**Moderator Rachel Breidster:** Hello and welcome to Public Health Live!, the Thursday breakfast broadcast. I am Rachel Breidster, and I’ll be your moderator today. Before we get started I ask that you please fill out your online evaluations at the close of today’s webcast. I also want to let you know that the planners and presenters of Public Health Live! do not have any financial arrangements or affiliations with commercial entities whose products and services may be discussed in this activity; and no commercial funding has been accepted in this activity. As for today’s program, we will be taking your questions throughout the hour via phone at 1-800-452-0662, or via email at phlive.ny@gmail.com. Today’s program is Alzheimer’s Disease and Advance Directives: A Primer for Primary Care Physicians. Our guests are Wayne Shelton, a professor of medicine and bioethics at the Alden March Bioethics Institute at Albany Medical College, and Kevin Costello, an assistant professor of medicine and attending physician at the Department of Medicine at the Albany Medical College. Thank you very much for joining us. We’re excited to have you guys here. So to start the conversation, Dr. Costello, I’m going to start with you and ask why is it so important that we begin to educate primary care physicians about Alzheimer’s disease and advanced directives?

**Dr. Kevin Costello, MD:** It is on the front lines of elder care and they are in a good position to recognize the early signs of dementia. And this gives them a window of opportunity to engage patients while we still have the capacity to make their own decisions and to participate in the advanced care planning.

**MRB:** And so, before we delve more into these issues and go in-depth, what do we need to know about Alzheimer’s disease just for the purpose of having this discussion today?

**KC:** Alzheimer’s disease is a nerve degenerative disease—that is currently untreatable. It accounts for 60% to 80% of dementia cases in our country and it’s a terminal disease that eventually results in the loss of capacity. It is often associated with co-morbid conditions that occur as people age, and the average median survival from the time of diagnosis is about three to nine years. It progresses differently in different patients depending on inter-current events that happens such as stroke and other events. The incidence and prevalence increases with age.

**MRB:** So are there any warning signs that someone is developing Alzheimer’s before they actually have dementia?

**KC:** We’ve come to recognize a phenomena called mild cognitive impairment, or MCI, and this is defined as a measurable change in at least one cognitive sphere that doesn't interfere with occupational and social functioning. There are different types depending on the domains that are most effective. The prevalence is 20% in those over 65, and of those, 10% to 20% a year progressed to clinically overt Alzheimer’s disease. Not all patients with mci go on to develop dementia, though.
MRB: Okay. Why is Alzheimer’s disease something that primary care physicians other providers really need to think about.

KC: Well the prevalence of Alzheimer’s disease increases with age, and average life expectancy has been increasing over the years, and because it's chronic disease, the number of people living with the disease increases dramatically as a result.

MRB: Now, when you say the length of years that we're alive and increasing, and so the number of people is increasing, what are the implications of that for our health care system.

KC: Well, the entry of the baby boom generation into the ranks of the elderly will produce a surge in the population of those susceptible to the disease, and the personal care needs that it brings with it. Fewer than 8% of Americans carry long-term care insurance right now, and almost a quarter of the expense for institutional care and in-home care is born out of pocket by the patients and their families. Providing care to these patients will strain our resources and drive up the cost of Medicaid and it will have a dramatic impact on the health care system overall.

MRB: So, certainly something we need to be considering. Now how does Alzheimer’s compare to other conditions that significantly impact our population in the United States.

KC: The centers for disease control estimates that Alzheimer’s disease is the sixth leading cause of death based on data in 2010—in which they accounted over 83,000 deaths in our country. However, more recent studies indicate that as an actual cause of death, Alzheimer’s disease actually ranks number three in our country, accounting for over half a million cases every year.

MRB: Those are pretty startling numbers. when we look at those numbers, the 83,000—or whichever set we’re looking at—and we look at the population that’s affected, is there any difference between, for example, men and women or all segments of the population are equally at risk?

KC: Women are impacted disproportionately by Alzheimer’s disease via two avenues and both as patients and as caregivers. 1 in 6 women will develop Alzheimer’s disease in a life time compared to 1 in 11 men. 2/3s of patients living with the disease are women. Consistent with the pattern of family care giving in general, the burden of caring directly with people of Alzheimer’s disease is borne disproportionately by women at a ratio of 2.5 to 1.

MRB: Not only is it impacting the general population, but it does seem to be disproportionately affecting women.

KC: Yes.

MRB: Now how does the Alzheimer’s disease affect the actual patient and their quality of life?
**KC:** Well, in many ways. Depression is a prevalent problem early in Alzheimer’s disease affecting up to 40% of patients within the first three years of diagnosis. It's important to recognize it and to treat it as a symptom. The eventual loss of capacity is inevitable, and the decline in current self-awareness—often tending to live in the past. A lot of patients would mistake their daughter who is caring for them as their mother, for example. Eventually they live in a reality of discreet moments where they can't remember from one moment to the next what's going on, and advanced stages of disease the patients acquire full-time care in order to meet all their basic needs and to be kept safe.

**MRB:** And so given the severity of how the disease progresses and how it's going to impact the patient’s ability. How does that translate to affecting the people who are caring for the population with Alzheimer’s?

