



Webinar Transcript

# **ADOLESCENT AND PEDIATRIC ADVANCE CARE PLANNING**

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Devon Ciampa, MSW, LCSW-C

Dr. Lori Wiener, PhD, DCSW, LCSW-C

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## ADOLESCENT AND PEDIATRIC ADVANCE CARE PLANNING

**CORA SAFTNER:** Alright, it's just after one o'clock, so we're going to get started. Welcome everybody. Five Wishes is pleased to present today's Practice Community Webinar, Adolescent and Pediatric Advance Care Planning.

My name is Cora Saftner. I'm the executive assistant at Aging with Dignity, and it's my pleasure to host and introduce today's webinar. This webinar is being recorded, so participant audio is muted. If you have or need any technical help with the webinar, please click the Q&A button on the lower bar of your Zoom screen, describe your issue, and I'll try to help as best I can.

This presentation will last up to 60 minutes and you are encouraged to ask questions throughout. To ask a question, click on the Q&A button on the lower bar of your Zoom screen and type your question for the presenters. We'll try to get to as many of these as possible.

It is now my pleasure to introduce to you Joanne Eason, president of Five Wishes.

**JOANNE EASON:** Our practice community is really your community. It's based on a bunch of the feedback that we've received from clinicians and providers and all of us in the healthcare settings to make sure that we have resources available that assist you.

And speaking of resources, we've based a lot of your feedback on some of the new products we've just released this year, and there's five of them.

And no, we don't always do things in fives, but we've updated our Five Wishes Digital experience by joining forces with our tech

solution partners, MyDirectives. It provides an enhanced user experience to assist in the completion of documentation and the ability to access them throughout the country.

Additionally, *Five Wishes* is now integrated into the MyDirectives platform, specifically for use with MyDirectives for Clinicians.

We also stood up our Five Wishes Certification Program, one for Facilitators and one for Community Presenters. This is a competency-based program for clinicians who have advance care planning conversations with patients, and for those whose role it is to spread the seeds of advance care planning in their communities.

As part of the Certification Program, we've developed four new online training modules housed at the Hospice Foundation of America's Learning Management System, and they come with CEUs for nurses and social workers.

There are also tools for patient education. We've updated our instructional video that walks people through how to talk about and document their wishes using *Five Wishes*.

And for faith-based initiatives, specifically for Catholics, we've released *Finishing Life Faithfully*. It's a companion to *Five Wishes* and it helps individuals and their families understand end-of-life decisions based specifically on Catholic teachings.

Today's topic, Pediatric and Adolescent ACP, is very dear to our hearts here at Five Wishes, as we're the only organization that provides planning tools for these ages: *Voicing My Choices* and *My Wishes*.

*Voicing My Choices* was developed through extensive research by the National Institutes for Health and by the great work of Dr. Lori Wiener, who is one of our panelists today.

And *My Wishes*, our pediatric planning guide, was developed at Central DuPage Hospital in Illinois, now part of Northwestern Medicine.

So, with that transition, let's get started on today's Five Wishes Practice Community Webinar. It's my pleasure to introduce Kathleen Taylor, Five Wishes Healthcare Programs Director, and today's moderator.

**KATHLEEN TAYLOR:** Good morning, afternoon, or evening, wherever you are, and we're thrilled to have you here for this webinar which, as Joanne mentioned, this topic was chosen based on feedback that we received from people who attended our previous webinars, which I think we've had 15.

And often during those webinars, we would get questions in the Q&A about pediatric resources or resources for adolescents related to the topic that we've been talking about, particularly during our Gamification episode of our webinars.

So, we thought, people are asking so much about this and people seem to be interested in either solidifying or starting programs for pediatric and adolescent populations, so let's just hit that nail on the head.

And I'm pleased to say that we got the best of the best really for you today as panelists. So with that said, I'm going to go ahead and introduce our panelists, and you can start your cameras panelists so I can tell them who you are and they'll connect that face with a name.

### **Devon Ciampa, MSW, LCSW-C**

Devon Ciampa is a medical social worker and therapist who specializes in working with adolescents and young adults.

She recently ran the Pediatric Oncology Adolescent and Young Adult Program at Johns Hopkins, and she's currently finishing up her doctoral program at University of Pennsylvania, where her dissertation is focused on advance care planning for emerging adults — so, those people that are on the cusp of it and young adults.

And we're pleased to have you Devon, Thanks so much for joining us.

### **Lori Wiener, PhD, DCSW, LCSW-C**

Dr. Lori Wiener is co-director of the Behavioral Science Corps and head of the Psychosocial Support and Research Program at the Pediatric Oncology branch of the National Cancer Institute.

As both a clinician and a behavioral scientist, she's developed clinical and research programs, and she's created innovative resources for children, adolescents, and young adults, and those resources are distributed worldwide and utilized widely by pediatric centers.

Dr. Wiener proudly led the team that developed the first evidence-based psychosocial standards of care for children with cancer and their family members.

And she's co-edited several textbooks and the storybook *The Gift of Gilbert's Feathers*, which I can't wait to hear more about, to help children through the psychological and behavioral process of preparing for a natural end of life.

