Decision Making for Alternate Nutrition and Hydration - Part 1

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- All right, everyone, once again, welcome to Part 1 of a two-part series. "Decision-Making for Alternate Nutrition and Hydration". And our presenter for both Parts 1 and 2 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, specifically medication review. Denise also works as a Forensic Speech Pathologist an expert witness in litigation involving dysphagia, choking deaths, and surgical errors. Denise, it is always a pleasure to have you here with us.

So I'm going to turn over the mic to you. Welcome!

- Hi. All right. I think we're all good. So let's move this out of the way. All right. So "Decision-Making for Alternate Nutrition and Hydration Part 1". I'm not going to spend time going over the disclosures, you've got those. Okay. But we do want to talk about the learning outcomes. So as a result of today's session, you'll be able to describe the impact of culture and religion on alternate nutrition and hydration decision-making processes. You'll be able to identify two advance directives that allow patients to make their choices known, and list criteria that are important to the patient and family when they are making those decisions about alternate forms of nutrition and hydration. So when we talk about Part 1, we're going to look at the concerns that impact the decision-making process from the patient and family perspective.

And we'll be talking about religious and cultural beliefs, things that they bring to the table that sometimes we may not be aware of. We'll talk about advance directives that you may find in your patient's medical charts. And we'll also have a lot of different resources for you that you can review and use those when you're discussing these options with your patients. So we're going to do an overview about what we know, but we'll also be talking about culture, religious beliefs, the advance directives, resources that your patients and families can use and how you can create resources that have good readability for the patients, so they understand. And then the criteria that patients and families may be looking at when they make these decisions.

So what do we know? One of the options that we may be looking at for our patients is a short-term placement. So this is usually the NG tube, but there is a high rate of pulmonary aspiration and many of our patients will self-extubate, one good chunk, and there it comes. Even the staff sometimes can inadvertently pull the tube and it's no longer in the right place, so now we have complications. Also, it's very possible that if the patient has a really vigorous cough or vomiting episode, that that tube can migrate upward and put them at risk. Now, one thing that we need to remember with an NG tube is in my experience, they've always looked at an x-ray to make sure that it was placed in the right position, but sometimes it is, but there's still other issues that kick in.

We had a patient where the tube actually kinked. So when we turned on the fluoro for the modified, what we saw was the two went down over the base of the tongue, it hit the epiglottitis and kinked. It came back up past the VLM and into the nasal passage. And then it came back down and went the right direction. So every time she was following that epiglottitis was hitting three NG tubes. So she was very miserable and she had every right to be because you shouldn't be hitting three NG tubes, so it can kink, and we need to watch out for that. When we're looking at more long-term placement, usually we're discussing a PEG or it's possible that the doctor may feel the J-tube is more important for the patient, but you can still have an aspiration event with those.

When we're looking at long-term, this is usually the option, our patients are given as far as the recommendation, but there are problems. When we talk about informed consent, or informed refusal with PEGs. Now, if you're using an IV, that's one way that we can rehydrate a patient, but another option is hypodermoclysiss. And it is placing a needle under the skin, and this is a way that we can rehydrate patients who have a mild to moderate dehydration. And if you take a look at the images on that PowerPoint slide, those are all the different positions where it may be placed. So we could put it on the thigh, or if we have somebody that really likes to grab, we can put it on the shoulder blade area, so they don't have good access to that.

But the nice thing about this is it's four times less expensive than an IV. It reduces the nursing care compared to an IV and it's easy to use, so it can be used in the nursing facility, but it can also be used at home by the patients and the caregivers can be trained as well, so that's another option. If we feel that our patient may not be appropriate for either an NG or a PEG, and there are certain times where that's going to be the case, especially when we're looking at advanced dementia, we could move into the comfort feeding. The Ethics Subcommittee of the Society for Post-Acute and Long-term Care Medicine suggested comfort feeding: as long as the patient was willing to accept the food and drink, and we would stop at the first sign of distress.

So in many facilities that I've been at, we will often feed them throughout the day. So this isn't just breakfast, lunch, and dinner is periodically throughout the day. So that's five or six times, you know, whenever the patient is willing to accept it, we're certainly going to offer it. And we give the caregivers, the nursing staff, things to look for that indicate maybe you need to stop. So if the patient begins to have coughing or their breathing pattern is changed from when you started, you just need to document, you did the comfort feeding until the patient exhibited signs of distress and identify that. So it's a way that we can provide oral intake for our patients who have advanced dementia.

And they're suggesting that tubes should rarely be placed if at all, in a patient who has advanced dementia, but we know that sometimes they are placed. Now, when we're looking at regulations, there could be institutional policies to ensure adequate nutrition, hydration, there could be regulations that your facility needs to work within to make sure that our patients get the nutrition and hydration that they need. But sometimes those policies can inadvertently impose requirements on this patient who has advanced dementia. That's not in their best interest. So we need to look at what works for that patient at this particular time and go from there. Now, there was a 2009 study, where they found only one out of three healthcare proxies, reported the doctor ever discussed the trajectory that dementia takes, they were never informed about how the disease progresses.

