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PRACTICE COMMUNITY

Webinar Transcript

SPIRITUALITY IN ADVANCE CARE PLANNING

Reverend Dr. Jim Kraft
Dr. Pamela Pyle
Chaplain Robin Walker
Paul Malley, President, Aging with Dignity
Kathleen Taylor, MA, LMHC – Five Wishes (Moderator)

A Program of
Aging WITH Dignity®

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SPIRITUALITY IN ADVANCE CARE PLANNING

DAVE SIMISON: Welcome, everyone. Five Wishes is pleased to present today's practice community webinar: *Spirituality in Advance Care Planning*. I'm Dave Simison, Vice President of Operations for Five Wishes, and it's my pleasure to host and introduce today's webinar. Please note that this webinar is being recorded and your audio as a participant is muted. If you need any technical help, please click the Q&A button on the lower bar of your Zoom screen, describe the issue, and I'll do my best to help you.

This presentation will last up to 60 minutes, and you're encouraged to ask questions throughout. To ask a question, click on the Q&A button on the lower bar of the screen and type your questions for the presenters. It's now my great pleasure to introduce Kathleen Taylor, Five Wishes Healthcare Programs Director, who will facilitate our webinar today. Kathleen…

KATHLEEN TAYLOR: Thanks, Dave, I appreciate that. Good afternoon, good morning — wherever you are in the country — to everyone who's joining us today. We're delighted to have you for this — I think this is our either 18th or 19th Five Wishes Practice Community webinar. And we are really excited about our topic today. As most of you probably know, or you will learn more today, most people consider spirituality important when they consider the end of life. And many people interpret illness and cope with their illness through that lens of spirituality and through some practices of spirituality that are personal to them.

That's why Five Wishes includes prompts to explore spiritual and religious aspects of the end of life and those spiritual aspects that bring a person peace. And that's primarily in Wishes 3 through 5 on the *Five Wishes* document and in the conversation framework that we have, which really ask people to describe for themselves what brings you comfort and includes some prompts to consider religious and cultural and spiritual practices.

Also, in our Five Wishes trainings — we have online trainings, we have web-based trainings, we have trainings that we can develop really for any size of organization and budget —but whenever we do these trainings and however we do them, we coach and mentor advance care planning facilitators to explore how and if spirituality and religious beliefs affect people's decisions about medical care and specifically about their end-of-life choices — what they would or would not want near the end of life for their medical care and their comfort choices — is any of that based on spirituality?

So, it's part of the competencies of being a good advance care planning facilitator to just explore that. And we'll talk more about best practices and how you can incorporate this kind of exploration regardless of your background and your expertise. There are some really simple ways to phrase this exploration. So, just a taste of some of what we do in training we'll talk about today.

But we're going to talk about this issue as holistically as possible today, and we're gonna squeeze it all into the next 56 minutes or so.

So, let's get started. I would like to start by introducing our wonderful panel that we have today. And you all may turn on your cameras now so everyone can see your faces. In no particular order:

Reverend Dr. Jim Kraft

First, we have the Reverend Dr. Jim Kraft, who's a distinguished leader in advance care planning with over 20 years of experience in the healthcare industry as the CEO and founder of Advance Care Associates. He's dedicated to guiding individuals and families through aging and serious illness with compassion and expertise. And he really does — I know him, I can tell you that. He's a sought-after trainer and speaker, and Dr. Kraft has made a national and international impact in transforming the healthcare experience. So welcome, Dr. Jim Kraft.

JIM KRAFT: Thanks, Kathleen. It's good to be here.

KATHLEEN TAYLOR: It's so great to have you.

Dr. Pamela Pyle

We have Dr. Pamela Pyle, who's a board certified internal medicine physician and hospitalist. She's the chair of the Board of Africa New Life Ministries in Rwanda. She's an author and she's a speaker. She speaks and writes nationally and internationally on the topics of Christian spirituality, healthcare, and end-of-life care. And she's been a featured speaker at the National Prayer Breakfast — which is wonderful, if you've never gone, please go to that — and the Refresh Women Global Conference. Dr. Pyle focuses on navigating the world of healthcare by uniting faith and medicine, so perfect for our topic today. Welcome, Dr. Pyle.

PAMELA PYLE: Hi. Great to be with you.

KATHLEEN TAYLOR: Oh, great, thank you.

Paul Malley

We also have Paul Malley. He's the President of Aging with Dignity, a role that he's held for 22 years now. Paul is a national expert and advocate for quality and dignified care at the end of life. He's served on the Florida delegation for the White House Conference on Aging and has guided the efforts of several aging advocacy groups to improve policy on advance care planning and patient rights. He has testified before state and federal legislative bodies in favor of patient friendly policies, is a frequent national presenter at palliative care and aging advocacy conferences, and has presented at international conferences on improving end-of-life care, and is probably the best Five Wishes expert and advocate that I know. So, welcome, Paul. It's wonderful to have you.

