in Hospice Care. He was, he was in, maybe what you call denial, and the family was on one end of the spectrum and he was on another, and I didn't really, I just sort of said, "Well, maybe we

should defer to his wishes as his final wishes." But I, because I didn't know if he had anything in writing and again, it was another state. How does Hospice Care handle these sort of difficult family inter-disputes, basically, about how that final, basically, facing the, a last round up, so to speak.

- Uh-hmm.

- Well, you actually bring up two very important topics. One is the whole philosophy and understanding of what we call grief and loss. Elizabeth Kubler-Ross, who's a pioneer, wrote a wonderful book On Death and Dying. And we talk about grief and loss, and it's not just end-of-life, it's losses that we have throughout our life, and we know that there are different parts that you go through, and it's not cyclical, it's not finished, you can be bouncing all over the place of anger, denial, anger, depression, acceptance, and then you think you've got it together, and you understand, and then you get angry again. So, this is very normal emotion that everyone has, and we know our families, situations of crisis like this, can bring out the best and worst in our families. It can bring out differences of opinions, we have all had experiences, and we all have opinions about how we define quality of life and how we live. I am an absolute passionate advocate about what we call advanced directives. Many refer to this as a living will or health care power of attorney, but it's really spending time with the individual and finding out what their wishes are. We think about this at end-of-life, but having a living will is something that we should have that will guide us, will give information about our wishes to those that love us, because there might be a time I cannot speak for myself. I can't say yes or no. I could be in a car accident and be immobilized, and how will anyone know what my wishes are. And so families always have the best intentions, they're trying to do what they think is the best. And this can bring a lot of conflict. So, there is a document that many of us know about. We always call it the "Do Not Resuscitate Form" "No CPR" "No Ventilation" and this brings out strong emotions in all of us. And at Continuum Care, we don't even use the Do Not Resuscitate Document anymore. Because the whole idea of thinking I'm not gonna do this and I'm not gonna do that, families can feel guilty. They'll think, am I doing everything, am I giving up too soon, am I letting my mother and my father, my family down? We use a document now that's called AND. It's called Allow Natural Death. It's a document that's being used across the country, and it really works towards the issue that we know we're not going to live forever. And if it comes to that time, that the cancer is winning, my heart is failing, my kidneys are giving out, the Alzheimer's, I'm bedridden and I can't get up, is do we allow death naturally to take place. So that when the heart stops, say yes, this is my natural passing. I don't need CPR, I don't want broken ribs, I don't wanna wake up on a ventilator. And it goes beyond this, not just CPR and tubes, but dialysis, nutrition, artificial nutrition, tube feedings. And these are things that when you can talk with families, and they're not in a crisis, you're really able to bring out the values, the morals of a family, of an individual, and for many, they haven't thought about this for a while.

- Oh, I think I love the phrasing, Allow Natural Death, because again, it gets back to what we, probably, for thousands of years have gone through, without the technology. And again, the guilt aspect, because that's really what I felt from the family. They wanted to make sure they did everything for the person. He wanted to do natural death, basically, he was one, he said, "Let me go home, I wanna be home with my family, in my own surroundings." And they, again, they went back and forth, back and forth, in a sense that he won out. He just wanted to be at home and that's where they succumbed to his wishes. But is there any type of grief counseling at the time of death with the family, does Hospice provide those services as well?

- We do. We actually start bereavement services when somebody comes on the program, because it is a process, it's not something that's just final. One of the programs about Hospice is, at the time of passing, the bereaved are followed. We have a bereavement program that lasts well over a year and based on a risk assessment, we identify with the bereaved, low, medium, or high risk. And sometimes, when someone comes on with the program, they might be at high risk because they're sacred, they're nervous. They don't know how to manage expectations, and when we're able to provide this companionship, education, nurturing, shepherding through this program, they are able to let go in the sense of, we talk about task of dying, to be able to say, I love you, please forgive me, I forgive you. Mommy, I'm gonna miss you, but it's okay, you can go. I'm gonna be okay. These are all of these things that, oftentimes, if a, individuals refer to Hospice too late, we go into a crisis mode of death and dying, and we don't have the opportunity to develop the relationship with the patient and the family. It's not just about the medicines

and the equipment, and that process. This is about the relationships with families, it's about reconciliation, spiritually and emotionally. And taking a process, as you said, that is part of our living process, that's why we've called ourselves Continuum Care, because this is that last and final stage that nobody wants to address. And then individuals are faced with it, and it's a very difficult process, so our bereavement services start from the beginning, and they go through even after the individual is passed.

