

Transcript: SickKids VS Despair

INTRO

Hannah Hunter is nine years old. She has a little sister named London and a dog named Daisy. She loves skiing and won her club championships last year. She's witty and smart. Her parents joke that Hunter is more mature than they are. An old soul. In June 2021, Hunter was diagnosed with an incurable brain tumor called DIPG. Fairly quickly, there'd be no more ski racing or swimming or even school. She felt stripped of everything in her life. Hunter was old enough to read about DIPG on the internet. She knew kids didn't survive it. Naturally, she started thinking about death a lot. And she had a lot of big questions. Here's Hunter's parents, Courtney and Jiles.

Courtney We got this one every day, am I going to die? Am I dying? What will it feel like when I die?

Jiles How do you know when you're dying?

Courtney What are the symptoms?

Jiles I mean, it's pretty much every question, difficult question that you or I would ask if I had a brain cancer today. And for a nine-year-old to live with those answers, I don't even know how I could live with those answers if I were to receive them, let alone a nine-year-old girl. And it's heartbreaking.

Hannah Around the time of her diagnosis, Hunter and her family were referred to the palliative care program at SickKids. The team offered Hunter an appointment with a Child Life Specialist named Shaindy Alexander, who you'll meet, along with Hunter. A Child Life Specialist is trained to give emotional support to kids dealing with major illness. Shaindy's role is fairly new within the palliative care team, and also unique among children's hospitals. Instead of seeing patients while they're in the hospital, Shaindy comes to their homes or sees them virtually. The idea is to meet kids where they're most comfortable, on their turf, which can make them more open. Hunter is home a lot these days. She isn't well enough to be in school, but she isn't so sick that she has to be in the hospital. When I talked with her, we were in the middle of another COVID lockdown, leaving Hunter with a lot of time to think about her situation. She was angry, sad and terrified to go to sleep most nights. Maybe Shaindy could help. Initially, Courtney wasn't sure.

Courtney It was kind of skeptical of like, I don't know how. You don't know the person is going to come into the family and how, you know, they're going to try to make things better when they're not my family.

Hannah Hunter and her family were still reeling. Her diagnosis was a freight train. It hit them fast and it hit them hard. Courtney and Jiles found it difficult to console Hunter when she broke down. They weren't sure how to talk to her little sister, who's seven. We have a natural instinct to protect children from bad news. When talking about tragedy or death, we shoo them out of the room. We speak in hushed tones. But that can actually be harmful for kids. Here's Shaindy.

Shaindy We think that if we talk about it will scare them, but if we don't talk about it will scare them even more, because then they have to figure it out. They look around, they see, they know, they feel. So they see everybody's sad. And if nobody's saying, 'Hey, I'm

feeling extra stressed because your body is not healing the way we wished it would from the medicine' — if they don't bring the children into that conversation and the teenagers into the conversation, then it's really isolating. And they also have a lack of control of their own experience because they don't know what's going on. And something that can happen sometimes is that kind of protective thing where parents are protecting kids and kids are protecting parents, and then nobody's talking about it. And everybody thinks, Oh, they're fine. They're not talking about it. They're fine. They don't have questions, right? But why wouldn't they have questions?

Hannah So how do we talk to kids about serious illness? What should we say to a sick child about dying when most of us avoid the mere thought of it? The answers may surprise you. And that within the unbearable sadness of death and dying, there is a remarkable focus on living. Welcome to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank and this is SickKids VS Despair.

Hannah [ad] SickKids breakthroughs are only made possible with the incredible support of our donors. That's why we're proud to recognize CIBC as the premier partner of the SickKids VS podcast. The bank and its team members care about making a difference. CIBC has championed SickKids for over 30 years and is the largest corporate supporter of the SickKids Cancer Sequencing Program. CIBC also generously supports SickKids through CIBC Miracle Day and an active employee giving and volunteer program.

ACT 1

Hannah: Shaindy has been a child life specialist at SickKids for 20 years. Here's how she describes the role.

Shaindy We're there to partner with children, with teenagers, with families as they deal with illness or trauma or disability and help them navigate their experience, the system, so that they can be active participants in their care and not passive observers, that they can build resiliency and coping and control and hopefully mitigate some of the anxieties and stress that illness and hospitalization can bring.

Hannah Child life specialists have been a standard part of care at SickKids since the 1980s. And some hospitals had a child life program as early as the 40s. Back then, they were sometimes called play ladies because playing is the main tool of their trade. But that's not to downplay the importance of what Shaindy does. Playing is how kids process their world. And for child life specialists, playing creates opportunity and space for kids to talk. It can be a way in.

Hannah I'm interested in how you start conversations with kids.

