Ethical and Legal Issues in Dysphagia Management - Part 2

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- [Amy] Bare with me. Once again, welcome to our webinar today. Ethical and Legal Issues in Dysphagia Management, Part Two. Today our speaker is Denise Dougherty. She owns and operates a private practice where she conducts therapy with both children and adults. Since 2007, Denise has served on the expert work group of the Physicians Office Quality Measure Project for Quality Insights of Pennsylvania, working on initiating quality measures for CMS, to improve effectiveness, efficiency, economy, and quality of services delivered to Medicare beneficiaries. She is a past president of The American Academy of Private Practice and Speech Pathology and Audiology, and a past member of ASHA's Healthcare Economics Committee. Denise also works as a forensic speech pathologist and expert witness in litigation involving dysphagia, choking deaths and surgical errors. So we're very pleased to have her back here with us. Denise, we're looking forward to part two.

- [Denise] Well hello everyone. We have a lot to cover so we'll go ahead and get started. As far as disclosures, financial disclosures, I am in private practice and I am receiving an honorarium from SpeechPathology.com. Non-financial disclosures, I'm on the governing body for Anew Home Health organization and also on the Quality Insights of Pennsylvania Committee, dealing with medication review. So we know when we're getting involved with our patients we're doing the dysphagia valuation, we're doing therapy, we often are faced with challenges. How do we handle that patient and, or, family that does not agree with the recommendations, and this happens quite frequently in my practice. So we're going to talk about ethical and legal considerations we face when we work with this type of client, and we'll talk about waivers and patient-centered plan of care. Learning outcomes. You should be able to describe the differences between what is considered skilled versus unskilled care. Describe how to develop a plan of care that facilitates safe swallowing on the highest level appropriate diet, or least restrictive diet. Everybody says it just a little different. And then explain how to honor resident choices and mitigate risks, when patients choose to opt out of the recommended dysphagia plan of care. So when we do our plan we are going to talk about, or use, interventions for our patients to improve the status of their swallow. We need to consider that our patients have the right to make decisions about their plan of care. So we need to understand what they're comfortable with and what they're not comfortable with. I never want to force a patient to do a particular exercise or treatment technique that they're not comfortable with. And we need to honor that request.

So if you'd like to do the Shaker exercise or you want to do electrical stimulation, and they have very strong feelings about that technique or that exercise, we need to honor their choices and respect their wishes. So the plan of care has to be something that they are fully in agreement with. We need to make sure that our interventions are facilitating positive health outcomes. So we're always looking at this particular patient, very specific patient. What works for one does not work for another. And the interventions that we're going to utilize should reduce the risks our patients face when they're consuming. So we need to keep in mind they have the right to make their own choices. Whether we agree or not, it's something that we need to respect and honor. So these are points that we need to consider when we're deciding should we treat this individual.

We need to look at is treatment reasonable. So we're looking at the appropriate amount, frequency, duration of therapy, in accordance with accepted standards of practice. But we really don't have a lot of good data as far as how many sessions are optimum for our patients. But we do need to keep in mind that our patients often are frail individuals, they fatigue very quickly. They may not be able to endure the type of exercises that we would like to utilize or they can't do as many reps as we would like them to use. So sometimes we have to do baby steps and then raise the bar. No one gets better in their comfort zone. But I want my patients to feel successful so we may have to start very low in that number of reps or number of minutes that we're going to utilize for this individual, and then gradually increase things as they can endure a little bit more and put forth a little bit more energy and effort. Is therapy necessary? So we're looking at the diagnosis, we're looking at the conditions our patients are dealing with. Not too long ago, with ALS patients, exercise was considered something we didn't want to do, but now there's research out there that talks about using exercise in moderation, that it does have benefits for that ALS patient. So we're rethinking our approach for that particular disorder. We need to look at specifics. What are our treatment goals, what are we trying to target, what are we trying to fix? When we talked about part one we know speech pathologists don't often structure therapeutic exercise to match the deficits that were documented in the instrumental assessment. And based on my professional experience, we are getting fewer and fewer sessions now when we request therapy for our dysphagia patients.

So I want to make sure that what I'm giving my patient in the plan of care for exercises really targets what is not very functional for them. So rather than throw everything and the kitchen sink at them, what is going to target the areas of deficit. But sometimes, when we get those instrumental assessment reports, they're not very clear where the deficits are. So it puts us at a little disadvantage. But I'd like the exercises to work on the deficits that we've identified. Therapy needs to yield improvement in a reasonable amount of time. So when we're looking at perhaps utilizing chin tuck as a strategy, how long before we recognize this patient isn't going to get that chin tuck, they can't do it, they don't want to do it.

So we need to keep that in mind when we're looking at length of therapy and improvement. Sometimes they just could care less about the chin tuck or they're not going to be able to do it because of their cognitive deficits, and they don't get the cuing. So we need to think about what is going to improve their situation in that reasonable amount of time. And we're looking at skilled. So, again, we're going to be talking about what is considered to be skilled versus unskilled care. And we know that skilled care requires knowledge, it requires our clinical judgment, and this is often very complex decision-making on our part. So we'll talk about the skilled and unskilled care. Now really important when our patients are making those decisions. We want it to be an informed, educated decision but they can't do that if they don't have the information. So they need to know what is the nature of their dysphagia to begin with. What are we going to do in the plan of care? What is the cost going to be? What are the benefits of different approaches? So, again, we can offer them several different ways that we can address their dysphagia, but we want them to be comfortable with whatever approach. But we also need to talk about no treatment. That is an option for them.

