

Dr. Lynn McPherson:

Hello, this is Dr. Lynn McPherson and welcome to Palliative Care Chat, the podcast brought to you by the online Master of Science and graduate certificate program at the University of Maryland. I'm very excited. We have two guests today who are no strangers to our podcast series. This is a return command performance. I'm excited to reintroduce Arlen Gaines, MSW, LCSW-C. Wow. Alphabet soup. She's a clinical manager with JSSA hospice in Bethesda, Maryland, where she's worked for the past 13 years. From her years in the field as a hospice social worker, she developed a specialization in supporting children and adults with special needs around grief and loss. And partnering with her is her writing partner, Meredith Polsky, also LMSW, MS in special education, who've been working at the intersection of social work and special education for close to 20 years. She founded Matan, Inc in 2000, recognizing a significant gap in the Jewish community's ability to include children with special needs and their families. Ladies, welcome. It's delightful to have you back. How are you both today?

Arlen Gaines:

We're doing great. Thanks so much, Lynn, for having us back.

Dr. Lynn McPherson:

Absolutely.

Meredith Polsky:

Thank you, we're thrilled to be back with you.

Dr. Lynn McPherson:

Awesome. So I see you ladies have been up to no good and you've been cranking out books like nobody's business since we last spoke.

Meredith Polsky:

We're trying.

Dr. Lynn McPherson:

But you're doing an amazing job. So it's been four years. You were one of our first podcasts that we recorded. And as I think I was just sharing, we're almost at 50 now, so this is pretty exciting stuff. So can you re bring everybody back up to speed about what you're doing and where have you been and what's the scoop?

Arlen Gaines:

Absolutely, absolutely. Well, again, thanks so much for having us. I can't believe, I think it's been about four years since we were last together. So what a treat to be able to chat together today. So, yeah, this is Arlen speaking now, and I was a field hospice social worker for many years. I've moved now into a manager role, and I've always had a real interest in children's coping with death and grief and how they've been doing. And I noticed a trend over the years when I was out in the field, that many of my patients had an adult child or a grandchild at home with special needs, and families were really struggling with how do I support them? What are the resources that are appropriate to support them around death and dying?

Arlen Gaines:

And I really came to understand that many of the books on this subject use animals as the main character or metaphors that were very beautiful, but quite out of reach for kids who might think in a more concrete manner. You think about how we often talk about death, beautiful images like someone might after their death, they live all around us and in our hearts. Beautiful concepts, but can be very confusing for children who really need some more concrete facts and don't think so abstractly.

Arlen Gaines:

So I had a dream of writing a book. It turned out to be the first book on death and dying that was really geared toward children with Autism Spectrum Disorder or other special needs. And I felt like I could bring the expertise of the grief piece, but I really needed a partner. And so I turned to Meredith, who I had known for many years, and she has expertise in the field of special education. And lucky for me, she said yes.

Dr. Lynn McPherson:

Meredith, anything you want to add to that.

Meredith Polsky:

Yeah. Again, thank you so much for having us and congratulations on your long and successful podcast run here.

Dr. Lynn McPherson:

Thank you.

Meredith Polsky:

I was really excited Arlen came to me originally. It wasn't something I had ever necessarily dreamed of or thought of, specifically writing a book about death and dying for children with different needs or neurotypical children, or sorry, children who weren't neurotypical. But when she talked to me about it, it really made a lot of sense. And I look back on my own experience with children and families, and I realized just how right she was that so many of the metaphors that we use with children around death are just not accessible. And in my work, I try to really aim to make everything as accessible as possible. And you may be getting to this, but Arlen alluded to it.

Meredith Polsky:

When we got the draft book cover of I Have a Question About Death, anybody who might have it or look it up, it's kind of like, I have a question and then in a bubble it says death. And I think it was my husband, maybe Arlen's husband too, who said, "Well that looks like a series." And we started hearing from people once they read the book about death, they started asking, "is this part of a series? Are you going to write other topics?" And people started writing in with the topics that they wish that we would address, other challenging topics that they have found in their dealings with their children, truth be told, with or without special needs. I always say special education is just really good education.

Dr. Lynn McPherson:

Absolutely.

