



Webinar Transcript

THAT'S WHAT IT'S ALL ABOUT: ELEVATING HUMANITY IN ADVANCE CARE PLANNING

Dr. Lucy Kalanithi

Dr. Matt Tyler

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DAVE SIMISON: Welcome everyone. Five Wishes is pleased to present today's practice community webinar, *That's What It's All About: Elevating Humanity in Advance Care Planning*. I'm Dave Simison, Vice President of Operations for Five Wishes. It's my pleasure to host and to introduce today's webinar. This webinar is being recorded, and note that all 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 we'll do our best to help.

This presentation will last up to 60 minutes, and we encourage you to ask questions throughout. To ask a question, click that same Q&A button on the lower bar of your Zoom screen and type your question for the presenters.

It's now my pleasure to introduce Kathleen Taylor, our Five Wishes Healthcare Program Director, who will facilitate our webinar today. Kathleen...

KATHLEEN TAYLOR: Thanks, Dave. And thank you all for joining us to have this important conversation today about elevating humanity in healthcare and how advance care planning can help us do that. Advance care planning conversations have tremendous potential to improve communication and build trust between people. And when we do advance care planning really well, we at Five Wishes know that these conversations can help us explore, truly understand, and honor the humanity of the person that we serve as our patient,

and importantly, also to extend and exercise our own humanity in that encounter.

Today, we're going to have a conversation about how and why to hit that mark of elevating our shared humanity in providing healthcare and specifically advance care planning. We're so lucky to have our expert panelists with us here today, and I would like to introduce them now.

Dr. Lucy Kalanithi

We have Dr. Lucy Kalanithi. She is a clinical associate professor of medicine at Stanford University and an advocate for patient-centered care. She's the widow of Dr. Paul Kalanithi, author of the bestselling memoir *When Breath Becomes Air*, which was nominated for the Pulitzer Prize and for which she wrote the epilogue.

Dr. Kalanithi has implemented novel healthcare delivery models in primary care, hospitals and health systems, and served on leadership boards for TedMed, the Coalition to Transform Advanced Care, and the American College of Physicians. She has presented at TedMed and appeared on NPR, PBS NewsHour, Yahoo News with Katie Couric, and in the *Washington Post*, the *Wall Street Journal*, *Elle*, and the *New York Times*. Her award-winning podcast called *Gravity* explores what becomes possible when we think about hardships differently. Welcome, Dr. Kalanithi. We're glad to have you.

Dr. Matt Tyler

Dr. Matt Tyler has over a decade of experience helping people living with a serious illness to create personalized medical care plans centered around what matters most to them. He's cared for people in the hospital, the clinic, and even at their homes. He serves as the Section Chief of Hospice and Palliative Care at Ascension Healthcare and is the creator of How to Train Your Doctor. It's a coaching platform designed to help patients and caregivers confidently make medical decisions related to serious illness at the end of life.

He specializes in creating educational bite-sized videos that cover a variety of topics related to hospice and palliative medicine, and I encourage you to check out his latest content on YouTube and Instagram. Welcome, Matt. Good to have you.

Paul Malley

We also have Paul Malley, who's the president of Aging With Dignity, a role that he's held for the past 22 years. Paul's 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's 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 also presented at international conferences on improving end-of-life care. And he is my friend and one of the nicest people I know. Welcome, Paul Malley.

KATHLEEN TAYLOR: Good to have you all. We're thrilled to gather all of you and to have this conversation today. And as all of you may know, and as those of you listening may know, *Five Wishes* was created — that's the origin story of *Five Wishes* — it was created to help elevate and preserve the humanity of people as they consider, and as they experience, the end of life. Working in Mother Teresa's homes for the dying, Jim Towey saw clearly that people needed the opportunity to define dignity for themselves, and that it makes a difference when people share what that means with those who will care for them.

What we see in our Five Wishes training and our facilitator certification program, we emphasize communication skills. We emphasize that connection between the facilitator and the person you're facilitating with. And what we see over and over again from people who go through these programs is that we want to connect, both as the clinician — the facilitator — and as the patient. People are hungry for that connection. People want to do this, they want to know how, they want to practice the skills and have the mentoring. So, this is a topic that's near and dear, I think, to all of us and to all the people who are viewing today, and will view this webinar in the future.

So, to get us started with this, I want to ask the big ridiculous question first. Why do we even need to have this conversation? Why do we need to talk about preserving and elevating humanity in healthcare? There's so many articles — this is not the only thing happening right now talking about this topic — there have been a rash of articles. They seem to, kind of on a time-based release, these happen every couple of years, where we talk about the challenges

in healthcare and what we can do to restore humanity and connection. So, my question is, why do we keep taking it out — and how is it being challenged right now? So, we'll open kind of with the challenges and then we'll move past them, but I wonder if any of you want to start with that. What are some of the practical and personal challenges that we feel like are in the way of humanity right now in healthcare?

MATT TYLER: I'll take a crack at it.