So if you're going to do therapy and then before we upgrade an individual to a thinner liquid consistency, my protocol, what I would really like to do is get another instrumental assessment, especially if there's a silent aspiration issue with this individual. But sometimes the patients can't afford to go for another test. They can't afford the ambulance transportation. Or they're not going to follow through with anything that we would get out of that study. So it would be a moot point. We need to talk about all the different forks in the road that we can go down for this individual so they can make an informed, educated decision.

Doesn't mean we would like their decision but they have that right to refuse. We need to recognize that patients are considered competent unless we have evidence that says they're not. Just because they don't like our recommendation doesn't mean that they are not competent, so there are legal ramifications here. And there are laws that protect our right to accept or reject any treatment decisions. Again, whether we like it or not, we still need to honor and respect their choice. Now if you have been working with this individual and you've done any type of cognitive assessments, formal, informal, we may be able to contribute to that decision-making process. Are they capable to make that decision, comprehend the choices that they have to make? There is a tool called the MacArthur Competence Assessment Tool-Treatment, and it guides us through the dialog we need to use with our patient, and it addresses four functional abilities of decision-making. Using process of informed consent. And what's nice about this is it uses the patient's own unique decision that they have to make instead of some hypothetical situation. So you may start seeing this particular assessment tool in your patients' charts. Very important that when we are doing our education of this individual, that we talk about the risks, especially when this individual might be moving towards opting out of what we are recommending. They need to know the risks. So what are the possible consequences of things that might happen if you choose not to follow the plan of care or this diet or liquid consistency? And we need to talk about aspiration pneumonia. We need to talk about choking deaths. They need to understand these are possible consequences.

Not everybody who aspirates ends up with aspiration pneumonia but it could be a risk. Now really important that when we're doing this education we're documenting. We're documenting who we talk to, what we said, what questions they asked, what our response was. This is not a note that we can do on 144 characters. So if you're doing electronic medical records this may be something that you write out and then scan it into the medical records, because you're not going to get all of this in some of those dropdown boxes that you have.

That paper trail of that education is really important. When I start looking at medical records I need to see that there was a discussion with the patient, with the caregiver. They were trained on compensatory strategies and so on. That helps when the families decide to enter into a lawsuit. So you can refute that, there's documentation here that says, you know, we talked about this. You're documenting the conversation. So that paper trail is very important. Now we talked about beneficence. We're looking at specific interventions and we're looking at the benefits and the burdens with this individual. So an example would be chin tuck. We know that's a strategy that sometimes works for our patients. But is it going to be a useful strategy if they won't use it or if they're embarrassed when they go to social events or it calls attention to them in the dining room. So is that strategy worth it if they're going to shut down. Sometimes our patients are very frail, fragile individuals and chin tuck, it doesn't use a lot of energy but they may not have a lot. So I'd like them to save the energy that they've got for the chewing and the swallowing, and maybe we just don't utilize the chin tuck in this particular patient situation. If this is an individual that requires constant cuing for that strategy, there are times this person is going to get agitated. If you tell me one more time to tuck my chin I'm just gonna hit you. And we don't want anybody getting hurt.

So is this going to be actually a beneficial strategy for this individual. Sometimes yes and sometimes no. So you need to look at that with your particular individuals. When we talked about nonmaleficence we never want to do harm. So when we take a look at our recommendations, some of the things that we run into. We know that there is studies out there that indicate when you alter the diets it can result in dehydration and malnutrition. So when we thicken the liquids the patients just stop drinking. When we put them on puree they stop eating. There's studies out there that talk about this risk of dehydration and malnutrition.

And I know some of the doctors I've worked with, and you probably run into this as well. They will sign off on the order for the modified diet and liquid consistencies, and then they'll call and say you know what, they're shutting down, I'd rather deal with the potential risk. But I need them to eat and drink. And that's their call. So we need to look at the benefit and the burden. Is this going to really create a problem with oral intake? We know that if you aspirate honey thick liquids that's more dangerous to the lungs than aspirating thin, and your hospital stay is longer. So it's always that fine balancing act between the benefits and the burdens. If there's going to be more bad things maybe this is a recommendation that we just don't do. We're also going to look at justice. What does the individual need? So this goes back to the ASHA Code of

Ethics, and that is principle one, rule one in our code of ethics. So that fine line, the balance. Benefits, burdens, you know. We don't want to do harm to our patients but sometimes that can really contribute to an issue with our individuals. We have a lot of people that the minute we walk into the room they point the finger and say you're the one that did this to me. You're the one that changed my diet. So it can be really difficult sometimes to have a good working relationship if that's their mindset. That we did this to them. So when we're looking at how to minimize harm we've used these approaches. We've modified the diet textures. We've thickened the liquids. We've looked at removing foods that are considered to be unsafe or liquids that are considered to be unsafe, and there are times where we absolutely have to move into a feeding tube situation because the severity of the impairment.

