

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Strap on your Oxygen Mask First: Being a Parent with Cancer'***

#### **Description:**

Join us as we speak to Dr. Meredith Hemphill Ruden, who had an informative session at CancerCon on Parenting with Cancer. Meredith is a licensed clinical social worker, 13-year Melanoma cancer survivor and Executive Director of the Feather Foundation. In this episode, Meredith dives into the challenging topic of being a parent while dealing with a cancer diagnosis and treatment. After becoming a social worker following treatment, she started to notice that there weren't as many resources to help parents who had cancer. To combat this shortfall, she started The Feather Foundation, a nonprofit organization dedicated to supporting parents throughout their cancer journey. This episode highlights the importance of making self-care a priority and how to find hope as a family while dealing with cancer.

#### **Transcript:**

**Edith:** Welcome to *The Bloodline with LLS*. I'm Edith.

**Lizette:** And I'm Lizette. Thank you so much for joining us on this episode.

**Edith:** Every year Stupid Cancer holds an annual conference for young adults affected by cancer called CancerCon. In this conference, patients, caregivers, and healthcare professionals all join together and participate in various panels, workshops, and engaging social activities.

Today we'll be speaking with Dr. Meredith Hemphill-Ruden who had a very informative session called Parenting with Cancer. Dr. Meredith Hemphill-Ruden is a licensed clinical social worker, Doctor of Social Welfare, and is the Executive Director for The Feather Foundation, a nonprofit organization for parents who have cancer. She teaches within the social work program at New York University and has acted as a guest editor for the *Clinical Social Work Journal* for a special issue on social work and

healthcare and contributed research and writing on the topic of hope-centered work with cancer patients.

Welcome, Dr. Ruden.

**Dr. Meredith Hemphill Ruden, DSW, LCSW:** Thank you for having me. Hi, guys.

**Lizette:** Hi. Welcome.

**Edith:** Now before we get into today's topic, Parenting with Cancer, we want to get to know a little bit about our speaker, and we definitely like for our listeners to get to know them as well. So, what led you to your profession in starting The Feather Foundation?

**Dr. Hemphill Ruden:** That is such a great question, and it is sort of a winding road for me. I decided to go back to school for social work. I thought I wanted to work with kids. It helped me then actually through difficult situations which relates to what I ended up doing and am doing right now with The Feather Foundation.

And as I was preparing to go back to school, I actually got a diagnosis of melanoma, so skin cancer. I remember it very vividly finding out the news. I was actually with my dad on a vacation and my siblings. And at the time, I was trying to understand what lay ahead. It sounded like I didn't have a lot of information to begin with and so for about a week before I found out more and just found out next steps, I was wondering really what this meant. And afterwards too when I got the surgery that I needed to get done I started to see the need for adults who are going through cancer treatment needing additional support and counseling to get through something difficult like coping with cancer.

Now in my case, I had the surgery, and I didn't need any follow-up care except for meeting with my dermatologist every six months. And I have been cancer free for over ten years. But as I was going back to school and thinking about the help I wanted to provide and the impact I wanted to have, I started to think about working



with people who have cancer, and I worked in a hospital through my schooling. And afterwards I worked in other hospitals and cancer organizations.

And through that I noticed the different needs. At first, I started off with this idea just generally speaking of I just want to learn more. Place me wherever you will within a cancer center, in an outpatient environment, you know, when people are getting chemo or radiation or inpatient. I'm just a sponge. But I started to notice that there were definitely some areas that were more covered and there was more support in some areas where not, and that could be by a cancer diagnosis, that could be by your circumstance coming into the cancer center or the organization.

So, one thing I noticed, and I have been thinking about continually since that time and since that beginning is what's available for parents who have cancer? So not just the kids who are dealing with the parents' diagnosis. And there was actually some support around that. I was lucky to find great organizations like Klein and CancerCare had some support for kids helping them talk about their parents' cancer diagnosis and also work through some of those thoughts and feelings around it. And it would often involve the parent, but the parent wasn't necessarily the focus.

And mulling over those thoughts for many years, I eventually became a parent myself. I now have a seven-year-old and a five-year-old and it just communicated to me all the more, gosh, here I am thinking a lot about my children's welfare and how I can be the best possible parent I can be, most attentive I can be, and I am stressed by the everyday things. What must it be like for somebody who on top of all of that is going through cancer treatment, who is concerned for themselves, and, of course, and this is something I've heard again and again from parents who have cancer, they weren't just concerned for themselves, concerned for their kids because so much of getting through this the focus is not just about oneself but how we as a family are going to get through this? So that was the beginning of The Feather Foundation.

