

Lynn McPherson: Hello. This is Doctor 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 super excited to have two guests today, Arlen Grad Gaines, who is a licensed clinical social worker with an advanced certification in hospice and palliative social work. She received a Master of Social Work from the University of Maryland, yay, with a specialization in aging. She has worked at JSSA Hospice in Rockville, Maryland, for the past 10 years and has developed a specialization in supporting families who have children with special needs, around death and dying. Her partner in crime is Meredith Englander Polsky, who also has been working at the intersection of social work and special education for more than 15 years. She founded Matan, Inc., I hope I pronounced that correctly, in the year 2000, recognizing a significant gap in the Jewish community's ability to include children with special needs and their families.

And the reason we're doing this podcast today is because these ladies have written a most amazing book and they have fulfilled and unmet need in children's grief and special needs literature by publishing the book, "I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs." It was published in March of this year, 2017. The book was a runaway best seller. It's a number one new release on Amazon in its category in the first few weeks after release and was recently awarded a bronze medal by Moonbeam Children's Book Awards. The next book in their series is "I Have a Question about Divorce", will be released in February 2018. So, ladies, welcome. I'm super excited you're with me today.

Arlen Gaines: Thank you. We're so excited to be here.

Meredith Polsky: Thank you. We're so happy to be here.

Lynn McPherson: Thank you for a copy of your book and I read it a couple of times, actually. I found it very interesting but I guess first, if we could just start off with, what the heck is autism? We've all heard the word. I think everything I know about autism I learned from that new TV show, "The Good Doctor". So, maybe you could introduce the topic for us.

Meredith Polsky: Sure. So, I like "The Good Doctor". I think the autism community, there's mixed reviews, but so, autism spectrum disorder is the name for a group of developmental disorders. It includes a wide range of the spectrum disorder, so there's a wide range of symptoms, skills, levels of disability. So, we always say if you meet one person with autism, you meet one person with autism. People with autism are affected by ongoing social challenges. That includes difficulty communicating and interacting with others. Often times you'll hear about people with autism have trouble making eye contact. They might have repetitive behaviors. They might perseverate on certain activities or interests and it really varies from person to person sort of how it presents and how they're affected by it.

Lynn McPherson: Okay. So, what I'm hearing you say is a person with autism, not an autistic person. Is that correct?

Meredith Polsky: Yeah. So, my training really taught me to use people first language so that a disability never quite defines a person. I will say though that there are plenty of people with disabilities in the disability community who actually feel the opposite. So, I think it's important to represent that viewpoint as well.

Lynn McPherson: Okay. Thank you for sharing that. So, why this topic? What brought you to this subject of autism and grief and why is this relevant?

Arlen Gaines: Well, I've been working, as you mentioned at JSSA Hospice for a number of years and I just noticed over the years that many of the children and grandchildren of the people we were caring for were on the autism spectrum or had other special needs and many of the families were struggling with trying to find appropriate resources and good books to help support them through death and dying and the lack of literature on death and dying for people who are very concrete thinkers really became even more apparent to me personally when my own grandmother died about six years ago and I couldn't find appropriate books on the subject that I felt approached death and dying in a very direct manner for my own kids. Most of the books that we see for children on this topic, as you probably know, use animals as the main characters instead of people, or often use metaphors that are out of reach for children with special needs.

So, I did a lot of research and I discovered there really was a true gap in children's literature on this subject. I knew I needed some help and so I approached Meredith, who I've known for a long time, about collaborating on this project.

Lynn McPherson: You know, I agree with you. I know when my grandfather died, my daughter was four and I was kind of in a tailspin of what to tell her. Should she come to the funeral? How do we explain this to her? And I did turn to the grief and bereavement colleagues that I work with in hospice and they were quite helpful. But what are some other ways in which children with autism spectrum disorder, or other special needs, process grief and loss? There probably is a difference, I would imagine.