Thank you so much, Lori. Thank you, Devon, for being with us.

**KATHLEEN TAYLOR:** Let's just jump right in. I think maybe to get us started and help all of our attendees understand a little bit more about how you are experts and why you are experts: Can you tell us a little bit about the most formative experiences for you in your pursuit of this field, and in your work with these populations? What's been the most — what have been the biggest highlights in the areas where you learned the most about what you're doing?

Why don't we start with you, Devon?

**DEVON CIAMPA:** Sure. Thank you so much, Kathleen. It is such an honor to be here, and especially an honor to talk about this topic, because it is, in my mind, one of the most important things that we can do with this age group when they're facing something [as] traumatic as a life-threatening illness.

And it's really about choices. That's what I focus on as a medical social worker that focuses on this population is the choices and the options and making sure that these kids and young adults, that they have a space to express what they want based on these choices, that they still have some agency, that they have agency right up until the end. That's the important part.

And I think for me, one of my, one of the best things I've ever experienced, one of my best experiences with this was the first time I really saw directly what a communication tool something like this is. And I, as I said, I focus on choices, and I always approached advance care planning as something that these, as an expression of the patient's voices, and I didn't see it farther than that.

And I was so wrong, because this is a communication tool, not just for the patients to express their wishes, but also for the caregivers and for medical providers.

*"...they had so much worry and fear to bring it up to the other person, and here's this amazing tool that has a lot of questions made out for them. And through that I was able to see so much conversation, so much expression and comfort given between caregivers, especially with parents and their children or patients."*

And I have some wonderful experiences where I saw firsthand a parent saying, "Are you sure you want to talk about this?" and, the patient being like, "Yes, yes, I'm okay to talk about it, but I didn't know you wanted to talk about it." And then the parent in turn is like, "I didn't know you wanted to talk about it."

And they had both been thinking, they both had so many questions and they were thinking, they had so much worry and fear to bring it up to the other person, and here's this amazing tool that has a lot of questions made out for them. And through that I was able to see so much conversation, so much expression and comfort given between caregivers, especially with parents and their children or patients.

And I think it could be the same for medical providers, that medical providers are not necessarily trained in how to have advance care planning discussions. And, appropriately, they are focused on cures and making someone feel better and making sure that they have the appropriate treatments. And this sometimes can seem like it doesn't fall in line with that, but it is, again, such a great communication tool for that patient to know how to talk to the

medical provider, and in turn the medical provider being able to talk to, and able to find out more about what that patient really, really wants.

And at one point I went to the funeral of a patient who passed away and her dad came up to me and just said, without knowing what her wishes are, we would have had no idea what to do in this situation, and yet we feel like we're honoring her, we're honoring all of her wishes. And I think it was a really, poignant moment for me to, to see firsthand how delicate this conversation is, and also how important it is and how much comfort it can bring, which is a word that maybe sometimes we don't come up with when it comes to advance care planning. But it is, it's a wonderful experience to be part of that.

So, for all you providers out there that are listening to this, being a part of these is not something to fear. It is something to reach

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**KATHLEEN TAYLOR:** That's a great perspective to remember that it's more than what it seems like. And really, I don't want to say it's a barrier buster, but in some ways advance care planning kind of is. Just to present the opportunity to have the conversations, and then people — you're usually surprised when people want to have some piece of that, or their families are surprised with one another.

That's great. Thank you, Devon. Lori, what about you? What have been your most formative experiences in your career and in working with, with this population?

**LORI WIENER:** Well, thank you. And let me just start by saying I love working with Devon, and so I'm so glad that you started with Devon, who has participated in several of our studies.

And the tool that Devon was talking about is *Voicing My Choices*, which there will hopefully be a new adapted version of *Voicing My Choices* becoming available soon.

I would say my most formative experiences really began over three decades ago — I've been doing this for quite a long time — when I noticed that youth were not sharing their worries and their fears and their anxieties with their parents. And the parents weren't sharing their own worries and fears and anxieties about what could happen with their child. And so, they ended up coping in emotional isolation from one another at a time when families just need to bond. And unfortunately, when that happens and after a child dies, the parents are often left with a lot of regret. You know, "What were they

*“...having a document where they can be able to put down... instructions for the family for how to be able to live if I can’t live, and what a gift and what a comfort that could be for the families afterwards, because they’re not second guessing what my child may want. They’re able to honor their thoughts their way, they’re able to honor their wishes, and they’re able to then communicate not just what the child may want or the teen or the young adult may want, but to also what they would want if they were in that situation. And that kind of communication is just priceless.”*

thinking? What would they have wanted? What would their preferences have been?”

And so I began with focus groups with youth at the time — youth with cancer, youth living with HIV — and asking them, do you think it would be helpful to have an advance care document that was created by and for people your age where you could share what your hopes and your dreams and your fears are, and how you want to be cared for, how you want to be supported. Not just advance directives, whether you want to have life support or not. There’s so much more to advance care planning. It’s the pivotal communication that could take place during an illness.