PAUL MALLEY: Thanks, Kathleen. It's good to be with this group today.

KATHLEEN TAYLOR: And I will introduce in advance another one of our panelists who is having, as all humans do, a slight technological glitch with logging on to her Zoom link.

Chaplain Robin Walker

So, when she appears, you will know that this is Chaplain Robin Walker. She's the Manager of Chaplain Services and Spiritual Health at the University of Maryland Capital Region Health. She's a board-certified chaplain, she's a commissioned NAD Pastor and Suicide Prevention Counselor, and she has served as a chaplain in hospice and hospital

settings. Chaplain Walker calls herself — and I love this description — a spiritual clinician helping you and those you love reconfigure hope in the face of illness, one visit at a time — which I think is, if ever a chaplain had a description for what they do, that's a perfect one. So, we welcome Robin and we hope to see her face soon.

KATHLEEN TAYLOR: So, I'm going to get us started off just by introducing our topic. As we just discussed, most people, when they are asked, do say that spirituality is important to them when they consider the end of life. People with serious illness —and though I've not had an introduction, I come to this work from about 30-ish years of work in hospice and palliative care, much of that bedside work — so, from experience and from research we know that people tend to bring these issues up when they consider the end of life and as they face the end of life.

And sometimes spiritual needs look like fear of dying or fear of death, fear of just not existing anymore. Sometimes people talk about illness having them feel like they've been abandoned by God if they've led a particularly spiritual or religious life, and now they're dying of cancer despite their prayers. People will bring up being at peace,

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which I think has its roots in spirituality, and finding meaning in their illness, which can often be addressed through spiritual, what we would call interventions, and we'll talk some about that later.

So experience and research show us that religion and spirituality are not peripheral to the delivery of healthcare or to medicine, and they don't exist outside of healthcare delivery, but they really have measurable effects on several domains of patient care quality and patient experience.

I want to start us out by just defining what's the thing we're talking about, and there's two words in particular. So, one word I would like to define for our audience is, "What is spirituality?" and as practitioners, how you've experienced that with people. And the second piece is, "What is religion?" and how do those intersect and overlap? Because sometimes they do, sometimes they don't.

But let's define for everybody what these are. And I want to offer a definition to start — and pardon my glasses, I need bifocals and don't have them yet. One definition from Puchalski in the Journal of Palliative Medicine is, "Spirituality is the way individuals seek and express meaning and purpose and experience connectedness to self, others and the significant or sacred." I think that's a, I like that one. And there might be more, for us…

So, what else would you add to a definition of spirituality and what it is that people experience that we're talking about around thoughts of the end of life? And anyone can go first. Paul, why don't you start…

PAUL MALLEY: I'll jump in. You mentioned, you quoted Dr. Christina Puchalski, who's a great pioneer in this whole field of spirituality and healthcare. She has an

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institute at George Washington University, GWISH (George Washington Institute on Spirituality and Healthcare). She was actually one of our advisors when we created *Five Wishes*, too.

And looking at the spiritual dimension and faith tradition, religious dimension, that people want to bring to advance care planning — Kathleen, what you said is that it's not peripheral. It's, and I would say, is right at the center of decision making, not just on medical decisions, but for families as we think about how do we take good care of the people we love? For a couple of decades, advance directives, living wills, durable powers of attorney for healthcare, from when they started in the late 1970s-early-'80s, they didn't touch any of the issues that we're talking about today, spirituality and healthcare.

When Aging with Dignity looked at the kind of the practical way that we could help families talk about what's really important to them, and thought about advance care planning, we were inspired, of course, by the story of Mother Teresa and her life and how she cared for people near the end of life. It was this recognition that there's something huge that's being missed if we're not talking about meaning and purpose and our connection to our Creator and thinking about what it means to go home to God for those who are of that belief.

So, I think to tee that up, advance care planning, spirituality is both a door opener for people that might not otherwise be interested in advance care planning and might not take up the invitation to have a conversation about life support treatment or feeding tubes, they might be more interested to have a conversation about spirituality and the larger questions of faith. And also what we've seen after these past few decades is that if we're doing advance care planning and we're not presenting that opportunity to talk about those things, then we've missed something that's really important. So it's both an opportunity and, I would say, a must.

And speaking of opportunities, I see one of my favorite chaplains just joined the stream with us.

ROBIN WALKER: Hi, everybody. I had a little difficulty getting on.

