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End-of-Life Care for the SLP: Special Considerations for
Dementia and Delirium
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- [Amy] All right, I'd like to welcome everybody to our speechpathology.com webinar today. We have Dr. Amanda Stead joining us who is going to be presenting End-of-Life Care for the SLP, Special Considerations for Dementia and Delirium. Amanda Stead is an associate professor at Pacific University and Forest Grove, Oregon. Her research is in the area of language, change in healthy aging and dementia and evidence-based education in the area of geriatrics. It is her personal goal to educate students in the community, about the important role SLPs play in the care of patients with dementia and in end-of-life care. So welcome, Amanda and thank you for joining us today.

- [Amanda] Hi, everyone, thank you so much for having me. These are my disclosures. So today the outcomes that we're going to be focusing on are threefold. So the first is to identify at least two to three reasons why end-of-life care is complicated for patients with dementia and delirium. The second is to identify considerations for addressing feeding, in end-of-life patients with dementia. And the final one is describe at least three strategies for improving care for end-of-life patients with delirium. So this is a quote that I pulled from a medical FSS and I think it really speaks to the position that SLPs need to take with our patients, particularly patients that are poor communicators or patients near the end-of-life. And it's that if you can't talk to a patient, you don't know what the patient actually wants.

And this is the position we find ourselves in with not only all end-of-life care conversations but particularly in conversations when people's competence and capacity is really in question. So we already know that when you need to make a medical decision that this is a really complicated cognitive process. It really takes you to have incredible effort from your attention system and executive function, memory. We often know that when we're having these discussions, additionally they're really emotionally loaded which puts an additional strain on all of our cognitive processes. So because this is such an effortful task to make and process and think through good decisions and then we think about our patients with dementia and/or delirium, we think

about their ability to state clear choices. And so the first question we're having is, can they perform that complex cognitive task? Two, can they state a clear choice? And then, I think most complicated of all is when they do in fact state a clear choice is that choice really regarded as accurate or valid by families and physicians? This is the situation which is really putting patients with dementia and delirium at very high risk for a violation of their personal autonomy and their right to make their own medical decisions. So, we're gonna first focus on considerations about dementia and then we'll move to delirium towards the end of the presentation. So some of the questions I know I have about working with patients with dementia and I know colleagues of mine have in practitioner settings is, when our patient is refusing food, is he refusing food because he's not hungry or because he's confused? Like, what am I looking at on my plate? Do I realize it's mealtime? How do I manage this fork? How do I get that food into my mouth?

One of the questions we're often wondering and one of the highest risk points we see for our patients with dementia is just lack of intake for food. And that's a really complicated problem. Other questions were asking about our patients are, why is my patient so agitated today? Well, I'm wondering if she's in pain, I wonder if we need to step in with a medical intervention. But my patient isn't telling me they're in pain so is the agitation due to some underlying cause or are we just having a bad day? And I think really one of the most important questions and this is a question I think, we're having a difficult time always asking is, is my patient really happy and what is their current quality of life?

And I think this question for me is actually the most complicated because this question is at higher risk for you putting your own personal values and burden of what you believe quality of life is instead of us looking for evidence really coming from our patients, about their perceived quality of life and happiness. So how are we going to provide the emotional, spiritual and physical comfort for patients with dementia at the

end-of-life? So, without thinking about dementia, we know that patients near the end-of-life, need a really comprehensive set of structures and supports around them so that they can really achieve the type of sort of, quote, good death that we know patients and families are seeking. Now, as we add on a cognitive impairing illness or disease, how does that impact what are already difficult to achieve goals in end-of-life care? Well, the first thing that we really have to think about is, if we know that quality end-of-life care really starts with the ability for our patients to participate in that decision making, in that plan of care, the first thing we really need to think about is capacity determination.