They were never told about the complications, their loved one would experience such as feeding problems in the involuntary weight loss, they were never told that information. In a 2012 study, they looked at 36,000 patients in a nursing home who had advanced dementia and a feeding tube, in looking at that 36,000, they found only about 5.4% of those residents had a minimal difference in survival benefit versus those who did not have the feeding tube and remained as an oral feeder. When were you looking at the American Geriatrics Society, they suggest careful attentive, hand feeding. And when they looked at that versus tube feed, they felt that the outcomes were basically the same. The tube feeding is certainly much more invasive, there is a 30-day mortality rate with patients who have the feeding tube placed.

So they felt that a careful attentive hand feeding would be a better option. Now they talk about different types of feeding, and we'll go over those in just a minute, but there is direct, there is hand over hand, and there's under hand. And when they looked at how much time it takes to feed an individual, each one of these methods took about the same time. So there wasn't one that was quicker. They felt that using under hand or direct hand was better at managing the feeding behaviors that we often see in this population, the turning the head away, the clamping, the mouth shut. So it was easier to manage those behaviors in feeding them with under hand or direct hand.

But we do know that when our caregivers are feeding these individuals, they require some skills. They need to know how to manage the dysphasia, how to minimize the risk of aspiration. They need to know how to interpret and manage the feeding behaviors that our patients are exhibiting. We want this patient to feed themselves as long as they can. We want them to be independent, but there's a point where we need to do some assistance. When they compared those individuals who had the assisted hand feeding versus the NG tubes, there was no increased rate of hospitalization if they were fed versus having an NG. In fact, when they looked at patients who have the NG tube, those individuals had an increased risk of pneumonia.

So the feeding techniques, we'll talk about these. Now there's one that I wanted to address this called graded assistance. Now we've all seen staff talk to our patients in the dining room, pick up your spoon and eat and the patient doesn't, it's like, they're talking another language. So if we use graded assistance with that individual, all that means is we're preparing this person for the bite, but they're doing the self-feeding. We want this patient to sell-feed as long as possible, because every time you bring the food to your mouth, you're getting messages to the brain saying, get ready something is coming, and they know they're prepared. So with this graded assistance, you're putting the bite on the utensil, you're putting the utensil in their hand, and you're giving them a little kind of a jumpstart.

So they've got that reminder, okay, I need to bring the hand up. And when they put the food in, they put the utensil down, they chew, they swallow, and now they don't know what to do. So that is the graded assistance, technically they're doing the self-feeding, you're getting them ready and give them that cue to get the arm up. Now we can do hand over hand. So the patient holds the utensil, they just need some help getting the food from the plate to the mouth. So in this case, you're putting your hand over their hand and you're gently bringing everything up to the mouth. There are some individuals that really don't like you helping them that much, and they get a little bit feisty and lash out.

So you always need to look at your patients sometimes as much as you would like to use these techniques, they're gonna get agitated. With under hand, they can't hold the utensil. So you're going to put your hand under theirs and guide the utensil up to the mouth. So again, the hand is moving, they're getting that sensory input to the brain saying, get ready something is coming. And then we do the direct hand. So we're going to spoonfeed this individual. So they're recommending in the literature that you save this method for the late stage, when we've got nothing else to offer. If you come into quickly and you feed this individual, you're actually creating the excess disability.

We want to hold off and make that person as independent as we can make them. But we want to make sure when we use this technique that they can see the food coming, so it's not a surprise when all of a sudden you're, here's a spoon and you're trying to get it in their mouth. So when we're looking at choices, we always want to make sure, we're patient-specific. This is not a cookie cutter approach. So when we say there's no right or wrong answers, it is for that patient. So you always need to forget the cookie cutter and look at this individual, their set of circumstances and factor in everything. Is this a good recommendation?

So we can offer them a trial of alternate nutrition and hydration, but we need to be very clear that we're only going to do it for this amount of time, this many weeks, this many months. And if you're the patient, if I don't like my quality of life after this timeframe, we're done, it's going, take it out. We can do short-term, which would be the NG. We could do the long-term, which is your PEG. Or we can say thanks, but no thanks. So we have a lot of families and patients that say, "You know what, foods, my last pleasure in life, and I want my pie, I want my cake, I want my coffee.

" And if they have decision-making capacity, that's their choice. They have every right to make that decision for themselves. If they don't have decision-making capacity, then we need to look at the surrogate decision maker, the healthcare proxy. So there's a lot of different options that we can present to this patient. But again, we need to look at the set of circumstances to come up with what those are, and make sure that we're doing the education. We want this individual to make an educated, informed decision, whatever it is. Now, I have not seen a better number than this, but a conservative estimate for what just the two feed costs per year, is about $32,000. Now we know when you have the feeding tube, you're going to have disuse atrophy of the muscles.

You're not going to swallow except for a saliva. And a lot of our patients don't even have that to swallow. So there's very little movement of these muscles. So we end up with disuse atrophy, what they found is even one week in bed, leads to substantial muscle disuse. So we're talking about the small muscles. If they don't have saliva in their NPO, there's really nothing that they're swallowing at all. So we're going to see some really involved atrophy. Giselle Mann had mentioned that measurable within 72 hours, if we have that disuse atrophy kick in, and what will happen is the fast twitch fibers, the muscle fiber type two that we trigger when we swallow are really impacted by that atrophy, and it's very hard to reverse once we get into that MPO situation, or even when we're in a modified diet.