KATHLEEN TAYLOR: Great, thank you.

MATT TYLER: I think so many of these conversations come back to that famous quote that every system is perfectly designed to do what it does — I'm paraphrasing that — but I think the very cynical but also real answer here is that "humanity" is not reimbursed in healthcare. You know, the system is putting so much pressure on everyone to do as much as possible. And I include patients and caregivers in that as well, if not the top of the list, frankly.

Doctors have more responsibility and more demands on their time than ever before. Patients and caregivers are dealing with more complex medical illnesses and living situations, with still very little home supports. We're asking a lot, and I think a lot of people are just trying to get through the day and just do what they need to do to get through the day. And it's very hard in a pressure cooker situation like we have to pause or linger in a room, or check in, because I think we all sort of like don't want to know the answer to some of that stuff, right?

Because we want to do those things, but we also want to have the time to do those things, and we want to have, you know, time with our own families and time to

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recuperate and relax at the end of the day. The system is really making it hard to do what I think people want to do. It's just there's not space for it.

KATHLEEN TAYLOR: Yeah. There's a lot of it that's just kind of intrinsic to what healthcare is like now. Anything to add to that, Paul or Lucy?

PAUL MALLEY: Yeah, I agree. I think when we think about caring for somebody who's seriously ill, whether it's a family member or a patient, I think that's one of the most intensely personal and human things that we can do, right? Take good care of somebody who we love, take good care of our patient.

As a family caregiver myself, I know when my mom was sick and she had cancer, we wanted her to have the best oncologist

that she could have who knew the best information, who could give her the absolute best clinical care that I couldn't have provided to her. We needed that specialist. And at the same time, when my mom needed to think through conversations about, okay, where do I go on this treatment decision, we needed to reflect and to understand what was most important to her as a person — for me as a son to know that, and for me to help her doctor see and understand that too.

So, I think that's where we all kind of meet at this meeting point of advance care planning, because this is the space where we do have the opportunity to ask patients. And patients and family members, caregivers, have the chance to kind of fly the flag and say, this is who this person is, this is what's important to them, this is what we all need to know when decisions have to be made.

And, I would say, if it's *done well*. If advance care planning is done well and the conversation can be had among family members and with the healthcare providers, if it's not just a form that's saved somewhere and forgotten about. Keeping the humanity in it is what it's all about.

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KATHLEEN TAYLOR: Yeah. And we hear about, I think there are some efforts to improve this, but we hear stories about advance care planning — it's not just advance care planning, but advance care planning specifically — being reduced to — and I don't wanna vilify the electronic medical record because it is as much a blessing as it is a curse for all of us — but I do think that sometimes in the interest of efficiency and in the interest of being able to measure things, we do — there's a reduction sometimes when it's a pull-down and it's yes or no for an advance directive. That's really not a complete question, nor is it a complete answer.

So, it's something that is, it's a functional, technological, systemic kind of issue, and that's happening to all kinds of the interactions that we have in healthcare. We need to kind of put 'em in a box and measure them at the end of the day. Lucy, you look like you want to say something here.

LUCY KALANITHI: Well, it's just making me reflect — it's making me reflect on the idea of advance care planning in general, because I think even if — there's like the little check box that's yes-no, and then there's the actual document, and then there's the conversations, and then there's what happens in the moment, and then there's your real actual life and it's all sort of like telescoping, right? And so, I think this is one of those things in healthcare where it is a document, it is a checkbox, but it's also this giant, meaningful, loving, messy thing. And I hear you saying, if all you think about it as is the little checkbox, that's just this tiny little pixel in a big picture, right?

And then I think there is a flip side, by the way — this isn't where I meant to talk about

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And I think ultimately when you're getting back to this question of humanity, I think being with clinicians who understand that and who can help you sort of tease out — especially if someone can't speak for themselves or make decisions for themselves — who is this person and what is important? And this document gives you the right to speak for them, but your whole understanding of them as a person is what you're really bringing to this."

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So, I think the humanity piece kind of flips back in where even to enact advance care planning, it requires seeing and witnessing and understanding and knowing and acknowledging the messiness and the full humanity of a person.

So, I don't know, when we're talking, so far, I'm just sort of toggling between this idea of binaries, like yes-no...

KATHLEEN TAYLOR: Yeah. It does feel like that. And I think, to your point, it's important, I do believe, for us to acknowledge and to name these challenges that people experience — in the practice and in the receipt of health care — to that humanity and that connection. I think it's important to talk about them so we can address them and we'll do some more of that in this conversation.

But I also really want to do what you're talking about, which is to celebrate the humanity that already does and can exist, and that's inherent in it's... You know, advance care planning is a little oasis sometimes in healthcare. It's not a panacea, but it's a time when we do get to ask people, who are you, and what really matters to you, and how do you want this to go? That's different than a lot of what we experience in the routine receipt of health care as patients.

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So, I want to kind of keep that balance today where we talk about the challenges so we can acknowledge them and think of ways to address them, but also just celebrate what this thing is, this humanity thing that we're talking about today. So, thank you for that.

