Good afternoon and thanks for joining us; I am Judy Simpson. We make decisions every day from choosing what to eat for breakfast to what clothes we wear to work. But among the biggest decisions we make or sometimes don't make are decisions about our health. As you're about to find out, today marks a day to think about communicating and document your health care decisions. I’m joined by Cindy Bruzzese the Executive Director of the Vermont Ethics Network also with me is Dr. Bob Macauley who is the Director of Medical Ethics at Fletcher Allen Healthcare and a professor at the University of Vermont’s College of Medicine. Welcome to both of you. Today has been given special significance by the U.S. Congress can you tell me about that?

Cindy.: Today is National Healthcare Decisions Day and it seemed like a wonderful opportunity to meet with you and share again and review the importance of thinking about and planning for future healthcare needs to review some tools that people have heard about before advanced directives for health care and also to talk about newer tools that people haven't heard of. Do not resuscitate orders, clinician orders for life sustaining treatment and to learn a little bit about how these tools are available to folks as their thinking and planning for future healthcare needs.

Judy.: I think people think there's one form you have to fill out and then you're done but actually there a lot of different changes and they can vary depending on what state you're in.

Cindy.: Sure and every state has their own version of an advance directive document and as Dr. Macaulay will talk about later this whole idea about out of hospital medical orders that some people need to make sure that their wishes are honored regarding certain preferences that they have for treatment. It's more than just a one-time thing it's an ongoing conversation because as we know people's healthcare status changes over time and their goals change over time. It's not one stop shopping check that off my list I’m done because things change over time and people need to keep thinking about it and keep planning.

Judy.: Why do you think it is and I will ask you both the same question. Why do think it is people don't think about that we plan for almost everything else in our lives?

Cindy.: It's interesting we did a short survey this fall and what people said is we know this is important but the excuse they gave was procrastination. It's not happening in the moment so you
don't really think about it and I also think in general it's really hard to think about and talk about when you don't have control over things and when your health may be failing and difficult decisions need to be made. It's tough sometimes it's tough stuff.

Bob.: It is, and I think we live in a death denying culture so we try to believe that were going to live forever or we act that way sometimes and it's difficult to say I'm doing okay now but what happens when I'm not doing OK and how am I going to make these decisions in advance. What I try to tell people is this is really a way of taking care of people you love even when you're not able to do so in real time because what you're doing is hopefully sparing them some incredibly difficult decisions by letting them know what you would want so they can act based on your wishes and not try to have to figure things out on their own.

Judy.: Especially in a time when people are living longer and there's more technology to advance life. When you talk about advanced directives can you give me an overview of what that means?

Bob.: Sure. An advance directive is basically an opportunity to say in advance what you would want or what you wouldn't want in certain situations or and probably more importantly to name someone to make your decisions for you. In Vermont we have a very good form that is accessible through the Vermont Ethics Network website that anyone can fill out and it says here's the person I want to to make decisions for me and here are some situations that if I'm in this condition this is what I want or what I don't want. It's always an impossible question though ultimately to answer because we can never predict if I'm this age and this happens to me but we can do our best to say these are the kinds of things that comport with my values and these are the kinds of things that wouldn't make sense to me if I got to the point.

Judy.: Do a lot of people have advanced directives?

Bob.: Nationally about 25% of people do and even those who fill it out sometimes what happens is people here folks like Cindy and me talk about this and then make a very great choice they go out and fill out an advance directive and then they say “phew” now the doctors know what they want to do when it comes to that. Unfortunately it doesn't work out that way because sometimes advance directive say things like if I'm not going to recover or if there's not a reasonable hope of my recovery than don't do extraordinary things but as a physician I'm not sure whether they're thinking when they said reasonable hope of recovery and I'm not sure what's extraordinary to them. It always requires interpretation that’s where that decision maker comes in very importantly at that point.

Judy.: Because a person would say I want to have a good quality of life but that's very subjective.

Cindy.: So having the person that you've selected that you no known as you well knows your values to be able to give that context to someone like Bob when they're saying would this be OK would they want to live in this way they need that person to interject that context otherwise we wouldn't have. Because in Vermont we don't have a standardized surrogacy law which says it's automatically your next of kin like a hierarchy we don't have that in Vermont which means it's kind of gray, in terms of who makes those decisions, if you haven't done this planning ahead of time. I think probably that's one of the most important things about an advance directive for folks is one: get them started in having the conversation and two: hopefully have them appoint a healthcare agent who can be that go-to person when there's a decision that we're not sure what it would mean for them and can provide that voice when the patient can't do it for themselves.
Judy.: And then I would say it's probably important enough to talk to people in your family about that and also to your doctor.