I was fortunate along the way to work and be friends with a lot of wonderful people in the cancer care space, and some of them really supported me as I started to think about this idea of creating The Feather Foundation. And, it doesn't mention cancer because it's, it's named after an Emily Dickinson quote and poem about hope. So, we're all about hope for parents with cancer and the quote is, "Hope is a thing with feathers that perches in the soul." So, we think that's a really important message to help families find hope through this cancer thing.

So, anyway I was very fortunate to have friends and colleagues who supported the idea I had to focus on this group that came together and have a commonality that isn't type of cancer but it's the fact that they're coming to cancer with some extra stuff, some extra stressors. And that board now is, part of The Feather Foundation. Those friends many of them are on our board and I'm, we're so fortunate to have that big a case. We have an oncologist, my dear friend Michelle Myers. We have people who have been working in other major cancer organizations, and they're all these wonderful people who have this combination of personal and professional experience.

**Lizette:** Wow, I love that quote and it's really interesting how you named your foundation. That's great.

**Dr. Hemphill Ruden:** Oh, thank you.

**Lizette:** On our *Bloodline* home page, we have a quote, and it says, "After diagnosis comes hope." So, I think it's very important that all of us are really trying to get together and let people know that there is hope.

**Dr. Hemphill Ruden:** Absolutely, there is. I'm very direct about what that hope is. when I say hope, it's not necessarily hope that just, of course, we want to get through this wholly bodily and, you know, be able to say, "That cancer thing was in my distant past," But I think as a secondary thing an area to focus on, it's hope that your family and you can get through this emotionally and be stronger. So that's a hope too. It's

not just hope that cancer will be in your past shortly, but it's also that you will be able to walk away from this feeling like it is a victory emotionally for you and your family.

**Lizette:** Definitely.

**Edith:** Also, congrats on being cancer free for ten years!

**Dr. Hemphill Ruden:** Oh, thank you. It's actually 13 years I realized. I can't believe how the time has flown. Yeah, it's interesting how it's changed when after this time. It does feel like a long time ago, but also every time I go back to the dermatologist, I kind of get thrown right back to you know, wondering if I'm going to have something that they need to test or biopsy? So, it's something that, you know, I'm still getting used to in a way even though it's 13 years ago.

**Edith:** Of course. So during the virtual session that you had in CancerCon, you mentioned that according to the American Cancer Society in 2016 about three million children live with an adult with cancer in the US, which to me is very overwhelming and I can't even process how overwhelming that might be to a parent. So, what advice do you give to parents when they have to explain a diagnosis to their child?

**Dr. Hemphill Ruden:** Well I think I mentioned that, that number just to communicate that you're not alone and it is more common than you think. I think we think of cancer often as something that is for people when they get, older and that just isn't the case. And there are, unfortunately, a lot of kids living in households where there is a cancer diagnosis.

When I talk to parents about this, it's important to remind them that there are people like them often trying to make the best of a really difficult situation and they might not yet know that there is a community out there for them. So I think at first it's, that's part of the mission of The Feather Foundation actually is to say, "We see you and you're not alone in this". We don't assume because, because historically parents haven't said, "Listen, let's talk about this issue." We don't assume that we know

everything there is to know about the complications associated to being a parent with cancer, but we're here to give some helpful guidance and also learn from the parents.

So, what do we say to parents who have cancer? We say to them, "Take care of yourself first. Make sure that you're adjusted to your diagnosis as much as you can be in the early days. You don't have to rush from hearing that you have a diagnosis to working out what you're going to tell your kids."

Having said that, you know, we do suggest that if you have things coming up like an appointment for treatment and something's going to change in your routine pretty quickly, then you want to keep your kids informed. And then there are all of these other pieces to consider at that point. What do you say to your kids? And that depends on their stage of development, what you know they understand about cancer. Maybe they've known someone who's a family or a friend who's had cancer. You can think about what words to use. Some people actually use the word cancer, some don't. It's certainly easier if you use the, the word that they might hear elsewhere attached to this. But certainly, if you have a four-year-old and you think that you know what, it's not needed right now to use that word, you might decide not to. When you decide what to talk to them about, you remind yourself that you're the expert on them. What do you think your kid can handle and how can they handle that?