- Well, tell me this, one of the unclear aspects of it is, does a doctor make a referral to the family that perhaps you should consider Hospice Care. How does it start, because I am, I'm getting mixed information in that regard.

- Uh-hmm.

- That's a very good question. Most often, referral will come from a physician. I think when Hospice is new in a community, we look to our physician. I also have to say, being a health care provider, I'm a nurse, I'm married to a physician, I work with many in health care, we go into health care because we want to fix, and heal and cure, and then all of a sudden, to say now I'm looking at something that is a different stream of care, it can be difficult. So, we do have eligibility requirements that we will work with physicians, to make sure from a medical standpoint, but we're now getting more referrals from patients and families that say, "Can we talk about this?" And sometimes we actually go to the physician, and say this family's talked to us. They've talked among themselves, and can we evaluate this as a choice the family makes. It does require a physician to certify that this is indeed life-limiting. And another physician, whether it's the Hospice physician to concur, but we wanna work within the family's wishes and what they want.

- Tracy, when you say family, are you talking about the intimate family, or family as a, you know [inaudible]

- Oh, we know in our families, we have aunts and uncles, and you try to...

- They want to express themselves.

- ...you try to say are you on your mom's side, your dad's side, and so, this is my aunty. I used to go to her house after school, she took care of me, she's family. And sometimes, you even don't know what those differences are. So, we, when we talk about family, we talk about family the way that patient tells us.

- Okay.

- We've taken care of families that are no blood relation at all, but they grew up on the same neighborhood, they went to the same school, they went to the same church. They're family.

- Yes, childhood friends, because you hear a lot about that. And now, we're ready for a station break.

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- Okay. Yes, good morning, welcome back to Ability Radio with Ms. Tracy Sanders from Continuum of Care, Inc. Tracy, following up on the issue regarding family, and one of the things that's happened to me over the years, and I try to accommodate families during guardianship issues, be it for a young child or someone elderly, is that, at least it happened a couple times, disputes between siblings, in regard to the documentation, whether as to, you know, who's gonna be in charge. Tell me from Continuum Care's perspective, how are some of those issues resolved, when they come to you for, basically, having the care of their loved one taken care, or handled by your agency?

- It's very much part of the referral and admission process. We are bound to informed consent, so that it's very clear and honest what we're talking about. Because we know that an individual may come to us, able to make their own decisions, that if we're talking about end of life, that capacity will lessen. So, it is very important for us to identify an individual, we might call them the primary caregiver. But I think we also talk about the power of attorney, so that somebody that can speak on their behalf. And sometimes within families, this is something that is disputed. There's a lot of what we call ruckus that goes on, because we have to look at the intent of why someone wants power of attorney. Things come down the, in fighting in families about the house and the property, and who lives here and who lives there. Although, we are very focused on the patient wishes, we certainly understand and embrace that this is part of the ongoing process that we deal with. So that's why we tie back into the advanced directive healthcare power of attorney, so that while an individual can make their own decision, when they're no longer able to make that decision, who was the identified person to speak on their behalf, and legally, speaking so.

- And where would that family have that document? Do they have it in their own hands or is there a person, and who do they present it to?

