



Webinar Transcript

ADVANCE CARE PLANNING LEGAL AND POLICY ISSUES

FOCUS ON PATIENTS AND PROVIDERS

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ADVANCE CARE PLANNING LEGAL AND POLICY DISCUSSION: FOCUS ON PATIENTS AND PROVIDERS

The *Five Wishes* Practice Community is a network of healthcare professionals who use the *Five Wishes* Program for advance care planning. The goal of the community is to enhance the quality and outcomes of advance care planning work through sharing best practices, resources, and information.

The following transcript is from a *Five Wishes* Practice Community Webinar featuring thought leaders and influencers in the field of legal and policy issues in advance care planning. This hour of discussion explores how the medical and legal practices of advance care planning can collaborate to benefit patients, providers, and the community – and highlights resources, practice examples, and legislative efforts.

DAVE SIMISON: Good afternoon and welcome. *Five Wishes* is pleased to present today's Practice Community webinar — *Advance Care Planning Legal and Policy Discussion: Focus on Patients and Providers*. My name is Dave Simison and it is my pleasure to host and introduce today's webinar. This webinar is being recorded, so participant audio is muted. If you need technical help with the webinar, please click the Q&A button on the lower bar of your Zoom screen, describe your issue, and I will do my best to help you. This presentation will last up to 60 minutes, and you are encouraged to ask questions throughout. To ask a question, click on the Q&A button on the lower bar of the Zoom screen, [and] type your question for the presenters.

It is now my pleasure to introduce Kathleen Taylor, Healthcare Programs Director for *Five Wishes*. Kathleen...

KATHLEEN TAYLOR: Thanks Dave, and thank you everyone for joining us today for the webinar *Advance Care Planning Legal and Policy Discussion: Focus on Patients and Providers*. This is our 13th *Five Wishes* Practice

Community webinar, and we're delighted that these continue to be so well attended and appreciated. I think we have around 800-ish registrants for the webinar today, so we're delighted that you continue to find these relevant and of use.

For anyone who's new, the *Five Wishes* Practice Community is for any and all healthcare professionals who are using *Five Wishes* tools and resources. So whether you're using the *Five Wishes* documents, our training solutions — Conversation Guides, patient education tools, outreach materials, custom built solutions, anything that *Five Wishes* offers in our Program for Healthcare — if you're using any of those things, the Practice Community is for you. And our primary goal with the Practice Community is to help ensure the high quality of your advance care planning work, and to empower you to have truly meaningful and effective conversations with the people that you serve. We want to make sure that that's happening when you're using *Five Wishes* tools — and when you're not — but this is an added bonus for using the *Five Wishes* Program.

We do this by sharing and highlighting best practices on these webinars and through other mechanisms, and sharing innovations and thought leadership. And that's what we're going to be doing today, so we hope you find today's webinar particularly useful.

We have the honor of hosting some thought leaders and experts in the field of advance care planning policy and legal aspects today to talk about lots of things that we'll get into shortly, and we're so grateful to have each of them joining us today.

So if you all can turn on your cameras, I will introduce our panelists today. In no particular order except maybe alphabetical, we have:

Marisette Hasan

She serves as the senior policy advisor for C-TAC —The Coalition to Transform Advance Care. And C-TAC is dedicated to improving the lives of people impacted by serious illness, advising decision makers, and leading the coalition of member organizations to advocate for the policies that ensure greater access, equity, and enhanced quality of life.

Marisette began her career as an oncology nurse in 1981. She's been CEO and President of the Carolina Center for Hospice and End of Life Care since 2018, following a career in healthcare and hospice. Thank you, Marisette. In her role with the Carolina Center she works with community stakeholders engaged in the delivery of end-of-life care in diverse settings, in addition to working with hospice and palliative care providers. Welcome, Marisette.

Sarah Hooper

She's the Executive Director of the University of California San Francisco UC Law Consortium on Law, Science and Health Policy, and a lecturer in Law at UC Law. She also serves as the Co-Director of the Master of Science and Health Policy and Law Degree, and the Policy Director of the Medical-Legal Partnership for Seniors Clinic, which we'll hear more about. Sarah has dedicated her career to developing innovative medical-legal collaborations that can advance equity in healthcare. She has a special interest in complex care, and in particular the role of law and lawyers in improving systems of care for underserved older individuals with complex medical and social needs. Welcome, Sarah.

Paul Malley

Paul is the President of Aging with Dignity, a role he has held for 21 years now. Paul is a national expert and advocate for quality and dignified care at the end of life. He 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, and is a frequent national presenter at palliative care and aging advocacy conferences. And he has presented in Canada and Australia as well, at international conferences on improving end-of-life care.

Kathleen Taylor, MA, LMHC

Kathleen serves as the Five Wishes Healthcare Programs Director. She has nearly 30 years of healthcare experience with specific focus in advance care planning, palliative care, and end-of-life

care. In her roles as a hospice clinician, program director, clinical trainer, and community engagement professional, she has fostered clear communication within families, care teams, and communities. Kathleen is a Florida Licensed Mental Health Counselor and Qualified Clinical Supervisor, and a Certified EQ-i 2 Emotional Intelligence coach.

