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**End-of-Life Ethics: Cultural, Religious, and Legal Views**

**Guest: M. Jane Markley, RN, MEd, LFACHE**

M. Jane Markley is a consultant and ethics advisor with 40+ years’ experience in healthcare. She works with individuals, families, organizations, ethics committees, and healthcare systems to help them understand the importance of advance care planning for themselves, their loved ones, and their members. A retired Navy Nurse, she is board-certified in healthcare management, a patient advocate, and a former hospital ethics committee chair. She trains healthcare advocates; speaks nationally and internationally; works one on one with individuals and their families facilitating completion of their advance directives; does ethics training for medical students as an Assistant Professor at the Uniformed Services University of the Health Sciences Bethesda, MD, and serves on the Maryland State Advisory Council on Quality Care at the End of Life.

**Host: Candace Pierce DNP, MSN, RN, CNE**

Dr. Pierce is a nurse leader committed to ensuring nurses are well prepared and offered abundant opportunities and resources to enhance their skills acquisition and confidence at the bedside. With 15 years in nursing, she has worked at the bedside, in management, and in nursing education. She has demonstrated expertise and scholarship in innovation and design thinking in healthcare and education, and collaborative efforts within and outside of healthcare. Scholarship endeavors include funded grants, publications, and presentations. As a leader, Dr. Pierce strives to empower others to create and deploy ideas and embrace their professional roles as leaders, change agents, and problem solvers. In her position as the Sr. Course Development Manager for Elite, she works as a project engineer with subject matter experts to develop evidence-based best practices in continuing education for nurses and other healthcare professionals.

**Episode 1: End-of-Life Ethics: Cultural, Religious, and Legal Views**

**Transcript**

Candace Pierce: This is Dr. Candice Pierce with Elite Learning by Colibri Healthcare, and you are listening to our Elite Learning podcast where we share the most up-to-date education for healthcare professionals. Welcome to today's episode, where we are going to be exploring the crucial topic of advanced care planning and its vital role in ensuring individuals receive care that is aligned with their values and their preferences, especially near the end of life. We wanted to discuss end of life, because it often involves some really complex decisions about treatment options, advanced directives, and the patient's wishes regarding their care. And it really involves navigating ethical principles, such as doing good and avoiding harm, fairness, and dignity, and really weighing those potential benefits and burdens of various treatment options, where we take into account the patient's quality of life and their personal values and preferences. And then there is of course understanding the cultural and the religious beliefs that can really significantly influence preferences and decisions. So as healthcare providers, we should be skilled in facilitating these conversations, and really ensuring that decisions are made ethically and in accordance with the patient's wishes. Our guest today is Jane Markley, an expert in the field who has dedicated her career to educating healthcare professionals, patients, and families on the importance of proactively communicating wishes through advanced directives. Jane, thank you for joining me in this discussion.

MARKLEY: Thank you for having a course on this. This is extremely important for everyone.

PIERCE: Absolutely, and this can be a really tough topic to discuss with anyone. So, I am really looking forward to learning from you today.

MARKLEY: Well, thank you. I am glad I am here.

PIERCE: Can you tell us a little about yourself and your expertise in this area?

MARKLEY: Well, my first experience in this area was when my mother passed me her advanced directive and said, “could you be my durable power of attorney for healthcare?” And that was back in the seventies when this was just not really thought about or talked about. It gave me the interest in the subject that led to my career in working with advanced directives. I was in the Navy for 27 years, and there you get to do whatever comes up. And so, I showed an interest in this, and therefore became an educator in this arena. I went back to when I retired, I went on to corporate America and I did ethics, but not healthcare ethics. And then my last career or last job was my own business doing advanced care planning work, facilitation work, education, and all over the past 13 years.

PIERCE: Well, thank you first of all for your service in the Navy. So, that is huge. Well, as someone who is deeply involved in advanced care planning, can you explain why it is really crucial for individuals and families to really engage in this process?

MARKLEY: Well, unfortunately in this day and age, people do not talk about this at home very often. Back in the early 1900s, people talked about it, because people died at home. People did not go to hospitals, and it was just something that is not now really discussed. So, it is important that it be discussed and to become normal. I think that is the big part of it. It needs to become part of the fabric of the society that talking about what is important to you and what kind of things you would want in certain circumstances is discussed. And it can be, and it is easy to be, if something has occurred, either it is a movie star who is died and all of a sudden, the issue is back in the news, or there is a family member who's ill, or friends have gotten ill. And that is when it is important for it to come forth and become a regular part of the daily life of people. Until it becomes that, it is going to be really hard to get people to talk about it.

PIERCE: When you were speaking just now, and you were talking about kind of the transition of back before, it was more of an occurrence, but now it is not as much of an occurrence. Have you seen like a reason that transition has happened?

