EPISODE DATE:  5/30/12

EPISODE NAME:  Start the Conversation: An Initiative from the Visiting Nurse Association

Today on Across the Fence we're going to start the conversation that all of us will face one day. What do we want for ourselves and our loved ones at the end of life? It's not necessarily an easy conversation so we called on two experts to help get us started. Good afternoon and thanks for joining us, I'm Judy Simpson. In our culture death and dying are often difficult to talk about. On top of that research and surveys have found that there are questions and confusion about end of Life Care choices. So this afternoon we're going to focus on an initiative by the visiting nurse association that encourages people to talk about end of life issues and care with their families and doctors. Joining me are Christine Wernerke and Geri Amori from the Visiting Nurse Association and the VNA's Madison Dean Initiative, thanks so much for being with us. Christine the VNA and its partners are encouraging people to start the conversation. What does that mean?

Christine.: As you said in your introduction so many of us are really on prepared to face end of life decisions either for ourselves or for our loved ones. At the VNA we care for thousands of family's every year and so many times we see them facing difficult decisions during a really emotional time. That's a very hard thing to do for family's when losing a loved one and also having to understand those options and choices. So start the conversation was created to help family's understand their end of Life Care options when they're not dealing with an emotional situation or a terminal illness or crisis. It also encourages them then of course to have a conversation and talk with each other about what it is they might want for their end of life experience or how they want to handle the decisions of that point in time. And most importantly to document those in an advanced directive.

Judy.: Why is it important for people to talk about? I know you mentioned you're not talking about patients you're talking to families because what happens to one person in the family happens to the whole family.

Christine.: That's right. When we're caring for people at the end of life we are caring for the entire family. Ed hospice care is of course there's care provided directly to the person who's dying but hospice care is also about working with the family? At end of life it's extremely important that people are in control of the experience. That's why it's so important to have a conversation. Just having your advance directive completed is a really important step but a lot of the times it won't answer all the questions. The
only way that we can be sure that our wishes are honored is if we have the conversations with their family so that they know and a certain situation situations you probably can predict they can make those decisions and not be worried that they didn't honor what it is that you know.

Judy.: Because most people don't even understand what hospice is.

Christine.: Most people don't in fact three out of four Americans don't understand the role that hospice plays or understand their options for end of Life Care. I think it's really important for people to know that hospice is not about giving up it's not just for the last few days. You can be on hospice for months and its care that is provided specialized care that's provided for people who no longer have options to cure an illness or treat at illness.

Judy.: So the VNA is partnering with others to start the conversation initiative?

Christine.: That's right and we're really excited about this because we're partnering with our sister agencies across the state so other VNA is and home hospice agencies have worked together to bring us to families and individuals in all communities in Vermont we're also partnering with our sister agencies across the state so other VNA is and nonprofit Home Health and hospice agencies have worked together to bring this to families and individuals in all communities in Vermont. We're partnering with Vermont ethics network that is the organization that's the expert on medical decision-making and advanced directives.

Judy.: You've talked about advanced directives most people don't have them what does it take to do an advance directive?

Christine.: That's right in fact only about three out of 10 Americans have an advance directive. Every state is different but in Vermont we have an advance directive form that you can fill out to help you name what your wishes are. However you don't need to fill out the form or use that form you could literally write it on a napkin and as long as it's witnessed properly you can use that and it will hold up. There are two important aspects of an advance directive first is naming a healthcare agent. That's going to be the person that makes decisions for you if you're not able to make those decisions herself.

Judy.: Husband and wife son daughter.

Christine.: And a lot of people feel that if they're unable to make those decisions then the law defers that decision to their spouse or a parent. That's not the case in Vermont home that the agent does need to be named and the rest of it is really talking with your Dr. Talking with their family and talking about what it is you want in certain situations in making those decisions ahead of time.

Judy.: Geri Amori is a member of the Madison dean initiative that's the VNA as program for educating the public on quality that end of life and Jerry I know talking about that and thinking about the end of life is not something that's very pleasant for most people but it really is critically important.

Geri.: Yes it is and people need to know what their options are. Many of us come to this very important stage of life and tend a separate death from living and death is actually part of the process of our life and a very important part of our process unless we think about and know what is available to us know about hospice for example which is on Medicare benefit that's paid for through Medicare than we really don't have a choice unless we know. It would be like having a graduation party saying everybody come and not deciding where the food is.

Judy.: Which is a good point to bring up. We plan for everything in life.
Geri.: We do we plan for all kinds of things. At least Americans are very autonomous and we want to play and everything so we need to think about this which is a very important part of life. Last year I heard an amazing statistic that kind of tickle me but it really is true that's an appalling statistic actually. The rate of death in the United States is 100%.

Judy.: Right that's the one thing you can guarantee.

Geri.: You can guarantee so are you going to do your way or are you going to let decisions being made for you by outside forces.

Judy.: So who should have this conversation and when?

Geri.: Everyone should have the conversation home and you should have that as soon as you think they have it. People have to have the conversations with their family's know what your options are talk with your Physicians which are planned into writing because when the time comes with stress no one's going to know your thoughts were what your values were and everyone's going to be worried upset and concerned and we'll think about those things. Are having the conversation first to their family members first for the people who are close to and by the way family can be defined in all kinds of ways not just a father mother sister brother children but where you consider family make that known clear in writing have your advance directive have your durable power of Atty. for Health Care. Know what you would like and all kinds of different situations. What if you develop ALS Lou Gehrig’s disease what would you want what would you want if you develop MS and do you want to be intubated do you need nutrition was if you're willing to have and in what circumstances.

