



Advance Planning for Independence and Autonomy February 15, 2018

TRANSCRIPT

Moderator Rachel Breidster: Hello. Welcome to “Public Health Live,” the Third Thursday Breakfast Broadcast. I’m Rachel Breidster and I’ll be your moderator today. Before we get started, I would like to ask that you please fill out your online evaluation at the end of the webcast. Continuing education credits are available after you take our short post-test and your feedback is helpful in planning future programs. I also want to let you know that the planners and presenters do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity. And no commercial funding has been accepted for this activity. As for today’s program, we will be taking your questions throughout the hour by phone at 1-518-402-0330 or via e-mail phlive.ny@gmail.com. Today’s program is entitled “Advanced Planning for Independence and Autonomy.” Our guest is David Hoffman, who is the Director of the Bureau of Community Integration and Alzheimer’s Disease in the Division of Long Term Care in the New York State Department of Health and Clinical Professor at the University at Albany School of Public Health. Thank you for joining us.

Moderator: So good morning, Dave. Thank you so much for coming back and joining us again for another show.

Hoffman: Good morning, Rachel. Great to be here.

Moderator: So to get us started on our conversation today, can you just start by reviewing what are the objectives that we have for today’s webcast?

Hoffman: Sure. By the end of today’s webcast, viewers will be able to explain the difference between advance planning and advance directives, list the benefits of advance planning and describe some examples of current initiatives in place to change the approach we have to advance planning.

Moderator: Excellent, thank you. And to get the conversation started, can you start by reviewing for us how do we get to where we are today and are there any historical cases that have really moved the nation in a different direction or pushed us forward in our conversations about advanced planning?

Hoffman: Absolutely. I would like to focus this morning on the Nancy Cruzan Case. Nancy Cruzan was a 25-year-old who was in a motor vehicle accident in 1983 and was left in a persistent vegetative state. A feeding tube was necessary to keep her body functioning and provide long term care. For seven years, her parents requested that the feeding tube be removed,

but the rehab hospital refused. Since Miss Cruzan did not have an advanced directive in place. Her parents ended up going to court in Missouri where they were from and all the way to the U.S. Supreme Court before finally getting a ruling that the feeding tube could be removed when the court finally recognized that there was what they termed clear and convincing evidence of Miss Cruzan's intent. She died in 1990, leaving us with a legacy of a story of why it's so important to do this planning.

Moderator: Yeah. Absolutely. Because that kind of scenario I feel like it's like a worst case, kind of a nightmare thing to imagine. So considering that information, what federal laws then did the Cruzan case help to initiate?

Hoffman: So one of the important changes that happened after the Nancy Cruzan case was actually part of the Omnibus Budget Reconciliation Act in 1990 and that was the Patient Self-Determination Act. It is all about requiring that people have good information. So in this act, Medicare and Medicaid provider organizations need to give written information to patients about their rights to make decisions about their medical care, maintain written policies and procedures about advanced directives and make them available to patients on request. To document whether or not a patient has an advance directive that's been executed by them. To comply with state laws, respecting advance directives and importantly to educate staff and the community about advance directives.

Moderator: So that's really at the federal level. Can you talk about any state specific laws for advanced planning here in New York State?

Hoffman: Sure. New York was actually one of the leaders early on, right after that federal law in 1991, and the New York State Health Care Proxy Law was signed which made it legal for anyone age 18 or over to appoint a health care agent for times when either temporarily or permanently they're unable to make health care decisions. That was followed in 2008 by the initiation of a law regarding Medical Orders for Life Sustaining Treatment or what we call MOLST in New York and a lot of other states it's referred to as Physician Orders for Life Sustaining Treatment or POLST and that was in 2008. And in New York we have the Family Health Care Decisions Act which passed in 2010 which provides health care providers and hospitals and nursing homes with an important outline and kind of a step by step instruction of what happens if there's not an advance directive or advance planning in place and really helps steer surrogate decision makers to what they need to do.

Moderator: Excellent. So it sounds like the Medical Orders for Life Sustaining Treatment or MOLST is a key aspect of advanced planning. Can you talk more about that.