MARKLEY: Oh, absolutely. It started when we started having hospitals. People went away to die. They did not die at home. It was not the normal, it was a big deal. Oh, they went to the hospital, and they never came back. So those types of things are what drew us to the point where we just do not talk about it as much.

PIERCE: Being in a military family, every time my husband deploys, this is definitely something that we talk about. But a lot of my friends, who also have families who are not in the military, this is not a daily, or their husbands do not deploy, or spouses do not deploy. And so, it is not really on the forefront, but because that was brought up, this last time we actually sat down and did a whole advance directive for if something happens, who is our power of attorney? So, if my husband is gone, who is my power of attorney, medical power of attorney? And what are some decisions that I want to make? So, that is a lot of information to walk through. So how do you walk through that process for facilitating an advance directive for individuals and families?

MARKLEY: Well, usually people come to me, and want to know more about it for whatever reason. Sometimes it is because there is something going on in their family and sometimes, it is just because they have heard something about this and know they do not have it. But, what I usually do is start by asking the people, why are they doing this? What is it that drew you to come to me to find out more about how to complete your advanced directive? That tells me a million things about them and helps me to understand what direction to go. Because the beauty of an advanced directive is that it hits the needs of autonomy that we talk about in ethical implications is that people are autonomous. It is the individual's right to make decisions for their healthcare. And if they do not know what they want, it is pretty hard for them to articulate it and many people do not. Many people need to have the time to sit and think about what is important to them, what would they want, and what kind of basic beliefs and values do they have that would drive their decision making. Because there is an entire process that we go through for facilitating advanced directives, and that process starts with the individual and then begins to pull in other people like their family members, their friends, even their next-door neighbors, depending on the circumstances that people live in. And then also eventually somewhere along the line, depending on how their healthcare is being received, bringing their provider into the mix as well for joining in the conversation.

PIERCE: And these are really hard conversations to even have between me and my spouse, because when he is getting ready to deploy again, and this is something on that list that we have to talk about again, it is very hard for me to not be anxious in those conversations. And I think it is because it makes you realize the mortality, the risk. Why do you think that we stray so far from these conversations? We change the subject when they come up. We do not want to have these discussions.

MARKLEY: We do not want to admit that death is inevitable for all of us. And it is easy to say, it is hard to get your head wrapped around that idea, because we all think we are invincible and going to live forever, especially the younger we are. And that is what is interesting in my practice, is that I am seeing more and more young people who realize that they are fallible. And that is really rare, because mostly the younger you are, usually the more you think you are going to live forever. But in this day and age with motor vehicle accidents, shootings, knifings, and drugs and all the other things that go along with today's environment and society, they see it and they get it. And they come to me and say, I do not want to end up like my friend ended up in the ICU for the last six months, hoping that he would come back to us. I do not want that if something were to happen to me. So, they come to me and say, how do I do this thing? And how do I make sure that everybody understands what I do want?

PIERCE: Absolutely. Now as healthcare providers, when is it appropriate to start these conversations with our patients?

MARKLEY: I believe it is appropriate to start as soon as they turn 18. And it is just, it ought to be part of the fabric of healthcare. In other words, we were able to do it at one hospital that I worked with. What happens is when someone comes in, it is a hospital that has clinics in it. So, when somebody comes in for their clinic appointment, they get the usual, do you smoke, do you drink, all the usual questions, what is your height, what is your weight, and do you have an advanced directive?

PIERCE: Aha, yes!

MARKLEY: And the answer is yes, the follow-on question is, do we have a copy of it? And if not, please bring it to us. If the answer is no, then we say, well we have some information to give you that we would like you to take home, review, and you do not have to talk about it at this appointment. You came for another reason, but review it, make an appointment, and come back to talk to our providers about it. Now that takes a little while, and it takes a lot of commitment on the part of the staff to get to the point where everybody is asking those questions. But if it is on the form, people ask what is on the form. So, what I affectionately say is you wear them down. If they hear this every time they come in for an appointment, it finally dawns on them that this really is kind of important. and maybe I better go in, maybe I better read what I was given, and maybe I better make an appointment to do something. It is just, it is again, part of the fabric of society.

PIERCE: Right. And when patients come into the hospital, one of the questions that we ask them is, do you have a direct, advanced directive? And if they say no, you check the box. If they say yes, you check that box. You ask them the question; can I have a copy of it? Can you have someone bring it to me? But I feel like most of the time when I am in different hospitals, being in the military, we have worked at a couple of different facilities, but it is like, here is a piece of paper. I hand them a piece of paper, but I am handing them a piece of paper in a time where they are being admitted to the hospital. It is scary, they do not know what is happening, and it kind of gets pushed to the bat.

MARKLEY: It is a horrible time. Well, it is also viewed by some patients as, oh my gosh, my surgery's worse than I expected, I am going to die. And that is not how you want somebody to come into the hospital. You want them to come in, and if you have been talking about it in the outside appointments and stuff like that, it should be fairly easy, you know? You know that thing we have been talking about for years? Did you finish it? No, is it there?