Meredith Polsky:

So when we can get it right for kids with special needs, we're doing a service really for all kids. And the topics. We have a long list at this point, but two of the topics that kept coming up over and over again, that families were grappling with, were divorce and cancer. So those are the two that we went on to write next, about one a year. As you sort of alluded to in your introduction. First, I Have a Question About Divorce, and then I Have a Question About Cancer. And then of course, when this pandemic started, Arlen and I put our heads together to create I Have a Question About Coronavirus.

Dr. Lynn McPherson:

Well, before we explore that, I do have a question. You very kindly shared a copy of I Have a Question About Cancer with me. Thank you for sharing that with me. I've enjoyed very much reading both of the books that I have that you personally shared with me. And I understand they're doing quite well on Amazon. They're pretty high up there, right? In this category? Which category does this fall into?

Meredith Polsky:

So we're not going to pretend to understand the inner workings of Amazon. It feels like a bit of a mystery to us. And I think it falls in different categories, sometimes children and illness, things like that. And yeah, they've done, it's a hard thing to say, "Oh, they've done so well." When we talk about our books, it's kind of like, "Hey, it's not the most uplifting topic." And unfortunately, over the past year, I Have a Question About Death has done, quote, unquote, "particularly well," but it's hard to necessarily be happy about that. But I think we've hit a need. I think we've filled a gap.

Dr. Lynn McPherson:

Absolutely.

Meredith Polsky:

And hopefully it's serving an important role for children and families who are in just really difficult situations.

Dr. Lynn McPherson:

Absolutely. I have that in my section of my personal library right next to Dog Heaven. I know that might not be a fair analogy, but boy, when you need it, you need it. You just really need it. When I have a friend whose pet has died, I say, "you need Dog Heaven or Cat Heaven." And your books are lovely. The one question I have is, I'm so intrigued by your book within a book idea. What's with the short book within the book. Could you explain that to our listeners?

Arlen Gaines:

Yeah, absolutely. We set out to write these books, as we mentioned, to really be inclusive of children with special needs. And we came to see over the years that all children were really responding well to these books. And one of the things that has worked particularly well is that we first tell a story and we use very simple images, very simple pictures, not gender specific, not person specific. So it really can work for anyone. And then we retell the story with what we call a short picture story. And that's incredibly effective for children who might process information with less words and do better with visual images. And for some children who are maybe early readers and who don't know how to read so much yet, and they respond better to just the really, really simple pictures and a few words. So it's been part

of our secret sauce, I think to have a book within a book. And we found it really effective for different learners.

Dr. Lynn McPherson:

Yeah. Well, I can say from looking at it, the book is very visually appealing and very attractive. I can see why a child would really enjoy it. So let's get back to this idea about a book on Coronavirus. There is some edge of this seat stuff. So tell about that, and how is this related to your prior work?

Meredith Polsky:

Yeah, absolutely. So when the pandemic first began, in a way it feels like a million years ago, but last March when schools closed for a couple of weeks here in Maryland, and like everybody, I think Arlen and I were feeling really overwhelmed about what was going on in the world, what this meant for people, what this meant for children in particular. We both have children of our own, they have friends. So we heard what they were talking about, what they were asking about. We noticed that there was this whole new vocabulary in our world. First of all, pandemic, quarantining. I remember the first time my 14 year old was texting and she says, "Mom, how do you spell quarantine?" Social distancing, physical distancing, all these things. And I called Arlen and I said, "I feel like we need to do something. Is there anything we can put out into the world?"

Meredith Polsky:

I was writing some simple, short picture stories for younger kids, just about school being closed and managing those transitions. And it kind of dawned on us. "Wait a minute, we have this whole template, basically, for talking to children about difficult things." And one of the things we recognized was that this wasn't something that anybody had ever encountered before, basically. So, whereas there were other books on death, other books on divorce, and we were filling a need that we felt for diverse learners, Coronavirus was really new to everybody. And it sort of leveled the playing field in a lot of ways. Everybody had so many of the same questions, ourselves included. But it takes about a year from start to finish, at least it has for our books, from the time of pen to paper until it leaves the printer.

