



Webinar Transcript

GAME ON!

ADVANCE CARE PLANNING GAMIFICATION

Nick Jehlen – Common Practice

Lisa Pahl, LCSW – Death Deck

Cindy Safe – Coda Alliance

Kathleen Taylor, MA, LMHC – Five Wishes (Moderator)

GAME ON!

ADVANCE CARE PLANNING GAMIFICATION

DAVE SIMISON: Welcome everyone! Five Wishes is pleased to present today's Practice Community webinar: Game On! Advance Care Planning Gamification. I'm Dave Simison, the Vice President of Operations here for Five Wishes. It's my pleasure to host and introduce today's webinar. This webinar is being recorded, so participant audio is muted. But if you need technical help, please click the Q&A button on the lower bar of your Zoom screen, describe the issue, and we'll do our best to help.

This presentation will last about 60 minutes, and you're encouraged to ask questions throughout. To ask your question, click on the 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 Joanne Eason, President of Five Wishes.

JOANNE EASON: Thanks, Dave, and thank you all for joining us on our sixteenth Five Wishes Practice Community webinar. This is an opportunity for us to share some of the thought leadership in healthcare, serious illness, and advance care planning with those who are part of the Five Wishes family.

And speaking of sharing, 2024 is a year of innovation here at Five Wishes:

- In the next few weeks, we'll be launching a new instructional video and companion Presenter's Guide.
- We'll be releasing a new publication, *Finishing Life Faithfully*, which assists people of faith on end-of-life planning that is consistent with church teaching.

- And after several years of development and a lot of sweat and equity put into this, we'll be offering certification designations for Five Wishes Facilitators and Community Presenters.

More information will be coming, so keep an eye on your inbox for that information.

And I'm excited today to have this event. I've been looking forward to learning more about gamification because I think it's a great way to inject different aspects of having serious conversations. The three organizations we're featuring today — Coda Alliance, Common Practice, and *The Death Deck* — all have developed really unique, fun, and tested ways to help people consider and reflect and act on what matters most to them.

Kathleen Taylor, our Five Wishes Healthcare Program Director, will be moderating today's program. Play on, Kathleen...

KATHLEEN TAYLOR: Thanks, Joanne! And thank you to everybody for joining us today. This is going to be a fun webinar, I think, because we're talking about gamification.

If you're new to [our] webinars, we do these quarterly. You can see, Joanne mentioned, I think it's our [six]teenth. We have all of the webinars online on the Five Wishes website. This one will be online as well. We will send you all a summary after the webinar.

But to just go ahead and get us started, I'm going to begin introducing our speakers. So if you can turn your cameras on, presenters, I will introduce you all. In alphabetical order, which I think is a fair way to do it:

Nick Jehlen

Nick Jehlen is the founder of Common Practice and the lead designer of *Hello*, the conversation game about living and dying well. Nick has been creating innovative social interventions for over 30 years. He's collaborated with housing and voting rights advocates, healthcare staff, state employees, student groups, human service organizations, and returning veterans of the wars in Iraq and Afghanistan to build tools that create social change and empower communities. Thanks, Nick, for being with us.

Lisa Pahl, LCSW

Lisa Pahl is co-creator of *The Death Deck* and *The E.O.L. — End of Life — Deck* games that inspire meaningful conversations about what matters most in our lives, and in our deaths. Lisa is also an expert contributor for *Health Texts*, which provides expert grief and mental health support via text messages. As a Licensed Clinical Social Worker with over seventeen years of experience in hospice and seven years in emergency medicine, Lisa helps people cope with illness, dying and grief. With a passionate belief that peace at the end begins with meaningful conversations over time, Lisa engages people in talking about and preparing for this important stage of life.

Cindy Safe

Cindy Safe is the founding Executive Director of Coda Alliance, and is now a Coda board member. She is also the Program Director of Older Adult Services for Catholic Charities, including the Santa Clara County Ombudsman Program. She's been an advocate for excellent end-of-life conversations for twenty years.

KATHLEEN TAYLOR: So, we have a ton of expertise here today for the webinar, and thank you to all of you for joining us and being part of our webinar today.

So, I'm going to start it off with, just what is gamification? That might not be a word or a concept that's familiar to everybody. So Nick, I'm hoping you can help us with starting us off with a definition of what is gamification.

NICK JEHLLEN: Sure, I'd be happy to. I'll say that gamification is either a word you've heard a ton of times, or just heard for the first time in the last few weeks. But, when I think about gamification, I think people often think about it as using the principles of game design to encourage people to engage in a task. And when it's at it's least interesting, I think, gamification is adding something like scoring or turn-taking to a task that people don't really want to do. At it's most interesting, I think, gamification is learning something deeper about what games are and how they function in order to help people change behaviors.

So, I guess before we really talk about gamification, it's important to think about what a game is. When I think about a game,

“Gamification is

...using the principles of game design to encourage people to engage in a task

...learning something deeper about what games are and how they function in order to help people change behaviors

...adding the fun and playfulness and levity”

at its most basic it's a set of rules, and they're usually simple rules if it's a good game, that make you behave differently than you behave in your actual life.

In normal life, we often sort of chafe at boundaries and rules, and the interesting thing to me about games is that, inside of a game, we embrace those rules for a specific reason. It's because playing a game creates challenging fun. So, think about a game that you really enjoy. It feels fun, but it also requires work, it requires focus, and it's that balance of those two things that, I think, are important when you think about games.

So, that's the real goal here: finding ways to use the structures of games, or actual games, to make people feel good while they're doing something that is good for them.

KATHLEEN TAYLOR: We were talking a little bit before we started about some of the challenges in promoting events that are about conversations about advance care planning and end of life, and we thought of an old marketing term, which is "an unsought service" — so, something that people need but they don't really want. And I think that's, when you're talking about the rules and having people behave in a different way than they do in real life, that certainly applies to this.