PIERCE: Right. So, what are some common misconceptions and challenges that you have encountered in this process?

MARKLEY: Well, the first one is people do not think that they want it. Well, one of them is they do not think they want to do it, because it is going to cost them money. They are used to wills and wills costing money. And this is something that anyone can do. And in 46 of the states, all it requires is two witnesses. In the four states, it requires a notary. But other than that, anybody can do one of these documents. You can write it on the back of a piece of paper. I say the back of a napkin, which has been used before. But there are so many forms and so many tools out there. It should not have to be done on a piece of paper. It can be done with good guidance from a lot of people who have done a lot of work in this arena. So yes, it needs to be brought to bear at that point in time that they review and do this.

PIERCE: So, it can be as simple as just calling the doctor up to write a do not resuscitate order.

MARKLEY: Yes, that is the second step. Basically, if an individual needs to sit down, and go through the process of thinking about what is important to them, what their basic beliefs and values are, then they need to learn about what is going on. I mean, what are my medical conditions? How healthy am I as a human being? What is it that might come to the forefront? And those are questions you need to ask your doctor. I mean, if you have got someone with heart disease or diabetes, there are other mitigating circumstances, and it is important to understand what your trajectory of health may be for your life. Someone who is in their 20s, 30s, and 40s is probably not going to want a DNR. They are not at a point where they need a DNR. And if they are, then they are going to have known about it, and there is going to be a lot of discussion related to that. But for the basic average human being who is just out there saying, I think I need an advanced directive, thinking about it, learning about what the pros and cons are of things like CPR, and we in the field know that there are many more cons than most people think.

PIERCE: It is tough.

MARKLEY: TV has not done us any great service along those lines. And then it is time to start formulating an idea of what it is you want to do. Now, what is it that you want to put down on this piece of paper? The paper is not the be all and the end all. The paper is just a guideline. Formulating those ideas and then communicating them with your loved ones. Who is it who is going to need to know that? Is it your next-door neighbor who is going to be the one who comes in and sees you every morning and oh she did not show up today and oh she needs help. Is it a family member, and making sure that you are communicating with these folks and getting ideas from them. I always tell people just because somebody does not agree with what you are putting down does not mean it is wrong. This is your autonomous you, and you have the right to make decisions for your own care. So, it needs to be your document, not someone else's document. And then you need to designate somebody to be your durable power of attorney for healthcare. And that is extremely important for everyone to understand, because that individual is the individual who will speak for you when you can no longer speak for yourself. And they need to understand. I cannot tell you how many bedsides I have been at where I have got beautifully executed paperwork that says, this is the living will, and this is the adorable power of attorney. And I pick up the phone and call, and actually get a hold of this person, and find out they did not even know their name was on the document. And let me tell you, that just takes ice water to your heart because they are useless to you. They just do not have any clue. So having a durable power of attorney who you have communicated with, and who understands your basic beliefs and values. Because there is no way anyone can write a living will, a durable power of attorney for healthcare, an advanced directive can anticipate how they are going to need it. Whether it is a motor vehicle accident, whether they have a heart attack on the street, whether they go into a drowning situation, you just do not know what your end point will be or how you will get there. So, knowing someone's basic beliefs and values is critical to helping the person who you designate as your durable power of attorney for healthcare, helping them to make good decisions on your behalf when you can no longer make those decisions that tie into what your belief structure is. Because they cannot make, they are not supposed to make decisions for your care based on what they want. It is based on what you want. And that is why many times it is not necessarily the best person to have a spouse to be your durable power of attorney for healthcare. Because the stress they are under at that point in time is horrible. Many can and many do it very well, do not get me wrong. It is not that it should not happen, but it is not the starting point for everybody.

PIERCEL: Right And just my family's, what we did as an example is, it was hard for me to have the discussion with my husband. I know what he wants, but we actually made his brother the executor over that, over those choices. Of course, he knows that, and we communicated, and you know, he would work with me, but then my husband chose to be the power of attorney for me. Of course, when he is deployed, it would be my dad. And that was a phone call that I had to make to my dad. That was a hard phone call to be like, hey dad, if something happens, it is you.

MARKLEY: Absolutely. And that is the problem in this day and age. You know, everybody thinks that the elder folk need the paperwork and need to have the conversations. And it is everybody. Because there are more and more seniors whose children, who are younger than them, are having problems. And they are ones who are less likely to have had that conversation.

PIERCE: Right. Now I have seen where they have healthcare advocates who really help with some of these decisions for advanced directives. Can you give me some insight into that? And is there official training or credentials for those who step into these roles?