KATHLEEN TAYLOR: So welcome to all of our panelists. Thank you for being with us. And to remind all of you, this is going to be a discussion. We're going to have a facilitated discussion together and talk about advance care planning legal and policy issues with the folks that we've got here today.

So, what I want to say just to start us off, to revisit the framework of this topic: Advance care planning — effective advance care planning — is, as best as I can understand it, a systemic endeavor. It involves educating providers, patients and families and

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communities; coordinating, eliciting and listening skills; documenting, witnessing; information sharing, storing and retrieving and updating; and good decision making. And all of this requires a system to do it well.

To be effective, advance care plans need to be medically sound, with decisions that are clear and able to be honored by medical professionals who may be present when the time comes. And they need to be legally sound, with wishes elicited and documented in ways that ensure their validity and integrity. And most of all, advance care plans need to be understood and understandable based on clearly and thoughtfully informed choices reflecting the unique values and experiences of the human beings that they concern.

So it's kind of a lot of legs to a stool there, but it's a systemic issue. And thinking about the collaboration between medical and legal communities and the *people* community, I wanted to first start with you, Paul, and just see if you could give us a general background of how the *Five Wishes* Program did that, because it's a pretty good example of partnering medical, legal and human beings in the community to build something new.

PAUL MALLEY: Sure. Thanks Kathleen, and it's good to be part of this discussion with you Kathleen, and Sarah and Marisette as well. So I think first of all, the very title of this webinar is interesting. *Advance Care Planning Legal and Policy Discussion: Focus on Patients and Providers*. So, you have four different lanes there that sometimes are seen as being in conflict, and I hope what you'll see today through our discussion is that there are ways that we can harmonize this. What we've noticed at Aging with Dignity — the nonprofit organization that created *Five Wishes* — when we looked at the process of advance care planning in the late 1990s, we

saw that the documents, the process that was available to people to complete an advance directive was very legalistic, transactional. Some of the first generations of living wills or advance directives were written in language that was very difficult to understand.

And there's a reason for that. When you go back and look at kind of the genesis of this idea, it really began in earnest in the late 70s or 80s when there was a need for patients and families to be able to communicate what their thoughts were regarding life support treatment, especially trauma emergency treatment. And to help with that, attorneys, and then eventually legislators, mostly in states, came together to craft laws and policies. Most laws governing advance directives are really written into state statutes

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and decided by state legislative bodies, so any of you who have been in any legislative committees know what an interesting situation that can be. And on the policy level, we have state departments of health as well as CMS giving guidelines, giving guardrails for advance care planning.

And our first focus, our primary aim, was to look at advance care planning from the lens of the individual — from the patient and his or her caregivers, family and professional caregivers. And there we also saw that there were some pretty clear headlines of what people cared about the most. When you ask people, "What would be important to you if you were approaching the end of life?" people say, "I want to be at home, I want my family to be with me, I want to be comfortable, I don't want to be in pain, I want my human dignity to be respected and protected and maintained." And they would also have some thoughts about treatment decisions, life support treatment and otherwise. So our idea that eventually led to *Five Wishes* was that we actually could harmonize these things and put them together. That we could create a form of advance care planning and a program for advance care planning that had as its primary focus what was most important to patients and families. And — and here's where I'll underline that and — and also follows state legal requirements.

I mentioned that it's state statutes that govern advance directives and their policy and their law. We were grateful to work with the American Bar Association — Charlie Sabatino at the ABA Commission on Law and Aging — and looked at the statutes of all 50 states. And here's a pivot point: We could have decided and made the decision and crafted *Five Wishes* around the idea that clinicians would want to honor a patient's wishes no matter how they're expressed — and I think

“What we chose was what the ABA called the Gold Standard Approach — was to put that discussion, the Five Wishes document, in terms that were understandable to the patient and that satisfied the legal requirements written in the state statute. So that was intentional, that we would create a document that did ‘both and.’”

that’s true, and I think that would happen. What we chose was what the ABA called the Gold Standard Approach — was to put that discussion, the *Five Wishes* document, in terms that were understandable to the patient and that satisfied the legal requirements written in the state statute. So that was intentional, that we would create a document that did “both and.”

And since then, since it was introduced nationally it met the legal requirements in 32 states. **Today...the standard *Five Wishes* document meets the advance care planning requirements in 46 states. So there are just four outliers, and we have solutions for those states as well.** So on the grand scale we’ve seen the pendulum swinging, we think, in a positive direction to give people more flexibility to make decisions on their own terms.

An then what we’ve created — and Kathleen, you’ve been so helpful with in the *Five Wishes* Practice Community — is making sure that the legal and the policy requirements are met so that hospital legal counsel can also have peace of mind to know that advance care planning that’s happening within their institution is following the legal requirements. And from their perspective, I

would underline, that means that all of the protections that are written into state law and state statute — the immunity provided to healthcare providers who are acting in good faith and following a patient’s wishes — those are all guaranteed only if that document meets those requirements. That’s why we think *Five Wishes* has been so successful and well-received on the patients’ side and the providers’ side, and then this Practice Community now is providing more resources for the clinical side, so that it really does harmonize all these parts of the advance care planning process to show that it can work for all the interests of each of those groups.