Anybody else — just help us with rounding out this definition of what gamification is before we move on.

LISA PAHL: I'll say with *The Death Deck*, our gamification aspects — there's a little bit of rules, but it's mostly adding the fun and playfulness and levity. So that's kind of our interpretation of gamifying. You can partner up and guess each others' answers, but rarely do people actually play by those rules. But it's more about making the conversation

more lighthearted and a little more — have a little levity to it.

KATHLEEN TAYLOR: That's great, and I think important for this. Cindy, do you want to add anything?

CINDY SAFE: The only thing that would want to add is — hello everyone — is that, I think the *Go Wish* game is not as much a game as it is a tool. And I do think it's similar to what Nick and Lisa are saying, that you're kind of focused on something and looking at it in a different way. And that's what we aim for at *Go Wish* as well, that it gets people to start talking, and in a different way than they might have before.

KATHLEEN TAYLOR: And I think that's the key, and why we're talking about this today, is really kind of trying to understand what it is that games do that help people discuss topics that are difficult, or that might seem taboo or challenging, unpleasant, whatever the words are that we would use for that.

So, anything else about how games help people to get into things that they otherwise just wouldn't — they just wouldn't do it?

NICK JEHLLEN: I just want to add one more thing that I think is true of all three of these tools, which is that you — from my perspective, a great thing about games is that it takes some of the work out of being a facilitator or having to run a conversation and allows you to play a different role. And I think that's a really important thing about a game, is it sort of acts as a facilitator, or takes the place of some of the facilitation so that you can play a different role.

And it also creates unexpected results — I think Lisa touched on this for a second — but the thing I find most interesting about playing our game with a group of people that haven't experienced it before is that

"...a great thing about games is that it takes some of the work out of being a facilitator or having to run a conversation and allows you to play a different role... And it also creates unexpected results... people say and do things that I'd never expected... if you go in open to the possibilities, there's some really amazing conversations that can come out of this kind of tool."

people say and do things that I'd never expected, and if you go into this using this kind of tool thinking you know what the conversation is really going to be like, you'll probably be disappointed, but if you go in open to the possibilities, there's some really amazing conversations that can come out of this kind of tool.

KATHLEEN TAYLOR: Yeah, that's — I think that's true, and I think that, particularly in advance care planning education, it's important to move — we want to have experts doing didactic education, of course, that's important. But it's also important to sometimes remove the expert and just let people talk — just have a conversation without somebody instructing about the concepts and just talk freely. And I think these games really allow that to happen and allow people to generate the conversation without an expert weighing in on how that should be done or what the parts are that should be addressed. It's just conversation. And with advance care planning, that's the goal, that's what we want people to do, is have conversations, to talk about these things. And that's the challenge, I think. So

I'm glad that you're all here talking about these.

With all that said, I think the most exciting part of this webinar is going to be actually looking at all of your games. So again, I thought, in alphabetical order we would review them. So Nick, can you take us through your game and how that works and just let everybody see what it is?

NICK JEHLLEN: Sure. I'll give a real quick introduction. So this is *Hello*, and it comes — so, this is the home version of *Hello*, we also sell a much larger community version for 25 or 50 participants, but the components are the same, it's played the same way.

So, inside the box, there's not very many components. One of the components is this book of questions. There's 32 questions in this booklet and I'll give you a couple of examples. There's a set of instructions, which again are very simple. And then there's these chips. These are called Thank You chips, and they're an important part of the game that I'll explain in just a second.

So, after you explain the rules, which again are very simple — there's only like five rules and it's mostly about not interrupting each other. There's a particular rule that we wrote in there that everybody writes the answer to their questions inside their own booklet, but nobody's allowed to speak until all pens are down. And that turned out to be one of the most important rules of the game because it prevents people from speaking over each other and allows people to take as much time as they want. Some people will write an answer in just a couple of seconds, some people will take full minutes.

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But the rules — as I talked about at the beginning — the rules are really important. In the very first test of *Hello*, I remember laying out these rules, and one of the first people started talking before someone else was finished writing, and the other player grabbed the rules and said, “No, you have to let me finish.” And that’s where facilitation sort of gets passed from a facilitator telling somebody to be quiet to a player empowering themselves.

So, the first couple of questions to set up the game... But let me read you Question 3, which is, “Write your own epitaph in five words or less.” And I’ll read one more... “Who haven’t you talked to in more than six months that you would want to talk to before you died?”

So, you go through these questions in order so everybody’s answering the same question. Everybody writes their own answer and then you go around. And again, you’re

not allowed to interrupt. Everyone has to get a chance to read their own answer.

And then the Thank You chips come into play at that point. Thank You chips are just a way of expressing gratitude during the game. It’s a little physical token but it’s another way of keeping people from interrupting each other. Instead of discussing what the other person is saying you can give them a chip while they’re talking in order to express gratitude for what they’re saying.

But the thing about Thank You chips is they get used very differently in every single game. People use them sometimes even after the game. People use them to make a joke sometimes. The nice thing about having a little physical thing with a name in game like this is it allows people to sort of make up their own practices and rules, and I think that’s the most exciting part.

And, in our game, there is a winner, so the Thank You chips play a role in determining the winner at the end of the game.

So that's how you play *Hello*. There's videos and stuff like that on our website if you want to get more detailed about it, but it is the kind of game that you can learn to play in less than five minutes.

KATHLEEN TAYLOR: Did you want to pull up any of those slides to look at pieces and parts or instructions and rules, Nick, or does that pretty much capture it?

NICK JEHLLEN: I think that captures it pretty well. I mean, if we want to go back and talk about details, we can, but the rules are really, again, really simple and they're mostly about keeping people from interrupting each other.