MARKLEY: Okay, let me start by making a clarification statement. A healthcare advocate and the work I do are not necessarily synonymous. A healthcare advocate is someone who normally advocates for an individual on all their healthcare issues. Okay. I call myself a healthcare advocate, with a primary function of advanced care planning. Most of the time you will find people who do the work that I do call themselves advanced care planning facilitators. A healthcare advocate has multiple meanings, and it is confusing to those of us who are clinical, let alone the community as a whole. So advanced care planning facilitators is probably the best term. And most of those people have some training but they do not have, there are programs that are out there to provide some training levels, facilitation levels. Respecting Choices is one of them. Many hospitals and healthcare facilities have their own training programs, but there is no national board of folks like this who are trained. Most people are in it because they have had a bad experience somewhere in their life, and they do not want to see anybody else go through that horrible experience. So, they are out there to try to prevent that from happening.

PIERCE: Are they being hired? I have not worked in a facility where we had someone who could help with this training. Is this becoming, are more organizations hiring for this role or?

MARKLEY: It varies. There are some hospitals and healthcare systems that have advanced care planning facilitators within their program, and they have hired them. Usually, what hospitals will do is hire a lead for advanced care planning within their facility and/or their local community. And whether that is done or not depends on the culture of the facility, and the beliefs of senior management. If you have someone in senior management who gets it, who understands advanced care planning and why it is important, not only to the patient and the family, but to the healthcare staff and to the institution. Because if these are done wrong, people are today suing, not because someone died, but because we in healthcare kept somebody alive against their wishes. And that is a real surprise to many healthcare providers. They think, oh my gosh, you know, I kept this patient alive, why am I being yelled at? Well, it is because the patient did not want that treatment that you gave them that kept them alive. And that can be for an institution, that can be an extremely expensive litigation.

PIERCE: Absolutely. So, when you have these advocates that are really trying to help you navigate some complex healthcare decisions, particularly regarding end of life, does that start when you are admitted in the hospital? Can they, do they have offices that, I mean, how do you advertise this? How do you bring them in? How do you start that conversation?

MARKLEY: Well, a lot of facilities will, they have someone in that position, and they build their policies and procedures around that person and usually, unfortunately, around that person's personality. So, if they leave, sometimes it is difficult to replace them. But they work with the ethics committee, and they work with admissions to identify people who come in who do not have an advanced directive. And again, not the best time to be doing this. So many hospitals have, what they have done is they have, particularly hospitals where they have, they are the one of in the county, in the community. They invest in their community by doing outreach and going out into the community with programs on advanced care planning and why it is so important and what that is. La Crosse, of course, is the standard for that, having gotten 98% of its population to have an advanced directive. But that was two hospitals working together with committed people who were being paid at the time to do this work. If the institution is not willing to finance somebody to support this, it is going to die on the vine.

PIERCE: Absolutely.

MARKLEY: And it just does not work as effectively as it does, if in fact the CEO primarily and those below him get the fact that this is an important piece of the puzzle.

PIERCE: I could even see this as something that would be a benefit from hospitals to their staff.

MARKLEY: Absolutely. HR in some areas outside of hospitals use this as a benefit for HR benefit. You know, we have got the advanced directive forms here, we really think you need to fill them out, it is going to help you and your family, it is here. And they frequently will build a cadre of staff members in that company who have done it. And that impacts their financial issues related to the insurance.

PIERCE: Absolutely. So, I know earlier you mentioned working with ethics, being an ethics advisor. So, what ethical principles really help to guide the healthcare professionals and family members when they are making these difficult decisions?

MARKLEY: Well, first you need to remember the autonomy. The individual is responsible for their preferences and their choices. I mean, yes, they definitely need education as to what is going on with their healthcare, what their options are. They need the fidelity too, to be honest with their patients. And that is one of the problems that healthcare has in this day and age is the goal is to keep the patient alive. Whether that is the altruistic mode of that is what I am here in healthcare to do, whether it is a financial issue, we have got to keep this person alive, there is all sorts of both good and not so good implications there. But having someone be honest with the patient to let them know, here are your pros and cons, this is what you are looking at. People think that if the doc comes in and says, oh, we have got this option, we can use this option. Well, this option may be, what is the percentage? And what is it going to do to the person along the way to get to the end of that treatment modality, and how much is that going to impact the patient. And they need to be able to make that choice, whether it is worth it to them to be miserable for a period of time.

PIERCE: Right. So, it is some tough decisions to make. Jane, thank you for shedding so much light on the importance of advanced care planning and some of the key principles involved in facilitating these vital conversations. In this next episode, we are going to go a little deeper on the collaborative aspects of ensuring patients' wishes are honored. And our guest, Jane, is going to share some perspectives on some interdisciplinary teamwork with physicians and social workers and other individuals who can help us with making sure that we remember those cultural and ethical and religious traditions. So, you will join us for episode two as we continue to demystify the best practices in advanced care planning, because you know it has been a mystery to me for a little while. I honestly thought that you had to have a lawyer to do advanced care planning.