And so, from that and from those focus groups, from that research, from interviews after interviews, and now in many countries, learning what’s most important, and having

a document where they can be able to put down...what would be of comfort, the word that Devon had used.

But also, kind of like instructions for the family for how to be able to live if I can’t live, and what a gift and what a comfort that could be for the families afterwards, because they’re not second guessing what my child may want. They’re able to honor their thoughts their way, they’re able to honor their wishes, and they’re able to then communicate not just what the child may want or the teen or the young adult may want, but to also what they would want if they were in that situation. And that kind of communication is just priceless.

**KATHLEEN TAYLOR:** So, as you’re both talking, and these are — everything you’re saying sounds so necessary to me and so important — just paramount to good care and helping people through this experience.

And a lot of what you’re saying resonates with the way we talk about advance care planning in general. Advance care planning, which in most of our education is defined as a process for adults over 18, that advance directives are important and appropriate for adults over 18.

So, can you talk a little bit about what is different with advance care planning with people under 18, since we talk a lot about it over 18, what’s different under 18? And I think the obvious part is the involvement of parents, but differences in how these discussions and decisions are documented and how the discussions are led.

Can you then, that’s a broad question, but can you both talk about that please?

**LORI WIENER:** Devon, you want me to start or do you want to?

**DEVON CIAMPA:** No, you can start, Lori. That's okay. This time you start.

**LORI WIENER:** Well, once you're over the age of 18, you could legally sign paperwork and that this is really going to vary from state to state, but minors too can participate in advance care planning by expressing their wishes and their preferences regarding their healthcare in the event that they become unable to make decisions for themselves.

And this can include discussing their values, their beliefs, and their goals for their medical care with their parents or guardians, with their healthcare providers and other relevant parties.

We talked about *Voicing My Choices*. That's a place to be able to put that down, but it's more than that. It is a way to be able to say, I don't want more treatment if this doesn't work. I don't really want to spend more time in the hospital if I don't need to. My preferences right now are to be able to be with my friends or to be able to be at home, or to be able to have pain control. Or my preference may be to do absolutely everything, I don't care how aggressive it may be, because if it gives me a chance to be able to live for another day or to try something new.

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*"...being able to have those conversations... It's just a privilege to be able to talk about that. And as many people on this webinar probably know, it's not always afforded to youth. It's expected the parents will be the ones in the room, they'll be the ones to be able to make the decisions. They don't often feel like they have permission to be able to speak up. So, giving them the opportunity to be able to have in advance a way to be able to plan for their future, whatever that future may be, again, would be a gift that we all could be able to provide for them if and when they're ready."*

It varies person by person, it varies by development, and it varies by where they are in their treatment trajectory. It's communication. Advance care planning with youth is all about communication as it is with adults. It's the cornerstone of care and quality of care and quality of life.

What are they thinking? What are they feeling? What are they experiencing? What will bring them for that day joy? And being able to have those conversations and to be able to share those conversations and being able to honor, to respect and to be able to honor what their hopes and dreams are. It's just a privilege to be able to talk about that.

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And sometimes we just need to pave that road because they're not ready to be able to talk about it now, but to know they can at a future time. To you, Devon.

**DEVON CIAMPA:** Thank you. Thanks, Lori. I think for me in having spanned — I worked with mostly patients 15 and older — so I had an enormous amount of patients that were under 18 as well as patients that are over 18, and I personally did not experience much difference in how I approached it.

Just like Lori said, when a child turns 18, of course, legally, then they're signing their own documents. They are their legal medical decision maker. But, you know, five seconds ago they were 17. And so, it's not necessarily a magic time when all of a sudden their brain is developed and they know exactly what they want to do and they can do it on their own.

It's not about that. And I think discounting kids that are under 18, not considering that they can make their own decisions or that they have wishes that they can express... I've worked with some kids that are 15 years old that are unbelievably mature when it comes to this topic and ready to talk about it, and I've worked with some young adults that are 25 that really need their hand held through the process. So I don't think it necessarily has to do with that age.

Not approaching it with a patient who's under 18, I think would be a mistake, or at

least that's what I experienced. Just going to their caregivers, just going to their parents, it takes out the most important voice in this entire thing. And it robs them a little bit of being able to have a conversation with their family. And it obviously is about the patient, but it's also about giving some relief to the parents as well.

Like I said before with my example, I experienced an enormous amount of situations where parents on both sides maybe didn't have that advance care planning conversation with their child, and when their child was in need of them to speak, a need for their parents to speak for them, the parents were like, "I don't know what to do. I don't know what to do. I wish that we had something that had the wishes of my child. Am I making the right decision?"

And then I've experienced the same kind of situations where it's like, "Oh, thank goodness we had the conversation. I know exactly what they want."

And to make a decision, sometimes a life-or-death decision about your child is nothing if not unbelievably difficult. And that's not even the right phrase for that.

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So having, giving the conversation, giving the space and the room for a conversation with the child and with the parents is going to help both sides.

