

“Getting Used To it”: How Children and Teens (and their parents) Cope with Cancer

Children and adolescents diagnosed with cancer face months to years of chemotherapy, sometimes including radiation and surgery. These life-altering disruptions place demands on children, teens and their parents.

The diagnosis is usually stunning and unwelcome, followed rapidly by tests, treatments and lots of information. Yet helping children, teens and families cope with this unexpected and unwelcome intruder is vital to physical and psychosocial health.

Listen in as Kristin Stegenga, PhD explores typical patterns of coping among children and adolescents while touching on the role of parent and family coping in these patterns. Ideas for supporting children and teens will also be discussed.



Featured Speaker:

Kristin Stegenga, PhD

Kristin Stegenga is a nurse scientist with a special interest in supportive care research with adolescents and children with cancer and their families. Simply put, her goal in life is that while others cure children and adolescents of their cancer, she will be working to ensure they are in the healthiest place to take full advantage of that cure. She is also editor of the Journal of Pediatric Oncology Nursing and has presented and published on topics related to symptom management and supportive care in multiple venues and journals, both national and international.

Transcription:

Dr. Michael Smith (Host): Today's topic is “Getting Used to it: How Children, Teens and Their Parents Cope with Cancer”. My guest today is Dr. Kristen Stegenga; she's a nurse scientist with a special interest in supportive care research with adolescents and children with cancer and, of course, helping their families, as well. Dr. Stegenga, welcome to the show.

Dr. Kristen Stegenga (Guest): Thank you very much.

Dr. Mike: So, I noticed that in your bio that I received from Children's Mercy, you had mentioned that what you want to focus on is helping children with cancer be in the healthiest place that they can be in to take full advantage of the treatment and the cure. How did that come about for you?

Dr. Stegenga: Well, I like to focus on strengths, actually. You know, I think that we focus a lot of times on the illness of the child and the family, but really they bring a lot of strength to the table and our focus is on their care, so I want to make sure that when we are done, hopefully curing them--the overall cure rate for childhood cancer is 80%; that's not good enough yet, but that's pretty good--but that we have them in the healthiest place when we're done and that includes making sure that they are healthy psycho-socially as well.

Dr. Mike: Yes. Okay, so, let's talk then a little bit about how children cope with cancer. I mean, it's tough for adults, right? So, what does a child go through when they receive that diagnosis?

Dr. Stegenga: Well, initially, just like any child that comes into the hospital, they're scared. They don't really know what's going on and, for younger children, anything that involves a poke is really the worst thing in the whole world, and so, certainly, all of the things that we do to come to a diagnosis of cancer is pretty scary. So, a lot of the things that we do to help them cope are really explaining what we're doing, getting Child Life involved, things like that, to really help them know what's going on to the greatest extent that they can understand. And then, they start to kind of get sort of into the rhythm of the things that are going on here. And, any kind of coping, which really is looking at the situation. "Okay, what is going on?" and deciding what to do about it and kids do that, too. They quickly figure out who their friends are. That's where some of the great things that we have here are so helpful. We have therapy dogs; we've got Child Life; we've got music therapy, but all these things that kind of help them realize that the hospital isn't as horrible a place as when they first got there. And, so, they start to quickly kind of appraise the situation and realize what things they like and what things they don't and they start to kind of process what's going on. One of the most fascinating things that I learned through some of my research is how quickly kids actually get used to this, so it's interesting how we think, as adults, that this has to be absolutely the worst thing that ever happened to them and it's certainly not a party, but they actually get used to it and they actually probably process better than their parents, to be honest.

Dr. Mike: Right, yes. Well, okay, so you mentioned something like therapy dogs as an example. Why don't you tell us a little bit more about some of the specific programs and activities that Children's Mercy offers that helps them to cope?

Dr. Stegenga: Yes. Well, so we have Hunter and Help. Hunter is actually our therapy dog that is for hematology/oncology, and he does a few other things, but he is predominantly for us, and he comes in and he might just give a little love. He might just come in and let the kids pet him; it kind of depends on what the child is looking for, or for some of the kids, interestingly we're noticing--we're getting ready to do another study--he seems to be anecdotally a really great companion for the older school aged and young adolescent boys. He just seems to come up and just hop up on the bed and hang with them and that can be really helpful for them to just have a guy to hang with, so to speak.

Dr. Mike: Yes.

Dr. Stegenga: And, we have music therapy and they do lots of different things with kids that are age appropriate interventions. We're actually doing some research that way, too. We've got a new study that's looking at helping parents and school-age kids 3-8—or, actually that's a little bit younger than school age--with coping with hospitalization and so, then, they also do lots of things that aren't research to just help kids feel like kids. I think it's so important to remember, even in the hospital, even with the cancer, that kids are still kids and teenagers are still teenagers, and probably the biggest thing that we can do to help them cope with this diagnosis is to treat them like they are still kids or teenagers, regardless of their diagnosis to the extent that we can. Of course, there are some things we can't do.

Dr. Mike: Well, I mean, so that was going to be my question. Even in the environment, right, even in the patient's rooms, are they set up differently? Do you allow them to hang some stuff on the walls? I

mean, how far do you actually go with that?

Dr. Stegenga: Oh, absolutely. They're allowed to hang things on the walls--okay there are some things that are not allowed. There's rules about paint, and stuff like that, but we have ways that they can secure things so that they don't wreck the paint, but still are able to make the room look like their own and we really encourage that because it's important for them to feel like that's their room. When they make art here and things like that, we encourage them to display it in their room, and that's the other thing about, one of the greatest thing about being a pediatric nurse, which is my background, is that we get to come in that room and admire that art, and sometimes even help with it, and things like that. You know, really those things--notice the kid in that patient and what their special things are.