Meredith Polsky:

And especially for a book like ours, that's hardcover and in color. And of course, well, it turned out, we sort of did have a year, but [inaudible 00:11:08] as quickly as we could. And we also didn't want any perception of really profiting in any way off the pandemic. And so we reached out to our publisher and we said, "Hey, would it be okay with you if we wrote this book and just put it out online as a free download? You could put it on your website, we'll put it on our website. We'll try to spread the word." And we were really fortunate that they were fine with that. They're actually based out in London and they were appreciative of the idea, they were okay with it. And so Arlen and I just got to work really quickly, based on the questions that we were hearing from our children, from their friends. We didn't do quite as much research as we've done for the other books, but it felt important to get something out there to get families talking and to help children navigate this really new experience. So that's sort of how that came to be. Our kids helped us with the editing of the online formatting and things like that. And we were able to get it up really quickly.

Dr. Lynn McPherson:

That's amazing. That's a tremendous public service and I'm sure that's beneficial to way more than just special needs children. I mean, I think we're all special needs children during a pandemic. So don't keep us in suspense. What's the website?

Meredith Polsky:

So our website is Ihaveaquestionbook.com.

Dr. Lynn McPherson:

Okay. I have a question book .com. Okay.

Arlen Gaines:

It's a free download. Yep.

Meredith Polsky:

And right when you get to our homepage, you'll see I Have a Question About Coronavirus. Interestingly, you'll see it in a few different languages. English of course, and then Spanish and Greek, believe it or not. And this is really through the kindness of strangers who reached out to us and said, "This would really benefit my community. Can I take a crack at translating it?" And so they worked with us. And it's no simple task to translate a book. And they worked with us to make sure they were getting it right, they were in line with what we had envisioned. Some things are not quite exactly translatable. So they ran those things by us. A lot of it is our own trust. We don't know much any Greek or Spanish, but we think they did a great job and we really appreciate being able to offer those on the site as well.

Dr. Lynn McPherson:

That's wonderful. Well, let's get back to the pandemic itself. Can you tell us a little bit more about grief and loss and the pandemic? I know I'm very happy hiding under my desk. I'm best friends with all the dust bunnies. So, what do you think what's the impact on patients and families, with or without special needs people involved. What are your thoughts?

Arlen Gaines:

Well, I so appreciate this question, Lynn. I just think we can't talk about this pandemic without talking about grief. And of course we have so sadly lost the lives of so many people due to COVID. It was so interesting back in February when we hit the very unfortunate milestone of 500,000 deaths, the National Hospice and Palliative Care Organization put out a really interesting press release saying that for every person who has died, there are nine people grieving. Now I might argue there are a lot more, but this was what they suggested.

Arlen Gaines:

And when you add that up, that means 4,500,000 families and friends grieving just from the people who've died of this disease. So, so much loss, but there are so many secondary losses and this is what we've also seen greatly impacting families, children. Think about even our change in routine, the loss of familiar routine that can be so comforting to all of us. It's hard to think back this far now, but think back to last, over a year ago, to February, what was your day like? How did your morning begin? Maybe you packed your lunch. Maybe you went to work. Kids went to school. Think about all that has been lost over that time. It's almost unfathomable the change and loss in routine, loss of in-person interactions, not

being able to see your teacher and your friends. The loss of touch, not being able to hug a grandparent. For many families, loss of income, which has impacted ability to have enough food. So there is just so, so much secondary loss in addition to, of course, the many people who've died during this time.

Dr. Lynn McPherson:

My husband likes to watch MSNBC while we have dinner. And it's usually during the 5:00-6:00 hour and they always end with a life well lived and they tell a story about someone who died of COVID. So I pretty much cry through every dinner that we have now. And I remember how profoundly sad I was at the holidays. Christmas by Zoom? What's that all about? And Thanksgiving by Zoom. It was just horrible. So I can imagine. So what are some of the social and emotional impacts on children? I'm supposed to be a fully functioning adult, which some days I question, I have to tell you. How about being a child?