KATHLEEN TAYLOR: We explained that to our audience and we're so glad to see you, Chaplain Robin Walker. I introduced you when you weren't here yet, but I think the folks know who you are, and welcome. Thank you so much for joining us.

ROBIN WALKER: Thank you.

KATHLEEN TAYLOR: And what we're talking about right now, Chaplain Walker, is we're defining spirituality for the audience, and what we mean by spirituality when we talk about advance care planning and the end of life and healthcare delivery, because it's not like that's a segment unrelated to the rest of the experience in medicine and healthcare. We're defining spirituality, and then we're going to define religion and talk about how those intersect, overlap, do or don't, sometimes do, sometimes don't. So is there anything else any of you would like to add to that definition of spirituality? And thank you so much, Paul. That was a lovely review of why it's important.

JIM KRAFT: Yeah. So, I'm so thankful that, Christina [Puchalski] and others have tried to put a definition to it. It's like that old joke, you put four people in a room and ask them their opinion, and you'll get five different answers. It's, you know, in my research, it's hard for people if you ask people to explain or define what their spirituality is. It's difficult because for many people who consider themselves spiritual or religious, it is the essence of who they are. And it's hard to define, you know, your essence — who you are, what you're about, what your values are, what's most important to you.

And so, I think when you ask an individual, tell me about yourself, or do you consider yourself spiritual or religious, you know that yes is the answer, but they don't think about it very often in terms of definition, because it is just part and parcel to who they are. Their decisions run through their spirituality or their religious grids, the way they think, the way they talk, the way they act, everything comes out of their essence. And so, it's a challenging thing to, and that's going to look and sound different for every individual, although there'll become some commonalities between everyone.

KATHLEEN TAYLOR: I think that's a great point, Jim. I think that spirituality really is, you know, it's defined by the user, if you will. Everyone's definition of their own spirituality is unique to that — there's only one expression of creation that is you. And each individual has their own experience and definition of what that might mean to them. So, that's a really important thing to consider.

And then there's also just defining spirituality so that we help practitioners explore that thing and what that is. And I want to…

PAMELA PYLE: Can I just interject something?

KATHLEEN TAYLOR: Yes, please, Dr. Pyle.

PAMELA PYLE: And first I just wanna say I love how Five Wishes was a part of the early understanding of spirituality and the end-of-life experience, but it's really our existence of self throughout our entire life. And one of

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the things that I think for us to always learn as clinicians and those that are working in this world is that the term spirituality in our context is often completely different than if we were to ask a patient would you consider that you have a spiritual dimension?

And so, one of the things that I try to do is talk about how do you view yourself and sense of self and how that relates to your meaning and your purpose, your legacy, your value to others, your role in others' lives — and those are all horizontal discussions. But then how do you relate your sense of self to a spiritual being that would be considered divine, or you might consider faith or religion.

And having this discussion for those that are asking the questions is important, but as important is bringing those we serve to this discussion before they even need to have it in the case of a crisis. So, I love that we're doing this, and I love that we're all on the forefront of bringing this message to the people, that we all need to hear.

KATHLEEN TAYLOR: Mm-hmm. Thank you. That makes perfect sense to me. And I think we're getting to, I'm going to put a little flag in this and bring it back up again later, because I want to, once we get through some other content, I want to offer to the people we have on the webinar right now some ways to ask about it. So, once we get through some of our discussion, I think let's come back to this.

And Dr. Pyle, I love how you just talked about there's a real difference in directly asking someone — and I think this question is important — "Do you have any religious or spiritual beliefs that affect your medical choices?" Important question, but people may not perceive of things as that definition. So, also asking what brings you meaning and purpose, what do you want your legacy to be? Those are other ways to ask that question.

So we'll circle all right back around to that. But I think those are really great things to bring up in terms of spirituality. As Jim said, it's defined by the person experiencing it. And as you were saying, it may not necessarily have the terms that we're attaching to it right here.

And I have to, I specifically — Chaplain Walker, I have to ask you, because you are such a master with helping people illuminate, helping to evoke that from people. Is there anything that you would add in what we're talking about, the definition of spirituality for folks. And maybe you can get to that next question, the difference between spirituality and religion and how those intersect, because that's where chaplains get it all done.

ROBIN WALKER: So for, what I would say is, I typically don't ask someone, are they spiritual? I typically say to them, you know, tell me something about yourself. What are your core values? Do you have any wishes?

> *"I typically don't ask someone, are they spiritual? I typically say to them, you know, tell me something about yourself. What are your core values? Do you have any wishes? And then once they start describing — sometimes they say, what do you mean by core values? And then I would say, what are the things that make you you — what are your pet peeves? And then, we get to it."*

> *"…we seem to think that it's always spiritual, but… the holy could be a cat at home, and I was rushed to the hospital, and I'm really worried about how my cat is going to eat. So then, how do we advocate for that to happen so that they can feel comfortable in this sphere?"*

And then once they start describing — sometimes they say, what do you mean by core values? And then I would say, what are the things that make you you — what are your pet peeves? And then, we get to it.