And that kid, however old they are, they have those years of life that they've already lived. They have wishes and they have dreams and they have desires. And they have stuff. I think a lot of people forget that it's not just someone that owns a house that might have something that they want to will to someone. These kids have pets, they have personal items. They want to have a conversation about who should take over these things. Who should be the one to care for their pets? And that's important. That's just as important as figuring out who's going to be the one to take over your house. So, no matter how small it is, it's about the individual and it's about making sure everyone's voice is heard in the conversation regardless of whether they are their legal medical decision makers at 18 or not.

And the other thing about working with someone that's over 18 is, including loved ones I think, is just as important, that even though they're over 18. It doesn't necessarily have to be a parent or caregiver. It can be friends, it can be a boyfriend, [or] just a close person that they trust. And I think what's important also, is the same can be applied whether someone's under 18 or over 18. It should be kind of like a joint effort with everyone that's there to support them to really make sure everyone's on the same page.

**KATHLEEN TAYLOR:** Something you said just now resonated. We've actually — there's so much material about advance care planning, including a lot of Five Wishes material where we talk about loved ones and having your loved ones around, and

we're beginning to shift our language to a trusted network, or your loved and/or significant ones because it is more than that. And I think especially sometimes for kids, for teenagers — friendships for teenagers are love affairs. I mean, they really are. That's so important to include those people.

And you talked about providing families — the patient and the family, the child and the family — with the opportunity to have this conversation and the space and the room to have the conversation. So, we have a good question that came in from an audience member: First of all, at what point do you begin these conversations? At what point in the patient's illness do you know it's time to start and give the opportunity and the space and the room for this conversation? And then how do you start it?

It's a great question and I think it's the thing everybody wants to know. So, since we started with you Lori last time, Devon, you want to start with that?

**DEVON CIAMPA:** Sure, of course. It is an excellent question, and it's a question that I think appropriately would be on anyone's mind that is going into this. And it's such a delicate, sensitive topic. It's so personal, it's so vulnerable that knowing how and when to actually broach that subject is scary. And I personally have certainly learned from myself as I've gone through this process.

It's not like someone told me you start it at this time, and I've always done it that way. It's slightly different for each patient, but a rule of thumb is that, try to start it earlier rather than later.

The worst thing that I think I've seen happen in this realm is that it's been too late to have conversations, or it's right at the end of someone's journey. And I think to really get to have conversations, to really capture what

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So maybe their wishes changed during their journey. Maybe their goals have changed. And I think it's important for them to be able to get some help expressing that through their whole journey.

Also, advance care planning is not just about end of life. So, I think that also it's scary if all of a sudden someone's like, "Well, this treatment didn't work, why don't we talk about advance care planning?"

And, you know, our brains are automatically going to go to the worst-case scenario. And it's not about that. It's about it's always good practice to have an advance care planning conversation as early as possible to avoid that — the correlation between, oh, advance care planning automatically equals end of life. It doesn't. So, I think, to help people understand about advance care planning, to help your patients and their loved ones, or their trusted network — I like that — to really embrace the process of it, it should be done earlier rather than later.

And maybe there's a palliative care team where some of you work or maybe there's some other people that have experience

with it, but I wouldn't hesitate to bring it up as early as you feel like that family and that patient needs to hear it. Even if it's not the entire, even if you're not being like, okay, we're going to go over this whole packet the first time you mention it. It's good to just mention it so that it is not as terrifying as you move on. That it's a process.

**KATHLEEN TAYLOR:** Well, my thought with that is, we encourage with adult advance care planning for people to have the conversations when they're healthy, before there's any kind of medical crisis. And that's interesting to me to think about. I don't know that we would bring it up with every healthy child, but when a child is going, has a medical condition, that's interesting. That's a new way for me to think about that, bringing it up as early as possible, even with children. Lori, what are your thoughts on this, about at what point you bring it up and how you bring it up?

**LORI WIENER:** I agree with what Devon had said earlier it is always better and in a non-threatening time and not in a time of a crisis because if you first bring this up at a time of a crisis, it's too late. You know, parents that say it's too soon, but it's too soon until it's too late. And so, if you want to have a meaningful conversation, broaching it early, as I said earlier, just in terms of paving the road, is the way to go.

And so I begin by what are your — what are you expecting things to happen? How do you understand your condition right now? What do you think is going to happen in the short term or in the long term? What are your hopes? What are your worries? And I really use their words, to build on their words, to be able to be able to take that conversation further.

*"I ask them, what about that worries them? What about that scenario concerns them? Think it through, talk about it and reassure them that talking about something doesn't make it happen. I think that's a philosophy. People think if I talk about it, it will happen, and in some faiths that is the way that they believe. But the relief that they will feel when they're able to be able to talk about something and they're still sitting here and can be able to explore what some of those concerns and worries are, it's palpable to be able to do that."*

If it is that they're afraid they're going to relapse, they're afraid they're going to have a disease progression, they're afraid they're not going to live a long time, I ask them, what about that worries them? What about that scenario concerns them? Think it through, talk about it and reassure them that talking about something doesn't make it happen. I think that's a philosophy. People think if I talk about it, it will happen, and in some faiths that is the way that they believe. But the relief that they will feel when they're able to be able to talk about something and they're still sitting here and can be able to explore what some of those concerns and worries are, it's palpable to be able to do that.