Shaindy So I really try to keep the door open instead of getting the door shut to me. So I think a lot of people are worried that I'm going to come in and start disclosing information, or that I might make their kids really sad, or that if their child knows that they're dealing with a serious illness, that they might give up. Everybody deserves an extra layer of support, and especially when you're dealing with serious illness. You know, adults have those people knocking on their doors, be it friends, be it community providers, religious leaders, social workers, health care team but for kids, sometimes it can be super isolating, and a lot of adults don't know how to start those conversations. And so they might be sitting with a lot of their big feelings and questions on their own.

Hannah How can we avoid that?

Shaindy Yeah, it's really important to talk about life and death starting at a young age. And kids will understand it differently at different ages, and they'll have different questions, different wonders, at different times. And so really helping kids understand that that's a normal process and giving them space to ask questions so they don't have to make up answers in their minds because that can be even more scary. Right. And we say really confusing things to kids. We'll say things like they've gone to a better place. Well, what does that mean? They might be like, Oh my God, my brother went to a better place. Well, why can't I go? Right? Why are they so lucky? Why did they get to go to a better place? Did I do something wrong that I don't get to go to that place? Or they might say they're sleeping now. They've gone to sleep. Then they might say, Oh my gosh, well, if I go to sleep, will I never wake up? Right, so it's so, so important kids are so literal. It's so important to use real, concrete, honest ways of explaining these normal life events to kids so that they can learn from it and understand and not feel scared.

Hannah For the last two years, Shaindy has been working solely with patients in the palliative care program, which is called PACT. It stands for the Pediatric Advanced Care Team. You'll notice it does not include the words palliative care. That's on purpose. Here's Dr. Adam Rapoport, medical director of PACT.

Adam I want to be clear for those who understand what palliative care truly is, there is no better term to describe what it is that we do on the PACT team. The reality is that palliative care has sort of become usurped by end of life and death and dying. And that's certainly a part of what we do on the PACT team but indeed, it is really just a small part of what we do. Our main focus is on quality of life, on helping children, helping their families who are going through a difficult time, who've been dealt a very challenging hand, live their best life possible.

Hannah PACT is a largely donor-funded program. Its small team of clinicians are trained in the art of palliative care. They know how to open and guide difficult conversations with families, and they do this by getting to know each family and determining early on what is important to them. What does good quality of life look like for their child? And decisions are made through that lens.

Adam When a child has a serious illness, although we are well-intentioned with our efforts at SickKids and as health care providers, we quickly sort of turn children from people into patients. It's just something that seems to happen naturally. Very quickly, parents and families get sort of sucked into this medical world. They learn the lingo. They talk using the same medical acronyms that we do. They're used to commenting on fluid balances and in and outs and vital signs. And the PACT team is a reminder to these families. Hey, you know, we don't have to stop doing those things, but let's not forget that there's a person here as well. And that we don't have to make a choice between living life and being happy and having fun and focusing on medical care and making sure that we're giving the best health care possible. We can do both together.

Hannah Though PACT patients can often be in hospital, most of the time they're at home. They're in between treatments or they're well enough to go back to school. Or they've exhausted all treatments. Maybe they're close to dying. A few years ago, it became clear to Adam and the PACT team that kids at home needed emotional support. But this help was tougher to find in the community. There aren't a lot of people trained in palliative home

care, especially for children. The irony is that even though there are child life specialists, social workers and psychologists available in the hospital, it's not where patients are most receptive to emotional care.

Adam When kids are in the hospital, they're usually quite sick. That's the reason that they're there, and that often puts them in a mind frame that doesn't allow them to do the psychological work that they need to do. They're just too unwell. They're not looking to get into deep conversations and think about things. We know that the dynamic changes when you're in hospital, you're on our ground, you're in our strange rooms. Yes, we do our best to make sure that those rooms are comfortable, to try to make them your own but we know that there is a power in difference. We know that the hospital is our territory and you are a visitor there. There is something completely different that occurs when you are looking after patients and providing health care in their own home. Suddenly, they're in charge. You get to see a whole other side of things. It really can open up new ways to understand situations and for us to provide optimal care to the people that we're looking after.

Hannah That's why the PACT team created a new role. Someone out in the community attending to the emotional needs of young patients and their siblings. That's Shaindy.

Shaindy Kids aren't like adults. They don't just sit in that grief and that space. I wish there could be a camera on the wall for some of these interactions because they literally can be that quick. They might say, I know one of my parents believes in reincarnation and one of my parents believes in heaven, and I don't really want to be reincarnated because if I'm going to die one day again, I don't really want to come back, so I'd rather go to heaven and just hang out and do all the fun things that I want to do.