And often, we seem to think that it's always spiritual, but it could be, the holy could be a cat at home, and I was rushed to the hospital, and I'm really worried about how my cat or my dog or my fish is going to eat. So then, how do we advocate for that to happen so that they can feel comfortable in this sphere?

The other thing too that we must always remember is culture. Your culture, your environment, all play a part of that. So, who are the people in your life that give you meaning? What are the fun things you like to do? What are your routines? Those are the things that create spirituality that often we forget. I have a routine, I eat a bagel every morning with cream cheese… Now I have diabetes, and now you're saying I can't have that. That might be important at that time. That might be a real spiritual thing, you know?

So, those are the things that we are looking for. What are your core values? Then, when we talk about organized religion, how do you live that out? Do you have — not so much a faith tradition — do you have a community where you worship? Then you might find that they're bi-ritual. Then how do you address that in the spiritual care plan?

KATHLEEN TAYLOR: I like that. I like the way you, you're so good at this. I mean of course you are, but you're wonderful at just being a human with another human and asking, who are you? And somewhere in that, there's going to be… Some of the — I don't mean this to be misinterpreted — but some of the most spiritual people I know in terms of the way they live their lives are atheists. So it's not always… I think we need to use the terminology that the person in front of us enjoys, and that resonates with them.

ROBIN WALKER: Can I weigh in on that for one?

KATHLEEN TAYLOR: Oh, yes, please.

ROBIN WALKER: I want us to understand that if a person is an atheist, that is a belief system.

KATHLEEN TAYLOR: Yes.

ROBIN WALKER: And we need to address that. One of the beautiful things, and I don't want to take too much time from the others, but one of the experiences I had in my 21 years of doing this was a woman I never prayed with. We watched Barbra Streisand's last concert. She drank a glass of wine, I had a glass of cider. We talked about our kids. And then I wasn't her chaplain anymore. I went to another hospital. But her family found me to do her service after she died.

KATHLEEN TAYLOR: Mm-hmm.

ROBIN WALKER: I knew so much about who she was in that short period of time. So, what I want us to understand is that spirituality could be the love of our children,

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PAMELA PYLE: And I would just say they won't describe, like the atheist as you described, if you were to ask them about their spirituality, they would not recognize that their belief system is a part of how healthcare determines the definition of spirituality. So, understanding who they are before even asking — that's kind of a tough question — "tell me about your spirituality." I love sitting down and also learning who they are, looking them eye to eye, and when I'm doing a physical history in my social history, tell me about what gives you strength. What are your current stressors? And a lot of times you'll find there's many direct links, not only to the answer of spirituality or religion, you'll find the answer to the source of their disease, in terms of timing. So, really not using too much medicalese or religious words before you get some sense of who they are is really helpful.

KATHLEEN TAYLOR: I think that's great.

JIM KRAFT: One of the things that, when we define religion, we tend to put it in practices and rituals and traditions, things like that. And so, we tend to think those are the more, the people who have a faith in a higher power, in God or a divine. And yet, some of the most religious people I know are people that don't assent to a divine or a higher power, but they find their spirituality in and their sense of essence in yoga or in martial arts, or in these practices that, in many ways they're more religious and more faithful to their yoga practices or their various practices than I am, say, in reading my scriptures or in attending services or the rituals that would be associated with being overtly religious.

So, I think it's, we need to make sure that we have a broad definition of not only… Many people — I think the highest percentage — say, "I'm spiritual and religious." So they start with the spiritual emphasis and say, "I'm religious as well." I think there are people that will say, "I am religious." But depending on your, in some cases in your denominational affiliation, that there are

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those various denominations that would start and say, "I am more spiritual than religious." And then you have different denominations that are more liturgical in nature that would say, "I'm more religious than spiritual."

KATHLEEN TAYLOR: And I think, and we'll get to this more when we talk about just offering people some, you know, easy — a lot of clinicians are not comfortable in approaching these topics because they don't feel like they're qualified. They don't feel like they know enough to do it. So, I want to make sure we give people just some phrases and some simple ways of opening the door, and then making sure that you refer to your chaplain if you feel it's out of your wheelhouse to go in depth with that. But I think the top headline I would put on all of this is not to ever assume that we know anything, and to inquire and let this person define who they are and what matters to them.