Meredith Polsky:

Yeah. I think children have been incredibly resilient over the past year. I think we owe them a lot of thanks and appreciation for just how they have managed to even do as well as they have over the past year. It is not easy. We know many, many kids are struggling in so many different ways. I think one of the really difficult things right now, even as there's a bit of a light at the end of the tunnel, and here in Maryland some kids are finally returning back to school, and all over the country there've been different phases of going back to school. But one of the things that really strikes me is we often talk about how children thrive on routine and knowing what to expect. And this past year has really been the opposite of that, right?

Meredith Polsky:

So we know that separate from a pandemic, we know that none of this is good for children. Not knowing what to expect, not having their sense of routine. And as children go back to school, I think in many ways they felt that even more acutely because we hear stories all the time where a child wakes up one day and thinks they're going to school, but somebody tested positive and now the class is quarantining for two weeks and now it's online and tomorrow it's going to be this. And so, children all over the country are really waking up each morning not knowing what their day is going to look like. And I think that has a profound effect on their ability to just handle day-to-day things and be able to cope with everyday transitions that we might expect them to be fine with like simple transitions throughout the day. But these bigger things are really having an impact on them and their ability to really cope as well as they're usually able to.

Dr. Lynn McPherson:

Well, I know as an adult, and I guess I should be more mature, but when I think about, going back to life the way it was, I have to tell you I'm a little trepidatious about that. Even though I've had both vaccinations, so has my husband, we live in a county where it's a very low rate, but still I'm really kind of nervous about doing that. So I'm sure that's got to be just as bad for a child. Would you agree?

Meredith Polsky:

I would. I think it's a combination, for children, for all of us maybe. I think it's a combination of the health concern, right? We've practiced over the past year plus being really worried about our health and the health of those around us and how we impact each other. But I think there's another thing going on now that we've also all had a lot of practice being alone. We've had a lack of practice with social skills and social interactions. And I think even those of us for whom that comes more naturally, being out of

practice is being out of practice. And for children or adults for whom that doesn't come as naturally, all the more so, it's very difficult to spend a year like this and not practice those skills on a daily basis. And so I think there's the very real fear about health and illness. And then I think there's a very real anxiety around just being out in the world, being around people, interacting in the ways that we were previously expected to.

Dr. Lynn McPherson:

It's even silly things. I don't think I have spent a dollar bill out of my wallet since last March. I mean, everything I buy is online and it's all by credit card. I don't think I've driven 10 times in the past year because I don't really have to go anywhere. So what suggestions do you ladies have for parents and caregivers to support children during difficult times like this such as a pandemic? What do you think?

Arlen Gaines:

Well, it's a great question. And I think it really starts with communication and taking into account the child's developmental stage, where they are at, and really tailoring your presence with them in that way. So we know it can be really, really daunting for adults to be talking about these difficult topics, whether it's death, whether it's a loved one with cancer, whether it's a pandemic. I mean, these are not easy topics for adults. But what we have found is that it can be scarier and almost more anxiety-provoking for children to sense that there are changes going on, but not to be told explicitly.

Arlen Gaines:

So finding ways to use clear, honest language, whether it's about the pandemic or any difficult topic, and parceling out information as they can take it just a little bit at a time, knowing that you'll need to circle back. This is not a one-time conversation where we just present something, that these are continuing conversations. So that's one thing that can be helpful.

Arlen Gaines:

And then really addressing concerns. For children, it's quite normal that they might worry that someone they love might die, or that someone might get sick, and really addressing those concerns and validating them. And in general, just realizing that there are many questions that we have answers for, and there are some questions that we don't. And that is okay too. Just really acknowledging and validating. So focusing on ways that children can feel healthy, or for the pandemic, what are ways that they're staying healthy and contributing to helping out during this time? Whether they're wearing their masks or washing their hands, these kinds of things. So we find that can help decrease some of the anxiety.

Dr. Lynn McPherson:

Yeah. I would imagine that if a child observes one of their parents being upset about something, that could be very disconcerting if they don't understand the backstory. I remember when I was about 12, my mother was making dinner and she was crying and I said, "What's the scoop?" And she said, "Oh they found a spot on your grandfather's kidney." And she was so upset. I didn't want to push that anymore. But I remember thinking, "what does that mean? What does that mean exactly? Does that mean he's going to die? Should I ask her? Should I let this go?" And if she had just explained it to me, I think I would have felt a lot better, even if it was not great news, for example. So was my impression correct? What do you think?