Hoffman: So the MOLST is a tool that is really important especially as people age and approach the end of life and may have some serious health conditions. It's important to recognize that most states have some form of MOLST. It's called something different as I mentioned in many states. So it's important to check on individual state requirements for those who are not New Yorkers listening this morning.

Moderator: Sure.

Hoffman: And the slide that we had up a moment ago is actually a shot of the top of the MOLST form which is typically on bright pink paper so it's something that stands out and gets noticed and it's not something that's just -- that gets shuffled into somebody's medical file.

Moderator: So what exactly is an advanced directive?

Hoffman: An advanced directive is a legal document. So it identifies our future health care decisions and it does so in such a way that a health care proxy who is identified, that's one form of legal directive to identify who you want to make decisions for you. Or having a living will describing what your wishes are. For a point where you might not be able to make those choices yourself. Those documents are advance directives.

Moderator: Okay. So what are some of the medical orders that might be included in advance planning?

Hoffman: So as with everything else in health and public health, we have acronyms to describe almost everything.

Moderator: Of course we do.

Hoffman: So we refer to DNR, do not resuscitate. DNH or do not hospitalize. So someone who may be receiving health care at home who would choose not to be hospitalized can include that in their wishes. And DNI or do not intubate. So for someone who doesn't choose to be put on life support that would be included in their advanced directive.

Moderator: These are all helpful terms I think for us and for the audience to be aware of. You have mentioned that legal documents are only one part of the process. So can you tell us more about the other parts of the process.

Hoffman: I think the key word you just used is process. The legal documents are a piece, but the process is really what's important. That's what I'd like to focus on in our conversation this morning. Traditionally advance planning really emphasized those legal documents. And the Nancy Cruzan case is an example of why. Having a legal document there would have saved a tremendous amount of angst and pain on the part of her family and the providers in that situation. So legal documents also tend to focus almost exclusively on the end of life. Advanced care planning can focus on a number of other things, later in life that's important for us to recognize. So a single form or a checklist can't really cover everything medically related that you might anticipate during your lifetime. Advance planning on the other hand is going to focus on things like where you live, how you live. And who are the people who are involved in your life. That's why to get back to that word the process and the discussions that take place in terms of long term care planning in addition to using legal documents is so important.

Moderator: So I noticed that you draw a distinction between advanced directives and advanced planning so can you talk more about really what the difference is. How would you describe advance planning?

Hoffman: I would describe advance planning as that process and it can begin at any time, it

involves conversation, it involves discussion about your life and your values. It involves what expectations you'd like to have in terms of long term care planning. So it's important to talk to a number of people in this process, especially whoever you're identifying to be that surrogate decision maker that we talked about. But the conversation should also include other family members and include things like what you're anticipating, what it's reasonable to anticipate. And what – how you feel about those things. This is a very emotional exercise for people to go through. The institute of medicine defines advance planning as the process of discussing end of life care, a clarification of related values and goals and the embodiment of preferences through written documents and medical orders, those legal forms we mentioned. This process can start at any time and be revisited periodically, but it becomes more focused as our health status changes. Ideally these conversations occur with a person's primary health care agent, the person, the surrogate we talked about.

Moderator: Okay.

Hoffman: And primary clinician along with other members of the clinical team and the family. They're recorded and updated as needed and they allow for flexible decision making in the context of a person's current medical situation.

Moderator: So that's a much more comprehensive kind of picture than just thinking about filling out a document but you're talking about having conversations and involving all of the people, because really, when someone dies or when someone begins to get ill it's not just you and your partner but a whole community of people that are really involved.

Hoffman: Exactly. That's really important.

Moderator: Okay. So beginning a conversation about advance planning is not easy and can be uncomfortable. The Speak Up campaign in Canada offers information about how to start the conversation. Including the following video featuring stories from families and professionals.

Roll in- Mr. James Arnott: I would guess there's a big percentage of people who don't like to talk about it. And there's big percentage of people that it happens suddenly and you don't get a chance to talk about it.

Janie Oosterman: Of course, we're not talking about it.

Dr. Daren Heyland, Critical Care Physician: It's not part of what did you have for supper last night.

Mary Christie: We have to know what to do and what you want done.

Dr. Sue Moffatt Critical Care Physician: We need to talk about this. We should talk about it so that when and if this happens, you get the care that you want.