Now, this is particularly true when we think about that previous statement indicating that not all patients with dementia when they indicate a preference are valued and honored in those expressions of preferences. Because there is this question about the validity of those statements because of their diagnosis. What I have found professionally is that often the diagnosis named alone, is really the subversive act of loss of autonomy, despite not having any real documentation of capacity or ability to make decisions. So here's what we're gonna turn to, when you have the question is, "Oh, can my patient actually make this decision?" So here are the standards and these are very clear cut.

The first legal standard is understanding. And this is really the ability to comprehend both the diagnostic and treatment related information and demonstrate comprehension. Now, we could all go round and round about this one 'cause we know even for cognitively healthy folks sometimes it is difficult to understand the enormity of a situation and the complexity. And this goes back to also the way the providers, are communicating that information. So you can see how we have work to do on both sides here. The second legal standard we need to demonstrate in order to determine capacity is the ability to translate and determine the relevance or significance of the medical circumstance treatment or consequence, right? So can our patient truly

appreciate this moment and it's most importantly, often the potential consequences of this decision. So you can see if I make this decision to not go forward with this treatment, that means X and under, because one of the most important things, we have in our toolbox to really support the goals of end-of-life is capacity determination. We wanna be really thoughtful that we're meeting the burden of every one of these legal standards. We know that often patients with a diagnosis of dementia or delirium for that matter or any cognitive impairing illness, often are preemptively sort of stripped off their ability to make decisions.

We also know that when you look at what it means to have a, quote, good death, one of the most important principles in that construct is that patients feel like they have the right to participate in and make medical decisions. So instead of using a diagnosis as a standard for capacity, we instead are going to go to the actual legal standards and check for that capacity understanding. Because we know that a diagnosis alone does not mean that a patient cannot make decisions. So we're gonna go through them each individually because they're particularly important on their own and we would want to check them each individually in our documentation. So the first one is understanding and do our patients have the ability to understand and comprehend diagnostic and treatment information and demonstrate that? Well, that's something we're going to have to help them communicate.

The other part of this is there is a lot of burden on care providers to facilitate this understanding. So this is not just a one way street and I'm sure we can all think of moments where we've had medical information presented to us that has been difficult to comprehend. Now that's often on the providers shoulders but we need to help navigate that understanding piece. The second thing we want to really think of in terms of the legal standard of capacity is appreciation. So does the patient truly appreciate and have the ability to translate the consequences and significance of the medical circumstance they're in? This is particularly important when we think about, if I opt in

or opt out of a particular medical situation or procedure, what will be the consequences of those actions? Can the patient appreciate the gravity and the pathways that this one situation or decision will take? The third legal standard is reasoning. So this is the ability to employ logical processing and compare benefits and risks. So we really want to think about the ability to have calm, more complex conversations so that our patients can in fact demonstrate that they understand different aspects of different choices, different consequences of different choices and demonstrate that sort of almost like compare and contrast ability. The last legal standard is express a choice.

So the ability to actually generate a decision and state a preference. Now, based on what you know about patients with dementia, you can see how each of these legal standards can put us in a situation where we have to be very precise about documenting each of them and checking for each of them. So we know that dementia will impair understanding, attention, decision making and also expression. So we wanna be really diligent about, making sure we're meeting these legal standards. One of the places we find ourselves most engaged in issues of end-of-life care and dementia is issues around feeding.

And these are incredibly complex and really emotionally loaded for families. One of the reasons we find ourselves in the situation is, feeding and eating is really one of the last functional behaviors to be lost over the course of dementia. And we know that these decisions with families have proven themselves to be very contentious and complicated at the time. So you because of your mastery, not only in the disorder and disease but the cognition and the feeding, can really position yourself in a role to provide families with the information about ways or pathways that could lay out before them and help them think through ways they would proceed. We know that pneumonia, has a very high prevalence in dementia care and we know that poor nutrition is a contributor to risk for infection and dysphasia is also a contributor to risk.