KATHLEEN TAYLOR: What kinds of conversations do you find this particular game spurs for people? Is there any kind of trend with that or is it all over the map?

NICK JEHLLEN: It's really all over the map. It has more to do with who is playing. So, if the players are a bunch of teenagers, it's very different, as you can imagine, than a bunch of older people playing. It's really interesting when we have cross-generational games. One of the things that we spent a huge amount of time on when we were coming up with these questions — and I should say, the game is about ten years old, and before we released it we actually went to the Coda Alliance — Cindy's organization — to review these questions and to get feedback on them. We wrote each of these questions very carefully in order to make them open-ended, so that players in the same game often interpret the questions differently. And we did that because we wanted people — the questions are sort of thought-provoking and

"We wrote each of these questions very carefully in order to make them open-ended, so that players in the same game often interpret the questions differently... the questions are sort of thought-provoking and all that, but the real key to them is to give openings for people to talk about whatever it is that they have left unspoken to that point."

all that, but the real key to them is to give openings for people to talk about whatever it is that they have left unspoken to that point.

There's some questions where players will just quickly answer the question. Other ones will be really hard questions for people to answer, and those are the ones where I think you wind up with people starting to answer a question, and someone will ask a question in response to that. There's 32 questions in the game, but in a two-hour game, sometimes people play only five or six questions because they get into a really deep conversation. And those are my favorite games, where people sort of wander off from the game and actually have the conversation that they really needed to have.

KATHLEEN TAYLOR: How did the original idea for this, I mean, where did this come from, where you thought, oh let's make a game for this?

NICK JEHLLEN: So, this was originally created by a group of people... I used to have a design firm, started about twenty years ago, and — there's sort of two origin stories. The

first is that we had a giant contract with a state organization that we were really excited about, and we failed. We got fired and lost this huge contract and didn't know what to do, and one of the partners in the design firm said, "We should really consider whether or not this organization that we have is gonna die. What happens if it all just goes away?" And we designed a sort of precursor to this, where you sat around with a bunch of cards in the dark and talked about your feelings about putting your heart and soul into something and having it fail.

So, we really started thinking a lot about failure and about death and about when things don't go right, and that led us to people who we thought would probably deal with challenges like that every day, and that led us to interviewing hospice nurses.

And I can still — I mean, this was twelve years ago, and I remember exactly where I was, sitting talking to somebody on the phone — it was a hospice nurse — and the thing that she said to me was that she knew when she walked into a room with a family whether they'd had one good conversation about death and dying. And if they had, she could provide them with great care. And if they hadn't, she would really struggle.

And that sort of, you know — we had already been doing a lot of thinking about the death of organizations, and we decided to try and apply some of the principles that we had used with large community organizations dealing with challenges to these smaller but maybe more important conversations. So, that's where it comes from. It comes from losing a job and talking to hospice nurses.

KATHLEEN TAYLOR: Wow, that's so creative, and what a way to turn that around and

make something out of it. And now I do want to ask Dave if he can pull up your slides and we can look at some of the research about *Hello*. So Dave, if you can pull Nick's slides up, and we'll just scroll down to a research slide, which is down a little bit near the end...

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NICK JEHLLEN: Ok. So, I should start by saying all of the research that is done on *Hello* is done by a completely separate group from us, and I don't get any credit for doing any of the — any of this research. But it has been really interesting. We've worked with them for almost ten years. It's a group headed by Dr. Van Scoy at Penn State Hershey Medical Center, and if you really want to know all about the research, there's a link at the bottom [[commonpractice.com/research](https://www.commonpractice.com/research)] which has a good summary and also links to the original studies. I think there are about ten studies that have been published so far.

But...I remember the day they published the first one. I was sitting on a train and got a text message that they had actually found that people went on to actually take advance care planning steps after playing the game, at a pretty high rate. I think the first study is 74% of people within a few weeks had taken advance care planning steps.

Advance care planning in this case means either filling out an advance directive, choosing a health care proxy, or having a conversation with their doctors, or something like that—a wide variety of different things that you can do to do useful advance care planning behavior.

So, since then we've had a huge number of studies done across a pretty wide variety

Research on *Hello*

***Hello* leads to behavior change after gameplay**

All published studies demonstrated high rates (58%-88%) of subsequent Advance Care Planning behaviors within 3 months of playing the game.

People enjoy the game

In post-game focus groups, all studied cohorts (including patients and caregivers) across diverse demographics and cultures reported that the game was enjoyable and a good method for talking about end-of-life issues.

***Hello* is effective as a community intervention**

In a study conducted in 53 communities and focused on engaging underserved African American communities, the game was associated with subsequent ACP behaviors, including 41% of participants completing a new advance directive and 80% discussed end-of-life wishes with loved ones.

***Hello* is effective as a training tool for healthcare staff**

A study of healthcare chaplains showed that playing the game improved participants' confidence in having end-of-life conversations with their peers and with patients.

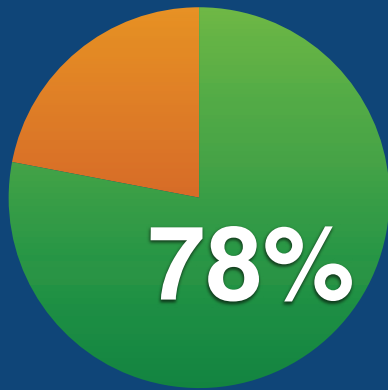
Full research summary available at: commonpractice.com/research

of communities, with different languages. There's currently some work being done... There's a Czech language version of the game that's having some studies done on it. There is a Korean language version that's in the works that's having some research done...The thing that people first focus on is that it actually leads to behavior change after the game, and in all of these cases it's, you play the game and then see what people do. There's not another follow up that comes beyond that, this isn't people being shuttled into a room and sat in front of a facilitator to do their advance directive.