Meredith Polsky:

Yeah, and that's such an interesting example because all these years later you remember it [crosstalk 00:23:03]. Sort of this pivotal moment. And I think you've really hit the nail right on the head. And one of the things Arlen and I always talk about is that when we can help families lay a foundation for talking about difficult things, whether it's because of death, whether it's because of the Coronavirus, whatever the case may be, it's not like this isolated incident, like okay we talked about that one hard thing and it only applies to this one hard thing. No, you're really laying a foundation for that child to be able to deal with other hard things, other transitions as they grow and develop. So I think you're exactly right. How we address these things with our children can have a really significant impact.

Meredith Polsky:

And like Arlen was saying, and like you're saying, Lynn, in the moment, you're almost more worried. You're more anxious because you have all these questions in your head now that you feel like you either can't ask or don't want to ask, or I think of the word spot. To a child, what is this spot? Don't we all have spots? And that would be cause for more concern. And so it's really hard to have these conversations. It's why we've written these books. It's because we don't expect parents to just have all the answers in their back pocket. We certainly didn't have all the answers in our back pockets. But really thinking it through and thinking about how we can help make those conversations a little bit easier to have. It doesn't make them easy. We're not trying to sugar coat things. As you've seen in our books, we're very direct. But to help guide and facilitate those discussions, we think are really important.

Dr. Lynn McPherson:

It almost sounds like you developed a process where parents can help children develop emotional, critical thinking skills, which is so important. So I would imagine that these strategies you're talking about would be useful in all sorts of challenging times.

Arlen Gaines:

Yeah, absolutely. Arlen mentioned a couple of different things about communication. I would also say you talked about our short picture story, our book within a book, as you said at the beginning. And visual cues are something that I recommend all the time for parents and children. It doesn't have to be anything fancy. It can be stick figures, it could be home photographs, whatever it is. And it doesn't necessarily mean that a child has too much trouble processing information orally, but it's another way for them to gather information. It's something for them to refer back to. It's a touch point. It's something they can see and, again, just process in a different way. So we find that to be really, really useful. Even if it's visuals around the possibility that they're going to wake up and their day is going to be different, things like that, or whatever the challenge might be.

Arlen Gaines:

And the other thing we think about a lot, as you said, in dealing with all kinds of difficult things, is to think about the people who have been supportive of the child throughout their life. So when we think about children with special needs, they might have a speech therapist, they might have an occupational therapist. Any child might have a psychologist or a social worker that they work with or a school counselor that they like to visit during the school day. And so we don't want parents to feel that they're in this by themselves. We want them to really utilize that team that they have developed for their child and think about having everybody on the same page. Helping to deliver various messages and helping to understand what might be going on for a child during a difficult time. So really remembering that, you're

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not in this alone. And in the best of circumstances, you have a real support network. I know not everybody has that, but to think about who is in that network for you and your family.

Dr. Lynn McPherson:

Great points. So can I put in a request for the next best seller? How about I have a question about social justice? Or diversity? Inclusion? Equity? Oh my goodness. We have so many social issues right now, don't we?

Arlen Gaines:

We have so much work to do with such an important topic.

Dr. Lynn McPherson:

Absolutely. Well, ladies, I'm so excited with what you've been accomplishing. And thank you so much for your gift to the universe with your book when I Have a Question About Coronavirus. And again, that website is Ihaveaquestionbook.com and I'm sure everybody who's listening will go home immediately and download it. Any last comments you'd like to share with our listeners before we sign off?

Arlen Gaines:

No, just thank you so much, Lynn. We've really appreciated your support, and just such a pleasure to be here and to talk with you on these topics.

Dr. Lynn McPherson:

Well, thank you so much.

Meredith Polsky:

Thank you so much for having us.

Dr. Lynn McPherson:

For sure. Well, thank you so much for your hard work. And again, this is Dr. Lynn McPherson, and this presentation is copyrighted 2021 University of Maryland. For more information on our completely online Master of Science and graduate certificate program in palliative care, and pending approval from the Maryland Higher Education Commission, our brand new online PhD in palliative care coming this fall, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.