Mr. James Arnott: The same day I came in they told me I had leukemia. The leukemia is not going away and my wife and I have talked about pretty well everything.

Graham Christie: Well, we did talk when you're in the hospital.

Mary Christie: Oh, yeah.

Graham Christie: You did make the decision and we talked since then and before that.

Mary Christie: What did I decide?

Graham Christie: You decided you didn't want CPR or resuscitation.

Mary Christie: I still think that.

Barbara Harrison, RN: It's very difficult for a family member to make that decision if there's been no discussion. Most of the time we wait too late or often in a critical situation when we're asking those questions.

Janie Oosterman: So we need to talk openly about private things. I think it takes a while to get comfortable, because it is a privacy thing. And it's with your open family, it's not so simple to say what you want or what you don't want.

Dr. Daren Heyland, Critical Care Physician: We're in a situation where we're having to communicate with family members about decisions to either apply or continue or withdraw life sustaining treatment. Frequently, you hear oh, I don't know what mom would have wanted, mom never told me or never talked to me about this. So the family then in that acute moment has to struggle with helping us make decisions with what mom would have wanted. That's so much easier had mom communicated to her family in advance what her wishes or preferences or values would be.

Graham Christie: And 15 years ago people didn't talk about dying. You know?

Mary Christie: They're still going to die.

Graham Christie: Yeah, that's true.

Dr. Sue Moffatt, Critical Care Physician: I do a lot of interacting with families of critically ill patients because most critically ill patients can't communicate themselves or only minimally. By and large, people are very glad their family members are really glad to have this on the table.

Dr. Daren Heyland, Critical Care Physician: The most important person in the community is that person who will represent you in the event that you're unwell and not able to speak. My plan or my wishes would be that I would go this -- or I would not want that.

James Arnott: My wife and I have talked about pretty well everything. She knows what I want.

Graham Christie: What the main decisions are that you have decided what you would like and not what somebody else would like particularly.

Mary Christie: That's right. That's right. As a matter of fact, one thing --

Graham Christie: And not a crisis decision.

Mary Christie: No.

Graham Christie: I'm certainly glad that you and I have had this discussion.

Mary Christie: And then the kids can't say to you what did you do that for?

Graham Christie: Exactly. Exactly.

Mary Christie: Well, I didn't do it on my own. The old girl said that.

Moderator: Really important video. Really powerful message I think, very important for people to be able to hear from the people that are affected by this and hear what a positive impact it has, to be able to talk about these things, versus how hard it can be when we don't have the conversations. So in the video we heard Jamie Oosterman mention that having conversations about this private matter is really a relatively new concept for people and Graham Christie says 15 years ago, nobody talked about dying. I think that's really true. It's a whole new idea that we can talk about these things and it's okay to talk about them. Really we should talk about them. Can you share your thoughts on that?

Hoffman: Sure. First of all, I want to say thanks to the folks at Speak Up who let us use that great video clip this morning. I think what we heard from Janie and Graham and others in this little clip are very telling and informative for us. I'd actually disagree with Graham. I think it's not just 15 years ago, but today, people have a hard time talking about the end of life and talking about death. When we think about the best-selling book "being mortal" that the Dr. Atul Gawande wrote that came out a couple of years ago, he talks in the book about the difficulty of health care professionals talking to one another and patients about death. But he also talks in his book about the difficulty of talking to his family members about their death. And the challenge of doing that. We live in a culture where we don't talk about death. What the folks in Speak Up and others that we'll talk about this morning show us is that when people do take that step, when people have these important conversations what they find is that making decisions on behalf of patients become less burdensome and less stressful. Because the conversations have happened. Because someone's values and thoughts are written down. So it really can make a difference both to the patient whose experiencing medical problems late in life and to their family members, friends and people important in their life. Also to their health care providers.

Moderator: Absolutely. So you have mentioned that the conversations with the surrogate decision maker is a particularly important piece so what role does the surrogate decision maker actually play?

Hoffman: That's a great question. The surrogate decision maker can have a very confusing role.

That's a hard job for someone to take on. It's a big responsibility and it's daunting. We need to help people understand that their job as a surrogate decision maker isn't to make the best decision. Isn't to do what they think is best for the patient. It's to make the decision that the patient would make if they could. So again, the process, those conversations are so important because that's how the surrogate's really going to understand that.