But the thing that I am most gratified by is that people report in focus groups afterwards that they actually enjoy playing

the game. And that's for me the thing that I see — I've facilitated hundreds of different games, sometimes with four or five people, sometimes with hundreds of people playing in smaller groups. And you can tell that people are enjoying the game, especially in those big rooms, because it gets really loud, really fast.

There is this moment at the beginning of any gameplay event where people just are sort of silent and not sure what to do with it, and five minutes in, people in the next room will be coming over and saying, "You guys gotta quiet down, we can't have a meeting next door." And those are the ones — you'll see the line about community intervention — that's the stuff that I really enjoy doing



78% of people who played *Hello* went on to perform an Advance Care Planning activity

Source: Scoy, L. J., Green, M. J., Reading, J. M., Scott, A. M., Chuang, C. H., & Levi, B. H. (2016). Can Playing an End-of-Life Conversation Game Motivate People to Engage in Advance Care Planning? *American Journal of Hospice and Palliative Medicine*. doi:10.1177/1049909116656353

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with this game is having hundreds of people play all at once.

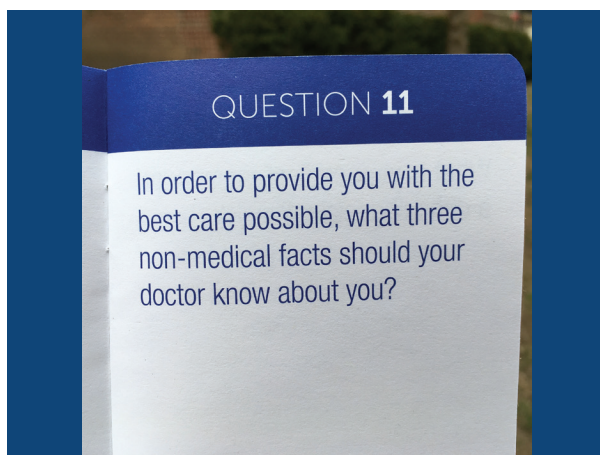
And there is this study that is ongoing right now, particularly for underserved communities, which is being played at sites across the United States. We're a couple of years into it — it was a little delayed by Covid — but I'm excited in a couple of years to get some really good results from that.

And then the other thing that we do, just to wrap up, is sit down with healthcare staff and play with them. And for them, the rules are very simple in the game, but there is an extra rule for healthcare staff, which is to play as yourself, not as your patients, not as, not from a remove. And I've had such amazing experiences playing with healthcare staff who open up and talk about — they're talking about end of life, but they're also talking about the struggles of dealing with people who are dealing with

“...there is an extra rule for healthcare staff, which is to play as yourself, not as your patients... And I’ve had such amazing experiences playing with healthcare staff who open up and talk about — they’re talking about end of life, but they’re also talking about the struggles of dealing with people who are dealing with end-of-life conversations and what it’s like for them.”

end-of-life conversations and what it’s like for them. And that is just — it’s been shown to be a pretty great way to help people have empathy for the people they’re working with and also to help them improve their skills [and] give them new things to do.

There was one inpatient hospice that adopted Question 11 as a standard question on intake. That was then posted, the answers were posted on each patient’s door, and it just changed the way they had conversations with each other and with patients, and I think that’s the best part of doing this kind of work is hearing about and



seeing the kinds of conversations people can have when you have a simple tool that gives them a little bit of a nudge toward something more like a healthy conversation.

KATHLEEN TAYLOR: Yeah. Those are great outcomes. Thank you so much for sharing about that. And Lisa, how about if we talk about *The Death Deck* and the End of Life, the *E.O.L.* game?

LISA PAHL: Yeah. I think I’ll start with a slide show, if you can help me with that, Dave...

Those are our two games, *The Death Deck* and *The E.O.L. Deck*. Those are the images on the box. You can go to the next slide...

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So, just a little bit — I know Kathleen introduced myself, but — our origin story is a little bit different than Nick’s. I worked — I currently work still as a hospice social worker, part-time. I also have worked in emergency medicine. And so with my personal experience, I saw and continue to see time and time again that people aren’t prepared for end of life.

When I first started working in hospice, a couple years in, I met Lori. Lori was the spouse of Joe. Joe had pancreatic cancer in his early 40s. And they were pretty prepared, they had an advance care plan, they had life insurance, they had a living will — but they had never had a conversation about what Joe would want if he did not survive his pancreatic cancer.

And so, I was the hospice social worker for Lori and I was helping her kind of navigate this. His family was in the room as well: his parents, his siblings. They had very different views on almost every aspect of Joe’s dying process. And Joe was kind of — he began transitioning as soon as he came on hospice.

TheDeathDeck.com



He was on hospice just over two weeks, but because he was in his early 40s, his dying process was a very long one. He did not want to leave his young family.

So, through that experience, Lori and I connected about three years after I stopped providing bereavement support for her, and we began a friendship, and started talking about, what can we do to help people be more prepared? Lori felt like, in her grief, she was second guessing a lot of decisions that she made and she just wanted that confirmation that she did what Joe would have wanted, and she felt like she couldn't totally get that, because they had never talked about it. Next slide...

So, we created *The Death Deck*. This is the game Lori wishes she had played with Joe. And the idea with this game is we're just trying to get conversations started. We're just trying to help normalize conversations on death and dying and get people to practice having conversations about death.

And then we want them to move on to advance care planning, but we really want to help people practice having these conversations before a medical crisis or before a terminal illness or a terminal diagnosis.