**KC:** The impact on caregivers is tremendous. It's a family challenge that affects not only a patient, but the caregivers who suffer together. 70% of people with dementia are cared for at home by caregivers rather than an institutional setting. There are tremendous indirect costs including the value of the caregivers' time, loss of income and out of pocket-expenses, and opportunity costs. The direct costs include the fact that about half of the caregivers have to decrease their work hours on their regular jobs and almost 20% of them have to give up employment altogether. In 2013, 17.7 billion hours of unpaid work were provided by unpaid caregivers and an estimated value in the current market of $220 billion a year. The average duration of care giving is about five years for patients with dementia, averaging 70 hours a week for care so more than a full-time job. It has impacts on the physical state, the social estate and the psychological state of the caregiver. At the physical level almost half have more visits to doctors, yet at the same time they tend to forego the routine preventive health care—with mammograms and colonoscopies and the like—and they tend to have more prescribed medication, higher blood pressure and poor cell immunity, poorer self-rated health, and especially among spousal caregivers, increased mortality. Socially, there's often an experience of loneliness and isolation. They often are overwhelmed by circumstances that they see as beyond their control. Feelings of being cheated, feelings of anger and frustration, marital difficulties and in cases where caregivers and the patient are isolated, elder abuse is at risk to occur. Psychologically, they suffer from high incidents of depression and anxiety and psychotropic drug use. The prevalence of depressive disorder in caregiver’s ranges from 15 to 32% and one in three caregivers suffer from some form of anxiety disorder.

**MRB:** One of the things that strikes me from everything that you just shared when we think of Alzheimer’s, we all can think of someone we know who has suffered from the disease and how devastating that's been, but then we present this big picture, it really goes so far beyond just the individual and the impact on that person's life, but all of these other health costs and financial costs, and it's a really complex issue that we're talking about today.

**KC:** Yes.

**MRB:** It would seem that having a conversation with an Alzheimer’s patient and with their
families about the diagnosis would be a difficult and complicated thing to engage in, so what would be some of the topics that you would want to include in a discussion with a patient and their family?

**KC:** It is a difficult discussion to have. Disclosing the diagnosis in the first place is complicated especially when you have a patient-caregiver dyad that you're working with, but frank disclosure is essential to the discussion of advanced directives, and provision of guidance in establishing and documenting them. So you really have to open the door by being frank about the diagnosis right up front. You need to assess the decision making capacity of the patient—and that's a key task to assure that you both respect the autonomy and recognize when there is a need for the proxy to be involved. Another key task is to assess and reconcile the immediate and long-term needs, values and expectations of both the patient and the caregiver. Making a disclosure acquires sensitivity and providers often fear that the reactions of the patient or the caregiver may be catastrophic—or they may fear doing harm by causing loss of hope. Systematic review of the research and disclosure of the diagnosis of dementia published in 2013 revealed that patients and caregivers favor full disclosure and many expressed relief at being told and in turn they were anxious for more information and guidance.

**MRB:** I think that makes sense and it's always hard to give somebody bad news, especially if there are no solutions and on the receiving end, you want all of the information available to you. Saying that you promote this frank disclosure and you think that is a critical component, from one of the things we hear is how busy physicians are, so I imagine having these kinds of conversations—one of the barriers would be they have a lot going on and they have a lot on their schedule so talk about some of the barriers that might be impeding these discussions from taking place.

**KC:** There certainly are barriers and as you alluded to, time is one of the biggest of all. Especially in the busy office practice when you have a set amount of time and a full schedule. The time constraint could be a barrier to even thinking about opening up the discussion. There is often confusion about the forms that are used for advanced directives and also concerns about reimbursement. There is a lack of comfort in some providers in initiating the discussion and there's the need for better and clearer resources for patients and caregivers. Patient hearing loss is a practical barrier that often makes such a delicate discussion more of a challenge.

**MRB:** So I guess the question I have, then, is from your experience and what you know, do these conversations often happen as they should?

**KC:** No, they don't. They often get put off until a time when we've lost that window of opportunity to have that discussion while the patient still has capacity.

**MRB:** So let's talk about what should happen when a patient comes into the office of their primary care physician's office and there is a possible diagnosis of Alzheimer’s in an ideal world and talk about what should be happening. What would you say is the first step?
KC: Well, you need to present the patient with the information that you have at hand that led you to the conclusion that they have cognitive difficulties, and then to move from there into what that means and what the ramifications of that will be in the future.

MRB: Can you elaborate, Dr. Shelton—this is more of your area—talk a little more from your perspective.

Dr. Wayne Shelton, PhD: Sure. I’ll just backtrack just a little bit. There is plenty of evidence that physicians just don’t engage in the live care discussions in a systematic way across the healthcare system. There is a great deal of variability among physicians and how they do it and sometimes they just don’t occur. We’ve gone over some of the barriers, but physicians also report sometimes not having the confidence—the skills and knowledge—to have the conversations. And of course, we’ve covered the amount of time it takes, reimbursements have been very poor and inadequate, and hopefully that will change which could improve matters a whole lot. But my sense is we have to get beyond these barriers and recognize the importance of having these discussions. And they need to occur as soon as the diagnosis of Alzheimer’s is made, and that needs to be the standard of care which we’re encouraging physicians to adopt today. But just to follow up on your question about what should happen. When there are clear clinical indications for diagnosis of Alzheimer’s disease, if when the patient is able to participate in the conversation and to express views about treatment preferences and understand what’s going on. The physician [sic] has an ethical and professional obligation to speak directly to the patient. Many of these conversations will occur with the family members present, they are usually the health care agent or proxy, and they need to understand this information, as well. The point you want to make now is when the patient is able to communicate and has capacity, the physician should speak directly to the patient and displace the diagnosis—which should include a clear description of the natural course of Alzheimer’s as a terminal illness. As a practical matter, patients need to understand the future effects of this disease so they can begin to prepare and plan for circumstances that will almost certainly arise.