So, again, looking at benefits and burdens. Is a tube feed recommendation really going to work out for this individual? So you go back to what is their diagnosis. We know with the dementia population that is not a good idea. It doesn't change life expectancy. It doesn't turn around that disease process. So we look at the benefits and the burdens. I've had a lot of family members over the years that felt they were kind of pushed into that recommendation for a PEG tube by someone, whether it was the doctor or some other individual on the medical team.

And then they regretted their choice. We need to keep in mind what are the advanced directives that this individual has already put into place. That is a legal document. If you have said I do not want a feeding tube, and it's at the point where you can no longer make your wishes known, then we go back to that document. There are times you've said no but you get one anyway. So if the doctor has placed the feeding tube against your wishes, that is considered battery. So we have to really take a look at that and honor those advanced directives. Know what they are. We know when we're looking at our patients, food has a very important place in their life. We're looking at different cultures, different food preferences that are very important. There's a lot of strong values to eating and drinking. So when we say this food that you like is risky, that changes everything for this individual. We need to keep that in mind. Culturally significant foods could be a challenge for this individual. And when we're doing our instrumental assessments, if our patient has certain ethnic foods that they eat all the time, we need to consider putting that into the instrumental assessment as well. We had a woman who was Korean, she met her husband during the war, came back to the States and now she's in a facility. And they placed her on purees which she hates and she won't eat. Well the husband comes in every day to feed her lunch and dinner and the staff is very respectful of their time. So when they bring in the tray they close the door and he feeds his wife.

Well one day he decided I'm really tired of my wife refusing to eat so he made her ethnic foods, rice and the vegetables and the sauces, and he brought it in in the duffel bag that nobody ever thinks about looking at. And when they brought in the tray and closed the door he pulled out the Tupperware container with her ethnic food and he fed her. She ate everything. He was thrilled, ran out to the nurses' station. Was so excited. "Look at what my wife ate." She finally ate. And the nurse pulled out the waiver of liability from the file cabinet, kind of slammed it down on the counter and said "Sign this."

Well, number one, there's no education. You're just getting a signature on a form and that's one of the issues that courts have with waivers. There is no education. They're just signing a form and they have no idea what they just agreed to. Now if this is something that would work for her, again if she's going for an instrumental assessment maybe that is the diet that we need to be looking at for this individual. But there are a lot of strong ethnic variables here that we're looking at with diets. We know that when we eat we have strong feelings associated with that meal. So when you think about your next meal, what are we going to eat, are we going out, when am I going to order. So we're always looking forward to the next meal. That's a positive experience but how positive is it if your patient is on purees and when they get the tray there's three ice cream scoops. That's not pretty, it's not appetizing. Or if you get that compartment plate with the puddle, that's not appetizing either. So you're not going to look forward to a meal, it's just another thing that you don't want to eat. And we have food memories, so if the food doesn't look like it should we're less likely to want to eat it. That could ruin our day. So you give them food that they don't like the appearance of. You give them thickened liquids that they're just not happy with. It can really negatively affect their mood. It can actually create the agitation and distress on top of everything else that we're dealing with. So there's not a lot of positive experiences with mealtimes in our facilities. If you're supposed to be on nectar thick liquids and what you get, the spoon stands straight up, that just ruins everything. So when you offer them a substitution they're so disgusted they're not gonna take it.

No, don't want it. And now we've eliminated the calories they would get for that meal. When we're looking at the culture, again, when we change this patient's diet it can change the relationship that they have with us. They blame us, look what you did to me. So, again, we need to educate our individuals. When we're looking at limiting those food preferences that can really throw our patients over the edge to the point where I would rather choke to death than eat what you're bringing out every day at lunchtime.

We're looking at now the vegetarian individuals, the vegans. So there's culture, there's different diets that our patients are on. It can get very difficult when we start modifying the diet textures or the liquid consistencies with these patients. So look at the negative attitudes, the positive attitudes. Many times, when we're looking at our male patients, having a modified diet is seen as a sign of weakness. I have to be on puree and that embarrasses me in front of my family. I used to be the strong man of the family and now I'm not. So when we start to see individuals become, and I don't like the word non-compliant, but they're not eating like they used to, we need to go back and reeducate. Why are we starting to see these changes that they're not consuming what they used to? When we're looking at this education, when we do an instrumental assessment, when we do a bedside evaluation, we should be talking to the patient and the family about what our concerns are and what our plan is. Now when we're looking at this education the minute I say you have a swallowing problem, you need to be on a modified diet or thickened liquids, they stopped listening. The minute you hear bad news you start having a conversation in your head and you miss the entire explanation. So we need to keep in mind that reeducation is critical. There's a lot of individuals on their medical team providing information and you can't absorb it all. So if you give them something in writing that they can take in at their own pace, when they have a free moment they can read it, the information sticks with them. So you've done the education. Tomorrow you come into work with them again and you start talking about what happened in the modified or what happened in the bedside and they're looking at you like this is brand new information, and it is.