Moderator: That's certainly -- that's a big responsibility to take on, So the better we can prepare somebody for that, certainly the Better and easier the process will go. So I can see that values are Really central to the topic and conversation about advanced planning. Can you talk about those values?

Hoffman: Sure. The conversation is the important part, but what you see on the slide is a definition of values that I frequently use with my students. I tell them that in order for something to really be of value to you, it has to meet three separate criteria. It has to be something that you prize and cherish, that you publicly affirm and that you act on consistently. And I chose those words very carefully. I didn't say it was very important to you. I said it was something that you prize and cherish. It's a step above important. Public affirmation is the way that we who live in community tell the people in our lives what we value. We acknowledge it publicly. Not necessarily in the public square but we talk about it. And that's one of the reasons why these conversations and this process are so important. And acting on things consistently is important too. So reminding folks of what's important to us, what we prize and cherish can be helpful to them later on when they need to make those decisions. What people report who use the process, who are actively engaged with the people they love in their life, and talk about their values is that when they have to make hard decisions in life, they're easier because they already understand what's most important.

Moderator: What a helpful framework. Thank you for sharing that. So have most people started advance planning? We talked about our culture doesn't like to talk about death, doesn't like to talk about getting older. And these are hard conversations. Is this something that most people are doing and why is it so important that we encourage people to do this if they're not?

Hoffman: well, I think it's important for every person as an individual but for us as a society it's important because the demographics that we see on the slide are showing us that we have a growing population of people. The baby boom generation currently 12 million boomers are receiving some type of long term services and supports. AARP and the Kaiser Family Foundation estimate that by 2015 that's going to be 27 million people. That's a lot of people who need to have some of these conversations. We also know that people turning 65 today have a 70% likelihood of needing some kind of long term services and support in their lifetime. And about 10,000 Americans are turning 65 every day and will for the next ten years.

Moderator: Wow.

Hoffman: That's a lot of people and that's a reason as a society we need to focus on this. It's also important because we get reports from the research that people who are arriving at an emergency department at a hospital or people who reside in the nursing home in many instances the studies vary a little bit. But somewhere between 20% and a third of them have some kind of advanced plan. Most people don't. That's a problem.

Moderator: That is definitely a problem. And with the numbers that you presented how many people are turning 65 and the percentage of people that are going to require services, those long term care supports that you mentioned those services are costly. So how are these kinds of things paid for typically?

Hoffman: That's a great question. We don't have a great organization in how we pay for long term services and supports in our society. We have much more organization when we think about how we pay for medical care. But in terms of long term services and supports, as you see from this slide it's expensive and what we see is about a quarter of long term care recipients are paying out of pocket. So 25% of people are put into the position where they're spending down their savings and assets to pay for care that they need. About one-fifth of all nursing home bills are paid out of pocket. So that that's the same thing happening there. Long term care insurance accounts for only a small portion of the expenses that people pay later in life. Plans like the New York State Partnership for Long Term Care which matched private insurance for long term care with Medicaid is one way that people can help plan financially for their future. But the primary payers are public insurance plans. Early on, Medicare pays for some care and lots of long term care is paid for by Medicaid when people spend down their assets to that level.

Moderator: Okay. So what are the benefits to individuals who are starting to? Engage in the advance planning and thinking about what they would like at the end of their life and maybe what kind of supports they would need.

Hoffman: I think it's important for us to recognize that everybody benefits here. So the individual who is the patient in this situation benefits. So do their caregivers and family members and the health care system. There are decreased levels of unwanted medical treatments. Which can be invasive, uncomfortable or painful. People report improvement in their overall quality of life when they have a plan. And there's decreased discomfort and stress, which is so important. Particularly when there's discomfort and stress with what's going on in your body to reduce the discomfort and stress that we feel emotionally or intellectually is a great advantage.

Moderator: Absolutely. And now you mentioned that it doesn't benefit just the individual but that care givers and family members of the patients that we're talking about here also benefit from advanced planning. Can you say more about that?