- Well, part of the federal requirement for any health care agency, when somebody comes on to their program, whether it's a hospital or home care, or hospice, we need to ask about advance directives. It's been a federal requirement for many years, to say, "Do you have an advanced directive, would you like information on advanced directives, do you have one, we would like a copy, would you like information, we will help you complete it." Continuum care has completed a health care power of attorney that is, it's not just a check off document, but it has sample language. It says, it walks through someone's thinking process of values and preferences. It talks about pain management, and caregiving, and what they want, do they wanna consider a burial or a cremation, or organ donation. We have it on both English and Spanish, it is on our website, and we do programs in the community, at no charge, for small groups, for families, for workshops, and we're able to get this completed so that it's nice when someone comes in to Hospice, and you ask about an advanced directive, they say, "Yes, I have it. " And what we advise individuals is when they make out their advanced directive, it isn't just said it and forget it. You have to update your healthcare directive as your situation changes. Marriage, divorce, children, illness, all of these things, and we make sure that on an advanced directive, it's properly dated, and we write down, who did you give a copy of this directive to? Gave one to the doctor, you gave one to your minister, you gave one to your attorney, you have one in the safe deposit box, you've got one at home readily available, if you gave one to your, each of your children, and as you update it, then you know who you have to give an updated directive to.

- Tracy, how do you deal with the denial of this document, because I know of a situation where the wife was really interested in doing it, but the husband was in total denial of this document being done?

- It, it is really an issue, and we find that commonly. We really do, and the aspect that we present is Continuum Care as your health care provider, we need you to give us direction what you want us to do. In the absence of having a directive not to do something, most of us are gonna do CPR. We're gonna call EMS, and when individuals really understand what that means, the pathophysiology of what CPR is, it's cardiopulmonary resuscitation, we are doing compressions on your chest, oftentimes it will break ribs, it can puncture lungs, and you think about that compared to what we talked about earlier, being at home surrounded by your family, and your love ones, and a process that is so normal in our not, in our life to proceed, and when you're in denial, if you don't wanna hear it, and sometimes you have to go over it a couple of times, and each time you go through it, a little bit more resonates with the person. So they might sign it and say, "God, this is the hardest thing I've ever had to do." And we understand that, and we come back to it. They need counseling, they need support, they need to know we understand that this is a difficult decision, but we are here for you.

- Uh-hmm. And that's interesting.

- Oh, I was gonna also ask, well, point out the fact that the Karen Quinlan Case was something that came up years ago, with regard to states implementing some of this advanced directives, as well as, one in the more famous ones was the Whitney Houston Case, which carried on in front of the public eye,

unfortunately, of the inner conflicts that come up with, amongst family members, but it's an important issue, like I said, I had to go through it at least three times with regard to what I recall cousins, they weren't actually my blood relatives, but being an attorney, they would call me when, get some information, and the advanced directive so, and they were in different communities. I've, I asked them to go seek an attorney, seek advice from the hospital and the caregivers, in order to get those documents in place. As well as, I'm thinking, do the religious community also gets involved with the continuum of care and addressing some of the family issues. I'm not, I'm not certain if that takes place with your organization, but I'm just asking, in general.

- It does. Spirituality is a huge component, and we have chaplain services as part of our program. Our chaplain is Vilma Perez, we've had Luz Walters. They've been an incredible intimate part of this process. When we talk about spirituality, I must state that oftentimes, people associate it with what religion you are, and sometimes individuals do not belong to an organized religion, and the spirituality is what gives our life meaning, what helps us make our decision, what drives us with what's right and what's wrong, and so spirituality of end-of-life is looking back and say, "Oh, I have to make amends, I feel guilty about this, I wanna reconcile." So, the spirituality is a huge part, and often, our patients and families will have their church, their temple, their congregation come visit them, and that's a very important part. And sometimes it's a process, wherein, initially, they will seek out their congregation, and as they get closer to passing, it becomes a more intimate environment of the family and the spirituality that is the essence of this core family unit.

- And that brings me to a comment in the top and another question, Tracy. How, one of the things that we use to we receive, from time to time is, well, how often are they supposed to be here? Because that's one of the things that keeps coming up, well, they come Monday, they don't come Tuesday, they come Wednesday, they don't come Thursday. Could you touch a little bit on that and can you also talk about respite care?