There's a — this isn't really a question but it's a comment that came in, and I want to read this to you because I think it's just perfect for what we're talking [about] right now — from Tim, who says, "As a Christian who works at Providence and fundraising for hospice, I found that I need to check myself when having conversations with donors as I've sometimes assumed a faith or religious background or spirituality that actually doesn't exist," and said that rethinking that has helped him to think about that part of the conversation, I think, more sensitively. So I think yes, it's, asking doesn't hurt. It's in kind of the way we ask and in making sure that we remain value neutral, and we don't assume as we ask.

And sometimes what you're talking about, all of you, in just saying the word spirituality

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— I don't think it's a bad word; I think you can say it, but I don't think we need to always lead with it — you can just start, as Chaplain Walker was saying, "What matters to you? What gives your life meaning? What's giving you hope? How do you find peace?" And then work your way to that question, if that feels more comfortable, most importantly for the person that you're working with, and also for us as clinicians and people who have these conversations.

So, let me just, to wrap up this part of our conversation, I think I just want to say that spirituality and religion are not the same thing. Sometimes they are connected and people express and practice their spirituality through a religion. Sometimes they don't. Sometimes people are doing one or the other, and there's not much overlap. It's all okay. And it's all just something that, in a really sensitive inquiry, you can let the person define that for you.

So, I want our folks in the audience not to be afraid of this topic. I think a lot of times in medicine, it just kind of gets left out because people think, medicine, that's a physical body, there's not a lot of spirituality

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in medicine. But what we know is that there absolutely is a connection. There is — we have research that shows us — that strongly links spiritual beliefs, communal practices, rituals, with beneficial health outcomes. And there's some really interesting research that I want to outline for you, and then I want us to have a conversation about this.

Research shows us that spirituality is associated with higher quality-of-life measures, period. And that's also quality of care near the end of life. And then there's a little twist. So, religion and religiosity has kind of a mixed effect on end-of-life care and quality of life near the end of life. So, this research is mostly from the Balbonis — that's Tracy and Michael Balboni. So, they have done a lot of literature review and research on how religion intersects with people's choices about end-of-life care.

And here are two points I want to discuss. One is that high religiosity has been associated with delays in seeking treatment for serious illness, with a higher desire for aggressive treatment near the end of life, and with wanting all measures to extend life. So that's one part of it. However, it's actually reduced, it's reversed when the medical team, meaning that the doctor, the nurse, the social worker, the chaplain, when the medical care team addresses spiritual issues, that trend reverses. And then we see a higher use of hospice, and we see less aggressive care, we see less choices about aggressive care.

So, there's something about the difference between being religious and community religious support — because high community religious support is associated with that higher aggressive care, [and] medical teams addressing spirituality is associated with that reversal, which is fascinating to me.

And I want to specifically start with you Chaplain Walker, if you can talk about what is happening and how do you see that changing? If you work with a patient who comes in and they've got that, I want the aggressive care and my religion tells me this — how is that shifting for people when the medical team speaks with them about their spiritual needs and supports them?

ROBIN WALKER: Well, one thing, let me just say this. There's three things that happens. You can do a spiritual screening, a spiritual history, and a spiritual assessment. The chaplain does the spiritual assessment. A spiritual screening is one of two questions that asks, do you have a faith tradition? Would you like to see a chaplain? That's normally when you come in and get the demographics. A spiritual history, you can have a social worker, a doctor that says, what gives you meaning, tell me about your life, that kind of thing.

A chaplain is going to do a spiritual assessment. They're going to establish care and trust. That's number one. Often, they're going to, if a person is very religious, they're going to be able to talk about the understanding of what faith means in that tradition, whether that be a Muslim, a Jewish patient, because they have the background to understand religions. So, they can meet the patient where they are in terms of their understanding about their background.

The other thing is, we have to remember, just because I am a Seventh Day Adventist doesn't mean that I follow all the dogma of my religion. So, we have a tendency to meet that patient non-judgmentally. If in fact they have a faith tradition or they have this idea, "I have to walk by faith and not by sight, God's going to heal me." And I'm going to ask the question, well, what does that look like? What does that look like for you? And does that mean that we're going to have enough faith if God says no? And can you accept the holy "No?" And is it a real hard "No?" What does it look like to live in the moment with the fact that yesterday you prayed for today? And that may be the miracle, just today. Then, when you start having that conversation, we can begin to pair your spiritual walk with the treatment plan of care, knowing that that treatment plan of care is the blessing that you prayed for yesterday.

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> - *A chaplain is going to do a spiritual assessment. They're going to establish care and trust… they're going to be able to talk about the understanding of what faith means in that tradition… because they have the background to understand religions… to be able to interpret clinical things, but at the same time speak my language in terms of my spirituality."*

And so, oftentimes that helps with getting through that process, because it's a journey. And somebody is journeying with me that is nonjudgmental, that has a clinical background to a certain extent, to be able to interpret clinical things, but at the same time can speak my language in terms of my spirituality. And I think that's why the article that you're referring to spoke about that. You know, where they saw that.