We also know and those of you who spend time in restricted living quarters with people with dementia know that oral care can be a significant, challenge in dementia settings. So patients with dementia are more likely to have pneumonia than older adults of the same age without dementia. And they are more likely to die of that pneumonia if they get pneumonia. So not only will they be diagnosed with pneumonia at higher rates but if they get pneumonia their chances of dying from it are higher, than healthy non-dementia folks of the same age. We know that pneumonia is gonna be more likely and more severe alongside cognitive deficits and that those cognitive deficits, will worsen after a bout of pneumonia.

And this really speaks to how complicated it is to have a cognitive condition and have any other health problem. So is it possible that the reason our patients with dementia have more severe bouts of pneumonia, higher mortality rates, when they do get pneumonia is because they could not in fact communicate or process the urgency of that medical request earlier on to get intervention? That they can't engage in the self-care to prevent the pneumonia. I mean, there are a myriad of challenges in this particular situation. The other thing that we wanna think about is this aspect of palliative care.

And I put this here because when I think about what palliative care really means, for me the aspects of having our patients with dementia engaged in long term palliative care, makes a lot of sense. So if the goal of palliative care is to provide the best quality of life for patients and families and provide that that care is life affirming that this care does not hasten nor postpones death. So this is a care that is based in the right interventions at the right time, providing symptom control and relief from pain and additionally addressing psychological and spiritual needs. The other aspects of palliative care, I think are really related to our dementia folks are supporting the patient and the family. These are complex moments where families are feeling really torn about what they know about their family member, when their family member was healthy and

what they see now and it's really important and palliative care can provide a wonderful option to think about the systematic family-based care for patients with dementia. So when we think about what's gonna happen next is as patients are continuing to decline, the way we wanna think about it is that if a person continues to accept and enjoy food, food should be offered. And where things get a little more complicated, this is idea of hand feeding, right? So hand feeding really should be continued as it is comfortable to the patient instead of with the sole goal of providing caloric intake. Now, where we're going to be going with this is this relationship between caloric intake and quality of life in terms of feeding.

And it doesn't take a big stretch to recognize that if you don't get enough calories, that really functioning and living and the stability of your body is gonna be complicated. So when our patients are no longer, ingesting eating enough food, we have to really think about, why is this happening? Am I entering an end-of-life care sequence? Or am I just agitated or confused? Or am I nauseous? Like, is this a primary or secondary issue? We see many facilities offering what we would call comfort trays and these are really used to offer for hydration and some pleasure feeding as we often think about the term. So when we are reaching an end-of-life moment with a patient with dementia, what we don't want to do is be feeding folks in the effort to maintain calories but instead in the effort to provide quality of life and comfort.

Now we've arrived at this moment 'cause we've already determined that all of our other strategies for increasing caloric intake are not going to work, right? So all that proceeding work and also that sometimes patients and oftentimes patients, are beginning their end-of-life sequence for something that doesn't feel overtly obvious to us. But it's clear that their body is beginning to move into one of those shut down processes. So the reality of the offers for what happens when patients stop eating is, really only a couple. We can engage in hand feeding or we can engage in tube feeding. And it is just really important that we acknowledge that many, many organizations have

indicated that tube feeding is not the right outcome for patients with dementia. And under quote, the benefits of tube feeding, do not outweigh the substantial, associated treatment burdens here and that they don't actually prevent aspiration, prolong survival or promote wound healing, in late stage dementia. So, we know that also the act of engaging in a very medicalized procedure, can result in a poor outcome just from the procedure alone. So the placement of tubes for feeding in patients with advanced dementia is not indicated in any way.

And we wanna be really thoughtful, about the way we're presenting information to families. And we want to really help understand, the way information regarding feeding is being presented by our partners in healthcare, the primaries, the charge nurses, the doctors. And so this is really a moment for us to do some great interdisciplinary conversations about what the evidence really says. And being thoughtful that we are presenting information in a way that is really not biased but it's really clear. It is certainly not our job to negotiate families out of feeding tubes if that is the choice they're making. But what our job is, is going back to all of those capacity pieces, are we confident that we have communicated the information in a way in which it was understood, that was appreciated for its complexity and really helped families and patients weigh all of the options.