And I talk to providers also about, they don't have to say, "Okay, here's your diagnosis and here's your treatment plan and let's talk about advance care planning." I mean, that's not recommended, but it is okay to be able to say when treatment

is starting, to be able to say, "I've learned from previous experiences that not having some conversations has gotten me into trouble, and so I want to be able just to broach some subjects for you to think about. No decisions have to be made, but is there anything I should know about things that are really important to you?" Like, some people say, no blood products, or I never want to go to an ICU, or if I ever get really sick I don't want this person to make decisions, I want that person to be able to make decisions. Or, I don't want to be in a hospital if I got really sick. "Are there things that are really important to you that would be helpful for me to be able to know? I have all anticipation that you're going to do well, I just want to..." — and that could be soon after the treatment started — "but I just want to be able to have you start to have those conversations, and when you're comfortable you could share them with me."

So you're, again, paving the road. And then if things aren't going well, you could say, "Do you remember when I had asked you about, we're not at a place where I'm really concerned, but it would be helpful for me to know what are your thoughts about that? What are your preferences about this? So I could take the very best care of you, just like you would want to be able to take that kind of care of your loved one."

And so I just build on that. And then I may introduce them, as Devon had mentioned, to *Voicing My Choices*. I may say, "There was a document that was created by and for people your age. Would you like to be able to see what that looks like? There may be some pages that really do resonate with you, with things that you've thought about as well."

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**KATHLEEN TAYLOR:** I'm glad you're talking about *Voicing My Choices*, because I think it would be helpful to folks on this webinar to talk — well, I want to talk about a lot of resources, but I wanted to talk about two in particular: *Voicing My Choices* and *My Wishes*, which are available, of course, through Five Wishes. And we've talked a little bit about those and the development of those, but what's the main difference between these tools, between *Voicing My Choices* — who is that for and how is that used — and *My Wishes*, and who is that really for and how is that used? I know the answer, but I'd love to hear your perspective on that as you have used it with these populations — either one of you.

**DEVON CIAMPA:** I think Lori would be best to start with that because she's so familiar with it.

**LORI WIENER:** So, I think *My Wishes* is for a younger child, just to be able to talk about

what their wishes are and to be able to put down what their favorite things are and what's most important to them.

*Voicing My Choices* is, again, a communication tool that's looking in more depth than *Five Wishes* are. What brings me comfort, how I want to be comforted, how I want to be supported, what I really want my family and friends to know.

So for example, there's parts of that page where you could be able to talk about, if I haven't had a chance to be able to thank you for something that you've done that was really cool and wonderful, allow me to do that now.

Or if I got to a place where I accept your forgiveness, or I want you to be able to forgive me for something, they could be able to document that. Teens and young adults are often more worried about their family member and friends than they are necessarily just about what's happening with them at that time. So it's a place where they can say, "I really want you to get therapy, get support. I want you to live a life that brings joy to you and value to you." There's places in there that they could be able to share parts of, again, what is most important to them and their values with others, whoever that may be. And they're often really concerned about siblings if they have siblings. And it's a place to be able to speak to them about that.

Different than *Five Wishes*, there are different scenarios. There's a scenario if you think that, if you would want to go to an ICU, if they needed to be able to have life support. There's a scenario if you are already in the ICU and you've already made that decision that's what you want, but things aren't getting any better, whether you

would want to be able to revisit those goals of care for you.

There's parts about spirituality because that may be very different. You know, there may be a family that practices one faith and the youth that practices that faith a little bit differently or no faith at all, or they find meaning in a different way, and they could be able to share that, but also to be able to recommend that their family member gets the support that they need.

There's a page that is talking about some of the stuff that Devon had mentioned, you know, who I want to be able to have my belongings, who they want to go through their belongings if they don't survive.

There's parts on the newer version talking about their passwords that — you know, social media. What about fertility? If they've participated in fertility preservation, what

*“Teens and young adults are often more worried about their family member and friends than they are necessarily just about what’s happening with them at that time. So it’s a place where they can say, “I really want you to get therapy, get support. I want you to live a life that brings joy to you and value to you.” There’s places in there that they could be able to share parts of, again, what is most important to them and their values with others, whoever that may be. And they’re often really concerned about siblings if they have siblings. And it’s a place to be able to speak to them about that.”*

they would want to be able to happen there. And if they have children of their own, how they would want their child to be cared for if they became very ill, what their hopes are for their child if they don't survive.

And of course, a glossary to be able to understand all of this.

So, there's much more to it than what you would have in *My Wishes* for a young child.

And necessarily for one that is a legal document, which is the *Five Wishes* for a person — who's geared for people 65 and older who've lived their life or a good portion of their life.

**KATHLEEN TAYLOR:** Thank you. Devon, anything you want to add?

**DEVON CIAMPA:** No, I think Lori covered everything, which is great. I think that, just like Lori said, I kind of think about it as like a developmental milestones line, and the older the patient is for me within the AYA world, the more they need to maybe put down.