Because they didn't get it yesterday. So that reeducation sometimes has to happen on a real regular basis. Sometimes it may be every session before it actually sticks with them. So we need to look at that education effort, constantly, with our individuals. We sometimes have conflict between the families, the spouses, the significant others. The patient may want to make a choice and they're competent to make a choice, but the family won't buy them the food that this individual has said that they wanted. So that becomes an issue when this individual goes home. So there's a lot of conflict when we're looking at a patient who chooses to opt out of a diet or a liquid consistency, our recommendations, and the family isn't pleased with that choice. So if this individual has some problems with communication it can be very difficult to determine is this individual actually refusing, are they misunderstanding the recommendations. Are they fearful? And they may not be comprehending everything that we're telling them. So that education is critical. We go to school for a long time to learn the big words and then we can't use them because nobody understands what we're saying. So it's difficult sometimes to take this down a couple of levels to the point where they can comprehend. And what is critical, if this individual is not an English speaking individual, that's not their native language, you may have to bring in a translator that can translate effectively what we're saying. They need to hear it in their language so they comprehend and can make a decision. I had a colleague that said one of her individuals spoke English but it was kind of sketchy and normally a Spanish speaking individual, and they talked to him in English about his dysphagia and he didn't realize he agreed to a feeding tube. And that's what he got so he was very upset. He misunderstood, didn't comprehend. And that can be very problematic. So bring in the translator so this individual can hear that information in their native language, comprehend it and ask the appropriate questions to make a decision. When we're looking at our feeding tube individuals this is a medical intervention. It can provide the calories for individuals.

Sometimes this individual who has a severe dysphagia, it takes such a long time for them to consume. It uses more calories than they're taking in. You can have an improved quality of life sometimes, depending on your condition, with the artificial nutrition and hydration. But the worst thing that we can do is have a feeding tube placed because it takes the staff too long to feed this individual. This is not a let's make it easy on the staff recommendation.

This is a patient benefit, not a staff benefit. If this individual is constantly pulling out the PEG tube or the NG tube we really need to think about the damage that we're doing. And there's an organization called ASPEN, dieticians often belong to that, and what they've found is if you have to physically restrain an individual to prevent them from pulling out the PEG or the NG tube, what's the benefit. So we need to keep that in mind as well. Looking at the benefits and the burdens. And when we're looking at our individuals, again going back to their values, do you know what their values are as many times we don't. So we're relying on family members. I'd like to point out this resource for you. This is a huge benefit to us as treating speech pathologists. It's the "Handbook of Patients' Spiritual "and Cultural Values for Health Care Professionals." This was last updated in 2013. Lots of information about different cultures and different religions that give you a heads up what you might be running into as far as resistance with the recommendations that we're offering. So that is a really good resource when you're making recommendations. I can't emphasize enough, patients have the right to refuse. So, again, they need to know the benefits, they need to know the risks of harm, they need to know the probability of possible harm of treatments, if there's reasonable alternative treatments, before they choose or refuse. So, again, we may think this is a bad choice on their part. We think it's unwise, we think it's irrational. It doesn't mean they're not competent. They've made a choice based on their own values and beliefs and we need to respect that. When we're looking at strategies these are things that we need to keep in mind when we're making our recommendations and communicating to the patients and their families.

We need to engage and educate the patients and their families when we're doing this informed consent process. So we need to do individualized approaches and explain what is the rationale behind what we're asking you to do. They don't often understand what this stupid thing you're asking me to do does for my swallow. So without knowing the benefits, what it is going to fix in their swallow, they may choose not to do it. We need to facilitate shared decision-making. So between the patient, the family and our medical team we need to come together and hash this out, knowing the patient has the right to all of this information. We can't hide things, we can't sugar coat it. And then we need to honor those choices. We need to look at clinical evidence and have an understanding of ethics, law and public policy. So we need to integrate that. We know our patients have the right to refuse. Do not forget that. So we're going back to the code of ethics that we hold the welfare of our person paramount and we need to look at the positive and negative consequences. We can't promise a cure, we can only tell them we're going to do our best. This is what I'd like to utilize in our plan of care to make a difference. Whatever difference we can make in your swallow. But I can't promise I can get you back to regular food and thin liquids, so don't go down that road of promises. This non-compliant issue. If you have given this person, the patient, the family, all of the relevant information they need to make an informed decision, an educated decision, we can't call them non-compliant. They have chosen to opt out, based on their values, their belief systems and what they decide is the quality of life they can live with. So, again, we can't back them into a corner and force them to do something against their wishes. We need to have them actively participate in this discussion and make the decision. So on my form that we have in our home health agency we do have a checkbox, patient and, or, family has agreed to the plan of care. So we've got that. Now when we're looking at comfort feeding this is careful hand feeding and we stop when the patient appears to be distressed. So we're going to provide them with oral intake and we look for cues.