Hoffman: Sure. Some recent studies looked at that surrogate decision maker we we're talking about a moment ago and the stress associated with being in that position and having to make decisions can actually cause health issues for those people. It's a very stressful situation so symptoms of stress, anxiety and depression are all reduced for surrogate decision makers and other family members when advanced planning is engaged and everyone knows what the expectations are. Clinical trials tell us that family members of deceased patients were more likely to report satisfaction with care for their loved ones if they had engaged in discussions and knew what the patient's expectations were. Since patients express their values during life and long term care planning conversations, the burden of that decision making is already taken care of.

Moderator: Sure.

Hoffman: So family can be focused on respecting the patient's autonomy and making sure the patient is comfortable. Which is really what a family should be focused on at that point, rather than anxiety about what should I do.

Moderator: Absolutely. So from what you have said the cost impact, both the financial cost and the emotional cost sounds tremendous not only on the patient, but also on the individuals, the families that are affected. But also on the health care system itself. So can you talk a bit about that?

Hoffman: Sure. It's important to recognize that most people who do advanced care planning and document it in legal documents do so to limit the amount of care that they would receive.

Moderator: Sure.

Hoffman: When I talk to classes or groups about this issue I'll ask the question, how many of you would choose to spend the last six months of your life in a nursing home connected to machinery and unable to communicate with your family, and no one raises their hand. That's reflected when people talk about their values and use these legal documents. So the cost savings are achieved through decreased wasteful spending due to the current provision of unwanted care. When we delay decision making, too much care occurs.

Moderator: Sure.

Hoffman: Health care costs on average are lower for people with advanced planning and another valuable outcome is reduced provider distress. Providers aren't in a position where they're providing what they view as futile medical care.

Moderator: We recently visited with Regina Betts and her daughter, Thea Griffin. Regina shares her experience with advance planning and how it's impacted her and her husband's life and how it provides a sense of ease for their children.

Roll in- Regina Betts: We moved from New York City and we wanted to raise our own food and we found a little house with some acreage. And we started to raise sheep. We got older, we never thought we would. And I broke my leg, George had some dementia. He had a heart condition. Breaking the leg forced me to make major changes. They had recommended rehab, but then I was thinking about George being home alone and I thought I could manage, you know, with my broken leg. And we got some aides to come in. Every need made us take a different step in planning. And it makes me feel more reassured to be able to plan and to have something in place. The benefit is that, one, I can be a little more secure. The best thing that we've done is financial planning, long term insurance. A good health insurance as well. When we moved to the country one of the first things we did was to buy a freezer so we can freeze the vegetables and things like. That we bought a wood stove and now we bought a generator where – in case the electricity goes out which it happens in the country. My husband has an ankle bracelet in case he would get lost, the sheriff would come and look for him.

Thea: I think you have always been ahead and I have always thought that you have been

planning ahead. And that you have always thought about what's in store. So when you made your will, all those years ago that's when I really first thought about you guys planning ahead and advanced care planning for you and that what your future would look like and that you would be okay in your later years. And then when the second move to an even more rural area on top of a mountain on a dirt road, taking aging and place to a whole other level, you know, I was wondering if you guys were going to be okay up here because it was so remote. So because transportation isn't readily available and you live in such a remote area, and to – and food, the nearest big grocery store is ten miles away. The doctor is ten miles away. So the services aren't so readily available. Your children were very concerned so we wanted you closer to us or at least closer to services and support. So when you said no, we're staying here, we were very concerned. But you made it work. And we had to let go of it wasn't going to be our way and you're doing it and it's great and I think that you're fortunate that it is happening and the aides and the nurse are able to come. You have your friends and your family.

Thea: So I appreciate now how much you really looked ahead and planned ahead and that created a lot of security for us. I learned a lot from you and that having long term care insurance, and that now where Dad had long term care needs where you have a nurse and an aide that comes and that the way that you are able to stay at home is by having long term care insurance. So plan ahead, plan early and plan soon and keep the conversations going. Keep talking to us.

Moderator: So it was a really lovely piece that I think provided a lot of information about planning ahead and what sorts of things might happen along the way.

Hoffman: I just want to thank Regina and Thea and their family for sharing that time and this information with us. I agree. I think they give us some terrific examples in that beautiful setting. But the reminders that we hear from them that where you want to live, how you want to live, how you're going to pay for how you want to live, all of these things we should start talking about much earlier than we typically do in our culture. And hopefully today is an opportunity for people to start thinking about that.