KATHLEEN TAYLOR: Thank you. I like how you talked about the Gold Standard really being that things are understandable. I mean, if it’s not understood by the people who need to understand it at the time when the need emerges, then I think all of us who have done this work have seen — people who have done the work of advance care planning, and then, you know — it’s rare that this happens, but these are the stories that stick with me — are the times when it didn’t work because somebody didn’t know or understand what the wishes were that were being conveyed. Or the wishes were conveyed in a way that was medically conflicting — you can’t have this *and* this — so the informed choice wasn’t medically informed in a way that actually was actionable when somebody needed that to be. So, I like thinking of the Gold Standard as being something that meets all of those requirements.

And Sarah, I want ask you as well, with the medical-legal partnership, [it] just seems like exactly what Paul is talking about in everyday working action. So can you tell us a little bit about how that started and what that is today?

SARAH HOOPER: Yeah. Thank you so much for having me. It's really lovely to be in conversation with you all. I couldn't agree more with sort of the general principles that you've outlined around advance care planning. I'll say a little bit about the medical-legal partnership model in a minute and what that actually looks like, because it's actually been around for a very long time and exists in about 400 health systems around the country and it's an evidence-based model. But it's applicability — I think it's particularly important in advance care planning. And I think about the role of lawyers, I think, a little bit more broadly in this space, and I think about it in two ways.

So, one is a partner for ensuring that these documents are accessible, and that they reflect the wishes of the patient, and that they are legally valid. But also that lawyers — and I think in particular about community lawyers who do broader disability and estate planning — have access and skills and tools to address the socioeconomic context in which people are stating goals of care. So if your goal of care is to age with dignity in your home, or to die in your home, but the conditions in your home are not conducive to that, or you're about to be evicted, and you don't have anyone to help manage your finances, your medical goals of care are not realistic, right? And so, I think more broadly about the role of lawyers in this space, and I think about our relative sort of skills as being

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MEDICAL-LEGAL PARTNERSHIPS

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complimentary. And so I'll say that's sort of like the big picture of what has come up for us in the medical-legal partnership.

So, a medical-legal partnership is a healthcare delivery model, as I said, in about 400 healthcare systems around the U.S., in which lawyers are integrated into delivery of healthcare.

And we do sort of three things. One is we provide training, and we also receive training, in partnership with healthcare teams around joint sort of medical -legal needs and advocacy of patients and caregivers. Training is huge. It is the, probably the most — I think the direct, there is a direct advocacy piece, but I actually think the training piece is really eye-opening for everybody, and it has been for me and for my colleagues as well.

Second, the healthcare team can actually make direct referrals to the legal team to actually provide advance care planning or other services like housing advocacy, appointment of durable powers of attorney for finances, which are critical, other estate planning... Some do help with immigration or other kind of broader family issues that come up. And that service is free to patients and caregivers, and it's targeted to people who are often least likely to have access to those services in the community. So we're really focused on complex care, that's kind of the population we're looking at.

And third, we do systems change together. And it sort of becomes a natural consequence of learning together, advocating together, and then seeing, "Oh, these challenges are coming up repeatedly, what can we do differently together?"

So that's the medical-legal partnership model. And so in this context we're working really closely with healthcare teams to understand what the clinical realities are, and then help explain sort of the nuts and bolts of the different forms, when each is helpful according to state law, and then help kind of myth-bust around, you know, perceptions of "Well,...I don't think this form is actually valid," when actually it is, or "Could we create a new form?", or "How do these forms work together?" So we definitely do that kind of thing as well.

And I will, I guess I'll just add, and then I'll just stop and see, Kathleen, if you have any follow-up questions. You know, we... Lawyers in the community are a part of the advance care planning workforce — a big part — and we know from some studies in California that patients self-report that they are actually more likely to engage in ACP with lawyers in the community than they are with

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clinicians. And whatever you think of that, lawyers in the community are part of the ACP workforce, and so I think our goal should be: How do we better engage and improve quality of advance care planning among the lawyers who are already engaged in it? And in the work that we've done with the ABA and the American Academy of Hospice and Palliative Medicine, you know, we've found that there's just a real disconnect between kind of the thinking around advance care planning as it's evolved in the last ten years in healthcare systems, and community lawyers who have not been part of those conversations who are like, dutifully churning out documents with really no awareness of these conversations that are happening, and kind of an assumption that these forms are more helpful than they sometimes often are. So that's a little bit about our model and I'm just going to stop there, and I'm happy to say more.

KATHLEEN TAYLOR: That's... I was trying to write down so many things that you said, because — and I'm glad this is recorded, because I'm going to go back and revisit that. That was a really great outline of the benefits and the purposes of medical-legal partnership. And I have to say, we have probably mostly healthcare folks on the webinar today. You know, the Practice Community is made up

mostly of...people who work in healthcare systems, some of whom may be legal counsel but most of which are probably clinicians on the call today. And as a clinician myself, I will say that I have that oversight — that blind spot that you mentioned is something that I have experienced myself. Because we often feel like...the most important part of advance care planning is making sure that these wishes can be honored at the time when someone is dying and that's what they said they wanted.