So, we use — so, *The Death Deck* has 112 questions: 80 are multiple choice, and 32 open-ended. And one of the reasons we use the multiple choice is to evoke humor to

The Death Deck

- 112 questions (80 multiple-choice and 32 open-ended).
- We use humor and multiple-choice questions to make the topic more approachable and, dare we say, fun?
- There are questions about general thoughts related to death (can mediums communicate with the dead?), personal beliefs and desires related to dying (would you consider sending your cremated remains to space?), and death preparation and advance care planning.

This is the product for when death seems a ways away

TheDeathDeck.com   @TheDeathDeck

the topic. So, within the answers, we're able to add just a little bit of playfulness to try to, like I said at the beginning, bring a little levity to the topic.

Within *The Death Deck*, there's questions about general thoughts related to death, personal beliefs and desires related to dying, and then death preparation and advance care planning.

This a general deck that you can — we call it stacking the deck — where you choose the cards that best meet your audience. So, at least 30% of the deck are advance care planning cards. So, some people just take those questions out for advance care planning conferences. Other — funeral

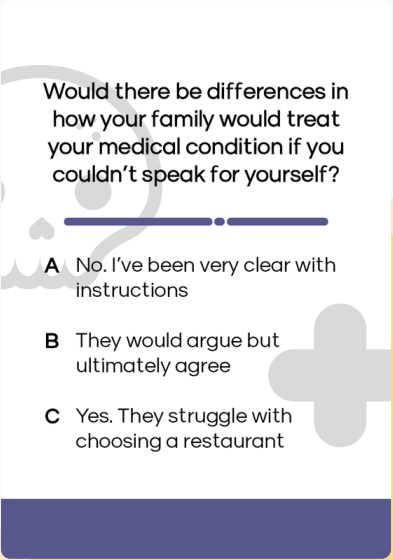
homes and mortuaries, there's a lot of disposition questions...

So, we've geared this deck to be versatile and able to be used in lots of different settings. But the goal and the audience is really people who wouldn't normally be having these conversations and to just give them some practice. Next slide...

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So, this is an example of one of our multiple choice *Death Deck* questions: "Would there be differences in how your family would treat your medical condition if you couldn't speak for yourself?"

And now to go to Nick's point, he was talking about how it can be so helpful to





Would there be differences in how your family would treat your medical condition if you couldn't speak for yourself?

A No. I've been very clear with instructions

B They would argue but ultimately agree

C Yes. They struggle with choosing a restaurant

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be able to blame the game, right? That's what we call it, stack the deck and blame the game.

So, you can orchestrate these conversations without it even appearing that you're doing so. And when you hold a card, instead of directly asking someone, it does provide this really nice barrier; it gives both people something tactile to kind of do; and it also — it takes it off of me asking the question and it's the game asking the question. And as Nick said, I think that's an important way to make people who are facilitating these conversations, to make family members who are afraid of talking to their family members about it, and also, with our *E.O.L. Deck* especially, with professionals who are

The E•O•L Deck

- Designed for people in their final chapter of life, including those with **life-limiting diagnoses, hospice/palliative care patients, and people of advanced age.**
- More sensitive, using softer language and images while also utilizing the casual tone and multiple-choice questions like our original product.
- The questions are more specifically related to end-of-life preferences (rather than a wide range of death-related topics) and legacy building.

This product is for when death seems to be sooner.

TheDeathDeck.com   @TheDeathDeck

struggling with having these conversations with people approaching death.

So, I'll move on to *The E.O.L. Deck* next...

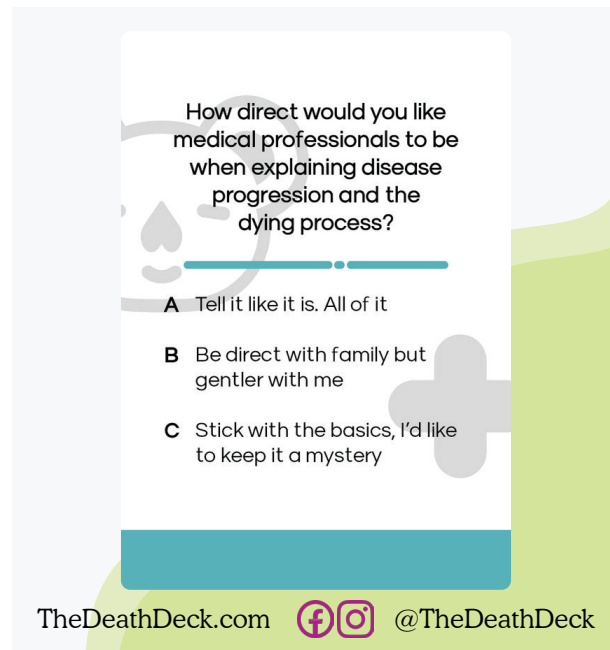
So, our *Death Deck* has our cute skeleton. The whole purpose is to talk about death, and we use death in the name, we have a skull on it. As you can imagine, I'm not bringing this into my hospice families unless they have a really great sense of humor, and then they love it. But you have to really read the room with that one.

So, we designed *The E.O.L. Deck* [with] this little koala and using the term E.O.L. instead of Death, for people who are in their final chapter of life: those with life-limiting diagnoses, hospice and palliative care patients, and people of advanced age.

And so, it's very similar to *The Death Deck*. We use multiple choice questions and open-ended questions. But instead of it having a lot of humor, there's just a little bit of levity, a very casual tone, just a smidge of sassy grammar, just to try to help — again — lighten the topic up. But this very sensitive, this is appropriate for hospice and palliative care.

And then with *The E.O.L. Deck*, as you can see, it's smaller, it's 52 questions. But we're really focusing on end-of-life preferences and legacy building. So, we're not asking general questions about how they feel about death and — you know, can mediums communicate with the dead, or these very general topics. We're really helping people talk about what they want their death to look like so that we can help honor those wishes. Next slide...