So, with regard to that, let's do talk about that. Let's talk about that relational realm of humanizing healthcare and how advance care planning specifically — I mean, we can talk about the whole larger subject, but I really want to keep us, every once in a while bring us back to advance care planning and how that's a place where we can do that, where we can find that point of connection between the person who is often the healthcare professional and the person who is in that moment the patient, and/or the family.

So, Lucy, you said in, I think it was your, in a TEDx talk, you talked about how completing an advance directive is an act of love. It's a pact to take care of somebody, and it codifies the vow to speak for you and honor your wishes. And I just, I think that's such a lovely way of putting it, and I want to just take a moment and have a conversation about that bit, that piece of what we can do in advance care planning conversations.

So, anybody just go ahead and — Paul, you always do such a lovely job of talking about the back half of *Five Wishes*, which some people call the comfort wishes. It's that squishy part at the end, Wish 3, 4, and 5 that talk about what makes you comfortable, how you want to be treated, and what you want your loved ones to know. And you've told me stories about the difference that has made for you personally. So, I wonder if you can share about that.

PAUL MALLEY: Sure. And I think — so, picking up on Lucy's idea that this is an act of love, too — I think one of the things that makes us distinctly human is this idea, a concept that I think is universal among all of us, that we want to take good care of the people we love. And as a son, that was what I thought for my mom, as a friend who had a friend pass away earlier this year and walked along the path with him — it was the same thing that I wanted to do for him, take good care of him.

And then the question becomes, well, what does that mean? And advance directives and advance care planning has been around for a couple of decades, but it was really created to answer legal and medical questions: designation of a healthcare agent, life support treatment. And those are important.

But our idea behind *Five Wishes* was to combine that with the matters of the heart and soul, to answer the questions and help kind of create a guidebook, an instruction

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book for what good care looks like to this person. And Kathleen, you mentioned the last three wishes of *Five Wishes*, 3, 4, and 5, that really let a person simply say, here’s what comfort looks like to me.

To my mom, when I was filling this out with her and my brothers and my dad, she was going through the checklist and one of the points says, “I want to be massaged with warm oils.” And she kind of chuckled at that, and then she kind of grimaced and she went to cross it out, and she said, “I got one massage in my life, and I couldn’t stop laughing, I was so ticklish. I don’t want anybody touching my shoulders.” And we kinda laughed and I said, “Well, mom, but how about you like to have manicures? Would you want a hand massage?” And she said, “Oh, yeah, I would love a hand massage.”

So, in the last week of her life, when my two brothers and I and my dad were at her bedside, we had hospice care for one hour

out of the day, and we were providing care the other 23 hours of the day. In addition to caring for her physically, my brothers and I, we gave her the best manicure that three sons could give a mom in that bed. And, you know, we did it — it wasn’t perfect — but we did it knowing that it would make a difference to her. And that made a difference.

That was, for us, it was a fruit of advance care planning. It didn’t have anything to do with a healthcare agent or a life support treatment, but it told us as a family, here’s what you can do as a caregiver that will make a difference. And that you can know it’s not just grasping at straws, but this is something that my mom asked for. That’s a lot. And it says a lot that we just remembered it. My brothers and I remember it today with gratitude.

KATHLEEN TAYLOR: Mm-Hmm. Thank you for telling that story. I love that story. Lucy...

LUCY KALANITHI: I really, that’s one of the things I really love about *Five Wishes*, the platform specifically, is that — that’s such a beautiful story, Paul, it’s such a beautiful image — is this idea that it’s not just about what is scary and what you don’t want. It’s about who you are and what you do want.

And one of the things my late husband wrote when he was dying was, sort of thinking about this was, until you actually die, you’re living. And I think that’s so important here, and it sort of gets to this concept in healthcare of, you know, this person is dying, there’s nothing more we can do. And I think there’s always something more, like the hand massage or like the manicure, or this idea of like, do everything, right? And it’s like, do everything in service of something else for this person to feel loved, for this person to feel comfortable,

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for you to move forward with a memory that can help carry you through the ocean of grief as you go forward. And that's really important too, I think. That's beautiful.

KATHLEEN TAYLOR: Yeah, it is. It's a great story. And Joanne Eason, our President, has talked about how advance directives and *Five Wishes*, these documents and these conversations do play out most often in the healthcare system. I mean, all of us know, most of us don't die at home. And that's not because we didn't tell someone we wanted to die at home. It's usually because there are challenges with caregiving, with finances, with all kinds of things, but most of us are not gonna die at home.

And our humanity is, as Joanne was saying, best understood by those who walk closely with us. So, advance care planning is one of those things that, it needs to have — healthcare professionals absolutely need to know how to have these conversations and all the different places in someone's lifetime where it's appropriate to have them.