MARKLEY: Absolutely not necessary.

PIERCE: So that is really good to know. So, we will see you in episode two.

**Episode 2: End-of-Life Ethics: Cultural, Religious, and Legal Views**

**Transcript**

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PIERCE: Welcome back to our two-part episode on advanced care planning. In the previous episode, we covered the crucial reasons why all individuals should proactively document their healthcare wishes through advanced directives. Our guest expert, Jane Markley, walked us through best practices for trying to facilitate these conversations and addressing some common misconceptions. So, in this episode, we are going to talk about the collaborative aspects of ensuring an individual's care plan aligns with their values, their preferences, and their cultural traditions, even in the most complex situations. So, we will explore the importance of some cultural humility in advanced care planning and get examples of how to thoughtfully integrate into diverse backgrounds and customs when you are working through advanced directives. Jane, thank you for joining me for this second episode.

MARKLEY: No problem.

PIERCE: I really want to start back with kind of what I ended with on episode one. I really thought that you needed a lawyer in order to complete an advanced directive, but I just learned from you that we do not.

MARKLEY: Many people have that misconception. It is not surprising. Everybody knows to do a will, they need a lawyer, so they automatically assume that it is the same with an advance directive. But advanced directives were made to be more easily available to the general public and more easily completed. There are many lawyers out there who do this very well. There are many lawyers out there who have not got a clue.

MARKLEY: As I have shared with you in the past, I have been at the bedside of people who have had a beautifully executed, eyes dotted, T's crossed, everything looks gorgeous, advanced directive, and when you call the Durable Power of Attorney for healthcare, you find out they did not even know that their name was on the document, let alone not had the conversations that were essential. And when that happens, you just do not have anybody. You might as well not have done the form at all, because it is just not there. And that is the responsibility of the lawyer to make sure that people have that conversation with their loved ones. So yes, they can be helpful, but they are not required. And that is why someone like me can work with people and get their advanced directives done. I do not sign them, but what we certainly did during COVID when we were working on this is we would have a next-door neighbor, and everybody goes out on the porch, and pass paperwork back and forth and sign it. And basically, what the person who is signing the document is doing, all they are doing is signing that the person whose name is on the document is the person who signed the document. They are not there to find out what kind of care you want or what kind of values you have. They do not even have to read it. What they have to do is verify that is your signature. People can get a little nervous about that sometimes. Well, I do not want my neighbor to know what I am doing. Well, I want your neighbor to know that you are doing an advanced directive, because they need to do one too if they do not already have one, but they do not need to know the details.

PIERCE: Is there a role for nurses when it comes to developing these advanced directives?

MARKLEY: Absolutely. They are in roles at every end of the spectrum. Going back to the lawyers, some of the elder law attorneys hire nurses to work in their offices to help people do their advanced directives. Some physicians in group practices will hire people like me and a cadre of nurses to deal with their patient population, give programs to help them through the process, and then work with the physician where that individual becomes necessary. I mean, it does not require a physician to do all of this. Many nurses can answer the question sometimes more effectively and efficiently than a physician can because they are in the trenches with the patients all the time. So, they see what goes on. So yes, nurses can be involved at so many levels. I know clinically and in the hospitals these days, there is not a whole lot of excess time, and this does take time. So having the dialogue outside in the community is an important piece of the puzzle as well.

PIERCE: Absolutely. What does collaboration look like among other healthcare professionals? I know we have talked a little bit about nurses, physicians, but you know there is also like social workers and…

MARKLEY: Well, my goal is always to get everybody involved. The more people who are involved, the more people who bring it up, the more you wear down the person who is supposed to be doing it. Whether it is your financial manager, or your accountant, or even your postman. I mean, if somebody brings it up, it is like, oh gosh, these people are talking about this too. Maybe I need to do it. In the hospital, your social workers certainly are actively involved in advanced care planning or should be if they are not. And the more people hear about it, the more they realize that, it is the norm, that everybody ought to be doing this and it ought to be completed and processed too. And again, you feel like you are swimming upstream if it is just you. So, it is good to have a group of people who understand and are doing things similarly. Whether you have a hospital hired person to be the facilitator of it, the ethics committee should be intimately involved in the whole process within the institution.

PIERCE: Can you share a specific example of a time when interdisciplinary collaboration was really essential when it came to ensuring that patients' wishes were honored?