MRB: Sure, and I would imagine that would be a challenge speaking directly to the person and the tendency that you want to involve the other party and if you’re not sure if someone understands, I can see how that would be a challenge for physicians. But one of the things you mentioned, that I want to talk a little bit about, is if the patient has capacity to make sure we’re speaking directly with the patient. How would you assess capacity? How is that defined, and as a physician, how do you know if the patient has capacity?

WS: Well, just to be clear I am not a physician, but I teach in a medical school, and I’m a bioethicist, I’m a clinical ethics consultant, but I know a fair amount about this because I’ve worked around the health care setting. There is a window of opportunity and that’s precisely what the physician should be looking for. If a person has capacity it just means that he or she is capable of making his or her healthcare decisions about both present and future medical treatments and interventions. And a key part is to determine the capacity, primary care physician doesn’t need to refer the patient to a psychologist or neurologist. The primary care physician can do this himself or herself. That means it’s really important to understand the
conceptual elements of capacity—and I want to go over them clearly: (1) A patient with capacity is able to understand the treatment and care plan options; (2) appreciate how the information applies to his or her own situation; (3) reason with the information in ways that are consistent with the patient's own values and preferences; (4) and finally to communicate or express his or her choices clearly. All of these could be determined in the conversation in a short period of time just by talking about the patient's medical condition and the treatment options being considered. If the patient is able to follow, participate, understands the consequences and can express his or her own values and preferences, chances are an Alzheimer’s patient has capacity and should be treated like any other patient with capacity.

**MRB:** Ok, so once a physician determines that and is able to, from a pretty short conversation, can determine that this patient does have capacity, what are the implications then in terms of understanding the responsibility of the primary care physician—their obligations to the patient?

**WS:** The most important application is this: a patient with capacity must be viewed as an autonomous, moral agent. Which means they have the moral and legal right to be self-governing and to make their own decisions according to the life plans and values. Of course, patients with capacity may elect to have any and all appropriate medical treatments that will provide benefits. We certainly want to make that point clear, but we also want to make it equally clear that when it comes to aggressive, life-prolonging treatment that may cause unwanted burdens, patients with decisional capacity have the fundamental right to refuse them.

**MRB:** Now, what do these patients' rights mean for the relationship between the physician and the patient?

**WS:** When physicians are caring for patients with capacity, the physician-patient relationship has to be predicated on the first principle of medical ethics which is respect for patient autonomy—this just means that the goals of care should be patient-centered. Physicians in this situation should engage the patient and in a discussion about what his or her goals are. This is showing respect for the patient's right to self-determination by allowing the patient to express preferences for medical treatment in the event that capacity is lost.

**MRB:** Ok, so now it sounds like the professional obligation around his relationship and respecting the patient's autonomy is fairly codified. 
Are there any actual laws or statutes that spell this out?

**WS:** Yes, you're right. This obligation to respect patient autonomy is in fact well codified within the American health care system both ethically and legally. It's a well-established right of all adult patients with capacity to be self-governing and to make decisions not only about the ongoing present healthcare decisions, but future decisions that may arise that you could anticipate to some degree of likelihood in the event that capacity is lost. This act is grounded legally in the Patient’s Self-Determination Act of 1991 (PDSA) which is a law that affirms that all
patients must be given the opportunity to express their wishes in advance about future medical treatments and event capacity is lost. So it's very important that physicians and all health care providers understand how to use advanced directives as a way to promote a patient's self-determination. This is particularly true for patients with early Alzheimer's.

**MRB:** Thank you so much. Now to put all of this in perspective, we thought it would be useful to see an example of how a physician might engage a newly diagnosed patient about advanced directives as a way to promote patient's self-determination. Let's take a look at our first simulated case produced with the assistance of the Patient Safety and Clinical Competency Center at Albany Medical College.

>>CLIP BEGINS<<

**John Crane:** Well, tell me doc, am I going to make it?

**Doctor:** Mr. Crane, you know I don't give guarantee, but I'm hopeful.

**JC:** It's like I always say, “I'll live till I die.”

**D:** Very funny! Glad to see you still have a sense of humor after everything you've been through this year. But seriously, John, I have new concerns I'd like to discuss with you today.

**JC:** Oh, boy, let me guess, have you're spies reported on me yet again?

**D:** I prefer to think of him as my foreman or the people that really care about you.

**JC:** Well, I know they're just really good kids, they just worry too much. What's the report this time?

**D:** They told me about your telephone being shut off....

**JC:** Oh, for Pete's sake, that's nothing to worry about! Clara always handled the bills, and I just haven't gotten into the habit yet. Anyway, that's all taken care of cause Mike's going to come over once a week and we'll do together. Not that I think I needed help, but I always enjoy his visits.