- Sure. We really call this, Iris, the plan of care, and the plan of care is what our interdisciplinary group. We have a team within Continuum Care, we meet on a weekly basis, and it is comprised of our physician, our nurses, our chaplain, our social worker, our volunteers, our bedside nurses, to be able to look at this patient and family unit, and what are their needs. There are some families that have a higher need level and there are some that need less. We talked about with, when we talked about Medicare, we have to address the concept of medical necessity. It's not, you automatically get two hours of care on Monday, Wednesday, Friday, and three hours in the afternoon, but there are some individuals that are gonna require seven day a week care. We look at not just what the life-limiting condition is, the word that we use is called comorbidities. It can be, where do someone live, do they live alone, some of our homes are really not places that we would want to live, but they live here, running water, electricity, availability of caregivers, finances. So, it's not a cookie-cutter because there are some situations they need a lot more care. They need three or four hours a day, and there's other situations that they don't, and these things can change because someone could be independent and says, "I don't want anything, I'm in control, I can walk, I can use my walker." We respect that, but as they're getting more frail and they're getting down a little bit more, they might need a homemaker to come in to help them with things around the house. They need someone to assist them in bathing. If they're confined to bed, they need someone to bathe them and turn them in skin care. So it really does depend, and we look week to week, and identify, do we have the right care, the right amount at the right time.

- Right time. Uh-hmm.

- And respite care, we know being a caregiver, is the hardest job in the world. I was listening to your show a few weeks ago when you had Denise Singleton here.

- Yes.

- And we can go on and on about caregivers. It's a twenty-four hour a day, seven day a week job, and it's backbreaking. And usually, it falls to one or two people in the family, and it's just non-stop. And respite care is a break that Medicare provides and each one of the benefit periods for up to five days to allow that

caregiver a break. Whether they need to take care of personal business, they need to rejuvenate themselves, emotionally and physically, where hospice comes in and assumes much more of the care for this. It can be done in the home, our caregiver support group, through the department of human services, has an excellent program that also provides respite, and we realize that our caregivers, they do need a break. Even if they need a break so they can go in another room of the house, and get a good night's sleep. So these are very important pieces.

- Yeah. Yup.

- Again, having dealt with [inaudible] services as well, in one of the cities, they had a facility where people were brought to the facility, as well as home care services, how does Continuum Care work here in the Virgin Islands?

- Uh-hmm.

- Here in the Virgin Islands, at this time, there is not what you probably refer to as a hospice house. And they are in the community. Medicare doesn't pay for the room and board for a facility, and someone would choose to go into a hospice house and pay a room and board, realizing there is 24 hour care of nurses and bathing nurses there. We've oftentimes looked at it here in the Virgin Islands, I do believe there is a need for it, but it's quite a large endeavor for an organization to embark in.

- That's interesting.

- And we were talking about caregivers, and recently, I think I wasn't here when Denise was speaking, Virgin Islands considered a caregiving act, and a matter of fact, I think you were a part of that group...

- Yes.

- Okay. Was, can we have some advice in regard to caregivers and the caregiving act.

- Okay. I think the Caregivers Act is something that really supports what we're trying to do as a community across many avenues. For example, if a patient is in the hospital and we realize, it can be very difficult for hospitals to be able to safely discharge someone. Who do they teach, what's gonna happen when they get home? Our goal is so that they're not turned around and readmitted back into the hospital, and this allows the patient to identify someone, even if it's not an immediate family member, it doesn't have to be their power of attorney, it could be their gardener, it could be their next door neighbor to say, "When I'm gonna come home from the hospital and you're gonna help me, the hospital is gonna include you in this discharge planning process, to know what are the medications, what procedures need to be done." So, it is really, I think, supporting strongly what our hospitals do, getting the patient out. I know having been a hospital nurse myself, you discharge a patient, you've taught them, you've gone, had them do, return demonstrations, they go out into the community, and you really wanna make sure that what you've taught is gonna be able to be done back in the home. So, I think this is a program to really enhance the coordination of care from hospital to home.