But if you don't have a professional chaplain that is trained that can be able to write a spiritual care plan to advocate and be able to speak in layman terms, "This is what you're facing." And did God, you know, do we really believe in Ecclesiastes when it says there's a time for everything? These are some of the things that we can talk about that they may not necessarily talk to the medical team about. And I think that's how come you see what you see.

KATHLEEN TAYLOR: Hmm. That's interesting. Anybody else on that, on why you think the, when the medical team attends to this, we see those trends shift? Dr. Pyle? Yeah…

PAMELA PYLE: Well, I want to say first that, to have that deep of a conversation with a patient from an acute care setting — which a lot of this type of discussion is in an acute care setting — when a clinician is able to sit down and have a deeper conversation, you often find that what they understand aggressive end-of-life care is, is different than what it actually is and what it actually

can accomplish. So, if you're able to discuss, well, let's talk about what that really means and what that would lead to, does it change the outcome of a disease that brings that person back to a life that has meaning for that person, or is it staying on machines waiting for a miracle?

And then there's this complexity of, for those that are highly religious, especially Protestant and Catholic traditions, there's a lot of confusion about the sanctity of life, and if I choose not to do machines, or to take my loved one off of machines or life support, I'm no longer honoring the sanctity of life, which is important to our faith.

And then the second is, that I've heard is, "I'm waiting on a miracle." And I love what the chaplain had to say about, well, what does that look like to you? And in 35 years of medical practice I can say I've seen a lot of miracles, and they're defined by the patient and not by me. But also I really give them, there's a, particularly in the Christian tradition, if you don't receive a miracle, it's because you didn't have enough faith. And that creates a lot of spiritual distress.

And so understand, like the way I describe a miracle, they're like solitary snowflakes that, in my case as a believer in divine being, is that God delivers them at his discretion and he delivers those to people of all faiths and no faith, which is, as we talked about, is also a faith. And it's not, you know, part of my role to define that for them. But it is part of my role to help them define it.

KATHLEEN TAYLOR: I think this is a perfect time. Paul, if I can ask you to, can you give a little background on, Five Wishes has a resource called *Finishing Life Faithfully*. You talked, Dr. Pyle, about sometimes people — well, all of you talked a little bit about this — sometimes people have an understanding of what the religion they subscribe to says about end-of-life care, and specifically about life-sustaining treatment, and whether you're valuing the sanctity of life or not. That's been of particular trouble sometimes for Catholics, for people with a Catholic background. Five Wishes — Aging with Dignity — developed this tool, *Finishing Life Faithfully*, specifically for Catholics to help them understand the Catholic teaching. Paul, can you talk a little bit about the background and how you all developed this and what's in it?

PAUL MALLEY: Sure. So, you're right, it is appropriate because it helps to answer some of these questions. It was just introduced just last year, so it's pretty new. A lot of people don't know about it yet. But it was introduced because there were questions coming from Catholics — the faithful, families, priests. And I offer this personally as someone who is Catholic —my brother's a priest — so I can speak from both the organizational perspective and personal.

And I think this is probably true — and there's a thread of faith traditions that are beyond just Catholic. But we know that it's important to us; we know our church teaching is important to us and our faith is. But, just like most of us haven't thought about the big questions of advance care planning in general, we also haven't given a whole lot of thought to what our faith actually teaches us about advance care planning.

So then if we're given an advance directive, we wonder, we think, oh, well my faith is important here, but how does that translate practically? So, I think that's where *Finishing Life Faithfully* comes in. It's subtitled *A Guide for Catholics on End of Life Care*. And, the way that we worked to develop it is that we

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> *…we worked with some ethicists and theologians to look at the official church documents and to summarize them. So it's not commentary, it's not opinion. It's saying, here's what the church teaching is. And it puts a focus on evaluating benefits versus burdens and treatment decisions. It puts a focus on where those treatment decisions should rightfully be made by the patient and the person who that patient trusts to make decisions for them."*

worked with some ethicists and theologians to look at the official church documents and to summarize them. So it's not commentary, it's not opinion. It's saying, here's what the church teaching is. And it puts a focus on evaluating benefits versus burdens and treatment decisions. It puts a focus on where those treatment decisions should rightfully be made by the patient and the person who that patient trusts to make decisions for them. It's language that I think palliative care physicians' chaplains would recognize and point to and nod their head and say, "This is right, this is true, this is good. Help our patients to understand this."