**D:** Sounds like you value your independence. Can you tell me more about how you feel about that?

**JC:** Well, you know, doc, I have a responsibility with the insurance company, and I felt that I can take care of it myself without somebody looking over my shoulder.

**D:** John, you and Clara were married a very long time, and these adjustments must be difficult for you. Spouses take care of each other in ways we don't recognize until one of the pieces are
missing.

JC: I’m lost without Clara, doctor, literally! She was the navigator, and the development has changed so much in the last few years that last week, I got lost driving home, and I made a few wrong turns, and I got back okay, but it was pretty upsetting.

D: John, I’m concerned there's more going on here than can be accounted for than by you losing Clara. You’re not depressed, and that’s good…On the other hand, you and I have known each other a long time, and I have to be completely honest with you…Remember the memory test you took earlier—the one you’ve always done fine on? It didn't go so well today. That coupled with the fact that you’re forgetting to pay your bills and getting lost leads me to believe there's something going on with your memory and other brain functions that are interfering with your daily activities. In my best judgment, what we're dealing with here are the early signs of dementia.

JC: Boy, you don’t pull any punches!

D: John, I have a great deal of respect for you, and I would be doing you a disservice.

JC: I know that, doc, and Clara and I always appreciated that. To be honest I thought something like this was coming. It’s pretty scary. I’m afraid of losing my independence.

D: John, you know the kids and I will do anything we can to preserve your independence. One of the most important things we can do is to make sure we understand your wishes regarding the medical treatments you do and don’t want.

JC: That sounds good. How do we do that?

D: Do you remember that conversation you had with Clara when she was in the hospital about advanced care directive?…That same that you and I had for the past five years at your annual physical?

JC: Oh, yeah, that talk! Reminds me of my working days when I was trying to sell life insurance—never easy to have a nice little chat about death.

D: That’s your sense of humor about you, John, some things about you will never change…but seriously, I want you to give thought into what you do and don’t want while you can still make your own health care decisions.

JC: I’ll tell you from the start, I don’t want there to be any heroics! But if I can’t even remember to pay my own phone bill on time, how can you be sure that I can still make decisions about what I want?

D: Well, John, even patients with moderate dementia don't necessarily lack the capacity to
make their own health care decisions. Tell me what you mean when you say “heroics.”

**JC:** You know, doc, pounding on my chest, sticking a tube down my throat, blowing air into my lungs—IVs everywhere. If that’s what it takes to keep me around, I’d just as soon be with Clara...don’t want to leave any doubt about what I want.

**D:** It sounds like you’ve already given a lot of thought to this.

**JC:** Yes, I have.

**D:** Okay, john, let’s make sure we take care of your wishes. Let's fill out this form today.

>>CLIP ENDS<<

**MRB:** So I think that was really helpful to see a visual representation of how a conversation like this could actually take place, especially given that I think we all acknowledge that it would be a challenging conversation to have. So, Dr. Shelton, in looking at that can you highlight some of the key points of that that you think are important about what took place in that scenario.

**WS:** First, the physician in this case initiated the discussion and took advantage of the window of opportunity. Once the conversation was up and running the physician could sense the patient’s ability to follow what was being said. So it was evident the patient was able to understand the information the physician was conveying and the patient was able to reason and apply the information to his own situation, and was able and willing to make a decision about his future wishes for medical care. During the conversation, the patient’s goals were explored and clarified, which would become the basis for understanding how to respect patient autonomy in this case. And most importantly, at the end, when the patient expressed his wishes the physician documented them at once so they would be on file.

**MRB:** When you talk about what was happening in that video and what should be happening in doctor’s offices, there are terms such as “advanced care planning” and “advanced directives”. Can you talk a little bit about what’s the difference between one and the other?

**WS:** Sure. In general, advanced care planning is a broader umbrella concept. It includes a range of concerns about how a patient plans to manage his or her affairs in the future when capacity is lost. This includes such things as wills, financial planning, and appointing power of attorney to finances and pay bills, and deciding where one is going to receive medical care such as at home or the nursing home. Usually the key reason a person does this type of planning is to lessen the burdens on his family and loved ones. But there’s also an element of self-interest, as well. A person is trying to promote their quality of life and to avoid prolonged suffering. In general, if patients are able to express their wishes in advance, then in general it is more likely that they will be followed after they lose capacity. This is where advanced directives become very important because they pertain only to advanced wishes about future medical care.
MRB: So can you give me some examples of what a type of advanced directive might look like?