- And then, that's a good segue into the fact that a lot of the folks when they're discharged from the hospital, despite the information that's given to them, at that point of discharge, when they go home into the, when they go into the community, kind of, gets lost when they have to readjust to being in the home and they may not be a caregiver, a family person to help them remind them of the times they have to take their medication, or even to eat.

- Exactly.

- You know? And that's, that would really help here in the Virgin Islands, because it's very difficult, from personal experience, it is difficult being a caregiver, but it's also difficult for that patient, who has to now try to realign themselves into, "Okay, I'm home now, what do I do?"

- Uh-hmm.

- You know, and yes, you might have given them information with respect to services, and perhaps, you know, they had information given to them by hospice care, but still, a lot of times, a patient is still hobbling along, like we say.

- Uh-hmm.

- You know? And...

- It's very, it's very difficult, and when someone is taught in a hospital, in an environment where you have all those safety nets, when you get into somebody's home, you're dealing with a lot of adversity that, you know, there might not be a solid floor to walk on, but on, even their stairs. There's a very narrow doors, a lot of little rooms, getting in and out of the shower, in and out of the toilet, trying to brush your teeth, all of these things, and that's why I think it is so important, the issue that all of us healthcare providers in the Virgin Islands, we take very seriously what we do and what we contribute to that part of the care, but we also have to look at how we refer to one another. I'm part of a coalition work group that, as healthcare providers, and we're trying to find out how do we refer to one another? What are the eligibility requirements? How can we help so that it's not just saying, "Okay, you're discharged from the hospital and you're going into the community abyss. What can we do to make sure, you know, the disability rights organization, home care, human services, department of health, Viatran, Able Transportation, all of these things together." And then the more we know about the other services, then all of us can be, take the responsibility to shepherd our patients in our communities, through each one of these processes. We know, firsthand, we have the frail and the elderly, and the disabled taking care of the frail and the elderly and the disabled. And individuals are doing the very best they can, and something that can be so obvious to us, we really have to breakdown into what I call bite sized pieces or how do we adapt what we're doing in the hospital, in home care, in hospice, in a clinic, and how can we make it work for this patient and their family in the home?

- Yes. That goes very well...

- That's a good point.

- ...with the patient-centered approach of the Affordable Care Act because all of those pieces, all of those intimate pieces, have to come together to surround the patient with the availability of services. And I think this is also a word of caution. One of the more common things that happens is that we have children who are all filing, calling back to see how they can set up something for their parents without being here. You know, so, they called for the, that long distance guardianship.

- Yes.

- What can you add to the, a word of caution for those kind of situation?

- Well, I think that's part of the process, that all of us healthcare providers need to do. We have a, we are blessed to have an incredible social worker on both programs, Dabney Worth over on Saint Thomas and Carole Bachuelo here on Saint Croix. And they're like our detectives. When we go out, and I'm a nurse, I'm looking to see how well people do, can they be compliant, are they doing all these things with their medications and their plan of care, and my focus is kind of myopic, to be honest. But the social worker is the one that goes in with the wide sweep. Do they have the financial resources, what's here? Who's there? And we'll build a family tree. Okay. Who is your mother? Where are your children? Where do they live? What's their names? What are their telephone numbers? We have to identify two components, willing and able. You have individuals that are willing and not able, you have people that are able that aren't willing. So, we try to find out what are the strengths? What can they give? Can they give time? Can they give financial support? Can they, what part of this, and we, that's how we build the plan of care. It's not just the nurse and the doctor, it's the patients, it's the family, it's the extended family, because at the focus of this, it's this person we love and we care about, and that's where we have to direct our energy. Is

this for the best wellbeing for this patient? Not what Tracy wants, not what the sister wants, not what the niece in New York wants, but what is best gonna serve the wishes of the individual we're taking care of. So, it really does come down to a patient's rights and the responsibilities that they have as the patient, as the family, and also as we, as caregivers.

- And this is what we've been saying since the show, we'd started to show, that it's about right and protections for the, for the clients, the patient, whoever it is that, consumer, whatever you call that person, but it's about their rights and protections. And you had mentioned at the beginning of this show that you're dealing now with Alzheimer's patients?