And what you just said about the — really, it's socioeconomic factors and other pieces of that — unless you've had a case manager [or] social worker who's really dug into that stuff — even if you have, they're still going to have to get some legal advice on some of these things. And I'm thinking about all the patients I've worked with who needed Medicaid counseling and that ends up being a referral to somebody who understands the legal aspects of that and can help them qualify for the kind of assistance they need to get what they want. That was just, that was tremendously helpful and I hope that's given everyone as much of a light bulb as it did for me.

I do want to ask you, kind of as a follow-up, what do you think are the primary — with your experience with the 400 programs that are out there — are there kind of sets of primary issues? I know there was a medical-legal panel, an inter-professional panel that was convened that made recommendations. Are there anywhere kind of the "Here are the things that you should be considering and how you should be partnering"?

SARAH HOOPER: That's a great question. So, we convened an expert panel, a medical-legal panel around advance care planning in 2018. We did this in partnership with the ABA

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and the American Academy of Hospice and Palliative Medicine, and essentially we were just trying to get a sense of their "state of the state" of these disconnects between these worlds. And so we did individual interviews, and then we met in a day-long convening and sort of iteratively asked people their opinions, summarized, shared back, and then developed a set of medical-legal ACP principles, and actually a practice guide for lawyers, that I'm happy to say the ABA House of Delegates adopted in an overwhelming vote in 2019. And the Hospice and Palliative care folks disseminated it as well. And I think — I don't think the principles will be very shocking to this group. I think they're probably things that are very common. But I think that this was one of the first attempts to really bring estate planning lawyers, elder lawyers, you know, law faculty like me into this conversation of what advance care planning should ideally look like.

And so we published this work, we published the principles and we published the practice

guide. And I think sort of just a few quick takeaways, we sort of concluded that the most important legal component at this stage of advance care planning is careful selection and appointment of agents. But... our goals of care can and should be addressed in clinical contexts. And again I think that lawyers can have a role here to support goals of care, but our skill set is really in addressing social determinants of health, that's actually what we know more about. And so I think that we can help support patients, clients, in understanding how they're going to pay for — how they're going to marshal the resources they need for long term care and for end-of-life. And that is, "What are your goals financially, what can you actually do?"

But the healthcare agent piece is a really critical legal piece because it dovetails with the rest of legal planning, right? So in some states healthcare agents have absolutely no authority over health insurance, and so you have to give it to them, you have to give that to them in documents or you have to give it to your financial agent.

So, it makes sense that advance directives are part of standard estate planning packages, because if you think about addressing a decision-making plan for a whole person, you're figuring out the decision-making architecture across all elements of your life, right, and so how your healthcare agent is interacting with all your other decision-makers is something that should be very thoughtfully done.

And we also, because people are getting care across multiple systems of care, a note in a chart that someone is an agent is not as helpful as a durable power of attorney for healthcare. So, we kind of separated out goals of care and really thoughtful conversations about goals and preferences

from the legal decision-making architecture that lawyers are better at, frankly, and we do more consistently, I think, and prioritize more I think than is happening in healthcare systems.

But certainly there's a shared value that advance care planning should be an ongoing process. It should be focused on values, goals and priorities and not specific treatments for sort of hypothetical futures you can't really predict. The forms are really helpful as conversation starters and not an end in themselves. We want more widespread document sharing and then of course we do think there should be greater medical-legal coordination at least in training if not in practice.

KATHLEEN TAYLOR: That's extremely helpful. And I'm thinking, as you're talking about this it's causing me to think about... and I've drawn this before somewhere, but if you were to kind of draw out the process — advance care planning is a, you know, it's an ongoing process — because these decisions need to be revisited with really any significant change in a person's condition or their life or their support system or their resources, all those things that affect the wishes that are documented.

It's also a different conversation when a person is healthy and it's purely hypothetical than it is when it starts butting up against what we would call a serious illness conversation — which still involves some components of advance care planning, but also begins to involve some prognostication and talking about likely complications, likely symptoms, how those can be managed, really getting into those kind of medical fears that are specific to this person's condition.

So I'm thinking about how crucial that partnership is, because as you said, there's

a place where the lawyers are just better at doing some of this procedural stuff, and there's a place where the medical professionals, you know, with training and skill development, can be very good at that other piece, which is really helping to inform the decisions, so that people understand the thing you're saying you want is really not medically possible.

Just like you were saying, sometimes the thing you're saying you want is not possible with your resources or how you're legally set up, but sometimes it's not medically possible. So, I really like the idea of partnering to make sure that all those bases are covered, and as Paul was saying at the beginning, and having it end up in language that's not legalese. I think that, speaking as a healthcare provider — I'm only speaking for myself — but I'm terrified of legalese. I'm terrified of things I can't understand, and trying to present them to a patient where they just look at it and go, "Oh my God, I don't know what this means, and trying to translate it, that becomes a barrier to the conversation. So I really like the idea of having that Gold Standard of taking all this stuff we're talking about and then making sure that every single person who needs to understand it is able to easily access it and comprehend what it is saying and what they need to do.