Cindy.: Hugely important, and I think we can’t really underemphasize that communication is the key to all of this. Is having these conversations and making sure not just the decision-maker but the whole group of your family members understands what your goals and values are so they can support one another if a difficult time arises.

Judy.: Why you think that people don't do this?

Bob.: I think first of all it is difficult to think about and second of all maybe they don't know where to start so physicians are taught to do certain things. If you go to your doctor for a checkup and the doctor doesn't listen to your heart you probably think well he's not much of a doctor if he didn't listen to my heart, but for whatever reason we haven't built up that expectation about advanced care planning. I would love to see that happen that physicians feel like that's part of their obligation to their patients and patients come to expect that to say why didn't we talk about what happens when things are not going so well. Because the best time to talk about advanced directives is not when things aren't going well the best time to talk about it is in a good healthy checkup for the 30-year-old or forty-year-old or sixty-year-old can say things are going fine but when they're not, what do you want me to do for you and how are we going to take the best care of you.

Judy.: Right; along with that if you are of a certain age and need a colonoscopy or start breast cancer screening and you should also be doing this.

Bob.: And actually a certain age I would say is as soon as you can in adulthood because the most important cases legally speaking about end of life care and advanced care planning for lack of it were women in their twenties over the last 30 years. That's not something that you do when you get to be a certain age if you're at a point where you're an adult and can do this I would advise people to start thinking about it; put it on paper even if it's just naming a decision maker because that will start the conversation and will also remove some of the doubt about who should be making decisions for you.

Judy.: Once you decide that you are going to do that there's actually several different ways you can go with this. There's the advance directive but there's also something called COLST?

Bob.: A COLST form is a little different than an advance directive. An advance directive is filled out by a patient. You can download the form signing yourself have it witnessed and your done and you share it with your decision maker and physician. COLST stands for clinician orders for life sustaining treatment. Which is Vermont’s version of a DNR order and other orders about what treatments will be done. This is a really important point which is that if somebody says I do not want to get CPR if my heart were stopped just let me be and don't do CPR. If that's their wish then filling out an advance directive is not enough because if 911 is called and the paramedics show up they're not going to have time to read a 10 page advance directive and try to figure out what they mean by this and it doesn't fit their qualifications about what type of condition they are in so they're going to go ahead and do CPR. If you're in a situation where you sort of say if this then that I'm not sure let's see how it goes fill out an advance directive and give all the guidance that you can but if you're a position where you say...
under no circumstances do I want to receive CPR or go on a breathing machine or to go back to the hospital or to get antibiotics or any of those things then you need to talk to your clinician usually your physician and say look we need to take a step further and have your doctor fill out a COLST form which then if 911 is called and you have a COLST form that says do not do CPR then the paramedics will not do CPR.

Cindy.: I think it's important to understand that some people will say then everyone needs a COLST form they don't need an advance directive and it's really important to understand that that is not the case. I would say it's the opposite everyone needs an active and there are some people depending on their goals if there in that category that Bob just described they're the ones that need the COLST form I would say in an ideal world you would start with having the conversation and filling out an advance directive and in the process of going through that and thinking through your goals and values and your preferences around different kinds of treatments. That would be the indicator to say oh wait a minute now I think I might need this extra step or no I'm done here depending on where I am in my life in my disease or whenever it is. I think that is the important thing people need to understand is that it's not I have one and not the other necessarily you might need both but you definitely need an advance directive first.

Judy.: So that's a good place to start?

Cindy.: A great place to start.

Judy.: As a physician Bob how do you use these documents in your practice when you work with patients?

Bob.: I direct a clinical ethics consultation service at Fletcher Allen. When we have a patient come in who cannot make their own decisions then we turn hopefully to their advanced directive to say what did they say when they could make decisions and that's fraught with all kinds of uncertainty. First of all, chances are they do not have an advance directive because only about 25% of people do and even if they have filled out an advance directive then there's the question does the situation they are in match up with what they were expecting and then we have to figure out what their values are and dig deeper to what they meant by this what kind of experience do they have what they say when other people are in similar situations what makes life worth living for them? That's a pretty time intensive involved process to try to figure out what they would want if they cannot tell us themselves.