So this is typically how I — when I have a hospice patient — I never introduce on the first time I meet with them. That's getting to know them, that's determining whether



they would be open to using *The E.O.L. Deck*, and if it's an open family system and all these other things that I'm looking for — are they ready to have conversations.

But this card itself is one that I find most patients are very comfortable answering, and it's incredibly helpful for our hospice team to know the answer to this: "How direct would you like medical professionals to be when explaining disease progression and the dying process." And so, once I can start the conversation with this question, most of the time people are intrigued and kind of want to know what other questions there are.

We have — within *The E.O.L. Deck* we do a lot of education. We have cards about palliative care, hospice, VSED, Medical Aid in Dying, green burial and disposition options. So, we're really trying to provide end-of-life education in an accessible language while we're adding that gamification factor and trying to get people to have these conversations.

KATHLEEN TAYLOR: Lisa, is there as part of *The E.O.L. Deck*, is there any kind of guidance for — I guess it would be for professionals — about how to assess if someone is ready to talk about these things and play the game? But how do you determine that?

LISA PAHL: Yeah, so we do have an instructional card for professionals in *The E.O.L. Deck*. But in general, people that don't want you to even say that the person is on hospice, I wouldn't recommend using this game with. So, there does need to be a general acceptance that this is end of life before using it. So I usually — it's a lot of clinical judgment, but in general, if the patient and the family system are at least having some conversations and they're able to talk about prognosis and what the doctors have told them — once we can kind of open that up a little bit, then you can start to use it. And I — again, I never use it on the first meeting to fully assess whether this is an appropriate family.

KATHLEEN TAYLOR: Sure, that makes sense. And then for these games, has there been research about their effectiveness or outcomes? Nick talked about some of the research with *Hello*, is there similar research?

LISA PAHL: No, but if anyone wants to help us with it, that would be amazing! No, we don't have any research. We do have — there's a professor from Ohio University that actually wrote a paper on how to use *The Death Deck* in the classroom to simulate conversations on death.

So, I've been presenting at quite a few death and dying classes here in L.A., and so we have a little bit of information on how to have those conversations, but we don't have any research.

KATHLEEN TAYLOR: Well, maybe you'll get some out of this, but I think the things that you talked about, how it eases some — especially for professionals, I think it gives professionals great questions to ask, and a more comforting way to ask them. As you said, it makes it maybe feel less intrusive to have a card asking the question than to have the person right in front of you. And that is the biggest stumbling block for clinicians in initiating conversations and talking to people, they just don't know how to get started. And I think your game can be a great way to get started.

Anything else, before we move on to the *Go Wish* game?

LISA PAHL: I'll just say one last thing. It takes bravery as professionals to have these conversations, it really does. I've worked in hospice a long time and I have colleagues that err on the side of just accepting things as they are and not really to push for conversations. And so, I do really recognize in working in this space how hard it is, and that's why I created the game, *The E.O.L. Deck*, to try to give us professionals just a tool. It's not applicable for everyone, it won't work for everyone, but [it's] at least

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“It takes bravery as professionals to have these conversations, it really does.”

a tool that we can have, because these conversations are hard, even with skilled professionals.

KATHLEEN TAYLOR: Yeah. And I like how these games have — they focus differently, so they have different uses that are becoming clearer. Cindy, walk us through *Go Wish*, and then we’ll see where that focuses as well.

CINDY SAFE: Thank you, Kathleen. I’d say *Go Wish* is kind of the senior citizen of this group.

KATHLEEN TAYLOR: How so?

CINDY SAFE: Well, we’ve been around for about — over twenty years, and when we first started *Go Wish*, there wasn’t really much conversation around end-of-life care, and one of the things that was really hard for people is, once they finally did decide they were going to fill out an advance directive form, what were they going to put on it. They had no idea, people had no idea what to do, and our game was kind of born out of that “what do we put on it?”

And the other reason that we decided to develop the game was because we were working with people in assisted living and we needed something a little bit simpler for people to understand and look at. Dave, do you want to go ahead and go to the game?

Live web presentation, slides not available.

So, Coda Alliance — what Coda means is, coda comes at the end of a piece of music

and it summarizes the preceding passages. So, Coda, the name Coda, was developed that way — just for your information. And then *Go Wish* is kind of a play on the name *Go Fish*.

And this is our website, the Coda Alliance website, and you can play the game on the website in English and also in Spanish. There’s also directions on how to play the game here. But we’re just going to play the game, because I can give you the directions.

So, what I usually do, if I have a deck of cards and I have a group in front of me, I ask them to take the cards and kind of start to sort through them, look at the cards, and as you’re looking at the cards — and you can do this here online — you click on the card and then there’s three different categories: Very Important, Somewhat Important, and... Not Important.

So what you do is, you click on the card, and then you click the category that it goes into... So, the instructions are the first thing on the upper right-hand side, if you want to click on those really quick...

And this just explains exactly what I just said. So, the object of the game is to consider the important and various choices that you would want to make at the end of your life.

And with this game, you can play it by yourself or you can play it with others. You can return to the game...

So, the cards are very simple. And “To have human touch,” for example, might mean one thing to me and something else to Nick and something different to Lisa and something different to Kathleen. And what I try to do as a facilitator is pull out from somebody, from a person, what it is that they mean by having a human touch. Do they mean they want someone to hold their hand the whole

— at the end of life, or do they just want somebody to in and touch their head, or do they want someone to touch everything, or do they just want to have a nurse be there holding their hands? It could mean a lot of different things.

So, I'm not sure is Dave if doing these cards based on what he thinks is important or not important... But what most people do is they put everything in the Very Important category to begin with, and they have a very hard time trying to choose which things are not important.