Meredith Polsky: Yeah. In some ways there a difference and some ways there's not. A lot of kids would understand, potentially, death a little bit better in really concrete terms rather than in metaphorical terms. But certainly children with autism spectrum disorder, or other special needs, often process information in a very concrete manner. So, as Arlen was saying, commonly used metaphors in ways of explaining death and dying, simply don't work. They just can't make that connection between an animal or an inanimate object and the death of somebody in their life. They may have a lot of difficulty with the abstraction of death and dying. I think it's sort of naturally an abstract concept. Right? We don't actually know what happens after a person dies. We know sort of scientifically

what happens. And the other thing specifically for kids who are dealing with the death of someone in their life, is that their daily routine may be really disrupted, depending on who it is in their life that died.

And that change in routine, that need to make quick transitions, is especially difficult for kids with autism and lots and lots of other types of special needs. They also, something else we address in the book, is that kids with autism may have difficulty understanding and interpreting emotions. Right? They don't necessarily read social cues in the way that other children might be able to and so you might be at a funeral and somebody might be laughing because somebody's telling a funny story about the person who died. Well, that can be really confusing if we're telling kids that death is a sad thing and we're really gonna miss the person and things like that.

And the other thing I would say is that a lot of kids with autism and again lots of other kinds of special needs often process information in a really visual way. So, the more that we can provide them with visual cues for what's going on, the more they'll be able to connect with the information and really understand what's happening.

Lynn McPherson: I like how in the book you say, you use the word die. Grandma died. And instead of saying, "Grandma is sleeping", which I recall learning myself when my grandfather passed away, for my daughter, I can imagine that would be pretty confusing. So, are there any other practical strategies that you can provide parents and caregivers and professionals in supporting children with autism spectrum disorder or other special needs?

Arlen Gaines: Well, absolutely and I think you hit the nail on the head on our big first one, which really is use direct language. We often, as you mentioned, try to soften the topic and cushion it for kids with softer language thinking that we're trying to help. But indeed it really does make it more confusing. And you mentioned going to sleep. But sometimes we'll say, "They've passed away or they're gone or they're in a better place." Even things like, "They live around us in our hearts." Beautiful, beautiful concept but completely confusing for many of these children who are very concrete thinkers. Going back to a little bit about what Meredith was mentioning, we certainly want to prepare these children for the range of emotions both they and other people might be experiencing. So, we might be preparing them that some people might be crying and we expect that. They are missing the person who died. And as Meredith had mentioned, how confusing is it when they see maybe someone's laughing? Well, they're laughing because they're remembering a nice or funny story about the person. So, helping kind of explain some of those things and what to expect.

One of the other really important practical strategies is to think about some of the sensory-based implications as to when someone dies. Everything is mixed up. So many people might be around, it might be loud, there might be a lot of people trying to hug them. Everything is disruptive. So, thinking about what has worked in the child's life previously and incorporating those strategies during this time.

Maybe they need a break in a quiet place. Maybe they need a preferred toy or some sort of fidget. Whatever they might need to help them cope with the sort of overwhelming sensory experience. And then as with any child, thinking about the use of structure and routine. So, thinking again about things that are important in the child's life on a day to day basis and trying to incorporate that routine and letting them know what they might expect and what's going to come. There are different ways we can help prepare a child if they're coming to the funeral, what they might expect to see, what it might look like. So, just thinking about the structure and routine and holding onto that as possible, 'cause it's very comforting.

Lynn McPherson: Okay. That makes sense. When I read the book, and again I've read it several times, I saw that you wrote the whole book, with pictures, but then you re-told the whole book pretty much, with pictures really being the focus. So, the short picture story, can you explain what's that all about and how can this be an effective strategy in working with children with special needs?