When we're looking at the advanced dementia patient and a PEG, there was a general consensus among gastroenterologists in the United States that there was absolutely no benefit for going this direction for anyone who had advanced dementia. What they found was, looking at individuals who had advanced dementia diagnosis in a nursing home and had a PEG, almost 20% of those individuals had to have the tube replaced or repositioned in a two-year period when they did follow up. And that resulted in more emergency room visits. So their cost of healthcare went up with that feeding tube. And what they found was, nearly one third of those individuals who did have the tube replaced needed it replaced at least twice.

When we're looking at the timeframe for survival after repositioning or replacement, it's about 54 days, median survival. And we know that when individuals have a PEG place, there's a high 30-day mortality rate with that. So we want to be very careful with these recommendations. When they looked at individuals who had an NG, they were certainly at a much higher risk for death versus those individuals who were fed orally. And there's a certain issue with survival, with a PEG fed group. They survive not as long as those individuals who continue with oral feeding. Now with costs, this is a little difficult to kind of grasp, but the cost of hand feeding a patient, and they looked at 11 individuals.

So again, we're looking at a small cohort here, but the cost of doing hand feeding was much higher than the cost for a patient who was tube fed. It wasn't as labor intensive, but when they looked at the costs that were billed to Medicare for the patients with the tube feed, they had higher costs than the patients who were hand-fed. And that's because we're looking at the cost of placement of the feeding tube, we're looking at complications that send them to the emergency room, we're looking at the higher costs of their inpatient care. So they're more expensive when they do send the bills to Medicare. What they found was if you had advanced dementia and a tube feed, and you were in a nursing home, you had higher odds of spending time in the ICU, and therefore your cost of healthcare went up and your complications went up, and it was all related to the feeding tube.

So when we come together, and we're looking at our options, everybody comes to the table with certain viewpoints. From our perspective, us as speech pathologists from the doctor, we know the disease process. We know what is going to happen over the course of this disease. We know the benefits and the burdens. You know, we've looked at studies, we know the good things and the bad things that happen, and it's our job to educate the patient and the family about the options, good thing, bad thing. The patient and the family come with a whole set of other issues and beliefs. So we're looking at quality of life. This is not the quality of life I want, or I want for my loved one, there is no feeding tube, food is there less pleasure in life, I want them to eat.

They have religious viewpoints, they have cultural viewpoints. So sometimes we're just in a battle, you know, with those belief systems between ours and theirs. So we can really reduce the number of clashes if we understand their viewpoints and where they're coming from. What they've talked about in the literature is a combination of health literacy and patient centered care. So the decisions that we make, the options that we offer our patients should be respectful of and responsive to the patient's preferences, their values and their needs, rather than this is just how we treat Parkinson's, or this is just how we treat advanced dementia, we're looking at the patient. We're also looking at health literacy, we need to make sure that whatever literature we give them is something they can comprehend.

You know, we go to school for a long time to learn the big words, and then we can't use them with anybody because nobody knows what xerostomia is. And it sounds really cool, but, you know, I don't know what that is. So we need to take it down, sometimes several notches for the patient and the family to actually understand. So we need to also recognize the culture, the religious, the social values that need to come into play, because if we're not recognizing that, we're not gonna have good communication, and the healthcare experience suffers for this individual. So the teach-back technique is something that is recommended. I'm sure many of you are using that already. We use this a lot in home health.

So we're going to explain or demonstrate the exercises. We're going to explain or demonstrate how to process the food and the same thing with thickening their liquid. So let me show you how to do it, and then you do it so I can watch. So we're making sure that after we do the explanation, the patient or the family can explain how to do it or demonstrate that they know what we were talking about. If they can't do that, we need to go back and do that education again. So I always like to not only do the verbal instruction, but leave them with a handout. So they understand they've got something to refer to once I leave their home or they leave the office.

Needs to have good readability, that changes how they take the information in, they may misinterpret it. And they may not even ask what this term means because that reflects badly on them. So we want to make sure, and this particular source was talking about taking everything down to about a fifth grade reading level. You'll see other sources that talk about the seventh or eighth grade reading level, but it needs to be something that they can comprehend, understand what we're saying and then be able to follow through. So we need both that health literacy and the teach-back method. Now USA Weekend, this was a 2009. So they were saying at that point, patients forget about 40 to 80% of the information when she leave the office, you know, I can explain everything, and the minute I leave, I just got a text from a nurse in a home health situation, and she was asking lots of questions that I had just covered with the patient, but, you know, they missed it, even though it was written down, we talked about it.

There were still, you know, some misunderstandings. So you need to make sure you've got that explanation. And also you've put it in writing that they can go back and refer to. There is a guide it's called Simply Put, this will help you create easy to understand materials. So it gives you a test for readability, and that can allow you to bring it down to a level where the patient may actually comprehend and the family can comprehend as well. So from the patient's standpoint, there's a lot of factors, certainly we know there's a disease process here, but we're also looking at their quality of life, which is a huge factor. You know, I want what I want, I'm not gonna have the tube, I want to eat, it's my last pleasure.

If I go, I'm gonna go out with a piece of pie, you know, that's their viewpoint. We have their culture and their religion. So it's that combination that sometimes gets in the way or changes their willingness to go with options that we present. So again, that culture clash between the patient and the healthcare providers, everybody's coming to the table with their own experiences, and many times they're not the same. Now you should a link to this resource that you can download. And I would strongly recommend that you download this and use, it's called the "Patients' Spiritual and Cultural Values for Healthcare Professionals". It's an 89 page handbook. I, it talks about Western religions, Eastern other religions and cultures.