And I think it's something that patients and families look at and they say, okay, now it helps me make sense. Now I feel like I can fill out *Five Wishes* or any other advance directive and understand what my faith tradition would teach and how it would guide me. And I think it's a great tool for families. It's a great tool for hospices and hospitals and physician practices that serve Catholics. And really, although it's Catholic-specific, it would fit certainly all Christian traditions and others too, just looking to incorporate that discussion of faith and spirituality in advance care planning.

And, you know, I'll just back up one notch, Kathleen, to your really intriguing comment about what happens when spirituality is injected by clinicians in the advance care planning conversation. To boil it down to practical terms, two different experiences that I had personally with family and friends. One was sitting in an oncologist office where a new test result was going to be relayed, and the test result was relayed. It wasn't good [or] encouraging. And then the oncologist provided the guidance on what the next treatment would be, and that was the basis of the conversation.

Part B was with a different person. The oncologist was relaying test results that weren't good. And the oncologist said, so let's talk about this. What's important to you next? And asked that question, would your faith inform decisions that are made here? It was that simple question. And then that person was able to say, well, actually, yes it would. And here's what's important to me, and I really want to be with my wife and

kids, and I want to receive sacraments. And then that changed the whole discussion.

So it wasn't just about here's what's clinically indicated, here's the next thing that happens after this test. It's, okay, here's what we know about your test result, and here's what we know about you. So now we can make a decision on the biopsy or the treatment or the test. It was simple, but it changed the whole course of how everything happened.

KATHLEEN TAYLOR: And I would say, or suggest, it is clinically indicated. This is not that people's spirituality and their personhood and meaning and purpose, again, as we said at the top, it's not separate from the experience of having an illness, being treated for an illness, receiving care for an illness. It's part of who a person is. So, I think it is clinically indicated to explore these questions. And that's why at the beginning I talked about how when we're training facilitators through any kind of *Five Wishes* training, it's not to make assumptions about this, it is always to inquire about it. And like you said, that second scenario B, that's all that happened. If someone just asked, tell me about what this means for you. Yes. Dr. Kraft…

JIM KRAFT: Yeah. Kathleen, you talked about Tracy Balboni and her research. She brings up a really interesting tool that they have developed. It's called the Religious Beliefs in End-of-Life Medical Care. And to your point, Dr. Pyle was talking about the sanctity of life, and that that is one of the pillars that will influence a decision to do something or not to do something. They have identified — Tracy Balboni and her team have identified — four kind of pillars. One of which is the sanctity of life. The second of which would be, Chaplain Walker(?), belief in miracles. Another pillar is the sovereignty of God: how much does the individual believe in the almighty sovereignty of God to make things happen? And then the last one I think is really interesting is the sanctification through suffering.

And so, those four pillars… Balboni has discovered that to the degree that the individual places high value on those — so sanctity of life, miracles, suffering — the degree that they, the higher the value placed on those, the more likely the individuals are to pursue aggressive treatment at all costs, even in the face of non-beneficial care. The least likely they are to engage in any kind of advance care planning, because if you believe that God is sovereign and that everything's in his control, why should I plan, right? That's the common thought is why should I plan? Because God's got it all, He is in control.

So, the likelihood of being proactive and going in and entering into advance care planning isn't there. Same with miracles: I'm just gonna go on life support long enough. I always joke and say, well, you're not buying God any time. You know, he can heal you just as easily before as after the intubation, or whatever. But that belief that I don't want to play God and I'm going to wait on God's miracle.

And so, those four indicators, if we would learn or use similar types of conversations to find out what do you believe about the sanctity of life. Catholic, somebody who is very, maybe they've never thought about it at the end of life, but they think about it a lot at the beginning of life, of the sanctity of life. If there's a high value at the beginning of life, there's probably a high value at the end of life. And so, that is going to, as a

clinician, that's an indicator that, hey, I may need to go in a deeper conversation here.

KATHLEEN TAYLOR: So, let me ask you then, Dr. Kraft — so, let's say that you're facilitating, because that's what you do, you facilitate these conversations with people, and you get to that point where someone says, I believe in the sanctity of life. I believe in the sovereignty of God, and therefore, why should I even engage in advance care planning? What would be your next response to that? How do you respond to that?

JIM KRAFT: So, I think in all of them, and illness in general, to answer your question regarding the difference between people who feel supported — and the definition that they put on highly religious means that they feel very supported by their faith community and they're at peace with God. So that's the definition of highly religious. So, I think in all of that, one of the joys or one of the opportunities we have is to pull back the focus from the myopic view of looking at simply the illness, to say, let's look back at who you are as a total person, your spirituality, your religion, what makes you you — and let's put your illness in the context of what you believe, what you understand your faith to teach.