There are some — there's some proposed legislation that is trying to lead us to the place that we're talking about. And Marisette, I'm hoping that you can help with all this. C-TAC does a great job — If you haven't been to the C-TAC website or participated in some of their webinars, please do that — they do a really wonderful job outlining bills and ways that you can get involved in advocacy, and they've done a great job summarizing the Improving Access to Advance Care planning Act. Marisette, can you tell us a little bit about

the components of that and what it proposes, and what that might do for the practice of advance care planning?

MARISETTE HASAN: Absolutely, Kathleen. I just wanted to first of all say thank you for the opportunity to participate in such an important discussion today from the medical-legal aspect of advance care planning, and [I've] certainly enjoyed hearing just the overview from Paul regarding what *Five Wishes* has done, and the evolution really, over these last several years, in creating those documents and tools for people, and then looking at how medical-legal partnerships can really help us. C-TAC has really been engaged in looking at, "What can we do to remove barriers?" You know, as we look at everything with a health equity lens, it is our goal and our desire to really remove those impediments that really keep people from having these conversations, especially further upstream and with primary care providers. And so, as you referenced, the advance care planning legislation — I hate to say we were not able to get it across the bar during the fall...especially when we were hoping to get it into one of the end-of-year packages. It didn't quite make it but it does not mean we're going to stop advocating for it.

So let me tell you about some of the components of this, because I feel like it's still — Blumenauer and Warner really were getting behind this with us, and it has four components that I feel like are still very relevant.

The first component that we really wanted to get to was to eliminate the advance care planning co-pay that Medicare has after the wellness visit. So if you guys remember, in 2016 CMS made available reimbursement to primary care practitioners and others to provide advance care planning conversations

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- The second thing we wanted to look at was how can we increase the workforce in initiating these conversations... who else on the team has the background that will allow them to engage in these conversations to get people thinking about what matters most to them...*
- The third thing that we talked on about was actually beginning to look at how can we educate providers around these ACP counseling codes and the value of really conducting these particular conversations...*
- ...the last thing that this piece of legislation would do is allow for MedPAC to do a study on the effectiveness — once you’ve removed the co-pays, once you educate clinicians, once you expand the workforce who can do this, how effective and what kind of outcomes could we see if we were to put those things in place?”*

with their patients. They would reimburse them for those conversations. And those conversations can happen at any point in a patient’s illness. And so — man, it was just wonderful — and so as we began to see that. But if those conversations occur after a Medicare wellness visit, then there is a co-pay for the patient. Now, you and I know, just as we were just discussing, that there are other trigger points that can happen with a patient — of course this is the Medicare population — Medicaid also has some similar things in place — but you could go to the emergency room, and need to follow up with your primary care physician later in the year and have to pay this co-pay in order to have this conversation. And so, we wanted to remove that barrier of people having to go into their pockets.

The second thing we wanted to look at was how can we increase the workforce in initiating these conversations? And so, looking at adding the licensed clinical social workers as another member of the team who could engage in these conversations and bill for that. Right now we know that those practitioners can have these conversations. We also know that physicians are having these. But, when we think of workforce, we have to begin to look at who else on the team has the background that will allow them to engage in these conversations to get people thinking about what matters most to them and what they would want.

The third thing that we talked on about was actually beginning to look at how can we educate providers around these ACP counseling codes and the value of really conducting these particular conversations. We know that primary care practitioners are absolutely busy. They have a checklist of things that they’ve got to go through. But we also know that many of them have

not begun doing this in order to bill. They don't understand that they can bill for initial conversation and extended conversation and then ongoing conversations. And so this would really allow us to educate them on the value and benefit of getting to their patients earlier upstream. I noticed that there was a question in the Q&A about when can this start.

And really they want people to begin thinking about this as young adults, before they have sort of a medical emergency. We want this to be around the continuum, when you're healthy what would you think about, and then when things change, or if they change, how do you have that? And so really being able to re-create that for primary care physicians.

In South Carolina we were involved in creating a "care mapping" for a couple of primary care practices that work primarily with African Americans and also rural communities. And the very first thing they said to us [was]: We don't have a process to really begin to talk with our patients about advance care planning. They'll find out, do they have a document, what would they need, etc. And that was very rewarding for us through some funding from the Blue Cross Blue Shield South Carolina Foundation to provide that support, educating their teams but also helping them create a mapping process.

And then the last thing that this legislation would do — and of course people would need to know the billing codes, right, so they can get reimbursed. But the last thing that this piece of legislation would do is allow for a MedPAC to do a study on the effectiveness — once you've removed the co-pays, once you educate clinicians, once you expand the workforce who can do this, how effective and what kind of outcomes could we see if we

were to put those things in place? As so, as I shared, we didn't make it across the bow last year, but we are absolutely picking this back up to work on this again for this legislative session. [This] gives us another opportunity to educate our national leaders, right, to let them see how important this work is.

And really, we want to create more access in our under-served and under-resourced communities for this to happen.

KATHLEEN TAYLOR: Thank you, yes. We're hoping this gets across the hurdle at some point. And there's been repeated attempts to pass legislation that addresses some of these things, so I know there will be continued attempts, and I'm hoping that people who are listening are encouraged. There are often opportunities to share — if you know of outcomes — this is one of the stickiest things in advance care planning for healthcare systems, for people to measure meaningful outcomes of advance care planning activities. We get a lot of counts — you know, counting completions — but that doesn't speak a lot to the quality of care, and to the experience of care, and the difference between someone who has had good advance planning and someone who has not. How does that affect the clinical outcomes, how does that affect the site of their death? Did they — is there goal concordance?