But it's also, advance care planning is also a family issue. This is also something that our faith leaders, our community leaders can engage us in. Families can have these conversations without the healthcare professionals and often do. It's not until the

rubber meets the road and someone's dying when these wishes are something that the healthcare provider even knows about.

So, I kind of want to ask this to you, Matt, specifically. You do such a good job of taking what can be a challenging, overwhelming concept and making it into something, just a little thing, that a person, whether they're the patient or the provider, can consider. I wonder what your thoughts are about helping people outside of healthcare to have these conversations more often and think of them as kind of a community and family endeavor?

MATT TYLER: Yeah. Lucy, I'm glad you gave us permission to go messy, right from the back, because I think this is certainly one of those situations. I think we ask a lot of advance care planning and advance directives in general. And Paul, I'm glad you point out that advance directives came about to solve a legal problem, not a human problem, or not even a healthcare problem directly. And I love that we're trying to do something more human with them. But I think often you can sort of feel like we're trying to square peg-round hole, when we come up with an advance directive that's going to be all things for all people all the time.

And I think what's often the tricky part for people when they engage in these conversations and plan for the future is that it's really hard to do that out of context. I think that's — it's one thing to sit down with your family and talk about like what you'd want in a hypothetical future where you've got some, like Hollywood heads-up about your, what's gonna end your life, and you can sort of plan for that months or years in advance. And it's another thing when you're in the hospital actively sick and you're trying

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to figure out, should we do more fluids? Should we do more antibiotics? Should we roll the dice and stay in the hospital a little bit longer or go home? It gets, that's where we ask a lot of the directives and where I often encourage people to put the onus more on the clinicians to kind of put their nickel down and like tell them what they think's gonna happen.

But you're asking about people talking to their families. And I think it is certainly — for folks who like to have the option to have as much control over the future as possible and able to hold that somewhat loosely — I think sitting down with your family, talking about your values and your priorities and how a serious illness would change them or not can be helpful, I think, so long as there are mutually agreed upon signposts to say, when would we come back to this conversation, when maybe that's at a particular event like a hospitalization, maybe that's just like an annual thing, to make sure that we're still on the same page.

KATHLEEN TAYLOR: Yeah, that makes sense. It's kind of an all hands on deck education effort. I feel like often that we're hoping to educate consumers, we're hoping to educate providers, we're hoping to educate community leaders, we're kind of trying to do this from all the different angles, I think. Which is important because you're right, it can't — the weight can't all be on healthcare.

But my — this is an opinion — I do think that it is on the healthcare practitioner when you have a person in front of you and there is the opportunity to ask these questions, then I do think it's our responsibility to ask the question. But it would be great if as a society we could broaden that — either opportunity or burden, depending on how you want to look at it — to have these conversations.

MATT TYLER: Yeah. And, and I just want to add one more thought to that, because I think it's worth plugging this back into my earlier comment about systems and sort of the reality that we accept versus the reality that maybe there ought to be. And I think in my clinical experience, often the advance directive or the advance care planning is sort of trying to give us a general blueprint of when would we consider hospice care. I think that it always comes down to when should we be kind of cutting bait on this current medical plan and focusing all our efforts behind comfort and allowing natural death, which is typically done by hospice.

And I think it's worth pointing out that we invented that choice with the hospice system, right? We force a choice between disease-focused treatments versus comfort-focused treatments. And we don't — that's arbitrary, like pediatric hospice care, you can do disease-focused therapy and comfort-

focused therapy at the same time. And the veterans hospice benefit, similarly.

And I think it's, again, patients and caregivers have to put up with a lot. And I think it's worth just acknowledging that we have invented a lot of false choices in healthcare, and it can often feel like this very gaslighting experience for patients and caregivers. And I just, I think it's just worth saying that out loud, because oftentimes it can just feel a little bit like, what's happening here?

KATHLEEN TAYLOR: Yeah. Yeah. That makes sense. And we, it almost seems like a — well, it doesn't almost seem like it, I think it is. There's, we're talking a lot about the relational realm of humanity in healthcare. And that is between — that's the interaction. That's the person and the person. That's the family, and that's human beings together.

But that doesn't exist in a vacuum. There's also, you know, we talked about some of the systemic challenges, and then outside of the systemic challenges, there's, we are in a larger culture and a larger even field of healthcare. Even if we don't consider that we're in a death-denying culture, healthcare is a field. And we have some emphasis on efficiency and measurement that just kind of has to be carried out. Why? Because we have an inefficient system and we do need to try and quantify what makes for high quality care.

So, I get it that the measures are important, but again, we have what can feel, once you take that from the field to the system to the individual, it feels like it reduces us to, I got five minutes to have this conversation with you, and then I'm just going to make a note yes or no in the EMR.

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So, I think that telling stories like you're doing is so helpful because it helps us realize that even with those challenges, this really comes down to moments of care. I saw that in an article I read that was actually in a business journal about creating luxury experiences, and they talked about moments of care. And advance care planning is one of those places where you can, just by virtue of asking people these questions, create a moment of care. It feels personal, it feels supportive. Help me out with that. What are some of the stories you have of just what those — how do we know when we're doing it, what those moments of elevating humanity feel like and experience as a practitioner and as a family member?