And so, *Voicing My Choices* really dives into a lot of areas that are affecting teenagers and young adults. But *My Wishes* is great for the younger generation that really doesn't have as much in their outside world maybe. It's still very focused on them and their needs, and that's very appropriate for that age group.

But as you get older, a lot of the thoughts that these patients are going to have, they're just going to like, grow and grow and grow. So, *Voicing My Choices* is a place to put that down, as developmentally their world is getting a little bigger.

But there, it's really important to know that those two documents exist, and that we can gauge, as providers and social

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workers, navigators, we can figure out which document is necessary for a certain patient.

**KATHLEEN TAYLOR:** Yes, and I think you're absolutely — you said to me one of the key words that has been helpful to me in differentiating which tool to use is the developmental milestones and really just developmental — where are they developmentally in thinking about these concepts?

And we have found that *My Wishes* is really helpful for people who have developmental challenges, even for adults who have

dementia, who have memory issues. *My Wishes* is great just for exploring what they think and what they want and what matters most to them. So, I think that's a great way to discern.

And we've had a couple of questions about how you use this and about people with developmental challenges. So, I think just to keep in mind these tools, and they're available through *Five Wishes*. If you go to the [FiveWishes.org](https://www.fivewishes.org) website, you can find both *Voicing My Choices* and *My Wishes*.

Are there other tools that you think are just fantastic? Art therapy, anything that you think has just been really useful with these populations?

**LORI WIENER:** Just before we just move over to some other tools: ways to use these tools I think are important to note as well. And I'm so glad that you raised the issue of different developmental needs and cognitive abilities because that's critically important. And just because a young person may be cognitively delayed or not have the same communication skills or not be verbal, how do you be able to access what some of their needs are?

And you can do that through art and you can do that through some writing, and you can do this by really matching their development to the kind of questions that are there.

Once I find out, especially for a younger person, once I find out what is most important from some of those pages from either *My Wishes* or *Voicing My Choices*, I ask if you would like to be able to put that on your door of the hospital — no names — so that before people walk in, they know about that person. They may know what their favorite color is, they may know what their

favorite foods are, they may know who is most important to them.

They may know how they want to be communicated with: “Please don’t talk to me alone before my family is here,” or, “Involve my, talk to my family first and then engage me,” or, “Please talk to me before you talk to my family, I want to know first.” Or, again, a way to be able to use some of that information so that the people who are

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coming in to be able to talk to them already have a way to be able to honor who that person is for their own being.

Other tools — there are many ways to be able to communicate. These are not the only ones. I think this is still the only advance care planning guide for teens and young adults, but there are in different countries, they have different tools that they use. Most of them are parent-based though. I haven’t really seen the tools where they’re really completely designed for the teen or the young adult. They’re mostly parent-based. But there were workbooks that they could be able to work on together. So we could put together some of those resources that are there.

**KATHLEEN TAYLOR:** Thank you. Anything else, Devon?

**DEVON CIAMPA:** I just, I love that Lori mentioned writing and the art and finding out what kind of works with that particular patient. It’s just amazing once you find what that patient gravitates towards.

And I think you’re right, I mean, whether someone has any delays or communication struggles or just is introverted a little bit, it might be hard to just have a packet, or just come in with some questions and expect a good conversation. And knowing that there’s other ways out there for someone to communicate is gold.

And I think some hospitals have the ability to have some great art therapists there, but there’s also organizations out there that provide some art therapy classes specifically for AYA kids with cancer, or specifically for this group. And there are ways to utilize that. There’s, for any of you that have child life specialists at your hospital, I would definitely engage them in this.



And a good story: One of my favorite stories that I have about just the writing aspect, so you might keep this in mind, is... I can't imagine someone on this call doesn't know about Make-A-Wish. And so — even for, I think a lot of people — what you think of with Make-A-Wish is those beautiful kids that don't have hair and they're at Disney World, and they're little, and then, that is a beautiful, beautiful way to honor it. But a lot of kids have, they're older when they get their Make-A-Wish, and they want to use it in a way that has to do with their legacy.

And so, one of my patients, she has since passed away, but she loved to write. And so, she started to really get into writing about her cancer journey. And then her Make-A-Wish was to turn that — she wrote poems, and to turn that into a book. And so, Make-A-Wish helped put it together, and she ended up having a book signing, and it really played into the legacy that she had and it helped so much for her to get the words down and for her parents and other, and friends, to read that. And I think that was a great way for her to leave behind. It's such a big part of who she is in her own words.

I mean, it was just, she even designed the cover. So, it's her picture, she used to be a ballerina, and the picture was her sitting on the floor in front of a stage door not being able to get in. She's wearing her tutu, she doesn't have hair, and she is attached to a chemo pole and it's just a very strong image.

And I think her parents were really worried about diving into this world with her. And here she is drawing it and writing it. So, to utilize that, just like Lori said, there's so many ways to get someone to communicate when it comes to their experience with an illness, that looking into other ways than just having a conversation or writing something

down in terms of questions and answers is to all of our benefit when we work with these patients.