So if you are doing any kind of quality improvement initiatives and you have some data about that — and I know people like to be proprietary with their data — but to the extent that it's shareable, you can share that, through channels, sometimes with C-TAC. A lot of times when there are open comments for some of these things, please share that data, and share it as a best practice so that other people know how to measure that, because the people doing the work — those

of us doing the work every day really are the people who understand why the things Marisette is talking about are important and why we need to — and why those pieces of legislation...really need to pass, and just get past the politics of it.

MARISETTE HASAN: Kathleen, yeah, I would put a plug in too that through C-TAC we actually have policy meet-ups. And we also have State Serious Illness Coalition workgroup meetings where we talk about a lot of the policy work that people may be doing at the state level, and how that can bubble up to the national level. So we really would truly love to have more people engaged. We have over 165+ members at the Coalition and many of them are working in state serious illness care coalitions, like myself in the Carolinas, and others. And so we really welcome that engagement and we learn from each other what that legislative language might look like.

Many people have gotten involved in doing, you know, palliative care advisory councils, or looking at, you know, study groups, looking at how they can get the ACP bills turned on. I know in South Carolina, through that state advocacy, we got the ACP bill codes turned on for the commercial payer. And that took us really working together to get that done. So, never minimize what you can do as a group coming together and pooling your resources for that advocacy, so...

KATHLEEN TAYLOR: A wise man once... 23 years ago, Robert Wood Johnson Foundation funded an initiative that was aimed at creating community coalitions all over the country to try and improve end-of-life care in communities. And I remember — I don't know if I can use his name so I'll just say a wise man — saying to me at some point, if you have a coalition that doesn't include policy

work, they're not going to make tremendous sustainable change. And I have seen that come true for 23 years.

It is true that if policy work is not addressed and not included, we see change that sometimes goes away when the people who are working at your organization leave. We want things to become institutionalized, and one of the best ways to do that is through policy work that really changes what is possible.

I want to get to some questions that came up in the Q&A because they're really good. We had somebody ask a question that I've had myself — and I don't know who can answer this, maybe everyone can answer this — but when we're working in a healthcare setting with patients and they need some kind of legal resources, what are the best options for free legal resources? That, again, it's one of the barriers to people including... It's one of the fears of healthcare providers is that we're going to send them to a lawyer and they're going to have to have a ton of money and they don't have a ton of money. So, what are the best resources for patients and families who need some of that kind of advice and how do we access that as we are caring for people?

SARAH HOOPER: It's a great question and I'm happy to jump in on that one. So, we of course don't have a Medicare for legal services in this country, and so most of it is self-funded, which is why we have sort of what we call the access to justice problem. But what I can say, for low income and even some moderate income folks, we do have a network of legal aid agencies across the country that provide free service. And so, there's a website you can go to called lawhelp.org, that allows you to put in your zip code and the legal issues that you're looking for, and it will do it by state

“...for low income and even some moderate income folks, we do have a network of legal aid agencies across the country that provide free service. And so, there’s a website you can go to called lawhelp.org, that allows you to put in your zip code and the legal issues that you’re looking for, and it will do it by state and by region to help you connect to free legal resources.”

and by region to help you connect to free legal resources.

For older adults and people with disabilities, under the Older Americans Act we are not allowed to means test. So if it’s an older person, you can contact your area Agency on Aging and find out who your contracted legal provider is. They will not be helpful to somebody who has a really lot of assets and could truly afford to, for instance, pay for long term care totally out of pocket — shoot, nobody can. But say you can, don’t go to that place. They’re overwhelmed, they’re not good at that kind of level of asset. We really need to preserve our scarce legal advocacy resources for the people who really need them. But we do help people who are over the threshold for Medicaid but who are likely to spend down because of their need for long term care and other healthcare services.

And I saw a note in the chat about someone providing pro bono services who ended up charging. I hate to hear that, that is not a true pro bono service. What some lawyers will do is provide free initial consultation. And then they should be telling you what their fee structure is, and if they’re not doing that, that’s deeply unethical. You could get

disbarred for that. So, if someone is holding themselves out as a pro bono resource and ultimately charging, please report them to the State Bar.

But go to your State Bar for referral, or to lawhelp.org, or to your local Area Agency on Aging.

KATHLEEN TAYLOR: Thank you. That’s super helpful. I hope — I hope people wrote that down, and just in case they didn’t, can you give that website URL again? It’s lawhelp.org...Thank you.

There’s another question here. And again, I think this is about having better relationships within the communities that you serve, between the legal and medical communities. When healthcare providers are asking patients if they have an advance directive, and they do, and that is something that they worked on with an attorney, there are some people who are reporting that they have had the experience of not being able to access that when it’s been done with an attorney. That advance directive is owned by the patient, by the person. So that’s not — in my understanding that’s not something that should be run into. That’s something that the patient, the person who did that advance directive, that is their advance directive, and should be shared with everyone in their life who is concerned about what may happen with them at the end of their life. So correct me if I’m wrong, but that’s something — if that’s happening, I think — you know, ask again, because I think you ought to be able to get access to that.