When we think about the other considerations, we're gonna have with feeding, what we know is that feeding is a tremendous moment, in the way we think about caring for folks. Everybody knows that comfort and food are sort of hand in hand and we find families and caregivers in a situation when someone is at the end of their life really wanting to provide that type of care. We also know that it is really concerning and the idea of a family member stopping eating, is incredibly stressful for caregivers. So what's that's gonna tell me and all of you, of course, is that we can predict where our caregivers are gonna need a lot of support. So this is gonna start with communicating what we know about feeding and end-of-life and what we know about comfort feeding.

So we're gonna continue to encourage our caregivers to feed patients as the patient feels like it's pleasurable and accepts that, right? So going back to our sort of hand feeding situation. We also wanna really communicate to our caregivers that if a patient doesn't feel like they wanna eat or is refusing it, that that's okay and that's normal. Because not eating and not receiving food, doesn't mean we're not gonna continue to care for your loved one and provide really quality end-of-life services. It's also really important that we indicate to our families that what our understanding of end-of-life tells us is that patients at the end-of-life, do not experience the same type of hunger or thirst as they do as a healthy person.

And I think helping fill in those gaps for knowledge and assuring the loved one that their person is not hungry and feels like they're being denied sustenance, that isn't what's happening. And so really stepping up with those counseling words and that emotional and spiritual support in these moments. So just to revisit our role in end-of-life, it's really thinking about consultation with the family and team related to all aspects of communication, cognition and swallowing. Also, of course, managing swallowing and we know that this is one of our quickest pathways into patients who are at end-of-life is issues related to feeding and swallowing.

We really wanna communicate with the hospice team and be a part of the hospice team. This is certainly an opportunity for us to partner with them and offer our services as a benefit, certainly not offering our services because we believe they are doing a poor job, right? So often we gotta be thoughtful, about the way we present those opportunities. And then as patients are entering, end-of-life sequence is we really wanna help families and care providers develop strategies to help patients communicate and help them maintain quality of life and socialization. So this doesn't mean long term intervention, it often means us stepping in and developing a handful of strategies and solutions to immediate problems so this patient can make decisions and communicate and achieve their end-of-life goals. So, when someone is diagnosed with

a life limiting illness, it's really important that they do documentation if they don't have it already. And I am putting this resource here. The Conversation Project is a nonprofit that provides really incredible toolkits for people to do end-of-life documentation. And they know as all of us as providers know, that documentation for patients with the diagnosis of dementia is complicated. And it's complicated for not only a myriad of legal and logistical issues but it's complicated because people have really complicated feelings, about a diagnosis of dementia. And for families that have been through long term care situations with a loved one with dementia already or imagine an adult child who cared for a parent with dementia who now has their own personal diagnosis of dementia, there is a lot of personal and emotional feelings going into those decisions.

And again, I just wanna say it's not for us to insert our personal values into that decision making but to instead empower our patients to really explore and take the time to make those decisions. One of the first things I do is when I work with families under a new diagnosis, is we have this conversation. We have the conversation about advanced care planning, plans of care, thinking through a lot of options. And that conversation isn't meant to be had sort of in one shot but kind of over time and the resource or the dementia packet or the Alzheimer's packet from the Conversation Project, is a wonderful place to start, it's a resource to provide families.

Because if someone has done their documentation, then when the time comes and you have questions about what they would decide, you already know the answer to it. And that's the best case scenario, right? Because we know then our patient has made this decision for themselves and we are simply enacting, their own personal decisions. This is certainly the preferred way to go through this. So this is a wonderful tool. The last thing I really wanna say about this, just on the side is that, care planning is not meant to be done one time. And it is a really good moment, when a family has a new diagnosis to revisit the care plan. Lots of families have care plans that are either, I'm gonna call them like covert, right? So they have them but like no one knows about

them and they're not documented anywhere or they haven't been updated in a really long time. And this is a good opportunity to normalize that documentation, right? And that's gonna be communicated in your words because if you're like, "Oh, yeah, I mean, you should, "yeah, maybe it's time to update that." That's a really strange and not supportive way to communicate that. If instead you communicate it through, often when I have these conversations with families, I wanna just give you the opportunity to revisit your care planning and really think through if anything is changing and if you'd like to change anything. And if you just act like it's normal, it turns out it's normal and it doesn't feel targeted or personal at someone with a new diagnosis. So I've included a few case studies in here.