Do we see a change in respiration, does the patient push the spoon away? Do you see increased coughing or throat clearing? Maybe it's time to stop. So we do that careful attentive hand feeding and we do this throughout the day. So this might be a person that's grazing. We're doing it not just at mealtimes we're doing it throughout the day. So this is not as invasive as tube feedings. We continue to do the good mouth care, the therapeutic touch. So it's not just let me feed you. We're interacting with this individual. We're talking to them. Really important, I see so many individuals being fed and the staff is talking to each other, they're not talking to the individual. That needs to be part of the feeding process. Communicating with the patient. When we look at PEG, especially in the advanced dementia patient, the American Geriatric Society came out with their position statement in 2014. And what they found was feeding tube use was associated with an increased risk for agitation, the use of physical and, or, chemical restraints, tube related complications and development of new pressure ulcers. So when they put everything together their statement was careful hand feeding was at least as good as the tube feeding when it came to survival, aspiration pneumonia risk, functional status and comfort. So, again, with that dementia patient we're not going to turn things around for them. This is just prolonging the inevitable. When we look at the individual at the end of life it is not unusual for them to stop eating and drinking. And, again, this is a person where that feeding tube is going to provide no benefit. Often it's very futile. It becomes unethical, it causes distress to the patient and the caregiver. So we go back to that comfort feeding, the careful attentive feeding. Providing food choices when they're interested and alert enough to consume.

Now what they found is a speech pathologist may adopt procedures due to either their inexperience or the practices in the institution where they work. We don't know the current literature or they may be uncertain how to apply current evidence in their plan of care with their individual. Sometimes we just have an automatic protocol that we use rather than making this a very patient-specific plan of care. And many times we don't recognize or fully appreciate our ethical and legal responsibilities. Speech pathologists often feel that they are under an obligation to follow the waiver practices of their employers.

Now there have been some states where if you do a waiver there's a lot of facilities that still use this and normally with the waiver of liability there is a witness that signs it. In some states if you work for the facility you cannot be a witness because it looks like coercion. You're pushing this person to sign the waiver of liability because it's cheaper for you not to puree. It's cheaper for you not to thicken the liquids. So it has to be someone who does not work in the facility that comes in and acts as the witness. So, again, with waivers you need to really check with your legal counsel that the facility has. But, again, waivers are not your best option. I'm going to give you a couple other choices that are much better, as far as documentation of the patient opting out. Sometimes we become very defensive in our practices. So, again, we're trying not to get sued. Bottom line, with our documentation, if we're writing down what happened in our sessions we're providing the details, it is actually better for us rather than a generic note. So you need to make sure that your documentation is very clear and discusses what you do with that individual, their tolerance to this and why you believe that they tolerated this particular procedure. And we'll talk about that as we go through. Now when we're looking at waivers the courts have deemed waivers to be unenforceable when they're against public policy of holding the health professionals responsible for this care that they're providing. And what they found is with waivers, we tend to shift the responsibility to the patient who really doesn't understand what the issues are. And you're holding them responsible.

There was a lawsuit that came up and it provided us with what is called the Tunkl factors and the courts use these factors when they're looking at waivers of liability and they've determined, because of those factors, that waivers are unenforceable in the medical context. They also believe that waivers immunize the professionals from their own carelessness, and it makes the patient assume the risk of substandard care. So waivers really not looked at very favorably from the courts. The next two slides have the Tunkl factors. So what they found in this particular lawsuit that medical care is a matter of public interest and concern.

So it's suitable for public regulation. Members of the public need the health care. This health care arises out of practical necessity, not choice. The service providers offer specific types of health care to whoever needs it. We, as the service provider, have an advantage over the person seeking the service. When we do the waiver of liability the patient believes there is no room for negotiation. It's take it or leave it, there is no middle ground. And when the individual signs the waiver they're actually placing themselves under the control of the service provider and exposes themselves or subjects themselves to the risk of carelessness by the service provider, because you've signed a waiver waiving us of responsibility. So what they've found is standard of care is common law and it cannot be modified by a contract or the waiver. And they've found that waivers undermine the relationship of trust that's very essential between the patient and the speech pathologist. Signing a waiver puts the professional's interest above the best interest of the patient. And that is in violation of ASHA's first principle. So if your facility is pushing towards the waiver you can always come back and identify this is in violation of ASHA's Code of Ethics. Now situations that you run into, or I've run into with waivers. You've probably run into them as well. The courts may believe that the only reason the patient signed a waiver is because they were coerced, they were pretty much forced to do that. And I've come very close to having that happen in a couple of facilities. We had an individual who was on nectar thick liquids and she loved them. It's rare that you have somebody that loves them but she was a happy camper. Problem is, in this facility the staff hates to mix. And they do it badly. Sometimes on purpose. They could care less, and, you know, we've done the education. They still don't know how to do it or don't do it well. So in the kitchen one day they're complaining about this woman on nectar thick liquids. Darn, we have to thicken this stuff.

And somebody has the light-bulb go off above their head saying ooh, you know what, if we have her sign a waiver we don't have to do this anymore. So that's their approach. Every time they bring this individual anything to drink, or a meal, they have the waiver in their pocket. They pull it out and kind of wave it in front of her face and say if you sign this you can have thin. And her comment is no thanks, I'm good. Now they're not happy because I gave you a get out of jail free card for thickened liquids and you won't take it. So now they're irritated and they get a little bit pushier. The next time that waiver gets closer to the individual's face. Sign this and you can have thin. No thank you. They get closer the next time so pretty much it's right in front of her nose. Sign this and you can have thin. There's a point where she may decide, you know what, give me the pen and then leave me alone. You don't do that. You never have anybody sign a waiver because you don't want to do your job, and that's exactly what was happening in this particular facility and thank goodness they kind of nipped this whenever the administrator found out about it. But it can happen. What usually happens with waivers, patients or family go to the nurses station and say we don't want this diet anymore, we don't want this liquid anymore and they're given a paper to sign. There has been no education. So from the family's perspective, I'm gonna get what I want or my loved one is going to get what they want and then when something happens they wanna sue. Well you can't have it both ways. You can't want that diet upgrade when it's unsafe and then hold the facility or the speech pathologist responsible when it went badly. So this is why you need to be very very clear and very specific in your education note.