MARISSETTE HASAN: Yeah, I would just say that there may be some things in place in terms of them giving permissions for certain people to give them that information, because it is private. The patient, if they have a copy, we usually encourage them to give those copies

to all the people who are significant to them, and especially if you have a healthcare agent. But if you're trying to get it from the lawyer's office and you don't have something that said they can give it to you, that's not going to work. So we want to encourage people to give that information themselves, make the copies that are necessary. You know, we do have some innovative technology now, which I'm sure Paul would love to talk about, that will allow you to electronically share your documents for people to view it that are in your close circle. But, so I'll finish with that. Go ahead Sarah or Paul...

SARAH HOOPER: I was just going to, really quickly, I was just going to completely agree with you, Marisette. If I call your doctor, and they give me your information, we'd be worried about that, right? And the same thing with a lawyer. If you call someone's lawyer and say, "Give me information on their client," they're going to say no. But the client can always give permission. This is how the medial-legal partnership model works. And so, as long as everyone has permission to share information, that's o.k., but I agree with the larger point that we all should be encouraging the spread of the document as widely as possible, and good conversations about that, and that's one of the principles that we agreed on. So Paul, I don't know if you wanted to add something to that...

PAUL MALLEY: Sure. And that's all helpful guidance, and I look at it through the lens of, what would I tell my own family, my parents or my wife. And Marisette, as you were saying, there are some good new technology tools available, with registries, and our *Five Wishes* Digital option allows for that easy retrieval within a health system or a healthcare setting.

My default is to make sure that everyone who might be by my bedside, my caregiver, knows

"...for families, for caregivers, for healthcare providers, if there are specific questions regarding legal issues and advance care planning, we're happy to find the answers to those. We have a national toll-free hotline that's on the back of every Five Wishes, and it's on our Five Wishes website too, so that you're not left on your own to try to figure out the answers. Or even if legal counsel has questions, we can help find those answers that will give everybody peace of mind to know that they're following the right instructions and following the laws of the state."

where my *Five Wishes* is, and that I know where my parents' document is located, so that I'm not relying on it being found in the electronic medical record, or a registry somewhere. I found that, even with my own parents, once we had submitted my mom's completed *Five Wishes*, I was asked for it several times, and if the only place where it existed was in the electronic medical record, it would have been a challenge. And back to basic technology, I had a PDF of it on my phone, and I could provide it whenever I needed to do that.

So I think those kind of simple solutions are helpful, and then what we exist to do too is to answer the questions that are specific to advance care planning that come up. We are not staffed with attorneys, so we can't answer the broader legal questions on all the aging issues, and that's why it's so important that Sarah provided the resources that she did.

But for families, for caregivers, for healthcare providers, if there are specific questions

regarding legal issues and advance care planning, we're happy to find the answers to those. We have a national toll-free hotline that's on the back of every *Five Wishes*, and it's on our *Five Wishes* website too, so that you're not left on your own to try to figure out the answers. Or even if legal counsel has questions, we can help find those answers that will give everybody peace of mind to know that they're following the right instructions and following the laws of the state.

MARISSETTE HASAN: And I had one other thing to share, Kathleen, quickly. And that is that, you know, you may have a community that's not technology savvy, or where they may not have had the forms, and so we really also want to encourage families to have conversations. You know, some of our communities have an oral history, and so they pass the stories down and talk to people about what happened with Mama and Papa and Grandpa and, you know, and so what would you want...

And so we really want to — in the culture that we're in, a lot of times we don't have conversations. And before you can get to a document, there needs to be conversations that we have with one another. I'm always talking to my husband about what I might want. Through the seasons of our life together as a couple — you know, when were having babies, o.k., what would I want now, you know, if something were happening now, we're on the other side, we're empty nesters. And so we still have to have those conversations, so that, if you can't get your hand on the document, you know what that person said, and you could be asked, "What do you think they would want?" I absolutely agree that we should have a piece of paper that is legally executed, right, but in lieu of that, we still need to have those conversations.

KATHLEEN TAYLOR: Right, and in lieu of or in addition to. Because you can still have the document, and if the conversations didn't take place — and again, I think we've all been at a bedside once where this happened, and once is enough to burn it into your memory — no offence to daughters from out of town, but the daughter from out of town comes in, and that's not her understanding. And in the moment, I mean, this is — there have been a few questions with people asking, "What is the definition of advance care planning?", so just in short to give, I think, a simple definition of that: The purpose of advance care planning is to prepare people to make decisions about end-of-life care in the moments where those needs have emerged. That's the purpose of it.

You can have the conversation well in advance, from the time you're 18 on. And again, we want to revisit those conversations any time there's a significant change that would change what you want, or whether you can have what it is that you might say you want. We want to revisit those conversations to better inform the choices. But the purpose of it is so that when the time comes, people can make the decision in real time. And that includes the medical professionals. If they're looking at something that is impossible to do — somebody wants CPR but they don't want to be intubated — that does not happen.