So, Alma had been forgetful for years but even after her family knew her Alzheimer's disease, was the cause of her forgetfulness, they never talked about what the future would bring. As time passed as disease eroded Alma's memory and the ability to think and speak, she became less and less able to share her concerns and wishes close to her. This made it hard for her daughter to know what Alma needed. When the doctors asked about feeding tubes or antibiotics to treat that pneumonia, she didn't know how best to reflect her mother's wishes.

So her decisions had to be based on what she knew about her mother's values, whether than what Alma actually said she wanted. Now, the number of times I had seen, this situation play out is pretty astounding. So we as a community and society aren't very comfortable, talking about end-of-life care and we find it actually really disturbing to talk about end-of-life care when someone is sick which is fascinating and it feels too targeted. So one of the problems in this situation is that when given the opportunity to have the conversation, that conversation wasn't had. And it also appears that there was a lack of documentation even when Alma would have been very happy. So when Alma had been forgetful in her early years, this would have been a great opportunity to have these conversations certainly after a diagnosis. And what

we're gonna talk about in a moment is ways to facilitate and understand what a patient would want even though they have, quite a bit of symptoms related to dementia. What we did right in this case study is that her daughter relied on her values. And if her daughter was designated as her proxy, that was certainly the right approach. So what her daughter didn't do was do what she wanted to do from her own personal sort of vantage point. What her daughter did was make decisions, based on her mother's personal values and lived experience and that was the best we could do in the absence of any real documentation from Alma herself. Here is a wonderful, wonderful tool, this article is relatively hot off the presses.

And what it's talking about is the ability to provide visual supports for people with dementia. And it was done specifically in talking about, decision making for things like feeding and swallowing and medical interventions. So we know that when people with dementia are provided with a visual support which takes the burden a little bit down, in their impaired cognition that they can participate more than when we just pepper them with verbal information. Now I love, love love studies like this because what they do is they confirm what we suspected all along.

And yet they give us permission to really do it a different way, they empower us through the documentation of their science. So this is a wonderful template from this article, I encourage you all to go visit it. But an example of how they're supporting decision making through visual supports is they use the template, if I had a swallowing problem the consequences are. And then they do coughing or choking, having a lung infection not having enough nutrition. So these are the consequences and you could pair them with specific images that you find out there in the world or from your facility to begin with. And this is a way where we get to say, okay, does my patient appreciate the consequences of a swallowing problem? If I'm trying to imagine, "Wow, I wonder if my patient, "would want more intervention if they had dysphasia?" Lemme understand, do they know what the consequences are? And that will help guide the further sort of

steps you would take with that patient. So when we think about delirium, this is something I think is really, I'm gonna say a missed opportunity for us and it is certainly true that so many of our patients have delirium and I think we're a little unsure about how to engage here. So dementia and delirium share a lot of clinical features in relationship to cognition. One of the big differences between dementia and delirium though is this alertness and state of consciousness piece. So patients with dementia are alert where in delirium we see this, disturbanceness of consciousness. We know that patients with dementia have a stable conscious state with a gradual onset. So when we consider how dementia and delirium are different and also are not I think what we really get ourselves at a pickle about is that they share so many clinical features. And I think in some ways SLPs have really considered, dementia as part of their practice and maybe not delirium yet. So one of them most common symptoms in both of them is just the impaired memory and thinking and judgment.

So this disruption in cognition that is pretty marked. So the difference really lies in the levels of alertness and consciousness. So patients with dementia are alert and have pretty consistent states of consciousness where in delirium, that's actually one of the big challenges. Is that they have a disturbance in consciousness and they have a rapid sort of fluctuation or vacillation of these symptoms. We know that dementia is a gradual sort of insidious onset and that is just not the case in delirium.