Meredith Polsky: Absolutely. So, a short picture story is a really commonly used tool in special education settings and regular education settings. I always say special education is just really good education, so it's a valuable tool for all kids. You know sometimes children need less talking at them, fewer words and a concrete way to wrap their minds around a particular concept. So, for children who may be less verbal or even for children who just want to go back and sort of review the story on their own, review particular concepts. They can go back and really focus on the images rather than sort of the wordiness of a typical book. So, they can sort of be self-sufficient in that regard. Or, they can just read the short picture story with a grown-up in their life and have sort of fewer words coming at them and be able to better understand the concept.

The illustrations that we use, we contracted with a company called SymbolStix and we chose them because the images are specifically not abstract. As you probably saw when you were looking at the book, they really don't leave a lot to the imagination. At the same time, it's not depicted as a boy or a girl or a grandma who died or a grandpa who died. It really, hopefully, leaves open all the various possibilities so that a child can really see themselves in the story and again make it that much more concrete for them.

Arlen Gaines: And I'll just add, as a social worker, I'm always thinking about ways to support people based on their strengths and we know many children with special needs are highly visual and process information best in that manner. So, the use of a short picture story can tap into that strength and support them along those lines.

Lynn McPherson: Sure. And an educator myself, certainly we all recognize that special needs aside, some people prefer to read and learn and some people prefer pictures or verbal or whatever. So, I think it's important to cater to different learning styles. But I think these are all awesome strategies but I can't help but wonder, are they only effective for children with special needs?

Meredith Polsky: That's my favorite kind of question. It's like I said earlier, my belief is that special education is just really good education and if we're implementing tools that will benefit kids with special needs, then we know that those tools will be effective and accessible for all children. We really believe that strategies that work well for kids with special needs enhance the learning of all kids and focus groups of kids with and without special needs have responded well to the book, really appreciating the direct nature and feeling like it answers their questions. I have a daughter who is typically developing and when she was about six, my aunt died and we spent a lot of time talking about it and we were very open about what had happened and for days, she really seemed to be struggling and really thinking about things and I tried to talk to her about it in different ways, tried various books and things like that and finally I said, "What's going on?". And she said, "Well, I don't want to die". And I said, "No, I don't want you to die either. But what are you really worried about?".

And you're gonna laugh, but she said, "I don't think I could stay still for that long". So, this was just maybe a younger child or just a child who does think very concretely and it never would have occurred to me that in the explanations that we were giving her, that was sort of an insurmountable concept and it was really helpful in sort of allowing myself to be in her shoes and sort of recognize how this all sounded to her. We both have heard a lot from early childhood educators, that they were really struggling to recommend books to parents that were accessible to young kids also and so we hope that this will bridge a gap in that market.

Lynn McPherson: Absolutely. I think I'm always, I continue to be surprised when I've not explained something clearly, not only to children, but to adults, how people will fill in with misinformation that can be very alarming. So, I'm sure that may be going on with children as well, particularly those with special needs. Well, ladies, I think you've done a wonderful job here. I think you've provided a wonderful resource for hospice and palliative care programs and all kinds of practitioners. So, I would urge all hospice and palliative care teams to get this book and keep it in your resource library and certainly you can share this with families and I think it certainly fills a unique niche. Ladies, is there any last comment you would like to make about your wonderful book?

Arlen Gaines: We just so appreciate the opportunity to be on this podcast and thank you for all you do and all the good work you do.

Lynn McPherson: Well, thank you.

Meredith Polsky: Thank you, so much.

Lynn McPherson: Thank you. So, I'd like to thank again Arlen Gaines and Meredith Polsky for their wonderful conversation and their book, "I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs", which is certainly available on Amazon.com. Amazon is the bomb. If Amazon doesn't have it, you don't need it. And if I don't buy something every day, they worry I fell in a

hole. So, signing off, this is Doctor Lynn McPherson and this presentation is Copyright 2017, University of Maryland. For more information on our completely online Master of Science and Graduate Certificate in Palliative Care, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.

How did we do?



If you rate this transcript 3 or below, this agent will not work on your future orders