It has to be something that can be understood by the family members, by the people who are there in the moment who can honor those wishes, by any legal professional you who might take it to. That's the purpose of having all these people collaborate to ensure that the end product is something that empowers people to make decisions in the moment.

So, it's appropriate at any age, it should be done at various stages, as Marisette was saying. There have been some specific

questions about *Five Wishes*, and what I'll say is that we're capturing all of your questions. If we don't get to it live today, we'll answer you through an email, just so we don't spend too much time talking about the specifics of *Five Wishes*, which is an advance directive document and guide for the conversations. We'll get back to you about that — because you're probably already using it if you're on this webinar. We want to make sure that you've got the correct information.

There is one question that I think is pretty good, and it goes back to some of what we were just talking about, with there being now new advance directive storage options. There is someone who is saying she does advance care planning as a social worker, and she has — she's wondering where can the advance directive be stored so that it is available to — so that we have care coordination — so that it's available to all the people who may have an interest in that?

And the short answer to that is, it should be in your medical record. It absolutely should be stored in the medical record — the medical record, the electronic medical record, or however it's done at your place, is supposed to be the one truth where, if it wasn't you that worked with this person, the next person that works with them ought to be able to look at that record and understand the conversation that happened, any decisions that were made, any decisions that need to be made, any information that needs to be filled in.

How you get it there is the harder part of that answer. And there are lots of different healthcare record, medical record solutions available now for advance directives and advance care planning, and there are national directories. Whether or not your organization will approve accessing the directive out of those national directories is

another — that's kind of where I wanted to go with all of us today. Those things exist, but how well in reality are they talking to medical systems right now? How easy is it to import an advance directive document from a national online storage entity into a medical record? Are we making patients do it three or four times again, that's my concern.

MARISSETTE HASAN: Yeah, I would say that we've come a long way with the technology. You know, integrations and interfaces are created so that it could be seamless. The pieces — whether or not that organization is going to put forth the resources to have that integration so you have that seamless ability to look from one entity through to another entity to see the documents. But the technology is absolutely there. It just depends on the state and the health system and the resources that they're putting in place to make that seamless for their providers so they don't have to look two places.

Most of your EMRs with health systems have an advance care planning banner in the record so that everybody knows to go to that particular section of the chart, and can see all of the conversations.

But they're really working hard to integrate outpatient with inpatient, and for folks that are in community, and that's where we have disparate systems. When you think about community and technology versus a health system and technology, that's where some things don't — you know, you may not be able to see everything. And so we still have some work to do, but it's still a whole lot better than it was ten years ago, in terms of being able to not have to go three places or upload something three different places in order to see what a patient's record is. We absolutely want to have ready access, and if you have — I would put a plug in for

information health exchanges because they connect to all the systems and in some states they also connect to the outpatient systems as well, and that would work really well. But each of our states have different things going on, so, and health systems have gotten a lot more savvy with that. And I'll just finish and let someone else chime in...

PAUL MALLEY: I think that's true, and I think what we've seen with many of our healthcare partners is that it's really difficult capacity-wise to ask healthcare providers to look somewhere where they aren't already looking, right? If they're not already seeing it in their electronic medical record — EPIC or CERN — or finding a way to inject that into the platform that they're already looking at, it's going to be a lot harder. So I know some of our work in our practice community has been in helping to join those two different dots together and answer the questions of how a health system would do that, or as Marisette said, with the health information exchanges, the state-coordinated registries. I think if there's a way that you can put it in front of the healthcare providers on a dashboard that they're already looking at, that can be helpful.

But then back to my own "What would I do for my family?" I'd make sure it was there and I'd make sure that my wife knows where a copy is, and that we've discussed it so that she's ready to make a decision for me.

KATHLEEN TAYLOR: The electronic medical record is there — but paper is something that's — I know we all want to get rid of it, but it's still something that seems to — I don't know if we ever will, and I don't know that we need to keep fighting that so hard. I think we do what works best for patients and

families, and if that means, you know, form follows function, then I think sometimes we have to offer access in different ways.

Out of respect for our panelists and everyone who's participating — again, thank you so much Marisette, Sarah, Paul. This has been wonderful. There's so much more to talk about. To remind everyone: We will send out a follow-up email. We will include the links that have been mentioned and the resources that have been mentioned. We will respond to the questions that we didn't get to live today, your specific questions about *Five Wishes* and using those tools, etc. We will send that in a follow-up email.

And thank you to everyone who participated today, and Dave, I'll pitch it back to you.

DAVE SIMISON: Thank you, and just as a reminder, this presentation was recorded. It will be available for you to view within seven business days, and you can find it and all of our other recorded webinars in our webinar library at FiveWishes.org/webinars. We encourage you to share this with your colleagues, and as Kathleen mentioned, we will send out an email letting you know when it's available, and also include links that were mentioned today.

On behalf of all of us at *Five Wishes*, thank you to our speakers, and of course to you, for participating. Have a wonderful afternoon.

END

This Five Wishes Practice Community Webinar was recorded live on January 25, 2023. To learn more about the Five Wishes Program for Healthcare or to participate in future live Webinars, please visit us at FiveWishes.org/Healthcare.