KATHLEEN TAYLOR: Tell me about the strategy of limiting the Very Important items. There are less of those than there are of Somewhat and Not Important.

CINDY SAFE: Right, right. And the reason that we try to do that is to get people to really focus in. Because if you read all 36 cards, they are, they all probably are very important, and usually when I'm in a group, the people grumble a lot: "This is too hard. We can't do it. We can't focus in." But then I tell them that sometimes the Not Important category is just as important as the Very Important.

Because, let's say for example, let's see what we have right here — "To have someone who will listen to me" — maybe you put that one in the Not Important category. And then I would ask you, "So why would you put it in the Not Important?" Well, somebody might say that they already have that — they have a very close spouse or a very close friend, or they're very close with their daughters, and they're not worried one bit about having somebody like that. So, knowing the reason why something is Not Important is just as interesting as what something is Very Important.

"I've probably played this game 100 times over the last 20 years, but my Very Important pile seems to change over time, and also it can change with moods. And so, you can play the game as many times as you like to see — especially if something happens critically in your life, if there's a divorce or a death, something like that, it really sometimes changes the way that you might do the cards."

And I can just tell you, I don't know how many times I've played this game myself. And I was going to say this when Nick was talking about the gamification aspect of this. One thing I really enjoy about doing *Go Wish* is I get to play this game, every single time I do it with someone else. So, it's like a twofer. They're getting something out of it, I'm getting something out of it, right?

So, I've probably played this game 100 times over the last 20 years, but my Very Important pile seems to change over time, and also it can change with moods. And so, you can play the game as many times as you like to see — especially if something happens critically in your life, if there's a divorce or a death, something like that, it really sometimes changes the way that you might do the cards.

KATHLEEN TAYLOR: I love that, because it makes visible the truth that we know about advance care planning conversations, which is that they're ongoing and they change over someone's lifetime. What people's priorities and what matters change with their experience of illness and with their

"...it makes visible the truth that we know about advance care planning conversations, which is that they're ongoing and they change over someone's lifetime. What people's priorities and what matters change with their experience of illness and with their circumstances, and this makes it really visible."

circumstances, and this makes it really visible. That's fascinating.

CINDY SAFE: Correct, correct. And the cards can mean something different over time to you as well. And if you have a close death, as you guys have — probably everyone has experienced — that drives what you want for your experience next, you know, like you'll — maybe somebody died by themselves, and you thought that was sad, or you thought that was meaningful. Then you can add that as a new card.

The other thing that we have with the *Go Wish* cards is a wildcard. And the wildcard can be — if you look through all 36 cards and the one that you're interested in hasn't come up, then you can create your own card. And so that's fun too at the end of the game to be able to choose something that is not in the deck. And some of the examples of the wildcards would be, "I want to have my dog with me when I'm dying," and "I want my last meal to be chocolate." It could be anything, so that brings in the aspect that Lisa's talking about, kind of the fun part of it.

And the other thing that I let people know is there's no wrong answers to this. Whatever you want at end of life are your wishes, and we're trying to make it so that you can think

about it and talk with somebody that you love so that you get your end-of-life care wishes. Because the thing that you want is what's most important. You're the star of this show. And that's the most important thing that we're trying to get people to do by doing these cards.

Our cards are used in a lot of health care settings because they were developed by Dr. Elizabeth Mencken, who is a palliative care physician. And she, speaking of the research and so forth, she did the IRB to make sure that no one was going to be hurt during the process, and so a lot of the cards are used in a lot of health care settings, but they also can be used in just a church group or anything like that.

KATHLEEN TAYLOR: Yeah, and that's one of the things that we talked about earlier before we started the webinar, but all of you have addressed it: These games are really useful with different audiences. Each game can be used with different audiences, but I like how the flavor is slightly different, and I can see these being useful in different situations and at different points in the lifespan for people, and also just different

"Whatever you want at end of life are your wishes, and we're trying to make it so that you can think about it and talk with somebody that you love so that you get your end-of-life care wishes. Because the thing that you want is what's most important. You're the star of this show. And that's the most important thing that we're trying to get people to do by doing these cards."

social contexts. And with that in mind, oh go ahead Cindy...

CINDY SAFE: What I was going to say is — I mean, just to your point — I've done the *Go Wish* game with a group of high schoolers, and also with a group of people who live in independent living and who are over 100 years old. So, it doesn't matter which group it is, like you're saying, they all have a — somebody has something to say about death — why, because we're all going to die.

KATHLEEN TAYLOR: Yeah. That's true. It's true. I want to touch on something that's been repeated, but I want to pull it out as a theme to address. Nick, you first said that there was a hospice professional who said to you she could tell inside of a minute whether people had had one good conversation and the difference that that makes in terms of being able to help people through the challenges of end of life.

And Lisa, you mentioned that the family that you worked with that helped you with developing this. They were terribly prepared and they had their advance directives, yet they had not had a conversation about what he wanted. And that just got me to thinking, that that is so critical in advance care planning.

It's not — advance care planning is not only the completion of advance directives. The completion of advance directives is not a conversation. They're forms. We really need to find ways to help people just talk about what they want with the people who matter most to them, so that those people aren't second guessing their decisions, aren't left with those challenges after someone dies, and also so that the person who's in this situation gets what they kind of hoped for.

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...I'm really appreciating the ability for (these games) to help spur conversations, and I'd love for everybody who's listening to think about how to use these and other non-threatening introductions to conversations."

So, I think these games — I'm really appreciating the ability for them to help spur conversations, and I'd love for everybody who's listening to think about how to use these and other non-threatening introductions to conversation. Because it doesn't — you don't have to sit down and say, "Hey, let's talk about the fact that you're going to die," because no one's going to go there.