So there's no coming back and saying you didn't tell me. It's very clearly documented. So waivers not enforceable. Again, the individuals that are involved in here, the different parties, they do not have equal bargaining strength. We, as medical professionals, know much more than the patient. They're not in a position to understand some of the ramifications of the possible consequences that can happen if they opt out of a diet or a liquid consistency. This is seen as a take it or leave it. You can only have thin liquids if you sign this paper, removing us from responsibility. Point number three. The release is ambiguous.

Am I saying I am not going to sue you like for this particular point, for this particular situation, or am I saying I'm not going to sue you forever. We don't know, you just signed a waiver. And legal contract. All parties involved should get something of value. The patient gave up the legal right to sue. The facility got the better deal here. There is an agreement not to bring legal action. The facility gave up nothing but they earned a lot. You can't hold us responsible because you signed this paper and most likely we didn't educate you to begin with. There is something called a shared decision-making algorithm. So this goes back to what we've talked about with education and repeat education. So we do the education initially. Why we're putting you on this diet or this liquid consistency. What is the plan of care? And then we reeducate. Now if you see an individual who is not following through with the recommendations this is the time where you address the reasons why, or that non compliance. So sometimes the family pushes or the patient pushes and they refuse a recommended diet. So we need to make sure everybody understands the rationale behind it, and then if they don't like it what are we gonna do about it. So there can be a lot of conflict between families, between the significant others, between the children and the patient. Everybody needs to be on the same page with this. Step number three in the shared decision-making algorithm is your team meetings.

So this is where we all get together. We have the healthcare team and the family. In this shared decision-making algorithm the speech pathologist should have the leadership role. We're the ones that made the recommendations, we've done the bedside, we have maybe the instrumental assessment as well. So we're talking about the reason why we're making these recommendations. We're talking about risks. We're talking about safety. What are the potential risks if you refuse to accept the modified diet or the liquid consistency, or you refuse the intervention options? There always is the option for no care. One of the potential negative outcomes would be a hospital readmission.

So they need to recognize that. When we do this meeting everything is being discussed. The patient and the family have a voice. This is not just the medical team lecturing the family, lecturing the patient. They're able to provide their input as well. This is a shared decision. What can we do to come up with a compromise that works for everybody? Now there are some difficult issues that we run into. I usually find the first scenario is what we run into the most. It's the most common. We have an individual who wants to eat and drink. The swallow is unsafe and they have a high aspiration risk. If they are cognitively intact, once they are educated, the risks explained, their questions answered, they should be allowed to eat and drink. That was their autonomous decision. They're okay. I'd rather eat what I like and if I choke I choke. But they need to recognize there are consequences that could come into play here. If capacity is an issue we need to talk to the representative or the advocate. And then they would make the choice. Are we going to allow this individual or are we going to agree to provide them with the liquid and the diet that they are asking for? Trying to keep them as safe as they will allow us, give an informed choice. The other issue is we have a patient who is capable of swallowing, they can meet their needs but they refuse. I really haven't run into that. If we have to restrain them to keep that feeding tube in we need to question the benefits. And if we're trying to get this patient to conform, what is that saying about quality of life. And it can really come back on the facility that you're forcing them to live under a recommendation or a diet option that they would rather not have. So, again, we're not doing that autonomous decision-making.

So in this education effort everybody's getting together, we're talking about what we're recommending. We're looking at what this patient and family are asking. So we can come up with an informed choice. All of this needs to be documented, everybody's voice is heard. We share our concerns and then we come up with an intervention plan. And these decisions are clearly documented following that meeting. So important that we have that. Many times the patient decides that their choice outweighs the potential risks and that's their choice.

Now they may agree to work with the speech pathologist and, or, the dietician, taking a look at the diet that they want, and we can work with them to find less risky options. Cooking options, food choices that aren't textured modified that may be safer than some of the other menu options. So you may have to look at the whole range of menus that you've got for the four week rotation and determine, okay, on this day when there's this particular food item we believe is just too risky for you, what can we offer you. When the individual is home, sometimes the family will refuse to cook the food that the patient wants or purchase it, but they may be okay when the patient goes to visit somebody and they eat what they want at a social gathering. So there's a lot of issues with patients and families. I often have a patient that is cognitively intact that refuses therapy. Will not work. And we don't give up on the first try but we go back several times and document the patient as refusing to work on the exercises, whatever. And I will have families that insist I keep coming back and I can't, because this patient is competent. They have said I don't wanna do it, so I can't force somebody to do therapy against their wishes. Now as far as the potential of losing your license, as long as you have involved this individual in the treatment plan, the formulation of the treatment plan, then your license should be protected. But, again, you need to make sure that you've documented all of this information.