So it covers amazing amount of information. So we're going to talk just a little bit about some cultures, some religion, but it's just going to be a quick overview. I mean, this could be an hour's long course if we wanted to make it that long, but the handbook should give you all the information that you need to look at religion and culture. We know in the United States about one-third of the population is made up of ethnic minorities. Many times when we're looking at these minority populations, they want to hide the information, the truth from their loved one. They want to protect their loved one from the truth, they want them to enjoy their last days, they know what's best for the patient, the patient doesn't, you know, you're getting better, mom.

So there's a lot of information that they were holding onto, the patient isn't privileged to know. You need to know because we can spill the beans, and we should not have said that in front of the individual. I always like to talk to my social workers because they've had more contact with the family perhaps than I have, I've may have just the patient, but they've seen the whole picture so they can give me, you know, ideas about who is the go-to person? Who is the healthcare proxy? Sometimes we think it's the family member that's in visiting all the time and it's not. So we will always want to direct our information to the person we should be talking to for these decisions.

We also have to be very careful not to generalize because there's always gonna be somebody that doesn't really follow the book on what their culture or religion states. So when we talk about these and when you go back to the handbook, you're going to see that they also talk about eye contact. They talk about personal space, how close can you come to this person before they feel violated, you're in my space. Sometimes when we're talking to an individual, they may not make eye contact, and we could be very put off by that, but in their culture, we're considered an authoritative figure and as respectful not to look at us, so we could take it as almost an insult when really they're showing us respect.

So you'll see the information about eye contact and how much personal space and touching that this culture is okay with, you know, some people are really touchy, feely in others. Like, no, no, you're too close. So when we're looking at European-American, generally speaking, they favor directives, they want treatment limited at the end of life. When we're looking at Asian, middle Eastern the family tends to make the decision, they want to protect the patient from the bad news. And they're not great with the eye contact, because again, you're considered to be an authoritative figure and I'm showing you respect by not making eye contact. With African-Americans, the general rule is they prefer aggressive treatment rather than limiting.

And they're more likely to be discharged to an extended care facility twice as likely to request life-sustaining treatment, if death is inevitable versus the Caucasian. If you're working with an older African-American there, and again, depending on the part of the country that you're working in, these individuals may have a real distrust of the healthcare system because of segregation, discrimination. And I think we've seen a little bit of that with the vaccine discussion that's been on everybody's radar. They may also have very strong religious beliefs. You might run into somebody that is considered to be a fictive kin. That's an individual who's considered to be family, but they're not a blood relative. With Native American, they tend to reject directives.

In fact, it may be the tribal leader that makes the decision. They focus on the self-fulfilling prophecy in many cases, as long as we don't talk about it, it won't happen. So the minute you put it out there, ooh, you know, it's gonna happen, you shouldn't have said anything. Generally speaking with Hispanics, they don't, I usually institutionalize or take advantage of hospice because they believe that denotes that we've given up. So they're more likely to have CPR alternative forms of nutrition and hydration, intubation versus the Caucasians. With Mexican-Americans many times, there was a belief the doctor knows best, and they could be heavily influenced by the Catholic faith. We want to spare the individual pain.

So it's going to be us that makes the decision. When we're looking at the Japanese culture, there may be the patient who defers to the family or the doctor to make the decision. 30% of individuals that were involved in this survey believe that ANH relieves symptoms. I, the Japanese oncologist, when they were surveyed, 24% said that withdrawing life supporting treatment was never ethically justified. So once you placed a feeding tube, it was there, we're not taking it out. They believe that IVs are the minimum standard of care. So same thing with alternate forms of nutrition and hydration, that is the minimum standard of care. So once we have, it is going to be continued until death. With Chinese, eating is as important as the emperor.

So food is really important and has a lot of significance. They often believe that if the isn't eating and they're starving to death, quote unquote, they will become a starving soul after death. And these individuals may be very heavy into utilizing Chinese medicine, herbal remedies, again, that's their culture. The eldest male child tends to be the primary decision maker. So you're going to work with that individual only. When you look at the Hong Kong Chinese, they commonly use, I, ANH, if there is for intake or there is a risk of aspiration, they believe the tube feeding is only a medical intervention when you're administering meds. They also think that if there is a problem with the swallow, it is disease complication that you need to fix, you need to treat.

Indian culture, they often are practicing alternative medicines. They believe that hospice is a place where individuals who don't have families go to die. So there's a lot of withholding information from the patient. You know, we know what's best feeding you is symbolic, that gives us more time with you, it's a basic act of caring. In hospice Foundation of America, they looked at a five-year study in Northern California, and they found that the Hispanics, Asian, and Pacific Islanders were 5.2 times more likely to have alternative forms of nutrition and hydration at death versus the non-Hispanic Caucasians. So many times, you'll see, I want everything done. Now, when we look at religion, yet everybody has some religious beliefs.