Hannah Shaindy calls this puddle jumping. She says kids have a remarkable ability to dip in and out of difficult thoughts. One minute, they're talking about reincarnation. The next they're singing Hakuna Matata.

Shaindy So when they're in the puddle, they can have the same kind of big feelings and thoughts and worries and wishes as adults. And they need support. They need people to sit in the puddle with them and support them. And when they're out of the puddle, they just want to be kids. For adults, when they're dealing with difficult life situations, it's like a river. You're in the river. The river might feel like it's flowing slowly or fast. The water level might feel, it would be high and you might feel like you're drowning. So for teenagers, you're a little bit of both. You're a little bit more in the river all the time. You still know how to jump out of the river and distract yourself and be a kid and be a teenager but it's a little harder to get out of the river sometimes.

Hannah Sometimes kids and teens don't want to talk about their illness, at least not right away. Shaindy recalls one patient who only wanted to play. It took a year of hanging out and building trust until she felt ready to open up.

Shaindy You know, we'd play a card game together and she'd say Shaindy, how do you know that after I die, I won't be buried alive? She wouldn't feel comfortable just asking a question like that right away, necessarily, but as we build rapport, as I'm like partnering in this journey, she knows, Oh, this is something I'm worried about and she has outlet. She has a way to ask that question.

Hannah Shaindy remembers that Hunter was different. From the get-go, she wanted to talk.

Shaindy The first time I met her, she listed all of the things that have changed and how hard that's been for her. And so I asked her, where do I start? Where do we start? And so she picked something off the list and we just dove into it. And she just shared whatever she wanted to share and there were some tears. And then she looked at me and she said, I feel better. And she said, I have a lot of big things in my mind. And it really helps me to talk about them. She is a fierce advocate for her own mental health needs, which is very unique because not all kids are able to identify the fact that it's OK to talk about this stuff, that this is hard stuff. And she knows what she needs, what's really hard and knows how to tap into the help that's around, which is really something that I think we can all learn from.

ACT 2

Hannah When I spoke with Hunter earlier this year, she had exhausted all treatments. The tumor had affected her vision and speech. She could no longer use the right side of her body. She couldn't walk, but she could still read and draw. Courtney was reading her Judy Blume, and they just started watching Beverly Hills 90210 together.

Hannah Can you tell me a little bit about Shaindy and your relationship with her?

Hunter I tell her how I feel and what I want to know.

Courtney What she wants to know.

Hannah She tells you what you want to know? That's so good. So what kind of questions do you ask her?

Hunter How does it feel when I'm really upset.

Hannah Do you find she gives you some really good answers and really sort of helps you understand those questions?

Hunter Yeah.

Hannah What are the kind of things that she says to you that make you feel good?

Courtney She tells you to keep calm.

Hunter Keep calm.

Courtney And that this is normal to feel like this, right. And she gives you activities to do.

Hunter And she's honest.

Courtney And she's honest. Yeah.

Hannah That's so important, right? Because you have big questions and you want answers and you want to be able to talk about those things. What kind of activities do you guys do together?

Hunter We draw.

Hannah You draw? Yeah, that's fun.

Courtney What's her muppet's name?

Hunter Herman.

Courtney Herman!

Hannah We all have stuffies!

Hunter Herman likes fluff.

Courtney Herman likes to eat fluff. You do ton of crafts together, though. Ton of crafts.

Hunter When I'm the artist.

Hannah You're the artist, yeah.

Hunter She copies me.

Hannah That's awesome. That's really fun. And do you guys talk while you're drawing?

Hunter I talk how I feel when I'm doing something.

Courtney They chit chat like friends.

Hannah Shaindy said, that you talk so well about your feelings. And, you know, I think sometimes having somebody to talk to, right, that isn't your family can be so, so great. Shaindy says that you have lots of wonderful, wonderful questions. And do you find it makes you feel better after you talk to her? Does it, does it help you a lot?

Hunter It helps me a lot.

Hannah Yeah, that's so good. What other kind of things do you guys talk about? Maybe things that you never even thought about before?

Hunter I'm dreaming.

Courtney She feels different. She feels like she's on a different planet.

Hannah Before all this, Hunter was an active kid. She was an avid ski racer. She swam. She could do the splits. The changes in her have been fast and dramatic, and for her family, the shock of this has been overwhelming.

Courtney You go into shock, right. You just realize that money can't fix it. Love can't fix it. You just have been like stripped down of everything. And then you pick yourself back up because you have to go forward. Your brain is in fight or flight constantly. It's like, is it, it's not happening, this is happening. No, it's not. It's like an unbearable heartache that can't be fixed.