Now what I really like, and I would suggest that you take a look at it, it's called the Rothschild Person Centered Care Planning Process. And it guides everyone, the staff, through this discussion, and it demonstrates to everybody that would take a look at it, whether it's the resident, the family members, state surveyors, that the care community has done their due diligence. We've assessed the patient's functional abilities. We've looked at their decision-making capacity. We've weighed the potential outcomes, positive and negative, of respecting and aiding the patient in pursuit of their choices.

We've reviewed the potential outcomes, positive and negative, of preventing them from acting on their choices. So it's very detailed and the form is, it lays it all out for you. So these are the five steps. You identify and clarify resident choices, discuss the choice and options with the resident and, or, the family, if they're involved. We determine how to honor the choice, which choices are not possible to honor. Communicate the choice through the care plan and then we monitor and make revisions to the plan. So if you go to this particular article they do have examples, looking at diet modification issues, consumption of alcohol. They give you a completed form to see what you should take a look at and then there's a template that you can use. So when we're looking at identifying and clarifying resident's choice, what do they want that is a concern for us. Usually it's a texture issue, it's a thinner liquid. So they would rather choke than eat purees or thicken liquids. Why is that important? Texture and taste. We have a food memory. This is unappealing to us. I'd rather have a healthy, nicely prepared and presented meal, that's a priority. We look at safety and risk concerns. Was there a choking issue? Did they have a Heimlich? So we're going to have that in this document. And then who was there to represent the resident. And who was there from the care team? When we get into discussing choice and options, we're looking at potential benefits to honor their choice. Potential risk to honor their choice. And then we're giving them alternate options to discuss and then we pick from those. So here we've given them several things, try modified diet texture. We work to find less risky foods.

Teach them the universal sign for choking. Maybe they participate in dysphagia therapy. Maybe we always have at least one soft preferred food item available for them. We discuss education. We talk about the risk. We explain to the family that the resident is capable of making this decision. If they're not, again, we're working with their advocate. We're looking at the patient's preferences and we're working with the staff and who was involved in that discussion. We're looking at how to honor the choice. So when we look at the options that are presented, patient finds the ones that are acceptable.

So we've got a couple here, family can bring in their favorite foods. The plate is more appealing in presentation. We look at less risky foods. If there's no option what do we do then and who is involved in that discussion. And point number four. We're communicating that choice through the care plan. And we always look at when the care plan was updated, what specific steps we're going to take to make sure everybody followed that option that we agreed on. And then we monitor and make revisions. So we assign responsibilities. Who's going to track comments, who is going to track consumption? So we've got everything down. That is your best option. You just follow the template and you've got everything. That is much better than a waiver of liability. When we get into the Model Medical Review Guidelines for Dysphagia Services, again we need to look at skilled level of care. So our documentation should identify that's what happened, rather than this was a non-skilled, we were just observing, writing down what they consumed, et cetera. So when we break it down into what is skilled versus unskilled, we can establish the maintenance, functional maintenance program, we can train staff, we can do the patient caregiver training, compensatory skills training. What is considered unskilled? Repetitive task with no change in complexity, cuing or level of independence. How many have ever seen in documentation patient tolerated diet or treatment. Well that is considered to be an unskilled statement because just about anybody could say that.

So you need to identify why you believe they tolerated that diet or treatment, so expand on that. When we look at diet and liquid consistency, national dysphagia diet, we're phasing that out and we're moving into the IDDSI. So if you haven't investigated the IDDSI yet, IDDSI.org I believe is their website. It's going to give you the framework, easy criteria for determining bite size. I always draw out on a piece of paper the bite size so they've got a visual, instead of four millimeters, which means nothing. And there's easy ways to test the liquid consistencies and there's a lot of frequently asked questions about breads and meats, indentation and show on, rationale for your recommendations.

So if you haven't looked at the IDDSI I'd recommend that you start looking there. When we're looking at the plan of care for therapy we want to get them to the highest appropriate diet or liquid consistency. But remember, it may not be thin and regular. Every time we do an upgrade we're taxing this individual. Their muscles. We're taxing the swallow system. So they may not have the strength, range of motion, tongue pressure, or the chewing to warrant that upgrade. And trials can certainly be misleading. We may not see fatigue with a couple of sips or a couple of bites. There's a big difference between trials versus an entire meal. If you're seeing this individual at breakfast remember lunch and dinner probably more fatigue in those meals. So don't make your diet upgrade based on one particular meal. And you may want to look at several different meal times before you make that recommendation for an upgrade. Be really careful with your documentation. So if you're talking about trials, what diet level did you try and then what food item did you try. If you say I did a trial of mechanical soft or IDDSI minced moist, what did you give them. What food? Was it a snack, was it a meal? And vary the meals so you can really take a look at the impact of fatigue. Did you just look at bites through the entire meal? Did they self-feed or were they fed? How much cuing did you need to provide? Were they able to self-monitor? Then look at their performance.