You know, they could be spiritual, rather than I am a very strict church goer. So it's really important, everybody is knowledgeable about the religious beliefs. You know, we can respect that in our discussions. So there's a list of religions where the patient has the right to decide, they don't want any extraordinary effort. When we look at Roman Catholics, there was the discussion that alternate forms of nutrition and hydration is appropriate, if the benefits outweigh the burdens. So as long as there's more good than bad, it's perfectly okay. Now, Pope John Paul made a statement about withdrawing ANH in patients with PVS, he felt that that was euthanasia, that tube feeding was not a medical act, it was something that we were obligated to do, it was moral, but he was talking about persistent vegetative state, not any other terminal States, and it seemed to be misinterpreted.

With Protestants, they're comfortable with life sustaining therapies. And they again, the general thought is if there's little hope for recovery, most would understand and accept withholding or withdrawal of therapy. So we either don't do it, or if we put it in, you know, we placed the PEG, we can take it out, taking it out is so hard, it's harder than not doing it to begin with. Greek Orthodox, withholding, withdrawing is not allowed even if there's no perspective, prospect of recovery. There is number of different sex in the Jewish religion, Orthodox Jews tend to be the most religious. So generally speaking, food and fluids are considered to be basic needs rather than treatments. But if you're in the final days and the patient wishes, you may withhold the food and fluids.

And by that point at the end of life, most patients really aren't eating and drinking anyway. They talk about the Four Tenets of Jewish and Secular Medical Ethics, this is really what we see in ethics to begin with. So being able to make your choices, we're looking at benefits versus burdens and avoiding doing harm. In the Islamic faith, basic nutrition should not be discontinued, it would be a crime in the religion. And when we get into the Hindu, Karma is a big concept, so good death versus bad death, and it all goes back to reincarnation. A bad death would be in ICU, many times, this individual have a do not resuscitate because that means it's going to be a peaceful death.

So the decision is left to the family. And then we have the Buddhist concept, they really don't have anything as far as a mandatory use of ANH. And in Confucian, you want to make sure the family has all the information and protect the patient from the knowledge. So when we're making decisions, especially at the end of life, you, we may have a lot of factors that we need to consider, especially when we're looking at individuals who have immigrated. Now, if they're a recent immigrant, they tend to really adhere to their religion and culture from their country. But as we have the additional generations, second or third generation, those individuals may be more interested in being more American, talking about the United States in particular.

So but what we found is in these studies that even though they want to abandon their original religious and cultural values, when they're facing death, they tend to revert back to their traditional cultural beliefs. When we're looking at advance directives, we want to take a look at what is called Advance Care Planning or ACP. And here's where we run into problems. Those conversations don't happen until usually the patient is in the hospital, they're actively dying or they're refusing to eat. So what we need to make sure we're talking about with our families and our patients, when there is a diagnosis, we need to talk about how this is going to progress. So they know, they need to be prepared.

What do I have to look forward to? What do I need to prepare for? So we can make your choices. Now you have decision capacity, you can make your choices, but if you wait too long, it may not be something that, you know, we can take your word for what you want, you're incapacitated. And this is really important now that we're dealing with COVID, 'cause we see so many times a patient goes into the hospital, they're young, they're healthy. And the next thing you hear from the family, oh my gosh, they're at death's door. So there are resources where you can talk about how to prepare for COVID, you know, what you can do now. One is called proactive planning, be prepared and take control.

So there's a lot of information out there. It can happen to any of us, you know, are we prepared for that possibility? What are our choices? And we talked about decisional incapacity, and they found that individuals in hospice or adult inpatients about 40%, weren't able to make their medical decisions, they were incompetent to do that. In ICU, about 90% or more. In general, for the United States population, only between 20 and 29% of individuals have advance directives. And when there's a crisis, now who makes the decision? They found that 70% of elderly who were in their final days, did not have decisional capacity. So again, with COVID, you're healthy and all of a sudden, we've got a crisis, and we weren't prepared.

We didn't identify a healthcare proxy, surrogate decision maker, and we certainly didn't communicate with and what we would want. And with COVID, there is a place for alternate forms of nutrition and hydration. When we're looking at palliative care, that certainly does reduce the healthcare burden, the cost of healthcare, and it eliminates unwanted care. So we can have the individual eat by mouth if they choose to do so. When they're in palliative care and move into hospice, there's fewer emergency room visits. So we can help the family and the patients start to discuss and come to grips with decisions that they need to make, given all the information. We want their decisions to be informed, educated choices.

When we move into hospice, we want their last days to be quality days for them. You certainly can have hospice in a nursing facility. Bereavement counseling is often provided many times for up to a year. There were studies done, that were published in the New England Journal of Medicine. And they were looking at patients and with a number of different types of cancer. And they found was, if they were in hospice, they live longer than those individuals who did not receive hospice care. So that is something to consider. And then we may end up with comfort measures for just keeping the patient comfortable, we're not doing a feeding tube, we're allowing them to eat as they feel up to it, there's a do not resuscitate.

And many facilities may have a do not hospitalized. I haven't seen that in every facility I've worked at, but some have that form. If they become short of breath and they become very anxious, they have the option to have sedation. So it kind of brings down that anxiety level, and we can make their days peaceful, you know, give them a really nice calming environment. We talked about concerns, informed consent for PEG, it's routinely poor. We know that the ethical burden for providing only beneficial care lies between the doctor ordering the tube and the doctor is placing the tube. And there's a lot of evidence, anecdotal evidence that suggests, patients' families were pressured into placing a PEG, and then they regretted it.