Jiles And so when people ask me, like, how're you doing? How are things? And they seem amazed that I'm holding it together, I truly just think I'm operating in the third

dimension and I'm quite numb. And I think when the journey ends, whenever that may be that it will be the time I'll fall and crash.

Hannah Has Shaindy helped you at all, as you know, as parents?

Courtney Yeah, I've talked to her many times. You know, I've had my sessions of crying and she gives you really good advice.

Jiles But I'm learning a bit more patience and just how to deal with it and maybe also the honest portion of it. You have to be candid and honest with your children, but there's a maybe a way to do it, and she's kind of showing me the path.

Courtney She's a very good therapist. And we're really grateful that she is helping us. And Hunter loves her and texts her all the time, pretty much every day.

Jiles There is an inherent trust right out of the gates. I think it's her ability, maybe not to sugarcoat anything, but yet responses to Hunter's questions in a delicate way, right. And very sensitive to Hunter and what she's going to. But does it in such a calm and thoughtful manner with emotion and she's patient. Sometimes she'll break when Hunter is crying, asking a question. Shaindy will often just let her have her moment and then help her out of that moment so that she can carry on. And that's a pretty powerful gift because I don't know how to even do it sometimes when Hunter breaks down.

Courtney I've talked to her in my pajamas and coffee, you know, and I'm sitting there crying.

Jiles You don't feel awkward.

Courtney No. It's like you're talking to a friend. I think the home access, I think, is way better than going into the hospital. I just feel like it's a way better connection.

Jiles I do think that it becomes really personal when she enters your private space. And Hunter at home is very comfortable here, so she's readily available, like she's literally like Hunter could be texting her right now, and they could be having a conversation. We don't even know about it sometimes, which is so remarkable and shows it speaks to how comfortable Shaindy's made Hunter, right?

Hannah Shaindy's job is not to cheer up Hunter or make her talk about certain things. She's there to be helpful in whatever way Hunter needs. It may be listening as she cries about the unfairness of her situation. It may be to connect her with a doctor who can answer her questions about dying. It may be giggling about a silly video or having a stuffy dance party. Or just being there.

ACT 3

Hannah A question Shaindy gets a lot is how do you do it? Or how do you handle all the grief and sadness?

Shaindy I think that anybody that's like reading a Facebook post or hearing a story in the news or in passing of a child that's dealing with illness or end of life or has died, you know, everybody's like, I couldn't do it or I don't know how they do it, or they just feel like a lot of sympathy and sadness. And when I'm sitting with kids and teenagers and families, it's

really beautiful. And I don't think people even can fathom that there'd be beauty and resiliency, the love and the life that people can have, even if it's shorter can be so remarkable. I do believe that some of these shorter lives actually have and do have more meaning and quality than some of these longer lives that people have.

Hannah There is something, too, about the proximity to death on a regular basis that softens its edges and brings into sharp relief the beauty of living.

Shaindy I'm not sure why, but we're really scared about talking about death and dying in our culture. A lot of people are, especially when it comes to children and teenagers. I think just from being able to talk to families and partner with kids and teenagers on this journey, is there's so much about life when dealing with serious illness. Most of it's not about death and dying and end of life. Most of it is about living and playing and being, and how to embrace life while dealing with serious illness. And so I do challenge people, like, if people don't want to listen, it means they're really scared about that topic and maybe they do need to listen so that they realize that death and dying, talking about those things can actually help you focus also on life and living because they're so connected.

Hannah Even bearing the crushing reality of terminal cancer and all the anger and sadness that come with that, Hunter has found ways to live, and Shaindy has helped her with that. Together, they hope that Hunter will be the one to survive DIPG. Yes, they worry, but there's always hope.

Shaindy We can always have hope. Nobody has to take hope away from anybody. It's so vital. Hunter told me when we talked last week, I am not letting cancer get in my way. That's what she said. I am not letting cancer get in my way. I said, OK because she wants to live and she wants to do fun things and she is living and she is doing fun things. Of course there's challenges, and she knows that she's dealing with a hard cancer to get better, but she is going to live the best life she can while dealing with these new limitations.

Hannah From SickKids Foundation, this is SickKids VS. Thanks for listening. If you want to support work like this, visit SickKidsFoundation.com/podcast to donate. And if you like this podcast, please subscribe and rate us on Apple or Google Podcasts, Spotify or wherever you listen to SickKids VS. SickKids VS is produced by me, Hannah Bank, Neil Palmer, Jasmine Budak and Gillian Savigny. This episode was written by Jasmine Budak. Sound Design and editing by Quill. Production Support by Ayesha Barmania. For behind the scenes extras and show notes, visit the SickKidsFoundation.com/podcast.