WS: Sure. First, and the most important topic of advanced directive is the durable power of attorney for healthcare sometimes simply called the healthcare proxy. It's a legal document. It's a document in which the patient is able to appoint an agent who is the spokesperson for that patient in the event they lose capacity. We hear the word ‘surrogate’ and ‘proxy’ also applied—those are the informal terms—they’re fine to use, but officially it's called an agent. This person has a legal and ethical responsibility to follow the patient's wishes as best they can. The next thing is a living will. This is just a written statement that records the patient's wishes about future medical treatment. Strictly speaking this may not be a legal document but it is a clear record—often referred to as clear and convincing evidence of what the patient's advanced wishes are—and they can be very important. Usually, there is a place for organ donation also in case people want to be organ donors. And finally, we often refer to ‘oral advance directives', or verbal statements, that the patient might make just casually at the doctor's office, or at the hospital. And these can be very important also if not other evidence is available, but they have to be recorded in the patient’s chart so it’s important they're documented. But I want to also mention a type of advanced directive also called advanced medical orders for life-sustaining treatment. These are really advanced medical orders and have are made in consultation with the physician. Elderly patients with Alzheimer's—and also any kind of disease where a person is elderly, and very sick and it could be someone who is even younger—may reach a point where they, or their agent, or their surrogate decides with their physician that there are going to be limitations in providing some or all life-sustaining treatment such as foregoing entirely, or limiting the use of: antibiotics, future hospitalizations and transfers from nursing facilities and cardiopulmonary resuscitation, and [sic] artificially administered fluids and nutrition. In the state of New York these medical orders have to be recorded in what's called a MOLST form. It's called Medical Orders For Life-Sustaining Treatment. Physicians need to be familiar with the forms that they use in their own particular state, and they do vary from state to state somewhat, but these advanced medical orders can be very important for frail Alzheimer's patients so doctors need to make these forms available and know how to use them.

MRB: Absolutely. Since today we want to talk a lot about these advanced directives, can you talk about why it's so important for primary care physicians to have that conversation with Alzheimer’s patients about the advanced directive?

WS: True. When the patients without advanced directives have acute medical problems and go to the hospital, they go to the hospital emergency room usually, and there the default option is to treat aggressively. This is as it should be for most patients. The Alzheimer's patient without an advanced directive is at risk of not having their wishes followed because they are simply not known. So it's very possible that a patient without an advanced directive might receive unwanted, aggressive medical treatments that may have unnecessary suffering at a time when a patient is very vulnerable. We know that patients without advanced directives have increased rates of hospitalization, feeding tubes, and resuscitations. On the other hand, studies show that
patients with advanced directives are more likely to receive comfort or palliative care instead of aggressive life-extending treatment. So advanced directives may help ensure the patient will have his or her wishes followed in the future that reflect his or her true wishes. This allows the patient and family member to have lower levels of anxiety, fear and distress about the future.

**MRB:** So it’s very important for patients with Alzheimer’s and advanced dementia to be thinking about advanced directives. Let’s get into some specifics. Can you talk about what are some of the key questions that physicians need to ask, both the patient and maybe even family members to think about when doing this kind of planning?

**WS:** Well there are a number of specific questions about future medical treatments that should be considered so patients-center medical goals can be established. For example, if the patient experiences respiratory failure, or has a heart attack, or goes into renal failure, would the patient want to be resuscitated, or possibly have an implantable cardio defibrillator? Does the patient want to be on a mechanical breathing machine or ventilator and be taken to the ICU? Would the patient want to be on dialysis? What if there are future situations in which there are questions about whether or not to insert an artificial feeding tube—or g-tube as it’s called—that arises because of swallowing difficulties and declining nutritional status or a waning interest in eating. What if the patient develops pneumonia? Would the patient want antibiotics? In general, the most basic question is this: does the patient want aggressive, life-prolonging treatment that prolongs life, but prolongs the dying process; or on the other hand, maximum palliative and comfort measures and the less emphasis on prolonging life once capacity is lost. These are conversations about how to define goals of care at the end of life, and how to balance quantity of life with quality of life. They're profoundly value laden questions for each to decide. For some Alzheimer’s patients with co-morbid conditions, these questions are even more urgent since having an acute medical problem could arise at any time.

**MRB:** Certainly sounds like very challenging conversations to have on a number of levels. But considering that many patients, either now or in the future, are likely to suffer from other conditions in addition to their dementia, it makes this conversation about the advanced planning and getting all of these details laid out right now a little bit more urgent to establish the patient's goals. Can you talk a little bit about that?

**WS:** Sure, you're exactly right. Some patients with Alzheimer’s disease or dementia may have other chronic and life-threatening medical conditions. This makes the critical questions even more urgent. Aggressive medical procedures designed to prolong life may not be effective and in fact, could be harmful for patients who are very elderly and frail. Patients and caregivers may come to the physician's office with preconceived, confused or erroneous ideas—sometimes with previous conversations from resources like the internet. As a first step it’s necessary for the physician to listen and to validate the patient, and the family members concerns with compassionate, thoughtful responses to reduce the emotional turmoil. This is not to agree with what they are saying, it’s just to listen and validate their concern. Then it’s necessary to clarify some of the basic medical terms and facts before exploring questions about future medical
care.

MRB: Now let's see how this type of situation might play out in the next simulated case also produced with the assistance of the Patient Safety And Competency Center at Albany Medical College.

>>CLIP BEGINS<<

Doctor Allen: Hello Mrs. Turner, hello Mrs. Jackson. How are you doing since coming home from the hospital?

Mrs. Turner, Mom: Good. Glad to be home.

Mrs. Jackson, Daughter: I’m glad she got out of there alive. That hospital doctor had her written off.

Doctor: What happened?