I've heard that from numerous families in the course of my career, they regret that decision, but they were made to feel like the worst child in the world. So they went along with it and it didn't go well for them. We talked about the 2009 study earlier, but there was a study done in a large community teaching hospital. And they were looking at adequate discussion of the PEG, benefits and burdens alternate approaches. They found there was only a discussion, looking at benefits, burdens, and other options in 0.6% of placements, not good numbers. So there was an international study where they were looking at a PEG in dementia patients, and you've seen the doctors' perspectives. 60% felt the PEG actually improved quality of life in the advanced dementia patient, you prolong their survival and improve their nutrition.

62% of the doctors felt they were driving that decision for placement where 30% felt the surrogate or the family was kind of pushing for that. 40% felt that and have experienced the fact that the PEG was placed despite their advice against it. We know that there is high mortality rate, at 30 day mortality rate with PEG placement, even given that information, the survey found that doctors still were looking at PEG as just a benign procedure, it wasn't a big deal at all. There's a bioethics research institute called the Hastings Center, and there's a lot of free resources that you can find on their website, but they felt that the first obligation was to the patient, to respect their choices or the choices of the surrogate.

Now we have to be really careful if somebody doesn't like our recommendations, you don't want to drop them right away because now they would have a case for patient abandonment, so we do the education. And if you really feel strongly about, you know, I really can't ethically be involved in this, then you transfer their care to someone else, but you can't abandon your patient. Everybody has the right to aspirate, if they choose to go against ANH, then we need to look at how to minimize the potential aspiration event. We need to look at strategies, precautions, educate, and make sure they've got that information, and you need to document that. Many times we do things and it never makes it into the charts.

So it looks like we didn't do it. Many times the patient is not in a condition where they can really make the best choice word, find, or identify the treatment option, it is most appropriate for them. So again, we need to make sure we're educating. We're talking about options, the benefits and the burdens. If the patient hasn't had that conversation with their doctor, they may not know how the disease progresses. They may not know the treatment options. And I've been in situations where only one option was ever presented. They need to know all of my options, especially what happens if I treat? And what happens if I don't? Yeah, I just want to know, lay it out for me so I can pick the choice that works for me, and my quality of life.

Many times, you know, when you are asking people what's important to them, they really can't answer very clearly. So there is something called a Values History Form, it's in the resource section, the different types of questions. You need to be able to put the paper to the paper and pencil together and write these out. Sometimes we think we know, but until you're forced to write them out, what's important to you, you really don't. So you can take a look at that. There also is the "Ottawa Personal Decision Guide" that is a free download, a lot of states have forms to assist you in identifying what's important to you. So by doing this, the patient is identifying the key factors and we need to back out with our viewpoints, as far as our values and culture, if they don't like the management plan, if you're not accepting it, we need to talk about, again, the benefits and the burdens and document of the refusal.

If the patient is decisional, they have every right to make the choices. Sometimes patients are misinformed, they misunderstood. So if you do the education, again, making sure is at a low enough level, they can comprehend, it may be all of a sudden crystal clear, oh, I didn't know that's what it meant, and they may change their mind.

So we can educate them about options, and then support them if they choose refuse. Sometimes advance directives aren't successful, because again, we're talking about, what is your legal right? We're not talking about quality of life, your goals and values. In this particular study, they were suggesting seventh to eighth grade language. And we talked about the fifth grade earlier, as far as reading.

Sometimes they don't know what the terms mean. If I'm in a persistent vegetative state, and you'll have somebody say, "Well, I don't want to be a vegetable." We need to make this more meaningful to our individuals, give them scenarios, so they understand what we're talking about. Sometimes we don't recognize, or our patients may not recognize that just because you wrote out an advance directive, doesn't mean you can't change it. And I can't, we only go to advance directives when you're not competent, but when we make these for usually healthy, and we may say, oop, nope, I don't want, no, nope, I don't want that. But when something happens, it may not sound like a bad idea now.

So you can go back and change those as long as you're decisional, you can repeat and, you know, rip them up and start over as many times as you want. But you need to make sure that your decisional. The only question that facilities are required ask is, do you have advance directive? So again, change as many time you want, but we need to know who is the decision-maker, again, based on the patient's directives, surrogates, proxies, and recognize that different cultures, religions have beliefs. Now with a medical directive, you don't have to be ill or seriously ill. And what you're doing is addressing different scenarios and situations, what you want, what you don't want versus a living will.

So there are pros and cons for doing one versus the other. Living will in many states, you have to be terminally ill to do that, where medical directors is not a situation where it's life and death. Now there are assessments that you may find in your patient's chart, or you may be asked to provide, Mini Mental Status Exam, Brief Cognitive Assessments, Saint Louis University has the SLUMS, Brief cognitive Status Exam is by Pearson, that scores by education level. And I believe the Montreal Cognitive Assessment also has education levels. Now we want to make sure that we're documenting, there was informed consent or informed refusal. So they have to be as decisional. They have to have that capacity, and we document patient agreed, or patient refused.

If the patient hasn't done any documents and now there's a crisis, there are standards of decision-making. One is called prior explicit articulation. And that means that you've heard the individual talk about what they want and what they don't want, they just never did the paperwork. So you've heard them say, this is what I would want or not want. The other is substituted judgment, knowing what about previous decisions, their values their beliefs, you believe this is what they would want in this situation, and then we go to best interest, what a reasonable person would want given this particular situation? So the more we can do this ahead of time, the better it is. Now, there is something called the POLST.