**LORI WIENER:** I actually have a, each person has their own file on my computer where we do different writing. I mean, if you ask a child, like, "How are you?" they're going to say, "Fine." "How are things going?" "Good." You know, like, "When is this going to be over?"

But if you engage in really open-ended questions like, "Tell me three things I often wonder about." "I often wonder what it would be like to have a million dollars." "I often wonder what it would be like maybe to go to Disney," and you learn so much.

But other resources, especially for someone who is not as verbose about talking about advance care planning as we're thinking about it, is, we created a therapeutic game here called Shop Talk, where they get to visit and go shopping in 10 different stores, and in each store, and it's all by themes. And so, in each store, they pick up, the person next to them picks up a card and reads it to them and they could buy, and they buy by answering the question. And if they do buy, then they buy one of the six presents from that store and they put it in their shopping bag. And by the time they get around to all 10 stores they could win. But you learn so much about that person that you're working with. And we use that individually, we do that in groups, we do that with families. There's a version for children, a version for siblings, and a version for children whose parents are ill.

And we also created a workbook that's out there. All this is on our website if you're interested, called This Is My World that's had many different iterations of the workbook, but it's also a gift for families because we

have in there, from what I learned from a very precocious 11-year-old when I first started, called My Mock Will, and that's for young. And that 11-year-old said to me in one of her sessions in working on my computer, that that would be a good idea to have a page called My Mock Will in this workbook that we were creating. And when I said, "Why?" she put her hands on her hips and she said, "You adults think you're the only ones who think about who they want to have their stuff?" And I said, "My Mock Will it is." And that became one of the most important pages of that workbook, but also led to the development of what we now know is more sophisticated advance care planning.

So, I think that those are just some of the other resources that are ours. But again, there are others out there.

**KATHLEEN TAYLOR:** Well, I was going to try not to say "out of the mouths of babes," but now I have to. Do you ever have, have you done group work with kids? For some kids, their peers are so important and there's a different kind of support that they get in working with peers who are going through a similar experience. And I'm wondering about group work around these conversations with kiddos. Have you done anything like that? Either of you?

**LORI WIENER:** Both of us have. I think, you know, some camp programs have Bring a Friend Weekends, which I think is great because they're able to, they're worried about going by themselves and they're bringing a friend, and to do that.

We've done different kinds of groups. We've done early — I'm really aging myself with telephone support groups, and now they're all video support groups.

If you say the word support group, most teens are just like, "Please no, don't send me to that." But one of the most effective programs that we have had is Photovoice groups and they're short term.

And so we have, we're doing this with people undergoing transplant here in different phases of bone marrow transplant and where they pick the themes and then they go with their cell phone and they take pictures to that theme and they bring it up into the next group and they show their pictures and everyone talks about their pictures, and then they talk about their life and other themes, and then they pick the theme for the next week and the next week.

And we do that in six or seven sessions. And then we put together something of like a montage at the end of their themes and their pictures that they picked.

So, it is very supportive, it is very therapeutic, but it's not called a support group. They're called Photovoice, and people do them in different ways, but they're powerful and they're empowering and they're supportive. And I think people learn a lot on different coping skills that way.

**DEVON CIAMPA:** Oh, I love that story, Lori. And just groups in general. You're so right, that support group, mostly no one's going to come if I call it a support group. But I have found that especially with the AYA group, which technically the age goes from 15 to 39, that I have an enormous amount of younger AYA kids that go to any kind of group, and they're with people that are 15 years older than them, in a completely different space in life.

And it's really hard sometimes, especially if you are kind of on that cusp of still being a teenager, but you're an adult, and you're trying to figure that out, how to find people

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that are going through similar things as you, and how to actually connect with someone that is around your age and understands what you're going through.

And one of the biggest — just to step back to developmental milestones — but one of the biggest that adolescents and young adults are going through is the formation of relationships. And they shouldn't be deprived of that just because they are going through treatment for an illness. So if there's a way for us to bring that in, it's important.

And so, I found that some of the groups, I just try to narrow the parameters down a little bit. So like specifically for patients who identify as women and they're going off to college, and then maybe they'll talk about how to explain to new people what they've been going through, and all these things.

So, the same thing can be said on advance care planning. Someone that wants to talk about that might not want to go to just a general support group because not everybody is talking about that, but a safe space where they can connect with someone who is their age.

I've gotten, I've also found it's good to, don't shy away from having virtual groups because

usually this is a population that is used to doing things online, used to texting, used to not necessarily getting in the car and driving and being somewhere in person every single time.

So however the group wants to meet, I kind of just gravitate towards that, and having a group that is all kind of facing the idea of legacy or facing the idea of having to talk about something that no one else in their population or their world is talking about. You know, mostly people at this age are thinking that they're invincible. They're thinking that they're just focused on future. And here we have a totally different way of thinking.

So, not just having an adult there telling this, but getting support from their own peers I think is so important for them. But I do understand for those of you out there that have tried it and maybe it hasn't worked, it can be really difficult sometimes.