So one of the easiest ways to sort of think about it is like, when did this happen and how quickly have things changed? It also should go without saying that patients with dementia can also get delirium and this is incredibly common. I mean, one of the most common causes of delirium in patients with dementia is a UTI. And this sort of accelerates and amps up all of the other symptoms that we're already seeing and then adds on these fluctuations in consciousness. So the reason I wanna talk about delirium here is that delirium is an incredibly common symptom for people at the end-of-life. We also know that delirium causes an enormous amount of stress on families. So delirium

is the most common and serious neuropsychiatric complication, in palliative care. And up to 33% of hospitalized medically ill patients, may have serious cognitive impairments. Your chances of working with patients who are in a moment of delirium is incredibly high and because of that we need to understand, okay, so how are we going to work with patients with this disturbed state of consciousness, impaired cognition that may be over and above an already impaired cognitive status? And how are we gonna step in and still support communication, feeding capacity, determination, all of the work we're already doing. Another thing that makes this really timely is that the incidence of delirium is rising. And we have shown that elderly patients admitted to medical wards, there is about 30 to 50% of those patients demonstrate symptoms of delirium at some point during hospitalization.

And we know that elderly patients who develop delirium during a hospitalization have a 22 to 76% chance of dying during that admission. Delirium is a predictor and barrier to good outcomes in these patients and it's happening more frequently. So we need to really figure out what are the right tools here. We know that it's also a significant predictor of heightened spouse and caregiver stress. So again, going back to what does a good death look like? Well, it often looks like calmness, caregiver engagement, ability to have closing conversations and all of that is really blocked, when a patient is delirious.

And medical approaches to non-terminal delirium may not be effective, when your patient is close to death. So what's that saying, like all things is that the treatments we would use to treat your delirium if you were just delirious, from an acute injury or an acute affection don't actually work to address the delirium associated in end-of-life care. So non-terminal delirium so just random delirium from a secondary cause we treat with antibiotics or we treat the underlying cause. And it remits and you go back to a stable state of consciousness. Where terminal delirium to the delirium associated with end-of-life care does not respond to those same amounts of treatments. So we

are often frequently unable to remediate that delirium as patient is nearing end-of-life. So, terminal delirium occurs in advanced stages of dying and we really cannot think about, using the same old medical interventions 'cause it's not responsive. Where non-terminal delirium, can occur in any sort of fragile patient and especially when they're ill. Again, this is the UTI example which is incredibly common and it usually responds to treatment of it's an underlying cause and then patients sort of return back to their normal baseline cognitively. So, a lot of medical causes at the end-of-life. So it is true that not only our geriatric patients but our end-of-life patients are experiencing issues of urinary retention, constipation and pain.

Well, if we treat those underlying issues, then the patient will no longer, demonstrate symptoms of delirium. So what are we gonna do when we can't fix the delirium and/or it's not responding to treatment and/or we are waiting for treatments to work? So what are we going to do specifically for our patients who have delirium? Well, you will get so much success if you consider, reassuring the patient in talking with those patients and families. Remembering that it may be unclear to you at this time, if this is terminal or non-terminal delirium.

But we know that the presence of that delirium renders our patients, in a very difficult situation to communicate wants and needs, feed accurately and is causing a ton of caregiver distress. So the first thing we are gonna do is reassure 1,000 times to the patient and family that this is normal in a lot of ways and give them a lot of support. I love the phrase an end-of-life care, like, this is not unexpected because in medical care you don't really want to be the anomaly all the time. You wanna be sure that your doctors and your providers know what they're doing, that they're not being caught off guard that they know how to treat the underlying issue. We're gonna think about what types of tools we can give the family for engagement. So if we know the patient is having this fluctuating stage of consciousness and is needing a lot more visual support, what can we give them? Can we give them a whiteboard? Can we get them

more pictures? Can we teach them easier communication skills? So, thinking about ways to simplify the language we're using, giving choices, thinking about offering solutions and using these visual supports. That's a good way to think about how we can interject ourselves here. Patients with delirium are particularly triggered by sort of chaotic environments and we know end-of-life environments, though people say they want them peaceful, are often very busy with a lot of folks coming in and out. People come in to say goodbyes, check on the patient, medical provider, family, all of this. So thinking about really maintaining that peace in the environment so you don't accelerate symptoms or distress. Thinking about if you're gonna medicate, what is your goal of medication? And that's really complicated because sometimes we give patients medications near the end of their life to control symptoms or to reduce what we believe is pain and suffering.