- Yes.

- I'm pretty sure that, you know, that's a big, big bite of your services, because as we all know, Alzheimer's is growing everywhere. Not just in the United States, but here, too. And we get calls. Well, what can I do? Who can I go to to get help for my mother or my father, or whoever? So, can you talk a little bit about that population?

- Uh-hmm. It's a very difficult diagnosis, and there's so much research being done on Alzheimer's. We're fortunate over on Saint Thomas, our Medical Director is Dr. David Weisher, who's a neurologist and he has such a wealth of information, and you realize is how do you get this information into a very practical approach of how to deal with patients and families in the home? They'll come to hospice, and they really don't understand the whole process of Alzheimer's. They don't know that there are certain stages, they don't understand the part of the person that's there is not the person you knew last year, last week, or some years ago, and how do you deal with that, the practical approaches. So, instead of trying to say, you're not making any sense, you're confused, you're not in Chicago, you're in the Virgin Islands, is to be able to address their issues of safety, being paranoid, wandering, we use the term purposeful versus non-purposeful. They get up and they wander, it's non-purposeful. So, what are the practical things we can do to help our families deal with that?

- Well, that brings up the interesting point, to having enough neurologists on the Island, is, do you think that out there in place for the Virgin Islands?

- We do, we certainly do. We do definitely need more neurologists here. It's, I was just talking with Dr. Weisher yesterday, and he works full-time over on Saint Thomas, and he was up this morning, and runs a full day every Saturday here on Saint Croix.

- Oh, wonderful.

- And there is such need out there, and it's not just Alzheimer's, it's the other neurological issues that we have that go beyond the medical part into psychology personality, and those other areas.

- Well, thank you, Tracy. I was, it is time for a break right now.

- Okay.

- And then we get back...

- We'll wrap up.

- Good morning. Back to Ability Radio, and Ms. Tracy Sanders, you mentioned so much information, and I was just wondering, is there any type of community training or community meetings where people can follow up on some of the things you talked about this morning?

- Sure. Absolutely. We've had a couple programs that we look to repeat, and I call it the Educated Caregiver. We've run the program usually in coordination with AARP, one of our important partners, and it's a six-hour program that we have caregivers come in and we go through all the components. It's kind

of, like, Caregiver 101, and you'd be surprised, the participants, those that are caregivers, those that are taking care of someone, those that anticipate taking care of someone, we do grief and loss training and support groups, as needed. We also do the training programs on advanced directives. We do a workshop where we actually walk through the program, walk through all those important pieces of information, and then we actually have them get in work groups and start completing one so that they realize, it's not as difficult to do, we like to get that pen to paper, and then also, every week, in the Virgin Islands Daily News in the Saturday, Sunday edition, Continuum Care writes an article called the Educated Caregiver. We talk about caregiver support, safely administering your medications, how to hire a caregiver, what to look for and what to be careful of, spirituality, we talk advocates for Medicare beneficiaries, a lot of different areas. Our physician, Dr. Weisher wrote an excellent brief article about dementia versus Alzheimer's. And anyone that's interested is certainly welcome to call either one of our offices on Saint Thomas. Our number is 714-2273, and on Saint Croix, it's 718-5683, and we're open Monday through Friday, and when the office is close, we do have an answering service so you can leave your name and number, and what information you need, and we also have a website, which is www.ccivi.com.

- Okay.

- Again, thank you, Tracy. It's so much great information. Iris, any closing remarks?

- Oh, I think this is wonderful, because we are, we are achieving what we proposed to come and do when we first started the radio show, and that's giving our community information about healthcare providers, healthcare issues. So, Tracy, thank you so much for being here with us. We really appreciate all the information you provided. And folks, take advantage, Medicare, Hospice Care. You work for it, you're entitled to it. So, please, we'll come back next week when we have another show for you and hopefully, we'll see you at the fair.

- Yes.

- Thank you.

- Take care, Virgin Islands.