LUCY KALANITHI: I have a couple things to mention. I guess there's a big picture thing, which was coming to mind as well, which is, you're talking about like, oh, there's all these metrics and things that have to be measured, things that sort of like have to be measured, things where it's like, oh, is this the only way we can get information about how everyone's doing? But it's so crude and it's so sort of like, yeah again, binary, et cetera.

But one thing that I've been really heartened by is all of the researchers and clinicians asking different kinds of questions that are showing that the humanity piece is not distinct from the other thing. Like, for

example, work that looks at the way in which clinician burnout is related to patient satisfaction and related to patient safety and quality. So, you know, even measuring things, measuring the humanity parts can help link together the business case for making some of these changes.

In answer to your more direct question about what does it mean to have those moments of humanity, I guess two that sort of came to mind as I was thinking of coming to this session. One was the Presence 5 project at Stanford. I don't know if people have looked at that, but Donna Zulman was the leader of that, and I think it was Steve Asch and Abraham Verghese put together this project at Stanford that was actually a really laborious research project looking at which types of clinician practices foster presence with patients, and they did a whole literature search. And then they did a Delphi panel expert review of gut-check against experts who were clinicians, and patients and community members.

And they came up with these five things:

- One was prepare with intention.
- One was about listening, which had some sort of operationalized pieces to it, like sitting down, leaning forward, eye contact instead of the computer — things that are intuitive but also hard to do and important to remember.
- Agreeing on what matters most, as we've been talking about, which is sort of directly ask the patient
- Connect with the story of the patient. So, acknowledge what they're doing and consider the big circumstances.
- And then explore the emotional cues. And so that's naming the emotion, giving space for the emotion.

Presence 5 is an example of really kind of like quantifying what those aspects of that are.

And there's this, there's another study I want to mention that also came to mind thinking about humanity and what does that mean and how does that operationalize, how do we actually do that? There's a researcher, also at Stanford actually, called Alia Crum, who I think is a psychology researcher, but she's done this research on the placebo effect. And the really interesting thing is, healthcare provider clinician competence and warmth in the encounter sort of like increase the placebo effect. But the placebo effect isn't really, isn't actually bad. Or in this case, it's something where outcomes are really changing as a result. So, the patient is more likely to adhere to the treatment, the patient is more likely to feel that they're going to get better, which can influence them getting better.

And she actually does this study where she takes some kind of allergen, like a local allergen and injects it and makes like a little rash on the patient's skin. And then they had this study where they sort of vary

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the perceived competence of the provider. Like was it a student or a fellow? Did they mess up the procedure or did they not? Like, actual measures of competence that a patient can be aware of in the moment.

And then they varied the warmth of the provider. So, that was very similar things — eye contact, asking about the patient's experience. And they had the provider apply a cream to the rash and say, this cream is going to decrease the size of this rash. And it literally did or didn't. And this was like a neuroendocrine access thing that, you know, is a little easier to measure in the moment. But it really made a difference in the rash for this patient at a particular time, and they were able to measure it.

And so, anyway, those things come to mind in terms of your question about what is humanity and then also sort of echoing into why does it matter? And I think there really are these real effects that are intuitive and everybody's experienced them themselves with their families, but also they're measurable to an extent, and they're distinct from the other things that the system does care more about, like outcomes or satisfaction or likelihood to recommend or actual measurable health outcomes as well. So, that's sort of exciting. And I think the questions being asked really matter.

KATHLEEN TAYLOR: It is exciting, and I love the statement and the realization that it is measurable. It is measurable, both the intervention, the humanity piece, and all the different ways that we look at how that looks in action. We can say what that is and we can also perhaps measure that and that we can look at the outcomes. We talk a lot about this stuff in our Five Wishes training courses, and the communication skills — about the difference that it makes to

have a practitioner who is indicating to you that they care about you. It makes all the difference.

And I had — I'll just say since we're telling some personal stories — I had a challenging surgery earlier this year, and one of the most impressive parts of that really involved experience came from a place I would never have expected. The anesthesiologist came to my — I know, right? The guy who's gonna put me to sleep did the best job of actually having a human conversation with me. He came to my bed, sat down, leaned over the rails, and just kind of hunkered and asked me all about myself, asked me what I do, found out that we knew a couple of people in common, told me about his daughter.

He spent, it probably wasn't more than 15 minutes, but for a person who's terrified right about to go into surgery, and that's a guy who can make sure that I live or not, I have to tell you that there was a real placebo effect from that because I instantly felt confident. I instantly felt known. I instantly felt like he knows who I am now, he's gonna take care of me. And he was the person who wheeled me into the O.R., was that anesthesiologist who had the conversation. So, it wasn't advance care planning, but it was one of those moments of care.