Moderator: So since you clearly understand the benefits we're helping our audience understand the benefits. How do we make this happen? Can you discuss what are some best practices for recommendations to get people to start having these conversations?

Hoffman: Sure. Historically, we have focused on what's called a legal transactional approach or on the documents. What we're seeing in the field today is a movement toward more of a communications approach. A focus on values and the conversations and moving in that direction. And there are ways that folks can do that. When we only focus on the legal documents sometimes we get stuck in that. The forms don't give us a lot of guidance. Goals and preferences of people can change over time based on their life circumstances, their finances, and the people who are available in their lives. Even who their surrogate is might change. Providers need to be aware too, so in terms of best practices including your health care provider in the conversation and including other important people in your life. If you have a financial planner, including the financial planner. If you have an attorney, include the attorney or making sure they know there is an advanced directive, we have had these conversations. It can really help alleviate stress later

on.

Moderator: So is there a specific place that the discussion should really begin and who can engage in these discussions? You mentioned the physician as well, but are there other people who should be part of this conversation in addition to, you know, the family members?

Hoffman: I think it's important to recognize that lots of people can be helpful in this process. And sometimes they are. So sometimes that's the primary care provider or a specialty provider. Sometimes it's a trained nonphysician facilitator. Someone who works in the health care setting. Maybe a social worker, a nurse, a discharge planner. Family and friends can be helpful. And the last group, the family and friends are the people who are often those leaned on to be a surrogate decision maker so it's important to ensure they're included in the conversation. Health care professionals need to have both the skill to have the conversation and be open to talking about it. Sometimes we hear from health care providers that they're really busy, they don't have time to have these conversations. Often just opening the door for the conversation to happen in a health care provider setting will leave the door open for that conversation to continue with family members and others afterwards. Appropriate providers are needed in this conversation so we have realistic expectations of what clinical implications are for the health conditions that we have. So that's a group that we need to include at least in parts of these conversations. And often they can be the people who lead them.

Moderator: Excellent. So what do you recommend as the best time to begin planning, either for oneself or for family members?

Hoffman: The experts say it's never too early. And I think that that's true. The conversation can really occur at any stage of life. It's a fluid process as we have talked about this morning. And it can continuously be updated as the wants and needs and priorities of the individual change over time. Some people recommend that the process begin around important life events. Maybe getting your driver's license, contemplating a serious relationship. Starting parenthood. Or making a big life change like moving to a new location. That can be an opportunity and trigger for the conversation to take place.

Moderator: okay. So what are some of the current barriers that are really? Hindering people from having these conversations and starting to really talk about advanced planning?

Hoffman: So some of the barriers and I mentioned a couple that the lack of time that health care providers have certainly, but also a lack of communication skills. As the doctor says in his book that I mentioned earlier, health care providers aren't necessarily trained to have these really hard conversations that are uncomfortable for patients and for the providers. There's a discomfort in dealing with patient emotions about these things. And those emotions run the gamut of emotions. Some people are happy to have the conversation, some people, you know, want to have a two-word conversation around call it a day because that's the way that our culture operates. Providers have a fear of eroding hope. Especially with someone with a terminal diagnosis they don't want to take someone's hope away and there's a fear of legal liability too. That the fear of liability really expresses a lack of understanding of what the rules are. So programs like this can help people understand and the resources that we're going to have online after the program can help people understand the rules and that hopefully will help address some of these obstacles.

Moderator: Thank you. Now, what are examples of some of the current initiatives that are currently in place that are designed to advance or encourage advance planning?

Hoffman: On the next slide we see the logos of some groups that I want to highlight this morning. The conversation project is a group that encourages providing cues to overcome cultural avoidance in the conversation of talking about death. It requires multiple conversations, not a single event. Some of those cultural avoidances are things like gender identity in our culture where, you know, men are supposed to be stoic and tough sometimes and so that gender may avoid the conversation. But there are lots of cultural obstacles to having these conversations which the conversation project really helps us understand and find ways around. Prepare for your care is another website I encourage people to meet. Prepare for your care actually is rolling out state by state specific tools and instructions and we'll be providing a link to the New York page on prepare for your care. There are guides and toolkits for discussing medical decision making with a loved one. With a focus on health literacy. Helping people understand what that decision really means, which is so important. Respecting choices is a project of a particular health system, the Gunderson health system. What they found is that by focusing as a health system on the need for advanced planning, in a recent – ten years after they started the project in a recent review, 96% of the decedents had an advanced directive. That's unheard of. The rest of the literature on this topic talks about as I said 20% to a third. So this was a tremendous success, but also in looking at their system what they found is Medicare expenditures for people who had an advanced care plan were in the range of about \$48,000 during the last two years of life versus a national average of around \$80,000.