Daughter: We had barely gotten into the hospital room and the doctor had asked mom to sign a DNR.

Doctor: What happened?

Daughter: She said it was important to have the conversation because my mom is in critical health, and she wanted to “respect her wishes”. I told her we weren’t interested in having that conversation, or signing a DNR. My mom has a lot of miles left on her and we’re not going to sell her short.

Doctor: It sounds like it was upsetting for you. What do you understand DNR to mean? It’s important we’re on the same page.

Daughter: doesn’t that mean do not resuscitate? So that if her heart stops, they’ll just stand there and let her die. For me that’s giving up on my mom and not giving her the care she needs, why would I do that?

Doctor: I can see where you’re coming from. Deciding against a treatment that is lifesaving can feel like you’re giving up on someone. Decisions about lifesaving treatment should be made by the patient, whenever possible. Since your mom is able to speak with us, let’s have a conversation about what resuscitation means in the context of overall health, Mrs. Turner?

Mrs. Turner, Mom: Please call me jenny.

Doctor: Okay, Jenny. Do you mind if I ask you questions about what you know about your health
and what you want from me and other healthcare providers taking care of you.

**Daughter:** I don't mind talking about it, but I'm just so used to everyone asking Gloria all the questions.

**Doctor:** This time Gloria’s going be in the audience with me, if that’s ok with you. Gloria will be the person for me to speak to if you are not able to speak for yourself. That’s why it’s important for now, while you can still make your own decisions for Gloria and I to hear what you want.

**Daughter** Do you think that my mom is really as sick as that hospital doctor seemed to think?

**Doctor:** Well, Jenny I have to be completely honest with you, your health is very fragile and this recent hospitalization is just an indicator of just how frail you are.

**Mom:** Was I really that confused?

**Daughter:** Mom, you didn't even recognize me, and you were really frightened...you don't remember?

**Mom:** I don't remember...why did that happen? Am I losing my mind?

**Daughter:** Well, Jenny, on your first visit, Gloria expressed her concerns about how you don't always remember that you're living with her now. It’s very likely this memory problem will affect you more, and you’ll need more help from Gloria as time goes on. The most common cause of this condition is Alzheimer’s disease.

**Mom:** Oh, dear, my friend Elizabeth had that, and she...ended up living in a home!

**Daughter:** Mom that’s not going to happen to you. Dr. Allen, you barely know my mom, how can you be sure she has Alzheimer’s?

**Doctor:** Well, I’m not clear yet but it’s clear she has problems with memory and needs your help. While I am concerned this is due to early Alzheimer’s disease, I don't think it means at this stage that you can't make your own decisions. Jenny, the things you said today reflect good insight and the decisions that are made should be yours. Jenny, you mentioned your friend Elizabeth, how old was she when she developed Alzheimer’s disease?

**Mom:** She was in her 60s.

**Doctor:** Ok, well you’re developing your memory problem much later in life, so we shouldn’t expect your experience to be much like hers. We also have to bear in mind that you have other health problems, besides.

**Mom:** You mean the heart tremble and the diabetes?
**Doctor:** Yes, and also those things that impact on your daily functioning, like your vision problems and your difficulty walking—

**Daughter:** And those things are why she needs my help, not her memory issues.

**Doctor:** I agree Gloria, and the fact that she accepts your help is a sign of just how good her judgement is. Let’s make sure we’re all on the same page as far as resuscitation and lifesaving treatments mean. To do this I would like to use a tool as our guide called a MOLST form.

**Daughter:** That’s the DNR form the doctor was waving around the other night!

**Doctor:** Yes, this might be the same form that you saw but it’s much more than a DNR form, let’s look at it together. This form will walk us through the important aspects of resuscitation and life sustaining treatment. It allows you to spell out your wishes for many aspects of your care. For now I want to move it as a springboard for our discussion.

**Daughter:** She has a living will, does she really needs it?

**Doctor:** Well the areas addressed are very similar. A completed MOLST form has the effect of a lawful medical order, and should be reflected as needed so that it still reflects the person’s medical wishes. Jenny, we may find that your feelings have changed since you’ve completed your medical will. Let’s take a look at the names of the interventions on the MOLST form.

>>CLIP ENDS<<

**MRB:** Looking at that scenario, how would you summarize some of the key points that are worth taking note of and what happened in that discussion, Dr. Shelton?

**WS:** Would say the physician in this case which was, of course, played by Dr. Costello, nicely validated some of the concerns of the patient and family member. At the same time diffused some of the emotion and turmoil and allowed the conversation to proceed and go forward. When the physician was able to clarify some of the concerns about DNR through open communication. Most importantly, he is able to disclose the likely diagnosis of Alzheimer’s and to provide realistic information about the prognosis and the poor likelihood of resuscitation being effective in the event of a heart attack and what we keep emphasizing is very important is the physician proceeded to document the patient's wishes in case they need it for future use.

**MRB:** Absolutely. Turning back to you for a moment, CPR is one of the conditions that you were mentioning in the vignette. Can you tell us more about the role of CPR and how that factors in?

**KC:** It’s important to note the success rate for CPR in patients with advancing age decreases. My
prognosis influences patient decisions regarding resuscitation very often. The survivor rate for cardiac arrest is less than 1% in community samples. Those who initially survive CPR face the care unit where most die within the first 24 hours and the intensive care unit produces additional problems such as confusion, risk of delirium and other problems.