It didn't take him a long time. I don't think he went over his allocated minutes for his intervention with me. But it certainly felt — it's all those things we're looking for. It felt personal, it felt intentional. He was really listening and really asking me questions like you would with anybody that you care about. And it made a huge difference. So, I think that's kind of the characteristics of these moments that we're looking to create. And they don't have to take a long time.

PAUL MALLEY: I think that's very true. I think it's about creating the space for them to happen and then if you allow it to happen at will. And when I think about advance care planning — and Kathleen, you mentioned electronic medical records, Matt, you mentioned that really there's no way that we can answer all the questions ahead of time in advance — I think the best use of technology would be to make sure that the information is accessible when it's needed, especially in emergency situations.

But also to kind of think of it as a mirror that needs to point back to the person, to what they said was important, to point back to the healthcare agent so that the actual emergency decisions aren't made in a vacuum, but that the electronic medical record can be kind of the breadcrumbs that give the clue about here are the hallmarks that you need to think about, but that point back to the person. And there are some ways, some examples that do this well, like MyDirectives and others, but it points, it makes sure the information is there and it points back to the person.

"I looked at her in the eyes and I said, 'Please take good care of my mom.' And she paused for about three seconds and just looked at me, and she nodded, and she turned around. That three seconds and her eyes looking at me, it let me know that she acknowledged what was important in that moment. She knew the significance of it, and she was gonna take good care of my mom."

Two examples that I'll just drop off as quick ones that are simple to do: Lucy, you mentioned how much can be conveyed in eyes. And it made me — through our eyes — made me think of my mom in the middle of her lung cancer treatment. She contracted covid, in the early days, and she had to be hospitalized. And I was the person who brought her to the hospital. So, you can imagine I'm wheeling her in, in a wheelchair. I'm wheeling her into the emergency department. I know I'm not going to be able to walk past the waiting room. And the thing that I remember about that encounter is that the nurse who walked out to bring my mom back, she had her mask on, I had my — everybody in the room had masks on, so the only thing that we could see were our eyes. And I looked at her in the eyes and I said, "Please take good care of my mom." And she paused for about three seconds and just looked at me, and she nodded, and she turned around. That three seconds and her eyes looking at me, it let me know that she acknowledged what was important in that moment. She knew the significance of it, and she was gonna take good care of my mom.

The third thing is that, one of my great mentors, Leslie Piet, she was a nurse at Johns Hopkins healthcare, a nurse for 40 years. She just passed away recently, and her memorial service is actually this weekend, so she is heavy on my mind. But in almost every encounter that she had with someone near the end of life, she would ask the question to them, she'd say — and usually it was while she was, might be while she was in the midst of other clinical things — she'd say, "Is there anything that you'd be disappointed if you didn't get to do?" That was the whole question. And the things that she as a nurse unlocked, often about family relationships, somebody who they

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KATHLEEN TAYLOR: Wow. That's powerful. I love that question.

PAUL MALLEY: Well, thanks to Leslie.

KATHLEEN TAYLOR: Yeah, that's great. And she's still teaching — 'cause through you...

PAUL MALLEY: ...will continue...

KATHLEEN TAYLOR: ...through everybody listening to that. That's a great question. Gosh.

We've talked some about the challenges to humanity and it's not, you know, sometimes, I mean, my experience as a clinician has been there. Also, there's just, you know, there's sometimes when it's just a bad day for me, and I've done a less good job at connecting with people because I didn't have the bandwidth for that. And I think that's something to acknowledge.

And I recently did, Five Wishes did a training for a health system, and they wanted to discuss, they had a high level of turnover. They had in their exit interviews some issues with burnout. This resulted from the — everybody had an upheaval in their staffing ratios, and all kinds of craziness from the pandemic. And what was left over is they had lots of these issues. And what they wanted was, "Come in and do a resilience training for our clinicians."

And Lucy, you said once that with regard to resilience training, if there's a canary in the coal mine, we can't just teach the canary to meditate. And that's kind of what happened with this resilience training is: I didn't actually do it for the clinicians, I had the leaders come in. And what we talked about was, what can you do as a healthcare organization to help alleviate burnout? What is the source of the burnout? What are the specifics of what people are saying to you? And what can you as a system do?

So, just for a minute, I wonder if we can talk about the organizational realm of humanity in healthcare and in advance care planning. And we know at Five Wishes that advance care planning programs really have to have full honest leadership buy-in and support to be able to operate in a way where this is

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the kind of experience that we're building for people in these conversations. So, what are some suggestions? And there's all kinds of white papers out with managerial recommendations and organizational recommendations, but I want to ask those of us who are at different places in the field here: What can healthcare systems try to do to make it easier, more possible to create those moments of care in our conversations with folks?

MATT TYLER: I'll bite.

KATHLEEN TAYLOR: I know you have ideas. I was thinking...

MATT TYLER: Oh, I got ideas. I'm just trying to see what I should say, what I'll get in trouble for. It's never lost to me [that] when we talk about ways to increase humanity — when I say we, I mean healthcare systems — it always seems to come back to the low stakes stuff. Like smile more, take a moment to ask people how they're doing. Like, yeah. When it's coming from the top of the chain, it's like, of course you say that.