And they have some very real consequences, things like terminal sedation where we seek to control pain but a secondary consequence of pain control is often the depression of respiration. So we really wanna think about walking families through symptom control and medication control and again, an appreciation of those possible consequences and an understanding and weighing of the goals here. And we should definitely get specialists and other providers and you don't need to accept an uncomfortable situation or bad situation, we ask for more help.

So we know that patients with delirium, unlike you know most patients with dementia can really suffer from hallucinations. What is really interesting about terminal delirium though is that the evidence really shows us and our experience shows us that those aren't bad. They can really upset family though so we know that lots of patients with terminal delirium see relatives that have previous passed on, believe they see things related to their own personal spiritual practices, believes they see guardians or children and this is common. And I think helping our families one, be prepared for that. So often, a lot of emotional distress, can be prevented if we would just communicate, a

little bit better with our families about what is possible. We also know that it doesn't take intervention because it's, in a way contributing to a patient's quality of life for happiness. If it's not not disturbing then we have no reason to really engage in it. So we really wanna think about also the other types of medications our patients are on and we're not contributing to more increased confusion. And also help our families, this is the goal of hospice and palliative care support families emotionally through it. So help our families see the good moments where they exist within a situation that is incredibly stressful. And this might also be true for staff and caregivers, particularly paid caregivers. So if you have delirium, we know that your capacity to communicate is really impaired. So going back again to our capacity determination. Can that patient understand? Have you checked for understanding? Can the patient appreciate the consequences?

Can they reason through different cost benefit analysis here of things that are gonna happen? Or express a choice. Often, the answer is no to a lot of these because of the state of consciousness the patient is in and the sort of inability to sort of be present in those moments. So we really have to think about if in this moment, this is the right moment for the patient to make a decision. Now, the thing with delirium is that we know it can be a bit transient.

So just 'cause someone fails your capacity check at one moment doesn't mean they will three hours later or three days later, so this is an ongoing sort of moment. This is also why we have our healthcare proxies to help us understand what a patient would want. Again, with delirium, you have got to work with your families to in spite of or in the presence of delirium, how are you going to support that patient and family's ability to communicate, manage disrupted cognition and swallowing? So because of the added, sort of the acute rapid onset of delirium and the added sort of presence of the sleep weight consciousness issue, the solutions you're using for your dementia patients which are like caregiver training and coming in with support are just a little

more volatile because they're not gonna work all the time. And also a family hasn't had time to adjust necessarily to this ongoing issue. So you're gonna have to move quick and really step in and say, "Okay, how can I patch in secondary tools "and consultation here to support this family "because this is a new immediately new problem."

Swallowing can be a really big challenge here, especially when people have a variable state of consciousness, we know their oral intake, is gonna go way down because they're not always conscious enough to eat. So what can we eat and when can we eat it? Is that pleasure feeding if it's terminal delirium? Is feeding still appropriate at all or should we do pleasure feeding during high alertness? Communicating with the hospice team, particularly true about strategies you have put in place for that family or any capacity work you've done in documentation.

And making sure that when that patient has the ability to benefit from strategies that they are well trained, implemented and surrounding that patient. So dementia and delirium are gonna put our patients at a really high risk to not be able to participate in decision making. And what I hope you can appreciate from this information is that a lot of the reason our patients don't participate, it's not 'cause they can't but it's this lack of external support to do so.