And I believe that is what chaplains do such a great job in. And that's what I tried to do when I was a chaplain, is try to help people broaden out the focus that is rightly so on their illness at the time, to what does your faith teach about that? When we can support them in both the community and in the hospital environment, then they see their illness in the context, "Oh, I believe that there's a greater, you know, that there's something after this life. I believe that there is an ultimate miracle even in death, that I'm

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healed even in death." And so, it starts to put those things in — it's no longer just about the healing of the person in the moment. Healing can come even in death. And so, we get a different perspective, I guess is what I'm really saying from that.

KATHLEEN TAYLOR: Yeah. And, and I think a lot of what we're saying is resonating with people. I'm looking at the comments coming through — and a lot of what we usually have are questions — and we are getting a lot of commentary from people just saying that they've experienced a lot of these things. And I want to read a few…

PAMELA PYLE: Kathleen, can I make a comment?

KATHLEEN TAYLOR: Sure.

PAMELA PYLE: Just real quick. One of the things that the doctor brought up is the studies. And we talked about the more religious someone describes themselves, the more likely they are to choose aggressive care and not follow through with an ACP. However, that study also showed if they attended church at least once per week, they were more likely to have an ACP and less likely to have aggressive end-of-life care.

And then the other kind of nuance about end-of-life care in the hospital, if they and their family are receiving spiritual care at the end, they're more likely to not choose an aggressive end and would like to return home. So, there's some really unique nuances between what people think they feel and what they actually do, depending on how they attend church.

And, and it's the same — you know, the discussion around physician assisted suicide and euthanasia. 72% of Americans are for euthanasia, which is not legal — that's the physician administering medication — and yet they also believe it's not a moral choice. And the more that they attend their religious services, the more likely they are to not be in favor. And also the reality is that every major religion does not support it, but we know that we are a blended community of spiritual people in our country.

And so, understanding where there's a rub around what we say, what we do, how we explain things, also is very helpful for… And then compassionate, and whatever a person's choice is, not bring who you are into their choice. You're there to reflect their choice in a way that honors them.

JIM KRAFT: We know that Christianity — I'll use the Christian faith as the example — no group is homogeneous. No group has — even though you have doctrines that will kind of set the boundaries, if you will. My research— and I researched 800 people that considered themselves highly religious, and we broke it down by denominations. And so, for instance, the mainline denominations were much more inclined to enter into advance care planning and be prepared because they felt that that was good stewardship of their body and their health and all the rest. Whereas the charismatic, the more evangelical — the more Assembly of God, Church of God, those types — were far less likely to have talked to their doctor, to have talked to their family, to have entered into any intentional advance care planning, any of that. And they were more aggressive in their end-of-life care. So, even within the faith group itself, there are nuances between conservatives and more liberal or more, you know, the different groups. So, it all goes back to your original — it begs to who are you, what's important to you, where are you coming from.

KATHLEEN TAYLOR: Exactly. And that's — we're at our time. I just want to end by saying — connecting this specifically to advance care planning practice and to Five Wishes — what we want to do is help any clinician or healthcare professional who wants help with this topic and with different ways to explore spirituality and religion and what brings a person meaning and purpose.

We do have, as I've mentioned, Five Wishes offers several different ways of providing training for facilitators to have more comfort and ease with these questions, and with this really important part of advance care planning. So if you're interested in any of those training options, please go to fivewishes.org and look at the training solutions we have for healthcare.

I'll also quickly mention that doing advance care planning community education through and in partnership with faith communities is wonderful. Always gets an amazing response. So, don't rule that out and consider all faith communities, all different diverse faith communities, not just — we have a lot of the Judeo-Christian focus, but there are a lot of other people in the world besides that focus.

And again, I think the feedback from all of this is that spirituality is very individual and inquiring about it is such an important piece of providing quality care and getting people to think about what would be most meaningful for them.

So, thank you to all of our panelists. I'm going to flip this back to Dave to close us and let us know about the recording and when that will be available and all that good stuff. Thank you all for joining us, and thank you to our panelists.

DAVE SIMISON: Thank you. Remember that this presentation was recorded and will be available to view within seven business days. If you registered for this webinar, we'll let you know by email. We'll also send out links to any of the articles that were referenced, cited by our panelists. You can find this and all of our other recorded webinars by visiting the Five Wishes webinar library page at fivewishes.org/webinars. Feel free to share the Five Wishes webinar page with your teams and colleagues. And on behalf of all of us at Five Wishes, thank you to our panelists, and of course to you for joining us today. Have a wonderful afternoon. Thank you. Goodbye.

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This Five Wishes Practice Community Webinar was recorded live on February 20, 2025. To learn more about the Five Wishes Program for Healthcare or to participate in future live Webinars, please visit us at FiveWishes.org/Healthcare.