And I think part of what's driving burnout, at least from my perspective, a lot of part of the burnout is this large disconnect between people who are making decisions for healthcare systems and people who are actually delivering the health care. And it's really hard to swallow that suboptimal

nursing ratio when your CEO is pulling in like eight figures. It just is. Because I think for — solving systemic burnout in the healthcare system is going to take a major cultural shift with government oversight. The whole country needs to care and say this isn't acceptable anymore.

I think it's appropriate to put that in context when we talk about other things, to not downplay how big the issue is. Because it takes, it's going to take a lot of money, honestly, it's got to come from somewhere. But because — you know, I'll try to — other than an act of Congress, I think it would be nice to see more emphasis put on palliative medicine.

I mean, we already exist. Some of these things already exist, and it's about using them. Case in point, I got a message from someone a while back through my platform on Instagram, and they said, "Hey, I wanted to let you know, I was seeing my oncologist the other day and I asked them for a palliative care consult to have someone just kinda manage my pain and symptoms better. And they said, 'Sure.'" And like, they hadn't even thought of it, and they were happy to do it. And now they're connected to a team literally devoted to providing emotional support, symptom management. And it was already there, and it just like took a little nudge.

So, I think certainly, there are moments to nudge like that, there's moments to remember that we do have some stuff there already and we could just be more mindful about using it. And yeah, and that kind of, the palliative care kind of ties it all together with the support and the advance care planning and all the other stuff we talked about.

KATHLEEN TAYLOR: Yeah. I've always loved the idea of primary palliative care, to extend palliative care from being a specialty that gets referred to, to being kind of a way of practice. And that's — I don't know, I've seen efforts toward that and I've seen the efforts start and stop and start and stop. I'm hoping that we're getting there.

One of the things I wonder... Lucy, I wonder if you can talk to medical training. We often hear from folks that they didn't learn this in their medical training. They haven't had any real training on having these kinds of conversation[s] and on moments of care and humanity and advance care planning. Is that, are we starting to see changes, just as a field? Is it something that's being built into the medical school curriculum — and it's not just medical school, [it's] nursing school, social work training — I mean, there we have a lot of different folks who touch people.

LUCY KALANITHI: Yeah. I mean, I think there's like two parts of this, because there's the curriculum and then there's the hidden curriculum. And there are so many curricular changes that really matter where this is coming out and these skills that we're talking about are being taught. And then there's the hidden curriculum, which is, well, you also shouldn't have your own emotions present, and you should be able to handle everything and process it really quickly and not tell anyone about it.

And so it's really, really hard to be — you know, I think one of the ways to increase humanity in healthcare is just to not take it away from people to start. Because medical students start out so eager and empathetic and with really high resilience and coping skills compared to their peers. And then somehow that gets taken away from them. And part of that is the hidden curriculum

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about, you know, needing to be perfect and stigma about seeking mental health support. And so I actually think that is changing too, and that may even be a more important part.

I don't know how many people are familiar with Dr. Jessi Gold, who's a psychiatrist, and she's now the Chief Wellness Officer at the University of Tennessee system. She just wrote a book called *How Do You Feel?: One Doctor's Search for Humanity in Medicine*. And that book touches on this a lot and the ways in which healthcare culture is changing and needs to change. So, I think that's it, too.

KATHLEEN TAYLOR: Yeah, that's great. And I'll just, for our listeners, we'll post in our follow-up email links to the things that are

being mentioned, so you won't have to hunt for that. We'll send you a follow-up with those.

Any other thoughts about that? I think about, you know, about training, about training including — I'm an emotional intelligence coach, and so much of that work I think just should, in any industry where you're going to deal with people, really ought to just be part of the training.

But I also look at our measures. What about having... We had the Triple Aim turned into the Quadruple Aim, which was like, it was a bit of an afterthought, but it still, we still got four out of it. But I haven't seen much about wellness as one of the most important quality measures, or a quality measure — wellness and engagement of our clinicians as a quality measure. I think that individual organizations can do that. I haven't seen it coming across through our models as something that we're needing to report back. Has anyone else? Is that on the horizon perhaps?

MATT TYLER: I don't know. I mean, we certainly, in our systems, we'll have employee satisfaction surveys and they'll try to get a bead on, how happy are you with your job? Would you recommend this place as somewhere to work to someone else? And so, I think there's that piece of it. But how they're measuring wellness beyond that, and on a standardized level, not that I've seen, although I'd certainly be nervous if I did see that, not knowing, or rather knowing, how multifactorial it is.

And it begs the question, what are we going to do with this thing that we're measuring? How are we attempting to move the needle once we've found the needle in the first place? I do think, on a similar note — and getting back to Lucy's point

about the hidden curriculum — I do think it's worth pointing out that part of the hidden curriculum is this notion that empathy and bedside manner is like a thing that you have or you don't, when we know this is teachable stuff.