**MRB:** What if a patient who again, has capacity also says they don't want to be hospitalized?

**KC:** Patients with capacity or their proxies have a right to decline hospitalization. Patients with advanced dementia can be kept comfortable at the end of life in a home or skill nursing environment with adequate supports. They're more likely if they do receive the hospice receive treatments that can cause further discomfort.

**MRB:** I think we've all heard about certain ethical questions that come up when you have a patient who has often less capacity. Let me ask you, can patients refuse any medical treatment or hydration or nutrition and the basic things that keep us alive and don't we often think differently than receiving foot and water than ventilation or dialysis?

**KC:** We tend to, but patients with dementia may continue to eat and drink long after they've lost capacity. At some point as the disease advances, the desire to eat and drink tends to wane, and they no longer do so on their own. Many with advanced dementia develop swallowing difficulties and may tend to hold food in their mouths and this puts them at risk for aspiration and a choking hazard. Many caregivers start feeling an obligation to feed the patient. When in fact, patients have the right to say please don't hand feed me if I reach the point that I am not able to feed myself, and this is also the point at which the body loses its natural ability to digest and tolerate food. So basically the patient is trying to avoid further discomfort. It's also permissible for patients to decline the feeding tube or artificial hydration as well. Patients with capacity can decide in advance to anticipatory autonomy to refuse medical treatment. Studies have shown that patients with advanced dementia doesn't benefit in term of the occurrence of loss of lean body mass and improvement in quality of life, survival and functional status.

**WS:** I'll make one quick point on that, as well. This is a big, as you suggest, a big issue in medical ethics, needing hydration and nutrition, but artificial hydration and nutrition is more than eating and drinking naturally and these are medical treatments that are artificial and like all medical treatments they can be refused and that's an a very important point for physicians to keep in mind.

**MRB:** Thanks for adding the clarification. Once the patient has expressed their wishes whether it's regarding artificial nutrition or CPR or other medical decision, what should the physician do to make sure those wishes are followed?

**KC:** Once a proxy is appointed, it's important to document the power of attorney for health care and have a copy of that as possible with the patient's medical record. It's a good idea to keep a blank, health care proxy form so that it's readily available when the opportunity for these discussions prevent themselves. Most can be printed out at home and familiarize
themselves with what's in their state and hospitals. It's especially important to the procrastination and it's easy to want to pull it off. If the opportunity does present itself it's really important to get it in the chart as soon as possible. We tend to relax and it's a chronic disease, and things happen and you can lose the opportunity when you least expect it. So it's important to strike while the iron is hot. The documentation is crucial because it clarifies the patient's wishes, and it takes the proxy in the future to have to make difficult decisions unguided.

**MRB:** Dr. Shelton, should the physician also speak to the family member or the person who will become the patient's decision maker once the patient loses capacity?

**WS:** Yes, the position should. As soon as they determine that the patient lacks capacity to make decisions moving forward. It's important for the physician to reach out for the health care proxy and have the conversation. To start with, it's important to clarify the responsibilities and moving forward. Much of this information has been in a prior conversation with the issues had with the family member and agents already and it's important to clarify them. The key point is that the health care agents' duty and the obligation is to make decisions as much as possible consistent with the patient's known wishes and physicians should be mindful of that and sometimes they need to be advocates for the patient if they know the patient's prior wishes and the families follow those wishes. This should relieve a burden because the proxy's job is to follow the patient's wishes and not to try to figure out for themselves what's right or wrong for the patient. The primary care physician should also address the needs that are concerns to family caregivers and be prepared to provide needed, supportive intervention such as education and psychological support and counseling and look forward to community resources.

**MRB:** So the primary care physician is involved and has an important role with the patient and family and not at the beginning and as it progresses as well?

**WS:** Yes, very much so by the time it's first diagnosed to the time he or she has capacity and the caregiver needs to be provided ongoing support and this requires a real team approach including social workers and others and these other folks have more time to spend with families and this is especially important when the patient still has capacity and can benefit by having someone to talk to with support and guidance. Primary care physicians should regularly confirm with the patient and particularly with the caregiver or agent that the advanced directives are still valid and check for the new concerns and questions that may have come up, and continually manage the patient's capacity and be sensitive to the time the patient becomes incapacitated. Clarify that the designated agent about major medical matters.

**MRB:** You both shared a lot of information with us today. I want to ask you, how would you summarize the central points of the discussion of what we've covered so far?

**WS:** I would say this, primary care physicians should take advantage of a window of opportunity to have discussions with their patients with mild to moderate Alzheimer's or dementia. They
should initiate these discussions in order to assess capacity and provide full disclosure of the diagnosis and the likely consequence of the disease as a terminal illness. Many of these patients they talk to will have capacity and these patients have the right to express their self-determination and their wishes about both present and future medical treatment. This includes the right to refuse all aggressive, unwanted treatment that may cause unnecessary, unwanted burdens. As soon as the patient makes his or her issues known, when it's important to document those wishes and otherwise the patient could be left in a position to receive unwanted treatment and finally, this is a key point, Alzheimer’s is a family disease. So health care providers need to provide support to the patient and family and that's a very key part of about this disease.