Moderator: Wow.

Hoffman: So again, back to the system benefits of this happening, it's there.

Moderator: Excellent. I noticed some of the initiatives are on starting conversations. I talk to people for a living about public health topics but are there other ways to encourage providers to start getting their patients to participate in advanced planning?

Hoffman: So we have some good news on this topic. Right now there are two CPT Codes available for Medicare providers to use the first is a code that began in 2016, so as I said this is relatively new. It reimburses for advanced planning, so it's a code that reimburses the provider who's having a face-to-face conversation, who's starting this conversation. It's designed to help take down that barrier of time by providing specific reimbursement to the provider for having this important conversation and starting it. And the second code reflects additional 30-minute face-to-face meetings that can take place with the patient, the patient's family and/or the surrogate. So those conversations are valued by the federal government now through Medicare, our insurance program for seniors and there's a way to try to address that time obstacle that we talked about a minute ago.

Moderator: That's excellent news. Now, along with these incentives I imagine that health care providers also really have to consider the ethics that surround treatment and quality of life particularly towards the end of life. So can you talk about some of the ethical considerations?

Hoffman: Sure. I'd like to focus on just the four basic principles of ethics that we talk about frequently, autonomy, which is the respect for the person and the respect for each of us as individuals to make our own health care decisions. And really advance planning is respect for autonomy. There's a nice match there. When we talk about justice and fairness in this system, it reflects back on autonomy. We want to be fair to people but we also want to be fair to systems. We don't want to see systems provide a lot of futile care simply because people didn't make decisions in advance. And that reflects the last two principles that I just want to mention quickly. Beneficence or the principle that calls on health care providers to do good in the work they do with their patients, and certainly engaging in this conversation is a way to exercise the principle of beneficence and do good. And then the principle that we often hear about associated with medicine, do no harm or non-maleficence. It's important to recognize that not paying attention to a patient's autonomy, not engaging in that conversation can actually cause harm, both to the patient and their family.

Moderator: Absolutely. Thank you. Now, can you start to share with us a few specific resources that you would recommend as we're closing out the show and thinking about what can we provide our viewers with as a takeaway?

Hoffman: I mentioned a couple of resources a moment ago. In addition to the slide you see right now has the national institute on aging which is currently funding research to develop advanced planning programs and training initiatives. Both AARP and the New York State Department of Health have online resources that include both the legal forms that we're talking about. And some links to cues for conversations and encouraging people to have those conversations. And the other resources I mentioned earlier, things like the conversation project and prepare for your care and five wishes, all provide concrete tools that are easy to use, very user friendly, and resources for both patients and professionals.

Moderator: Thank you. Now, did you have any final thoughts regarding advanced planning that you'd like to share with our viewers?

Hoffman: Just to recap, Rachel, advanced planning is a process. It's not an event. And it's not a document. The events and the documents are part of the process but not the whole process. So we need to move beyond the discussion of just legal documents or just end of life planning. And start planning for quality of life. I'm encouraging people today for themselves and their family members to begin this discussion to talk about their values. Using that three-part definition that you and I talked about a few minutes ago, thinking about long term care. If they need long term care, how would they like to access that long term care? And where, where would they like to live? And how do they plan to finance that action later in their life? Make sure that their loved ones understand their values for life planning. This alleviates a potential burden both for the patient and the family members as I have said. And to the viewers that are in a position to engage patients in these discussions providers and others, start with yourselves. And your family. Have the conversation. You'll be more comfortable talking to your patients about it when you have had the conversation yourself. And lastly, and maybe most importantly let's not forget Nancy Cruzan.

Moderator: Yes, can you remind us what does her legacy really show us and contribute to this conversation?