If you have something in person, always have food. That's just —

**LORI WIENER:** Yeah, no one's going to come without the food.

**KATHLEEN TAYLOR:** That's definitely a rule for all convenings.

**LORI WIENER:** You could also think about themes, you know. So, it's like a menu. So, you could say, we're going to have 12 weeks and come to the ones that you're interested in. So, you may want to have one on sexual health or on fertility, on peer relationships or cognitive issues. Or it could be whatever the theme may be, but you could have themes that we know that are really important to this age group. And so once they come to one, they may really enjoy the conversation and want to come back to others, or they

can pick and choose. And so that's also a lot less threatening.

**KATHLEEN TAYLOR:** And as we wrap up here, this has all been great and I feel like we could go for another hour, but we only have five minutes. I'd like to close with both of you speaking to our audience who are wanting to either strengthen their pediatric or AYA program or build a new one. What do you think are the most important components, resources, staff to have? Like, what would your advice be for people who really want to kind of hit a new bar or who are looking to start out?

**LORI WIENER:** I'm happy to get started if you want Devon, because we've done that just in terms of getting started. And that is, know your program and your audience, and I always suggest starting with a needs assessment to determine the specific needs and preferences of the pediatric and adolescent patients

And you could ask, what services would you want, what information would be helpful for you to be able to have, how would you want to get that information? And then to think about developing some guidelines and/or protocols for advance care planning that are tailored to the unique needs of the younger patients. And so it could be something that is a time point, like a trigger, for example.

So, if a person is going to be going into a bone marrow transplant, for example, this is what we do with everyone, having a systematic approach. Not, I'm doing this for Johnny, but I'm not doing this for Sally because I don't know how Sally's going to feel about this. So it's something, a systematic way that everyone has a buy-in for certain time points to have some of these conversations.

And then, as Devon had started educating, educating the healthcare providers about the importance of these issues, how to have these conversations, practice sessions. We do SIM training, just to be able to practice having some of these conversations in a very safe space.

And then having, making sure that you have resources and support for the patients and families to help them navigate decision making and the decision making process.

Always collaborate though with the other resources in your site. You may have great legal or ethical experts to make sure that your documents are both either legally valid or ethically bound.

Always consider language and culture and just who that population is. And then continuously evaluate and to improve the program to ensure that the needs that you are addressing now are being met because they could also be changing over time.

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So it could be a quality assurance project, a QI, a QA project, but having a small interdisciplinary group to get started and to be able to think about some of those steps as a pilot and then to be able to reevaluate how it's going.

**KATHLEEN TAYLOR:** Devon?

**DEVON CIAMPA:** Yes, I love that Lori brought up interdisciplinary, because that's one of my, one of the things I would love to leave with everyone. I have gone into it thinking that I could build it on my own, which was not true at all. And finding a partner or finding someone that has a level of passion that you do about this or just the desire to build it is really important. And more than one would be great, but someone who's not in the same department as you. So, like a fellow, maybe a physician, maybe child life specialist, maybe a nurse, and just to kind of build that interdisciplinary network where you want to build a framework.

You really want to make sure that it's not just, oh, this is what the social worker does, so we have an AYA program. It's not about that. It's about everyone kind of being on the same page in a way about their role and the importance of it. And it's something that can be pushed aside a little bit if you're in a really busy medical center.

But you, if you think it's important, then I guarantee you there's double the amount of patients and caregivers that think it's important. So, you advocating to have something like this is you doing your job exceptionally well, and there are going to be other people out there that also believe in that. So the interdisciplinary aspect was the best thing that I found to help me.

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**LORI WIENER:** And that interdisciplinary shouldn't only be professionals. If you have [people who are] AYA themselves or more than one, or a parent caregiver who could participate in the planning, all the better for making sure that it really is meeting the needs of the patient population. Those champion our efforts.

**DEVON CIAMPA:** Definitely.

**KATHLEEN TAYLOR:** That's so important. That's so important to make sure that we are building things that have the perspective of what we would call... We're not doing things to people, we're doing things with people. So, they're not care recipients, they're part of it. It has to be built with that in mind.

So that's a great place I think for us to wrap. I want to thank you both so much. This has been a really wonderful, really meaningful conversation.

I want to remind the people who are attending that we will send out a follow-up email to everybody who registered. We'll include some links to things that we've mentioned, specifically to *Voicing My Choices* and *My Wishes*, and some other tools.

And we thank you all for being here. And with that, I will turn it back over to Cora to help us close.

**CORA SAFTNER:** Thank you, Kathleen. And thank you to everyone for your participation

and attention today. This presentation was recorded and will be available to view within seven business days. You can find it and all of our other recorded webinars by visiting the Five Wishes webinar library page at [FiveWishes.org/webinars](https://FiveWishes.org/webinars). Feel free to share the Five Wishes webinars page link with your teams and colleagues.

And on behalf of all of us at Five Wishes, thank you so much to our speakers, and of course to all of today's participants, and I hope you have a good afternoon.

**END**

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This Five Wishes Practice Community Webinar was recorded live on June 26, 2024. To learn more about the Five Wishes Program for Healthcare or to participate in future live Webinars, please visit us at [FiveWishes.org/Healthcare](https://FiveWishes.org/Healthcare).



