Good afternoon and thanks for joining us I am Judy Simpson. November is National Hospice and Palliative Care Month. It's a time dedicated to increasingly understanding and awareness of care at the end of life. Death and dying are often difficult subjects to talk about so this afternoon we have asked an expert from the visiting nurses association to be our guest and to discuss hospice and palliative care. Angel means has worked for hospice for 17 years she's director of the end of Life Care Services for the DNA of Chittenden and grand isle counties. Thanks so much for being with us again.

Angel.: Thank you for having me Judy.

Judy.: Angel you must get a lot of comments about your name.

Angel.: I do. My birth name completely ironic sometimes hard to live up two and this line of work.

Judy.: Why is discussing hospice and palliative care particularly important for the state of Vermont.

Angel.: The state of Vermont is the second oldest state in the nation and we also have recognized we're in the low 10% for hospice utilization. We're very much trying to understand why that is. Some of that is due to lack of awareness about hospice.

Judy.: Is it also the habit of people not wanting to ask for help?

Angel.: It could be Vermonters are known to be very stoic and death and dying can be a very personal experience and sometimes bringing someone into that experience can be difficult.
Judy.: And yet there are a lot of reasons why that should be the case. Can you tell me a little bit about some of the benefits about taking advantage of some of these options and programs?

Angel.: I will start with hospice. Hospice is a very comprehensive well-coordinated program that provides skilled services for people primarily in their homes. It really takes an interdisciplinary approach to providing that care. Hospice is comprised of a team of experts and professionals that really interest the physical symptoms that may occur for someone who's dying. Provides emotional support psychosocial support as well as addressing the economic challenges related to dying and staying at home during that process.

Judy.: How does the process began as far as what's the first step when hospice cares is considered?

Angel.: Hopefully it starts with a conversation between an individual and their primary Physician. The Physician helping that person understand disease modifying therapies that they're receiving may no longer be of benefit and the burdens of that treatment may be outweighing the benefits. Helping them start understanding their options at the end of life planning for those being proactive about what may lie ahead and that really is the best place for that conversation to start.

Judy.: We're in such the habit of going to the Dr. and listening to what the Dr. has to say and it's all about cure cure cure but that does come a time when that changes.

Angel.: Absolutely and that is the best time to start thinking about hospice. Unfortunately here people access hospice much later then they could under the Medicare hospice benefit which is the primary insurer for hospice in this country. A person can access hospice when their prognosis is close to six months or less. Unfortunately the average length of stay and hospice in this country is more around 70 days and in our region it's as low as 45 days.

Judy.: Really in somebody could've been getting these benefits all along for months.

Angel.: Exactly.
Judy.: So what are some of the benefits to the patient of hospice and what are some of the things that can happen for patients?

Angel.: I think one of the greatest benefits as hospice provides individualized care home by home so what dying may look like for one person's family is very different then for another. We really tried to focus on what's unique about an individual and we may have a family who really benefits most from skilled nursing care or someone to help them bathe. From trained hospice volunteers to provide companionship and the care plan for individual can change over time as that person requires more care. We really try to meet the patient and a family where they are in their illness and dying process.

Judy.: It's interesting that you mention the family too because they're involved as well.

Angel.: Exactly. Hospice is a very focused on supporting family members and providing care even after the death has occurred. For those family members.

Judy.: What about palliative care what makes that different from other care?

Angel.: Palliative care is really a similar approach two hospice in that it's very focused on relieving whenever is suffering for that patient. Really helping to manage pain and symptoms. Palliative means to palliate to leave suffering or to eliminate set relieve suffering. The difference between palliative care and hospice is that palliative care really should focus at the time of diagnosis of a life threatening illness on through while someone is seeking disease modifying therapies. And they were transitioned the hospice more when those therapies are no longer working.

Judy.: What's the VNA's role?

Angel.: The VNA and the VNA's across Vermont all have a hospice program that services every region in the state. We provide palliative care home based services and also hospice home based services not only in individual homes we extend hospice into nursing homes community Care Homes hospital anywhere a person resides they can access hospice support.

Judy.: Do you find that mostly people do want to be home?

Angel.: Most people if given the right amount of support would prefer to die at home.
Judy.: In your mind is that support really out there for people? Do people realize that support is out there?

Angel.: I think there a lot of misunderstandings or misconceptions about what hospice can and can't do. I think some people feel like if you enroll in hospice you have to go to a place to die that hospice means a home so there's concern that they might have to leave their home. I think there are a number of barriers of people accessing hospice but we can provide and coordinate with other organizations to maximize support for someone to stay in their home. It's become a little hard are with our aging population because a lot of people do not have family support in a home setting so we may need to bring in other resources to help them remain there. If they can't we're very fortunate in our community to have the Vermont respite house in Williston. This is the only hospice home in the state of Vermont.

Judy.: When is a time for a family to step in and say palliative care and hospice care home is great but I think it's time to take it to the next level maybe you do need a place to go?