Hoffman: Well, let's remember that her accident led to a coma. Which eliminated Nancy's option to have those conversations. Right? So what we can learn from Nancy Cruzan is take advantage of the opportunities that life presents us. Just recently, I myself have seen this topic come up in an episode of "grey's anatomy" and an episode of "Chicago Med." Those are opportunities to have the conversation or at least begin the conversation. This is a theme that appears on television, in movies, in news stories, on a regular basis. Every one of those is a chance to start the conversation.

Moderator: Excellent. Thank you so much. Let's take a few questions that we have got in from our audience in the time we have remaining. The first question that we have says how do you talk about or learn what someone's values are so they can be considered when doing advanced planning?

Hoffman: I encourage people to ask the question directly. What's really important to you? And then spend some time and think about it. And revisit it. I have given students this assignment and said, spend 30 minutes in the next week and write down the five things that meet those three criteria of a value in your life. And then talk to someone about it. I tell them you're not going to hand it in. I don't need to know what your values are. But spend the time because it's a worthwhile exercise. And the evidence shows that people who do that, people who spend some time converse about what's really important, when life presents them with difficult decisions and we're all faced with difficult decisions at some point, those decisions are easier. Because we have already determined what's really important.

Moderator: Excellent. The next question that we have, what can be included in planning conversations in addition to medical decisions?

Hoffman: That's a great question. So thank you. I encourage people to think about some of the things that we have mentioned this morning. Where would you like to live? How would you like to live? Do you want to have the responsibility for a house? Do you want less responsibility? Are you happy in the climate in upstate New York or would you prefer some place warmer? How do you plan to pay for those things? Who will be involved in your life? You know, where are your family members you want to have relationships with? Where are your close friends who you want in your life? And what role can they play as your life progresses? So all of these other factors are very important for us to consider and again it's the conversation that matters. Because we might have that idea in our head of where we'd like to be and how we'd like life to be, but if we're not communicating that there's no guarantee we're ever going to get there.

Moderator: Excellent. Thank you. All right. The next question we have - this is a great question. Where should I keep my planning information and to whom should I give copies of the documents or as a provider what do I tell clients and their families about this?

Hoffman: So that's an excellent question. Many of these decisions relate to health care. So people should make sure that an advanced directive, the legal documents, the identification of the health care proxy, et cetera, are a part of their medical record. So your primary care provider should have it. And share it with the system that they work in.

Moderator: Okay.

Hoffman: So if you're a regular attendee at an emergency room you should have a copy and make sure others have a copy. Family members, your surrogate decision maker should have copies so that if you're traveling and go to a hospital that doesn't have your medical record, they can give them a copy and it can be added to your medical record. And in those ways, it can be simplified over time. Some of those other professionals I mentioned can also be very helpful in the development of advanced planning. And should also receive a copy like if you have an attorney. Make sure your attorney has a copy. If you have a financial planner, share the financial information about your plan with them.

Moderator: Excellent. I think those are such great questions because a lot of these are things that we think about, but don't ever quite know how to close the loop. So I think we have time to quickly answer perhaps one more question. Can someone revoke or change their planning at any time and if so, how can they do that?

Hoffman: Rachel, that's excellent. Absolutely. As long as the person has decision making capacity, they can change anything about their plan. This goes back to that principle of autonomy where we respect you and your ability to make decisions about your life, your body and what happens to you in the health care system.

Moderator: Excellent. Thank you so much for answering the questions and thank you for all of the information that you have shared today. I think this is a really helpful way to start as – to start the process and really give people some cues and clues and tips for how to start that conversation. So thank you.

Hoffman: Thank you, Rachel. It's great to have chance to share this important information.

Moderator: And thank you very much for joining us today. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available for today's program. To obtain nurse continuing education hours, CME, CHES or social work work credits learners must visit, www.phlive.org and complete the evaluation and the post test for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Please join us for our next webcast on March 15th, focused on Health Literacy. Additional information on upcoming webcasts and relevant public topics can be found on our Facebook page. Don't forget to like us on Facebook to stay up to date. And now, you can also let us know how you use *Public Health Live!* by taking a brief survey at www.phlive.org. I'm Rachel Breidster. Thank you for joining us on *Public Health Live!*