LISA PAHL: Kathleen, can I just add...

KATHLEEN TAYLOR: Yeah!

LISA PAHL: Yeah, you really touched on something, because when I — you know, again, working in the E.R. and working in hospice — when people are faced sometimes with hospice, a person, especially who has cancer, they can be doing relatively o.k. one day, and then they just start transitioning. And then they can't

communicate anymore. They're altered, they're confused, and there's just so much chaos.

And time and time again, what I find in my experience is, when there's dying conversations, that's what people remember. They remember that Dad said, "Don't let me get like this, I never want a feeding tube, if you do that I'm going to haunt you," or whatever these words are, these form these really strong emotional — these are strong emotional conversations that stick with us. And when we can hear the words of the person that we're trying to make healthcare decisions for in our head, people have so much more confidence. And then there's more agreement among the family, and then it's just like... And then us hospice professionals get to witness this very beautiful — most of the time — this lovely ending because there's all the communication.

So I just really wanted to highlight how important conversations are. Regardless of what tools you use or how you make it happen, helping people have these conversations will help improve the death experience for people.

KATHLEEN TAYLOR: I think it will. And there's been, throughout all the 30 years that I've been doing this, there has always been the issue of health disparities, access disparities in advance care planning. We know that there are certain populations who engage in advance care planning less — they're less engaged — than others. And I'm wondering how, or if, these games can help to address access and equity with regard to approaching advance care planning conversations. Any thoughts about that?

NICK JEHLLEN: So, two quick things. The first is that games, advance care planning,

"...professionals that allow themselves to be part of the conversation instead of leading the conversation, professionals who are willing to be vulnerable, show that they are struggling with the same kinds of things, is a big step forward. And I think all three of these tools make the space for professionals to step away from — not abandon the clinical side, but allow the human side to come forth and help them have a real conversation."

all of this sort of stuff is no replacement for a good strong healthcare system with well-paid staff members who can take the time to have these conversations. There's a lot of things you can do with really great tools, but until we solve the actual healthcare crisis, then people who are treated badly by the healthcare system will not get good health care.

That being said, in the system that we're in now, I think one of the things that I've seen, not just with our game, but with any group that — any family that is trying to get good health care — professionals that allow themselves to be part of the conversation instead of leading the conversation, professionals who are willing to be vulnerable, show that they are struggling with the same kinds of things, is a big step forward. And I think all three of these tools make the space for professionals to step away from — not abandon the clinical side, but allow the human side to come forth and help them have a real conversation.

And I think that's really important on a microscale, and if it's done at scale, then it can, you know, make real change.

KATHLEEN TAYLOR: I think that's well-said. And two questions that have come up, kind of related to access and equity in a way, are, just real quick, for all three of you: Are these games available in different languages?

CINDY SAFE: So, I'll answer that question. *Go Wish* is in about 20 different languages, and many different countries. And so, we own the rights to the Spanish and the English, but one of the ways that I was going to say provides access to populations who might not otherwise get this kind of information is to have the cards in that language. And so we have a Chinese group and a Japanese group and many groups that have developed.

Because it turns out that you want to talk about end-of-life care and death and dying with a common group, the groups of people you have common interests in, because you feel more open to discuss them. And sometimes, even with the Chinese cards, if the language is in Chinese and in English then, whether it's the older generation or the younger generation, they can both understand what's being said.

KATHLEEN TAYLOR: And we're getting — there's been three questions about a pediatric version of any of these games. Are these appropriate for pediatric patients and their families, or are there pediatric versions of any of these games?

CINDY SAFE: We have a — sorry, I didn't mean to interrupt — we just introduced a pediatric version of this game.

KATHLEEN TAYLOR: Oh, that's great! And is that available at the same website that we just saw?

CINDY SAFE: Yeah. But this pediatric version is for professionals, and so we found that that's a completely different group with end of life, and we had them developed by a person who works with children and death and dying.

KATHLEEN TAYLOR: And Nick, I heard you talking about 17-year-olds playing these games, but are there pediatric applications for *Hello* as it is or is there a different version?

NICK JEHLLEN: Nope, we use the same version. We tried to write the questions at a level that anybody could understand and use them. The games are very different when they're played by groups of six- and seven-year-olds, but we've definitely seen them played groups of six- and seven-year-olds and families with kids that young. And I've had really good success with cancer support groups for teenagers as well.

KATHLEEN TAYLOR: That's great. Lisa, what about your games?

LISA PAHL: Well, it's me and my business partner, and we both work other jobs, so we don't have the expansion of the other two games. We do have a Spanish in the works, and we've been approached a lot recently about a pediatric version, so we are trying to make all these expansion packs happen.

But I will say that, *The Death Deck* I have played with my son and his friends since he was nine, and so there's this lovely group of teenage boys now, wandering around with some death literacy. And we've also presented with high schools and middle schools. But not necessarily people close to

end of life, or pediatric patients per se, but kids and teenagers, yes.

KATHLEEN TAYLOR: Thank you. Well, we're at our time, and I want to be respectful to everyone with that, so thank you all so much for showing us the games, for talking about how they were developed, and giving us all really great information about how we can use these to broach conversations that don't have to be difficult and can actually be fun. Thanks. Dave, I'll pitch it back to you.

DAVE SIMISON: Thanks, Kathleen. And thank you to all of our panelists and to you for attending. This presentation was recorded. It will be available to view within seven business days. You can find it, along with all of our other recorded webinars on the Five Wishes Webinars page, which is at FiveWishes.org/Webinars. We encourage you to share the Five Wishes Webinars page link with your teams and your colleagues. On behalf of all of us at Five Wishes, on behalf of our panelists, thank you for attending and have a great afternoon.

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