**MRB:** I think personally, that was one of the things that we were going through that struck me that not only how the disease progresses and the vast impact that it has and how it has the ability to affect so many people surrounding the patient. I want to take a few moments to answer some of the questions we've gotten today. The first question we have is what if a physician gets a sense that the patient doesn't want to be informed of his or her diagnosis?

**KC:** That's a delicate thing. A lot of times I think when the patient feels that way you are aware that there is a problem and so you have to work with it and read the situation, and as a primary care doctor you have a long-term relationship with patients usually, so you have the sense as you would with a family member or friend, and so you can't hide behind that and not make disclosure at some point. Conveying what's going on without being brutal about it and at the same time you need to be frank about where things stand.

**WS:** This is an area where the art of being a clinician comes into play. You have to be an extremely effective communicator. There is an obligation to be candid and disclose the information, even though it's hard to do, physicians should tell the patient what the disease is and what the consequences are, each if the patient doesn't want to hear it at first.

**MRB:** We have another question coming in, how should the physician and the family work with the patient that refuses to accept his or her diagnosis?

**KC:** Again, it comes down to interpersonal relationships with people and sometimes it's especially a challenge with a family member coming in from out of town and doesn't know what's going on and when they do, it makes them feel guilty about not being around to help and that gets transmitted to anger, about why are aren't you doing more for my mom, and so you really have to kind of step back from that and not react to it defensively and just work with people, and again, it's not an immediate thing and it's a matter of bringing people along and working with them through this process.

**WS:** When people are coming from different points of view and someone, even the patient disagrees with what's being said. It's very important and a physician can't deal with the problems that require a whole team approach and sometimes people are very helpful.
**MRB:** Going back to my prior days and the whole idea of meeting the client where they are or meeting the patient where they are and not reacting to where they are is so critical. We have another question that says I am an Alzheimer’s patient, and why isn’t it the same as those for things like cancer? I've been told that laws prevent my caregiver from adhering to my wishes and I can no longer make them.

**WS:** That's false. That person should know that that is not true. I don't know where the information is coming from, but I think this person should know that he or she has a right to make decisions, make these decisions advanced about future treatments so I would find a good resource for information.

**MRB:** Okay, another question that's come in, what are dementia-friendly communities?

**KC:** Well there are many models of care for patients with dementia are institutional and others less so but they were set up in such a way that a lot of patients while minimizing the risk of wandering out of a building and out on to the street and into dangerous situations and so there are several types of models like that, and there are ways to make individual homes more friendly to patients with Alzheimer’s and there is a new technology being developed to remind patients about their daily activities and just to get by and it's quite remarkable how people get by sometimes with just a little bit of additional help and sometimes day care programs are beneficial and interacting with other people and becoming less agitated as a result.

**MRB:** That sounds excellent. Another question we have is, how long does it take from the diagnosis to the onset of dementia symptoms?

**KC:** The diagnosis is usually made after the symptoms have appeared. With mild cognitive impairment they determine whether the patient has mild cognitive impairment or aging or the key point there is that they do have measurable deficits, but they're not severe enough to keep them from functioning independently. They can still do their own activities including bill paying and things like that. It becomes dementia when the person needs the help of other people to get by.

**WS:** So, a person can have some degree of dementia and still have capacity. I want to make that point clear that we should emphasize. Just because you are starting to have cognitive deficits doesn't mean you lack capacity necessarily.

**MRB:** That’s a great point to reiterate. Another question, since primary care physicians have a short time with patients they may not have time to have a comprehensive conversation on advanced directive and financial planning. Where can they refer Alzheimer’s patients to receive any of the free training or assistance on these issues?

**KC:** That's a great question. Geriatric medicine is inherently a team-based activity care, so if you happen to have a social worker in your office or other type of case manager who has that, and
the staff can be very helpful in this situation. Organizations like the Alzheimer’s Association also can provide a very helpful publication and human support.

**MRB:** Thank you. We have time for one more question. What is the percentage of those with Alzheimer’s who receive treatment because they don't trust the health care system. That's a pretty specific question, I don't know if we have that data.

**WS:** I don't know the answer to that, honestly. There are people when don't trust the system and there are all sorts of reasons why that might be the case. The only thing I can say is that it's important to find someone you can trust because with Alzheimer’s or any serious medical positions you need someone to talk to and have confidence in. They're out there, there are plenty of good doctors and caregivers.

**MRB:** We are out of time for today and I want to thank you for joining us today and providing information on an important topic and comprehensive topic, so thank you for joining us. And thank you very much for joining us today. Please remember to fill out your online evaluations at the close. Your feedback is always helpful to the development of our programs and continuing education credits are available. To obtain nurse continuing education hours, CME, and CHES credits, learners must visit www.phlive.org and complete an evaluation and a post-test for today's offering. Additional information on upcoming webcasts and public health topics can be found on our Facebook page—like us on Facebook to stay up to date. This broadcast will be available on demand on our website within two weeks of today's show. This webcast will be available on demand on our website within two weeks of today's show and please join us for the next webcast on October 15th focused on the New York State of Health. Thanks for joining us on Public Health Live!