So we shouldn't take away a patient's ability to make their own decisions if we have not first determined that they are, in fact incapacitated to do so. And we also should really encourage our patients to use supportive tools and external aids to participate in those moments. So we can't be peppering our patients with impaired cognition with only verbal information. We know that doesn't play to our strengths so we need to support them. We also need to think about the supportive tools and family and caregiver training so that we can enable decision making or that a patient can still fulfill those roles, despite a significant level of dementia or the presence of delirium terminal or non-terminal. How can our patients still in end-of-life care, one, achieve the good death? But how can they still engage in activities they choose to engage in for as long

as they can? And again, maybe that's feeding and that's often our entry point here with these families. Other things we can think about is setting early goals for when and how we're gonna move through palliative care? When certain decisions are gonna be made. Maybe when we transition settings, maybe when we bring an extra caregiver support but again documentation early on. Thinking about all the possible pathways and really communicating your values to the people around you. We have got to support our caregivers during this time. So there is some really interesting, information coming out recently about how this movement to really have hospice at home and die at home. And now we're sort of seeing the swing about how disruptive that is and stressful that is for caregivers because caregivers don't realize the immense amount of medical care they're gonna be providing in home hospice. So we have to be really thoughtful about our caregivers and if the goals of your patient are aligning with the person that's supposed to provide that goals. We need to re-examine those goals over and over and over again and we know that the way you communicate, the language you use is gonna change the outcomes and our patients and families ability to take advantage of them. I just wanna thank you all so much for the opportunity to talk on this topic. I'm so happy to answer any questions you have, feel free to email me and I'm on the web. Thank you so much.

- [Amy] All right, well, thank you, Amanda. Always a pleasure to have you join us and talk on such an important topic. Not an easy topic to talk about but definitely a very important one. And I do have one quick follow up question for you since we have a couple minutes. You talked about supportive tools for patients and families and I was just wondering if maybe you could provide, a few examples of what those would look like.

- [Amanda] Yeah, I think a lot of those tools look like, I think what we would maybe consider like basic AAC or pain boards or whiteboards to draw on or paper to draw. I think offering options whether pictorial or holding to objects. I think the other things for

supportive tools as you think about the wonderful example, from that paper, that visual support. Some other things is, I think the best tool we can offer families, is a better environment. So helping them think through the environment which their patient is or their loved one is and if that's truly supportive to full participation. Is it well lit? Is it too busy? Is it reminiscent? And the last thing I would really say in terms of supportive tools is training our caregivers to talk in a way that is supportive of that patient's current cognitive status. So doing some training and teach back on simplifying some of the communication strategies, offering some binary choices, thinking about rate and rhythm to support that understanding from our patients.

- [Amy] Those are excellent. Those are really excellent examples and what's interesting is that when you're talking about hospice and forgive me 'cause this is certainly not my area but in my experience, sometimes it can change very rapidly for the patient, right? So it seems that that communication with the family is so important for it to be ongoing and constant with how it needs to change sometimes even on a daily basis as you're talking about end-of-life care.

- [Amanda] Well, and I think that's really the advantage to this idea of the consultative model in hospice care. Is that if you had a good consultative model and you worked on a really solid team, you wouldn't always have to be the one stepping in and teaching communication strategies because your whole hospice team and palliative team would already have gone through those. Great interdisciplinary trainings with you and really be working as a team. And I think in the service of patient care we can't always expect that we're gonna get the referral. But a consultative model has a lot of advantages for us to sort of get in there and I would really just encourage, if you work in a setting where you're seeing this happen and I know no one has time for another sort of lunchtime continuing ed sort of situation or in-service. But is a great opportunity to serve the patients, without always being the person on the ground.

- [Amy] Excellent, very good to know. Yeah, very good. All right, well, I think we can go ahead and wrap it up there. As always, it's a pleasure to have you with us, we learned so much. You have such a great way of just the way you talk about this, you have such a caring manner. So we really appreciate you sharing your expertise. So we can go ahead and wrap it up there, thank you.

- [Amanda] Great, thank you so much.