Judy.: And because it can constantly be changing.

Bob.: Absolutely and the situation changes and people's emotions are involved and one of the most difficult things and this is the advice I give to people when they fill out advanced directives is when you name your decision maker but don't always make the obvious choice. I have people who come to me and say my decision maker is obviously my spouse and maybe that's a great choice, but you that you have to realize that it's not a gift to give to somebody to make them your decision maker. You may be asking somebody to make a decision that you would want that is entirely contrary to their own best interest which is to let somebody go they love more than anyone else in the world. So these are incredibly difficult decisions to make.

Cindy.: I think you bring up a really good point about people changing their mind. I think that's an important thing to remember, you can always change your mind. Advanced directives are not
documents that people like Bob and his colleagues are looking at unless they can actually speak with you directly. You have the right to make your own decisions for as long as you have the capacity to do so. They are only looking at these documents when they're not able to get information directly from you. Sometimes what people think about in the abstract when they put down in their document when the situation actually arises.

Judy.: Wait I changed my mind

Cindy.: Is a way to change my mind and that's OK. You want to change your mind and people do because it's their first time traveling down this path and it takes time to wrap your brain around what's really happening. I think that's an important thing to remember just because you fill the one out. I don't know if that's one of the barriers that keeps people from doing it. What if I put down in writing then they're not going to talk to me anymore. So we want people to know that it's not how works and you do always have the right to change your mind or rethink and you can just verbally say I don't want to do it that way I want to do it this way now and clinicians listen to that and follow your wishes. I think that's an important thing to remember as well.

Judy.: The thing that's interesting too, because I'm thinking of my own mother and she’s in her early eighties that she has significant health problems as you would probably expect for many people in their early eighties that you are still in denial. She says I can't believe this is happening to me so we still have a conversation about it but I'm not sure she's going to have anything in writing. I don't know what her wishes are going to be. So that's a good conversation to have with her.

Cindy.: It's a good conversation and I think sometimes the less threatening part of it is if you weren't able if something were to happen even temporarily and you weren't able to tell the clinician what it is you want, who would you want to do that for you until you get back to making your own decisions again. Sometimes taking that first step of appointing a person to make their decisions is less daunting than thinking about and end of life scenario that they're maybe trying to avoid. Then to progressively keep initiating the discussion and start to talk about values and goals and things they would or wouldn't want. I don't know how that's worked in your experience?

Bob.: I think values and goals are because of the conversation should you have that procedure. I think it's a mistake to say we have to figure out if you want CPR if it comes to that I think the conversation is better had with what are your hopes what your goals what is a life worth living for you; what level of disability or impairment you might be willing to be able to deal with if you are able to do the other things in life that are important to you. And for many people they will say it's OK if I have some degree of disability. It is OK if I have some degree of impairment as long as I recognize the people I love in my life. If I can play with my grandkids or look out on a beautiful scene from my window. What is important to somebody and if we can identify that we can figure out what’s our probability of getting him back there. To try to figure out that’s what they would want.

Judy.: Because realistically how many times will patients face these kinds of decisions?

Bob.: In terms of my work? I see them pretty darn frequently in the sense of things that people didn't necessarily expect. We all have this idea or hope that will have a peaceful death and that we will be in the position where we can be surrounded by the people we love and we can be pain
free and have our dignity. The most people strive for the problem is they must make plans for it and may not be able to achieve that and that’s what this conversation is about.

Judy.: Where can viewers get more information about advanced directives and medical decision-making?

Cindy.: They can go to the Vermont Advanced Directives website. And also the Visiting Nurse Association of Chittenden and Grand Isle Counties in conjunction with all the home health agencies across the state have initiated a campaign called “start the conversation.” So you can go to any of your home health agencies and check out their start the conversation information which will give you information about planning and also redirect you back to the VEN site for the necessary forms that you might want to fill out.

Judy.: I want to thank you both for joining me it’s such an important conversation.

Bob Cindy.: Thank you very much.

Judy.: That’s our program for today. I’m Judy Simpson we’ll see you again next time on *Across the Fence*.

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