So instead of saying they tolerated it, let's talk about their performance and what you saw as far as any overt signs or symptoms. Be really careful with strategies because I see this a lot in lawsuits. Nobody knows what the strategies are. They don't know where to find it. Everybody has a different idea what aspiration precautions are or swallow strategies. So you need to identify what are we talking about with this. Don't assume everybody knows. When we're looking at staff education one facility I had to write out everything as far as the strategies that we're going to use. We need to also document these staff in service that we did, teach the staff how to do the feeding strategies.

So we did talk to the dietary department about bite size, you talk to your nurses about bite size so they know. They know what should come out on that diet level. And then where are we going to put all of this information. People need to know where to find it. Sometimes you'll have a communication book at the nurses' station, so anything that's new and different the staff is responsible to read that note every day when they come in and initial it, so they did get the information. So make sure when you're talking about education and training, who you trained, did you give them something in writing. Did you give it to them verbally? Did you demonstrate? Were they able to demonstrate comprehension? When we talk about trials, again, be much more specific so we know. In a functional maintenance program this isn't something that should take months to come up with. This is usually close to the end of therapy. We educate our staff and the patients and the family members. We may observe them for a session or two to make sure that they're doing what they should be doing, and then we back out. So be really careful. Again, documentation is key. That's important as somebody comes in to cover your patients. They need to know exactly what you were doing and sometimes the notes are very vague. Those dropdown boxes sometimes don't give us a lot of detail, so everybody sounds the same and that's bad news when there's a lawsuit because we don't have specifics. If you didn't write it you didn't do it. I see this all the time. I read it in depositions.

Just 'cause I didn't write it down doesn't mean I didn't do it. Yes it does. It has to be written or you didn't do it. So always remember to document your education that you've done with the patients, the families and the staff. That's usually what comes back to haunt you if there is a potential lawsuit. And then what are the strategies and precautions. What exactly are they? So everybody's on the same page. So take aways. Make sure you understand patients have the right to make an informed, educated decision but they can't do that without the information and all of the information. We need to recognize the impact of religion and culture when they make their decisions.

So go back to the handbook that I had mentioned. They can choose or refuse. Even if we think this is a bad idea it is their choice. That documentation is critical because it does tell us, it tells anybody that's reading this note it was a skilled treatment and you did educate. And then waiver's not our best idea. Shared decision-making algorithm or the Rothschild process. I would recommend either of those last two and skip the waivers, to be on the safe side. It gives you much more detail and again, with the Rothschild, there is no question who is involved in the meetings and what we did is far as our due diligence, to try to honor this patient's choices. Okay. So we'll open it up for questions now.

- [Woman] All right, great, thank you so much Denise we really appreciate you sharing your expertise with us. If you'd like I can go ahead and read the question for you and then you can just focus on providing a response. So.

- Sure, thanks.

- When completing documentation it is from my perspective, is it best to have multiple staff members document results of team meetings related to dysphagia care plans.

- [Denise] If you're doing a care plan usually there's somebody taking the notes of what happened and who said what, so it should be there. If you're not doing this in a care meeting, again if you can have a social worker talk to the individual, the dietician, the speech pathologist, the doctor. The more individuals that bring this information to the family, sometimes the better it is. I know I can say nectar thick liquids and the patient kicks me out. The doctor comes in and says nectar thick liquids and they say oh sure, because he's the doctor. He knows what he's talking about. So sometimes it's the messenger and they may accept one messenger better than other individuals. But again, if you go back to the Rothschild, everybody is involved. We document exactly who is there for those conversations and those meetings, and we have everybody's input in that form.

- [Amy] Okay great, thank you. Next question. How do you feel about family members providing comfort feedings? Does it require?

- [Denise] I think you need to educate the family on how to minimize the risk. You could observe them for a couple of sessions and make suggestions, and then discharge. I would probably do several sessions with them, different meals if you could, just to follow through with what they need to do just a little bit differently or a little bit safer. Position, bite size, rate of presentation and so on. And then document that you did that.

- [Amy] Okay great, great advice on that one as well. And we'll give just a few more moments to see if there are any additional questions.

- Okay.

- [Woman] In the meantime, again, thank you so much for joining us today Denise. We really appreciate your time and sharing all of your knowledge. For anybody who was unable to join us for part one, that is available in the library now so you can go back and take that at your leisure. And as Jill is saying, thank you, this was terrific. So I will definitely, I feel the same way. Okay here's one more question. In the hospital setting, after education is provided to the patient and family, and the patient wants to eat despite risk, does speech discharge the patient.

- [Denise] What I would recommend, if they don't like your recommendations and you immediately discharge you open yourself up for patient abandonment and you don't want that. So I would recommend that you work with the family, with the patient, for a couple of sessions, again just to look at strategies, bite size rate, position. Give them the advice and critique and document that you worked with them. They demonstrated comprehension. And then potentially you can ease out. There are a number of individuals that you still might want to do therapy on because you think you can still make some improvement in the muscle function. So just be careful not to discharge them as soon as they say no I'm not going to do this, because it looks very suspicious.

- [Amy] Great, okay great advice on that. All right, let's go ahead and wrap it up there for today. That is our last question so I'd like to thank everybody for joining us. We certainly do appreciate your time and look forward to seeing everyone again soon, take care.