Dr. Mike: Yes. And so, I guess, when you hear about a program like yours and you are doing such a wonderful job helping the children cope, I mean, we always want to do something that's better than what we've done in the past, right? I mean, that's what we're always striving for, whether it's treatment, coping, whatever it is. So, what has happened since you have really focused on putting them in the healthiest place, psycho-socially, physically--what kind of results have you seen?

Dr. Stegenga: Well, I think for one thing, even though, of course, as these grand dreams of everything being just better and better, there are incremental steps. So, one of the things that we studied a few years ago was helping adolescents while they're in transplant and they could make a music video with a music therapist, and that research definitely yielded information that said that that was helpful; that that gave them a way to focus on something other than their transplant and gave them a way, as it turned out, to make some meaning of their transplant. They were actually given that music video, mostly because actually it was something that teenagers are into. But, what happened was, we found out that most of them really did focus on thinking about their life and the people who were important to them and stuff, so then that research led to research the parents in that study told us that's great, but now they're opening up these conversations with us that we're not totally ready to have, so that led to another study that actually is just in analysis now. But, how do we have those conversations? So, then, we worked with in the next study, more adolescents and their parents, so we worked with the parents then, too. How do we have these conversations with our kids that can sometimes be tough because some of them don't make it and we have these videos that are so awesome, but now we're talking about really big things with our teenagers, and we want to talk to our teenagers, but let's face it: it's hard for parents and teenagers to talk sometimes. So, that was the next step. So, all of these things are these incremental steps to making life better. So, I know that I can speak for myself for sure, and I think everyone else who's trying to do this kind of work in that we definitely have job security continuing to try to make things better. You know, every step we take is an incremental step in making life better.

Dr. Mike: Yes. So, you mentioned the parents there, so that's obviously an important part of this conversation, as well. We know that and, obviously, this is a huge topic, when we're talking about the coping of parents, kids, and teens, but really they all kind of fit together, right? I mean, at the same time when you're helping the teenager or even the child cope, you must be doing something to help the parents, as well. So, are there programs that are just geared towards the parent who's going to have to deal with some of these tough questions, for instance?

Dr. Stegenga: Absolutely. And, all of this is definitely a team effort. So, as far as research goes, we're

just working on some of those things, but in all of our daily work here at the hospital, we have a wonderful social work staff, too, who's always working with them, and I think that it's important for all of us to remember that they are all interlinked and the fascinating thing, when you think about it, it's such an obvious statement, but everybody copes differently. We just finished a study that was actually educating parents of newly-diagnosed kids and we really discovered that even within a parent diab, one parent would want a whole lot of information about everything, and the other parent was just like, "You know what? Don't tell me. Don't tell me anything I don't have to know. I just want to know the basics." And so it just speaks to, you know, there's a lot of buzz about personalized medicine right now, and I think personalized medicine also encompasses what does a family need to know? And, how does that family cope, and how does each person in that family cope because, giving a one-sized fits all care doesn't work. One parent might want to know absolutely every single thing and they're going to be the one that's going to be looking on the internet and you're going to be helping them recognize what's a good source for information. And the next parent will be like, "Tell me only what I must know to take care of my child, because all of that information is very scary." And then the child, a lot of times we'll have kids that want to know stuff that maybe their parents don't want to know, and we have to negotiate that. So, there's the research aspect, figuring out best ways to do things, and then there's the day-to-day care that we all try to work as a team to give and it's such a big deal to really do right by these families, but also recognize that they are individuals. And sometimes, we have one--maybe it's the parent--that really thinks that things are very hard for their child, and then when you talk to the child, they're really actually fine, it's really that it's so hard for the parent to accept that this is going on for their child. You know, it's really a big deal.

Dr. Mike: Yes, well, and that's interesting. One last question, then. So, when I look at the title of this, it's "Getting Used to It", right? What does that mean? As someone who is really leading the way in helping parents, the families, the children cope, what does that mean to you? What does it mean to Children's Mercy when we say "Getting Used to It"?

Dr. Stegenga: You know what? It's fascinating. I am still learning what that means as a researcher and as a nurse. The kids are helping me understand that, little by little, through my research. When I did my first research study with kids with cancer, the teenagers, every single one in my study, used that exact phrase. They say "Well, you get used to it." And, I said how do you do that? And they all said, "You just do. Little by little, you just get used to this: having cancer." And then, I looked to the literature and a friend of mine at a different hospital had done work with younger children, and they were all talking about getting used to it, too. So, the children and the teens are leading us along, helping us. Because it's such an innate process to them of just coping through this and figuring it all out. They have a hard time explaining it to us, but they just do it.

Dr. Mike: Yes. So, that's interesting, too. So, the end game for a lot of the patients is just getting used to it, but how they get to that point can be very individualized, they can go on different journeys, some may want lots of information, some may want more social connection. There are so many ways to get to that point, right? So, you're allowing them to get used to it using multiple ways, right?

Dr. Stegenga: Exactly. Their endpoint is that they essentially adapt to their cancer but we have to help them find which path is theirs, but in their minds, it happens so seamlessly with the support they receive from their families and us, that they can't actually verbalize the process, but absolutely, that's their endpoint.

Dr. Mike: Dr. Stegenga, what great work that you're doing and the best of luck to you in all the research, and in continuing on this journey that you're on along with the patients and their families. You're listening to Transformational Pediatrics with Children's Mercy Kansas City. For more information, you can go to www.childrensmercy.org. That's www.childrensmercy.org. I'm Dr. Mike Smith. Thanks for listening.

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