And as long as we're plugging things that we love, I think this would be the great place to plug VitalTalk, with a nonprofit organization who's teaching clinicians how to have these really difficult conversations beyond the boilerplate "breaking bad news" that med students get now. That's not enough, frankly. It's not enough and it's not frequent enough. You do it once and you move on as if like, oh, now you can do hard things, good luck out there...

Whereas, VitalTalk really adds a framework to this and has quite a rigorous training program in difficult conversations when you need to make high stakes decisions. So, shout out for them. And again, coming back to, this stuff is out there, but it takes a system investing in making this the standard of how they train, whether that's a medical school or residency or a hospital system.

KATHLEEN TAYLOR: Mm-Hmm. Yeah.

PAUL MALLEY: And thinking about the wellness of the team, that reminded me of, I think it was about a year or so ago, I was talking with, it was a large health system that utilized Five Wishes as their advance care planning program. And they said one of the reasons that we stick with it is because our staff loves it. And the thing that the person said to me is that they often heard nurses and social workers say, this is why I got into healthcare to begin with, to help take care of people and to understand how their suffering could be alleviated.

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And so, I think just from a wellness standpoint or thinking about the joy of practice of physicians and nurses and social workers creating that space that allows them to practice in the way that they were inspired to lean into healthcare to begin with, there's a lot of opportunity there.

KATHLEEN TAYLOR: Yeah. We get — this has been such a great conversation, and I want to — we had some questions coming in. Lots of them look alike. So, I'll just tell you, kind of the theme of some of these questions is about technology. There are people talking about, they now have to do these conversations through Telehealth.

Just for those people asking, we did a whole webinar on how to do advance care planning well and make it effective, and all the humanity instilled in it. We did do a webinar on that topic, so we'll link back to that for those specific questions.

But how do you think things like check-in kiosks and all the stuff that we're doing to create efficiency — and honestly, to reduce human personnel, because it's cheaper —

how are those things...? I don't want to assume they're bad. I don't want to assume they're good either. What are we seeing with that effect on clinicians in terms of feeling the connection in the moment of care?

MATT TYLER: I think, I guess I'm just, I'm gonna be like the guy who hammers on systems guy today. But I think efficiency is great if it cuts down on the less human stuff, right? So, I think it would really come down to, was the check-in previously this warm person at the front counter where they asked you how you're doing, that a lot of people looked forward to? Or was it not? Or was it just someone who didn't look you in the eye and just like handed you the clipboard and you sat down with like the, you know, half-working pen?

I think if we're using efficiency, it's typically to save time. And then the question is, what are we doing with that time? Are we using those extra five minutes we saved at check-in to then give the clinicians space to talk about what matters with their patients? Or are we using it to schedule a few more patients in that day and we're gonna keep going at the same pace? Just seeing more people. And again, it comes back to what's the system buy-in for this stuff? And to, what are we serving with the efficiency increases in the first place?

KATHLEEN TAYLOR: Mm-Hmm. And they don't have to be, efficiency doesn't have to be the enemy of humanity, in my experience. I mean, you — Paul was talking about, it took two seconds for that nurse to look at you. It took 15 minutes for that anesthesiologist to have a very deep, you know, comforting conversation with me.

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So, I just want to advocate that I don't think these things have to be enemies, but it does call upon our leaders, our systems people who are coming up with the measures even, to think about ways that we can incorporate, these aspects of healing kind of back into healthcare.

Any last thoughts? We've got a couple of minutes before we close. And this has been a great meandering conversation. I just want to ask if there's anything else anyone wants to add before we close?

LUCY KALANITHI: I really like what you just said, it doesn't take more time, it just takes different time. I love that.

KATHLEEN TAYLOR: I think so.

PAUL MALLEY: The conversation about kind of the good and the bad of technology, it made me think, the importance of the human stuff and figuring out what the human stuff is so that there can be space for it. So that if I'm talking with my doctor and he's looking at me because there's some virtual scribe taking notes and he doesn't have to do that, that's great. And accessibility and medical records is great as long as still points back to the person, to the humanity, to the human stuff to make sure that doesn't get lost. So, guardrails are important, but efficiency can work right along with guardrails, hopefully.

KATHLEEN TAYLOR: Yep. Thank you all. This has been a great conversation. To everyone listening, we will send you a wrap-up on this. And with that, I'm gonna throw it back to Dave to close us. Thank you.

DAVE SIMISON: Thanks so much, Kathleen. And thank you, all of you who joined us today. This presentation was recorded and will be available to view within seven business days. You can find it along with our many other recorded webinars by visiting the Five Wishes webinar library at [fivewishes.org/webinars](https://www.fivewishes.org/webinars). We encourage you to share the Five Wishes webinar page link with your teams and with your colleagues. On behalf of all of us here at Five Wishes, thank you to our speakers and of course to you for attending. Have a wonderful afternoon.

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