MARKLEY: Well, it is very interesting because you have a team of healthcare workers working with a patient, and the patient, they are just not getting along. I mean, it is just not working. They are not, they each have their own opinion, and what happens is, I always encourage people, if you have got an issue, and you just cannot seem to meet up, contact the ethics committee. That is what they are there for. They are there to be the intermediaries when there is an ethical issue. And this is an ethical issue. If the patient wants this, and the docs want this and the two are bumping heads, do not wait. And I tell the nursing staff, do not let it wait. You know, bump it up. There is no reason that you as a nurse on the ward cannot go to the ethics committee and say, I think we have got a little problem here. Can you give us a hand? It is not anybody's, it is not that anybody's at fault. It is just that everybody's coming from a different position, and bringing in a group like the ethics committee where you have got multidisciplinary involvement, we found that most of the problems, when I was ethics chair at Bethesda back in the 80s, we found that most of the time when people asked the ethics committee, and the ethics committee would get involved, and we had set up a little meeting with the appropriate parties, it was purely miscommunication. There was not anything diametrically horrible about what was going on. It was just that they were each so involved from their own perspective, and the staff being very busy, this is not their only patient. This interdisciplinary, almost 90% of the time resolved the issue with one meeting. It just took taking a deep breath, saying stop, let us look at all the facts and talk about it. Now that does not happen 100% of the time, nothing does, but at least they are there to, and anybody can ask for an ethics consult. I mean, it can be the grandmother of the patient. It does not have to be a staff member. It can be anyone, the patient, the family, the nurse, the social worker, the PT. Now it does not have to be, and that is one of the misconceptions that I have found at many facilities is that, well, the doctor has to ask for an ethics committee consult. No, no, no. Ethics is important across the board for everybody to be involved in. And sometimes people see it differently. The physician is seeing is an obstinate patient who just will not do what I want him to do. And then other people see it a little bit differently. And the patient is so confused that they are putting their heels in. So having people otherwise involved is extremely important. And interdisciplinary makes it work.

PIERCE: Do you have an example of a case that has gone before an ethics committee?

MARKLEY: Yes, I have several, but we had one lady who was obviously end of life, and she had made it very clear that she did not want to eat or drink, and she did not want any more care. She was ready to go. And this was in the days when we kept people in hospitals a lot longer than we do today. Her son showed up and went, as can happen, very obnoxious and very loud. And he wanted to know why we were not feeding his mother, why we did not put a tube in, why we did not do X, Y, Z, all the other things. Well, that ended up being an ethics committee activity, because we needed to find a way to calm this man down. And not, we obviously were not in a position to follow what he wanted done, because we had clear guidance from the patient. And he was not her durable power of attorney and certainly would not have even been available as a durable power of attorney, because she was still conscious. But there was going to be a point at which she would no longer be and fortunately he was not. She really did not have any, but she had been clear and had been well documented in the nursing notes and the physician's notes that this is what this woman wanted, and sitting down and working with this man and getting him to understand that putting food in through a feeding tube was going to cause more harm to his mother than it was going to cause good. And that took a while. Educating on a one-on-one basis is time consuming, but extremely important, because we certainly did not, we were avoiding a litigation, we were avoiding trauma to the patient, we were providing for her autonomy, and making sure that she got what she wanted. And ultimately it worked out okay. It just, it was painful in the process getting through it.

PIERCE: Absolutely. And hard for the son to understand. My grandmother passed away. My brother is also, he is in the medical field. And so it was kind of left to me and my brother to make some of these decisions. And one of the things that I remember talking about with my brother was, I had an issue with dehydration. I do not care if she has anything else. I just want a little bit of fluid going in. For me, and that was my struggle, and so that was something, but we talked about it, and we knew, and that is definitely not as bad as trying to put a feeding tube down, and it does not come with all of those risks, but sometimes we just have to find that balance in the care. Do you have some other examples of how you are finding the balance in the care?

MARKLEY: The one that pops to mind, and again, it is balance and care, it is another food issue. We had a patient who, in military hospitals, it is unusual to have someone who has the same provider for 20 years, but in this case, we did. And the man who was the patient had been with this provider for years. He had cancer. He had been in and out as he got older. And that physician knew that patient better than the patient knew himself, I think. And when he was a DNR, he did not want to eat or drink. He wanted to let nature takes its course. I can remember making rounds as a supervisor one evening and going into his room and seeing a brand-new nurse, bless her Everybody has to eat. So, she was trying to force feed him

PIERCE: Oh man!

MARKLET: At his great reluctance and great resistance as best as he could. And again, it was a case of the enthusiastic healthcare professional who wants the patient to be normal again, who wants the patient to live. And she was doing everything in her power to make sure that he got fed. And that took very little time. Yes, that did not take an ethics committee meeting to solve. That was pretty easily solved. But again, everybody comes from a different perspective. And when you are dealing with end of life, you need to take your hat off and put that patient's hat on and try to understand where they are coming from and give them enough information that they can make decisions for themselves as far as what it is that they want, and that is hard to do.

PIERCE: Who typically makes up an ethics committee?