Now it stands for portable medical orders. And I, depending on what state you are in, it has different names. You may see it as MOLST, MOST, HOLST, POST, I, in the resources, we have a whole list of names, you can take a look at. Also this form has to be on a specific colored paper, in Hawaii, it's bright green, in Pennsylvania is this obnoxious pink. And you're supposed to have these forms accessible. So if there's an emergency, EMS knows where to find it. So they recommend taping it on the back of the front door or the refrigerator or the medicine cabinet, but it tells you what you want, it's your plan. And this travels with you.

So it's out of hospital medical orders. So anytime this is crisis, you've got the paper and it says, this is how I want treated. This is the care plan I want followed. So we'll give you some of those resources as well. Another one is Five Wishes. Now this came about the organization worked with Mother Teresa and as a result of working with her, they came up with this Five Wishes document. It's in 29 languages. It's in braille and it meets the legal requirements for advance directives in 44 states. You can use it in all 50, but in those states where it's not a standalone form, you may have to add additional paperwork. So if you go to their website, there is a link to check each state.

Do you need to add anything to it? Or are we good with this? So you put your wishes in writing and we've got it. Now that's for adults. They also have forms for children for the adolescent and the child. Now, again, if you're under the age of 18, the parent or the guardian has the legal right to make that healthcare decision, but at least the child, the adolescent is able to make their wishes known as well, so people can consider that. There's another one called, Let Me Decide, they have online education, videos, implementation guides, and what this is nice as far as something that's beneficial, if loss of functioning is not acceptable and not reversible, what would you want done versus if loss of functioning is acceptable and it could be reversible, maybe, what do you want done?

So you have different options that you can put out there. Now there's a lot of resources. When you take a look at the forms in your state, or you're making your own, in some states, there's a little bit of wiggle room. You may say, these are my choices, what I want and what I don't want, but there is a clause that says I am giving my healthcare proxy, the ability to take a look at the situation, look at all the facts, and decide based on the benefits and the burdens at that time. So there is a little bit of a wiggle room that your surrogate could act differently than what you have put in your form.

We want to make sure that we're looking at the benefits and the burdens. So if the scales are tipped, and there is all whole lot of bad versus just a little good, why are we even talking about this as an option, versus there's a lot of good and just a little bit of bad. That may be something that we want to present as an option. However, we know that a lot of our individuals, you, this tip, the scales are tipped, there's a lot of bad things here, but for whatever reason, whether it's their quality of life, whether it's their culture, whether it's their religion, that's the way they want to go. So again, we're educating, we're giving them all the information that they need and they make their choice.

Whether it's the patient who is decisional or the healthcare proxy. Now we want to make sure that we're giving this information to this patient at the appropriate time, is the decision right for this particular patient? Again, looking at their scenario at this particular time in their healthcare. And they're suggesting that maybe you need to reevaluate this on a daily basis and sometimes even an hourly basis. So when things change very drastically, do you want to rethink? Are we sacrificing the patient's right to make their decision because of distress, it would cause the family or cause the professional? So again, if they have capacity, they're in control, even though we may not like their choice. We want to make sure that we have ongoing communication, again, providing the information, making it easy enough for them to understand the terminology.

And we want to make sure that providing the support. So we want a successful outcome regardless of the course of action taken, whether we agree with it or not. So we want to make sure educated, informed choice. So our key points, I mentioned, we don't want this to be a cookie cutter approach. Every patient comes with their own set of circumstances, values, beliefs, religious convictions, and so on. We need to consider all of that. Advance directives are very helpful for patients, individuals who are healthy to make their wishes now, they only kick in when you are not able to communicate what your wishes are, and that's why we have the healthcare proxies that will stand up for us.

Many times, we really can't express what's important and what's not important. So that Values History Form is sometimes very valuable just to put things down, you know, oh, okay, let me think about this, give it a little thought. And we need to be sensitive to everybody's beliefs and cultures, that needs to be part of that decision-making process. We may not agree with it, but that is been their decision, once they've looked at all of the information educated, informed decision. So let me take you through, this is the Values History Form. So we're looking at their attitude towards life, health, relationships, what their thoughts are about independence and being self-sufficient, religious background and beliefs, relationships that they have with their caregivers and their doctors, living environment concerns, their thoughts about dying?

There is, here's the information on the Simply Put, there's also something called PEACE brochures, there are PDF files for physicians "Improving your End of Life Care Practice", and also for the patients. So this would be very helpful, print them out and have them available. "Living With a Serious Illness" When your Future is Uncertain, how to talk to your doctor, When You Have Pain at the End of Life, Making Medical Decisions for a Loved One at the End of Life. So that's duplication, I apologize for that. Some additional information on the POLST, and you have a lot of the different names that you'll see, depending on your state. And the difference between advance directives and POLST, POLST remember is a medical order where advance directives is a legal document.

Now on POLST website, they do have the resources for COVID, three things you can do now, proactive planning for COVID, and COVID-19, and you, being prepared and taking control. Additional information on Five Wishes for you to take a look at. I think there are more, here we go. Conversation Project is way to get in the discussions started, and they have a lot of information on COVID-19 as well, different scenarios for your families to look at. National Healthcare Decisions Day website has a lot of links.