Judy.: Which is really interesting because we really do have to educate ourselves on exactly what these terms mean and what it means for your family because it really is something that you're doing for yourself but are really doing it for your family as well.

Geri.: Write because if they don't know what they want their going to do what they can to prolong your life because they're not sure and they don't want to make a mistake at this important time of your life. These conversations should be started anytime any time. It doesn't have to be a sad time you don't have to have had a terminal illness you can do it at the birth of a child. News and take care of her child if something happens to us. What if were in an unknown car accident. What happens if you get married now we have so many blended families we have yours mine and ours. What happens for in a common accident how do we make sure that the financial aspects of things are taken care of and as part of that how do we want the end of our life to be. Do we want to be hooked up to all kinds of machines or what is it that we really want. Perhaps even well my husband die on the day of our wedding we signed our Wells 25 years ago because we knew this was something anything happen. We wanted to make sure that for our end of life it was handled them the right way. So watching a movie taking a part in the fundraiser any of those kinds of things can create the opportunity to begin that discussion about what is it that you really believe and one for yourself.

Judy.: What happens if a family member does not want to talk about this or does not want to engage in this kind of conversation? They think it's morbid. That look to talk about that.

Geri.: Well that happens really often particularly in the early stages of talking about it. I was just talking to Christine about a friend of mine who just last week her husband found out that he had terminal pancreatic cancer. Up until now he thought he would die of a heart attack and when we started talking about palliative care. Care to make the end of his life as rich as the beginning of his life or the process of his life and she was a ready. We know we will have to have that conversation more than once. We'll
have to come back to it. Resistance is usually based on fear. That someone not knowing what's out there and not knowing what needs to be talked about and we need to think that it's again not just older people younger people such as Nancy Cruzan Terry Shivo those are examples to us and the need to have the conversations pretty early on.

Judy.: You just explain for folks who may not be familiar with those names who these women were?

Geri.: These are young women who ended up in hospitals for a long time on machinery that basically prolong their life maybe not in a way they would have wanted to prolong. Creating some real controversy within their family's divisiveness within their family's divisiveness between their families in the Healthcare System and all of that surrounding something that could've been more easily handled.

Judy.: What about talking to children for these kinds of things because it can be scary for children of any age to think wait a minute.

Christine.: Yes absolutely and I was talking with a family recently and we were talking about the importance of having a conversation and they said my kids are in their twenties they're not going to have this conversation with us. We encourage them to try and at a minimum we say we know what it is we want and we have written it down in an advance directive. This is where does so if something happens to us it's here and give them a chance to ask questions. As Geri pointed out and was talking about her friend is that that is just a starting point so it's a process not an event. You don't have the conversation Monday night at 7:00 and then OK you are done.

Geri.: We spend a lot of energy in our culture talking about major parts of our life. We talk a lot about weddings or graduation or vacation even. That's amazing to me we spend more time talking about vacation and planning that than we do about probably one of the greatest transitions of our lives and wanting to be the way we want it. Recognizing that it's not giving up that's taking control it's a positive step not a negative step. Approaching our family's this way of approaching our doctors to sway knowing what gives you the sense of dignity and what things are going to want. And palliative care I think of them as your team. Value of care and hospice of the people who come in and there's Physicians and nurses and social workers and volunteers and a spiritual guide spiritual people to help you make this part of your life as rich and as wonderful as the most important occasion of your life and in many ways for many of us that's the last most important occasion of our lives. For everybody.

Judy.: Not only that keep bringing family into it but it is a huge relief to family members to know that these decisions are made and this is happening the way your love one want it to happen.

Christine.: It's really a gift. The oftentimes here about when those conversations have not happened and unfortunately the people that are left behind the children until children seniors our spouses are left was saying to do the right thing? Even though it's hard to have these conversations sometimes it's harder to not have them 'cause when you're faced with having to make those decisions and you don't have the chance to talk to your love one that's much much more difficult. We really encourage families and individuals that 12 initiate a conversation to keep trying.

Judy.: Christine there are additional resources for folks who want more information where can they find?

Christine.: The first place they can go is to the website start the conversation VT.org on that web site we have some materials that can be helpful to people because you recognize how hard this is. So we've created a conversation guide and in this guide we have a number of resources such as worksheets. Us questions what does that mean on everything and the spells that out. It gives you some areas to say if this happens what would you want this this or this. So it helps people to think through that process. We also
have some facts and information about hospice and advanced directives and we can send this also to you in the mail if you're not Web savvy.

Judy.: Thanks so much for joining us today and started a conversation here so hopefully folks at home can do the same. That's our program for today I'm Judy Simpson will see you again next time on across the fence.

*Across the Fence* is brought to you as a public service by University of Vermont Extension and WCAX TV.

Issued in furtherance of Cooperative Extension work, Acts of May 8 and June 30, 1914, in cooperation with the United States Department of Agriculture. University of Vermont Extension, Burlington, Vermont. University of Vermont Extension, and U.S. Department of Agriculture, cooperating, offer education and employment to everyone without regard to race, color, national origin, gender, religion, age, disability, political beliefs, sexual orientation, and marital or familial status.