MARKLEY: Oh, an ethics committee, there are specific guidelines as to what makes up an ethics committee. It is physicians, nurses, social workers, chaplains, usually an ethicist, again, that is a big problem because not every hospital can afford to hire an ethicist. If there is a medical school around, usually you can get somebody to come and help. I mean, we have had radiation techs in our ethics committee. We have had and there always should be a community member, somebody who is not necessarily medical, who is looking at it from another perspective. Again, the multi-perspective view of what is going on is extremely important. And having somebody from the community can be very insightful.

PIERCE: Absolutely. Now. we know that there are some cultural and religious differences. And so how do you approach advanced care planning in a culturally and religiously sensitive manner?

MARKLEY: Well, first, what I did with my training was to find out more about the different cultures that I might run into. So, I at least had a sense of where they were related to this. But again, you let the patient lead. What is it that the patient wants? What are their basic beliefs and values? All going back to include the spiritual side of things. Many times, and one of the biggest challenges is when someone has, one of our patients was Japanese, and in this woman's culture, she did not want to know anything, really hard for nursing staff. She wanted her son to know everything and he made all of her decisions for her and she made that very clear from the day one. Well, that is really hard for us to deal with, because you want the patient to know, but she did not want to know. So that is a good example of a cultural difference that causes disharmony sometimes within the staff, because they do not know how to deal with it in that manner.

PIERCE: Because we are taught autonomy. They are to make their own decisions and they need to be informed and make informed decisions. And so that really goes against the grain of our training.

MARKLEY: Absolutely, absolutely. And I know of one physician who also had cancer and was dying of cancer, and she did not want to know. She turned everything over to her husband. And let me tell you, she was a palliative care physician. And she said, I do not need to know. He is the one taking care of me, let him know. And those things are, you are right, against our grain.

PIERCE: I actually had a patient in an ICU who was dying, and her family never told her. And that was really hard for me.

MARKLEY: Why did the patient not be told by the healthcare community?

PIERCE: I was a new nurse, but that has always stuck with me, because I remember I did not actually take care of that patient. She was not, she was in the room beside my patients, and I remember, the nurse going in and turning the machines off in their room, and the family was all around her with chairs, but she was never told.

MARKLEY: Yes, and that goes so totally against what healthcare should be about and what advanced care planning is about. They need to, you know, there are some people who do not want to know, and that is, but that is their choice.

PIERCE: And maybe she was one of those that had made a decision, but this was a small town, small community, and it was hard to not, to know that the patient did not know, because you help each other as nurses, you go into each other's rooms, you let them have lunch, so it is not like we were not going in the room as well. And so, I just remember being so torn with that situation.

MARKLEY: Mm-hmm. And you know what, she knew. She just, no one wanted to talk about it, so she did not talk about it. And that is the same with children. Children know they are dying when they get to that point. They know it. You do not have to tell them. And people do not want to tell the child, well, do not tell the parents either. Everybody knows it is the elephant in the room and it needs to be talked about at some level.

PIERCE: Absolutely. Can you kind of give us an idea of some of the cultural and religious aspects of the of advanced care planning that we should be aware of that we might run into more commonly?

MARKLEY: I think the thing is knowing what you do not know about an individual's religion or, and it is not oddball religions we need to be thinking about. It is you know, the difference between Jewish faith and their belief structure and the Catholics. I mean, there is many Catholics who think that advanced care planning is not for them because you know, they do everything at all costs. Well, if you talk to their priest, that is not the way it is done. I mean, they can do advanced care planning and they cannot take treatment if it gets to the point where the treatment is too onerous for the individual. So, they have an excellent guide, and so does the Jewish faith on advanced care planning and how to do it in their faith base. And knowing those things are out there and utilizing them as a backup, Five Wishes is, well, last I knew it had 28 different languages that it is in. So, you can look at the one in English and you can look beside it and it is in Hindi or a variety of different languages. Those are resources that are already out there and available. And you do not have to go to your translator and try to use that as a tool to communicate with your patients, you can use these tools that are already out there in the community.

PIERCE: I know we have a lot of people coming into our country from like Mexico and from the Middle East. What are some things that we should know about as these populations grow in a lot of our areas in the US for advanced care planning?

MARKLEY: Most of them have not had any exposure to it, particularly the Middle East. And taking it even further, Singapore has a law on their books as a country that says, a doctor may not ask a patient for an advanced direct.

PIERCE: Oh wow!

MARKELY: Now, we are working really hard to get that changed. All of my friends in Singapore have been working on that very diligently, but it is okay for the patient to give the doctor their advanced directive, but they cannot ask for it legally. So those types of things are, again, how many times do you have a Singaporean as a patient? You do not, but they come with that as a cultural bias that, oh, the doctor cannot ask me for this. I need to give it to somebody. And when we deal with training people in Singapore, you always want to, as a part of your advanced care planning training, you want to tell them, hey, you need to not only complete the document, get it signed, do everything, but then take it and give it to your doctor so he knows what you want or she.