Angel.: It really depends on what that person is dying process is like and sometimes if a person is having some uncontrolled symptoms or some emotional challenges with dying that's keeping them awake at night the family may become quite fatigued in keeping that care. Hospice provides intermittent services and we'll work with the family to educate them and support them to be a part of that care. If the family becomes quite fit to you with that process or there's a breakdown in the family system in some way may be a frail family member to care for their spouse and they become ill themselves then we may have to help them with their resources and options.

Judy.: Why is it hard for people to talk about this do you think? We plan for almost everything our lives.

Angel.: Exactly. It has a lot to do with our culture death and dying. It's not seen by some as a very natural part of life it's not a comfortable topic we haven't been so good at the dressing in our Healthcare System we've focused more on treatment and very aggressive therapies. I think the way that a person approaches death and dying really has a lot to do with their personal experiences. If you haven't been a part of a good death or good dying process there's a lot of fear involved of unknown.
Judy.: How can individual Vermonters access hospice or palliative care?

Angel.: Like I said earlier there's a VNA program that serves every region of the state so contacting your local visiting nurses association talking to your primary care Physician.

Judy.: We're seeing some pictures here and maybe you could talk a little bit about where hospice care is provided? Lots of people do want to stay home.

Angel.: They do and a lot of people don't realize that if they for some reason can receive hospice care at home if they reside in a nursing home we can bring hospice into the nursing home in those circumstances. I think a lot of people don't realize that that they can still access their Medicare and Medicaid hospice benefit in that setting.

Judy.: Once again one of the things you should be considering and think about as you get older consider what you do want for plans for end of Life Care.

Angel.: Exactly. We have a fabulous resource in the state called the Vermont ethics network they have a wonderful website and they're very involved in creating tools that will help people write down their options their choices what they would like to see happen for them at the end of life under certain circumstances. Those are advanced care directives or advanced care plans.

Judy.: It's important to share that with a family.

Angel.: Absolutely.

Judy.: At the beginning of the program you mentioned that Vermont has a low utilization of hospice care why is that the case?

Angel.: In the 17 years I've been involved in hospice there's always been a need to educate consumers about the hospice benefit to try to eliminate some of the misconceptions about hospice. And Medicare benefit was designed in the late 1970s and not a lot has changed about that benefit over time but the demographics have changed so the needs are different. That's six months prognosis that's part of the Medicare criteria is very challenging. Sometimes it's very difficult to pin the diagnosis to really predict that kind of timeframe for someone. It's also very scary for someone did here they have a prognosis of six months or less. I think some people deeply hospice to maybe meaning there's no more hope. My primary care Physicians going to abandon me if I enroll in
hospice. I'm not going to have the kind of options that I made want at the end of life so we're always involved in educating consumers.

Judy.: What's Vermont doing to address the low use? What are some of the ways that educating I know there's an important memorial service coming up.

Angel.: We have a hospice annual memorial service in this community on November 6 at the Unitarian church at 3:00 and most hospices provide an annual memorial service and that is for to bereaved survivors of our hospice patients and really for anyone in the community who has experienced the death and that is supporting the grief process. We have an incredibly active and engaged Vermont State legislature. Last year they were very active in passing act 60H201. It was a bill related two hospice and palliative care. Really trying to understand some of the barriers in the state. There are programs we could not access simultaneously with hospice and they eliminated that barrier for Medicaid waiver program. Encouraging third party insurers to look at their hospice policies possibly brought in them out the on the six months prognosis so that there's not that barrier. Working with Vermont ethics network to help educate consumers about the importance of advanced care planning. We have at the VNA of fabulous program called the Madison dean initiative which is a volunteer program that provides a lot of time educating consumers professionals about end of Life Care creating educational tools.

Judy.: Where can viewers get more information?

Angel.: There is a statewide end of Life Care website that is VTPCRC.org the Vermont palliative care and end of life resource connections again I mentioned the Vermont ethics network website and then we have our own VNA web site which really describes all of the comprehensive end of Life Care Services that we provide VNA cares.org.

Judy.: So people should probably think about rather than hospice being something for the end of life think about it as a way to help all your loved ones who are going to be going through a very difficult situation as well as yourself.

Angel.: Absolutely yes.

Judy.: Maybe you could tell me two about the importance of grief and bereavement support during this time?
Angel.: Grief doesn't happen after the death occurs there's grieving all along the way. Hospice really focuses on anticipating what that grief for a family after the death but also preparing for the death preparing for families and individuals who are dying for that death. Because hospice does involve the entire family we really focus on the children's experience of that dying process and we have a pretty extensive bereavement program in this region and that we offer children and family bereavement camp each year. We mentioned are annual memorial service and again we individualize that support depending on the impact of that death for that family.

Judy.: I want to thank you for coming on and talking about all of this it's a very important of.

Angel.: Thank you Judy.

Judy.: Thanks angel. That's our program for today I'm Judy Simpson will see you again next time on across the fence.

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