Again, COVID-19 Resources, Five Wishes as well, My Living Voice to the POLST, so a lot of places that you can get information. And Project G.R.A.C.E, Empath Choices for Care.

There is information, the Jewish Resources are on that website. So we've got a lot of additional websites that you can take a look at. "Hard Choices for Loving People" does have a chapter that you can read online. A lot of the hospice organizations in my area, hand this out to families when they come in for the interview and the consultation, great information, easy to understand, and it does talk about the individual who has dementia and the feeding tubes. "Handbook for Mortals", you can get on Amazon. It is much more detailed, but it gives you the information, and there's some additional information on advanced dementia and strategies. So let's come back here to our key points. And what I'm going to do is send this back to Amy.

- [Amy] All right. Thank you so much, Denise. Well, as usual, an info packed session and there's so many wonderful resources in here, I really appreciate that and I'm sure all our participants will as well. I want to open it up and see if we have any questions from the audience. In the meantime, I wanted to let folks know that if you perhaps downloaded the slides handout prior to the event today, we did just add a second handout that has three links on it to some important resources. And I think they are links that weren't in the slides prior. So I hope they're not duplicates for you, but I guess better to have them twice than not have them at all.

But there's something from healthchaplaincy.org that the guide book for "Spiritual Preferences", I believe it was. And then Process for Care Planning for Resident Choice. And then another one about the POLST and MOLST, and the Benefits and Burdens of

PEG Placements, and some charts there. So we'd put some links into a second handout. I just want to make sure-

- everybody gets that.

- Amy-

- Just want to kind of pop in here. The Resident's Choice, there is a template in there. So if you have a patient that is really not happy with their recommendations for diets, liquids, MPO, it takes you through all of the discussions and meetings that you need to have and the documentation. So there is no issue if you have an audit and somebody comes in, it's very clear, you did your due diligence in offering as much as you could to make that patients-

- [Amy] Could you try again?

- I Don't know what that was. Okay. it gives you the form. So you can document you did that education piece. So waivers don't hold up in courts, this is going to be very beneficial for you. So the template is there as well as a filled in example.

- [Amy] Great. I'm looking at the Q&A, and here's a nice comment from Cheryl. Cheryl says that there's a movie on Netflix called "The Farewell" and it's about the Chinese culture and hiding the fact that somebody is dying, and it's based on a podcast from this American Life. I saw that movie as well.

- I thought it was

- Thank you.

- [Amy] So thanks Cheryl. That that's a nice resource. And then here's another question from Elizabeth. In your experience, are advance directives revised frequently as health declines?

- My experience is no. I think a lot of people feel once you've said it, you can't go back and change it. So as things change, we need to make sure the individual knows you can go back and revise those any time, as long as you were still competent.

- [Amy] Absolutely. Yeah, because, you know, thoughts on things change as you age or as different things happen in your life. So those are not luckily written in concrete and can never be changed.

- So, wonderful.

- Absolutely.

- [Amy] Any other questions we have just maybe a minute or two here? I'll make sure that no more come in, but I wanted to remind everybody that, one week from today will be Part 2 of this wonderful series. And if you're unable to make it to the live webinar that day, no worries, because we'll definitely offer it in self study format soon afterwards. Someone was asking, where can I find the template for the patient refusing NPO versus our recommendation? Was there a-

- I would recommend that you go to the Rothschild, the Resident Choice, that's going to give you everything that you need to follow, who to talk to, what to document. So it's clear, waivers really aren't a great idea, but that Rothschild, Resident Choice is going to give you everything that you need.

- [Amy] And just so you know, whoever asked that, the Rothschild link is on that second handout I was talking about that we just put up pretty much as the event started today. So you'll, there's definitely a link to it there, if not elsewhere in the handouts.

- Can I pop in for just a minute, Amy?

- I'm sorry.

- Yeah.

- We were talking about NG tubes and I just want to mention, I prefer to do the modified with the NG tube removed, but a lot of physicians don't like that, but there was a study done. And I believe the source is in that handout that Amy is talking about. There was a study where they looked at a modified with the NG tube in, then they took it out, waited five hours and did the modified again. And it was a completely different swallow. It was much better. So they're recommending that you remove the NG tube for a period of time. They were looking at a five-hour timeframe, but that way, the patient gets that field and it can acclimate to the change, much better swallow.

- [Amy] Maybe the sensitivity kind of returns a little bit to normal and so forth. Yeah. And I know that in the medical setting it can be a bit of-

- It's hard thank you.

- A sales job to the MDs of that 'cause they don't like to yank them and put them back down and yank them and put them back in. However, it's really important, if you have a good relationship with the MD to try to present them some evidence and that that study you were just speaking of, would be a nice piece of evidence that might convince them.

- I just didn't get that Amy when we were talking about NG tube, but I wanted to make sure you knew why that was there.

- [Amy] Perfect. Thanks so much. Well, I'm gonna wrap it up here today. Thank you so much, Denise, I look forward to seeing you back next week for Part 2.

- Okay.

- [Amy] And thanks to our audience today. Everybody stay safe out there.

- Absolutely.

- [Amy] See you next time.

- Thanks.

- Bye.