PIERCE: Absolutely. Yes. So, know what we do not know. Yes. And, you know, I was just thinking, you want to, that is a main practice here in the US is we are going to ask you when you go to the hospital, do you have an advanced directive? And I could just think someone from Singapore being like, is that illegal to ask? And so can you share some of the integrated cultural traditions and rituals and customs that you've kind of had to put into some of the advanced care plannings that you have work done.

MARKLEY: To be honest, I cannot think of any off the top of my head, because if the individual has cultural biases or cultural ways of doing things, and you approach it in the fact that this is your document, you talk about what is important to you, anything goes, guys. You can talk about, you know, you want the shaman there at the end. You can talk about, I had one lady who wanted to go out into the wilderness and die in the woods in the snow because that was how she believed that life should go. And, if that is what her preference is.

PIERCE: By all means.

MARKLEY: I am not about to, but again, you have to be cautious of legal implications for people doing things, doing themselves harm, but you be led by the individual, and let them really open up and talk about what is important to them. If you give them the freedom to talk, you will find out all sorts of things that are important to them and you will find out what they need to document in order to get what they want at the end rather than being forced. I mean, there is people who want to put in their advance care plan that they want their, particularly women, their facial hairs plucked so that they are not showing to anybody when they can no longer do that themselves. I mean, it is all sorts of strange things. Not necessarily cultural, though that could be cultural. But when you find out what is important to them, make them write it down. An advanced directive can have whatever it needs in it to get to them, to help the nursing staff give the kind of care they want to give tailored to that individual.

PIERCE: Right. So, on a little bit of a lighter note, I wanted to touch on hospice and pet therapy. How is pet therapy being used to help to contribute to the emotional wellbeing of patients and families who are really facing these decisions?

MARKLEY: It is wonderful. Pet therapy has a lot of positive aspects in general for hospice patients, but to have a creature that is not judgmental, who is just going to curl up beside you, love you, and let you love it, it gives people such peace and such quiet. And everybody thinks that the dog or other animal, depending on what kind of therapy you are having, is asleep. Well, I can guarantee you 100% that dog is not asleep. He is actively working to feel the sense of where that person is and what is going on. And I know that because the dogs that I have worked with at the end of a session, which is an hour in length, they are whooped, they are exhausted. And I had my dog, my husband had an accident and needed to be in the living room in a hospital bed for a while. And my dog, who was a pet therapy dog, we got a hassock for him, and he was able to bounce up into bed with my husband. Well, he did pet therapy twenty-four seven. On about the third day, I realized that my dog was knackered. He was exhausted. He was not, he was hardly eating. He was just so focused on his mission to take care of my husband, that I had to actually move him out of the house for two days to give him a break so, he did not feel like he had to be there. I mean, because that is his job and I have to go, and I need to be with dad. And that is that caring comes through to other patients who they do not know as well.

PIERCE: Oh wow, I had not even thought about that, how much it affects the dog. What a sweet story, but sad story at the same time.

MARKLEY: Well, it was a learning curve for me, that is for sure.

PIERCE: Yes, so we are quickly running out of time, and so we are going to be coming to the end of this episode. So, I wanted to give you an opportunity to just, is there something that you want to make sure that as we close out the listeners really hear, something that you want to emphasize?

MARKLEY: Oh, there are so many things, so much we did not get to. But I think the important thing is the advanced directive is not just for the patient, it is for the family. And many people say, oh, I do not care what happens to me, I do not need to write an advanced directive. Well, yes you do. Because, and I always say to people, do you love your children? And most of them say, oh yes, I do. I said, then give them a gift. Because if you should die without an advance directive, and should need care without having guidance as to what kind of care you want, your family is the one who is going to have to make the decisions. And if they have to make the decisions in a vacuum, it is not that they are going to make the wrong decision, it is that they are going to make a decision, and they are never going to know if it was the right decision. And there is some research out there that goes out 20 years that says 20 years after the fact for a family member whose loved one died without an advance directive and they just winged it, whether they gave everything or nothing, they still wonder, did I do the right thing? And that burden is not something that people want to put on their families.

PIERCE: Right, absolutely.

PIERCE: Absolutely. Jane, there is so much to take away from this discussion. So much more that we could have talked about, but we are at the end of our time. And just wrapping it up when we did with the pet therapy, that really just made me think about how important holistic care is even at the end of life. So, a huge thank you for having this discussion with me for sharing your invaluable expertise and your examples of how to approach this topic.

It is just such a difficult thing for us to talk about, but such an essential topic that we need to be talking about with our patients, and we need to do a better job of addressing it as a society. I do not think it is just for nurses. I do not think it is just on physicians and healthcare, but as a society. So, thank you, Jane, for being here.

MARKLEY: No problem. Glad to be here.

PIERCE: To our listeners, I encourage you to explore many of the courses that we have available on EliteLearning.com to help you grow in your careers and earn CEs.