And, you know, I think about my two kids and I would say they are very different in how I would communicate to them when they were at the same age. Having said that, though, I also keep in mind that if I were to tell them something like, "I have cancer," they will be talking to each other, so I would have to find something that worked for both of them to talk about. I don't know how I'd talk about that.

And then parents with cancer often want to know how to deal with tough feelings that might be attached to the news that their, kids are hearing that they have cancer. But I often remind them, "Actually, you know what, you can normalize it. You can say, 'It's

okay to be sad or mad or worried,” but often that doesn’t come up in the first conversation. Often, it’s just the basic information that you provide, and you try to connect it with changes and things that matter to them. So, it might be, you know, you’re preparing for chemo and you might be losing your hair. Well that’s a change that might matter to your kids, a change in your appearance, so you prepare them for that. So, you kind of think about what could be important to them.

And then the other thing that might be, of course, is very important for them is just to let them know that you’re here to talk to them, that you’re here to support them, and that, in terms of you being the parent that supports and loves, nothing has changed. And I think that’s really important to communicate in some way too. So that’s often-what parents with cancer come to me talking about.

But I’ve got to say what they don’t ask for is also really important, which is the piece on self-care for them. Really making sure, because they probably along this road will be facing some additional stress, that they are prioritizing their health and well-being, and I mean their emotional health too, and giving themselves permission to take breaks. To not try to replicate the kind of parenting they were doing before cancer, which might mean that they don’t do all of the school drop-offs or in this case, in the pandemic, you know, all the oversight of remote learning or things like that. Why? Because they need to give themselves the best chance of getting through this with rest and strength and also a reserve of energy should bumps come up in the road for themselves or for their kids and family.

**Lizette:** Sure. And I just wanted to go back and really commend you on really saying, you know, “We see you,” and actually providing this kind of support for parents. You said that there was a lot of support out there already for kids and children and usually that’s what we think of. And especially as a parent, usually you always think of the children first. But actually, knowing that that parent also has support needs I think that’s very important.

I know that, you know, in the cancer space, we've been talking to patients all this time trying to provide them with so much support and most of the time we haven't really provided the same type of support for their caregivers. And now is when we're recognizing that, oh my gosh, our caregivers are also going through this journey. And, unfortunately, they've been overlooked for so long, and we're trying to provide that support to them. But you actually coming out and knowing that the person with cancer really needs that support at this time, not just as a patient but as a member of the family, like you're describing.

**Dr. Hemphill-Ruden:** Right, I mean basically what you're saying is, "Here is the unique situation," but it's really true where you're dealing with someone who's a patient and a caregiver at the same time.

**Lizette:** Yeah. And I know that, Edith, you told me that during Meredith's conference, you had said that Meredith cited the airplane, when you're on an airplane.

**Edith:** Yes. She said, the same thing that airplane rules have, which is you strap on your oxygen mask first and then you strap on the child's. It's a great metaphor for parents and me who's not even a parent to understand.

**Dr. Hemphill-Ruden:** Yeah, I'm so glad you brought that up because it's really, I think, right up there with one of our biggest messages at The Feather Foundation is that you need to, trying to redefine what a good parent is in this situation and saying, "Here is a situation that if you don't help yourself get through it, like the oxygen mask, right, where if you don't put the oxygen mask on first, you're going to pass out and then your child can't get theirs on. So, it is a way to make sure you both have the best opportunity to get through something that can be a crisis.

So I use that all the time because I think with this kind of crisis, this kind of issue that you're dealing with when you have cancer, I think there's a little bit of a feeling that, you need to put the kids' oxygen mask on first because you need to make sure they're okay. And certainly, as a parent I totally understand that. I remember even watching



that little video in the airplanes where they said put yours on first and like there'd be this little surge of that just feels wrong. What about this kid who is in distress who is right next to me possibly?

But it makes more and more sense as I think about the situation for parents with cancer. You know, it just doesn't, it can't in the long term be good for the whole family unit if a parent say is running from chemo and is exhausted and feeling so sick just to pick up their kid from school and so doesn't have a chance to rest and rejuvenate. And yet I think that's happening all over the place.

Or even more, drastically, making decisions about one's care based on what works for childcare. First and foremost, it needs to be to make the best decisions for your health and your own well-being in order that in the long term this can be something that, is done with and kids are resilient and can be moved on from. I mean and I know we only have control of so much, but that's the best shot of getting through something like a crisis like being in the airplane where you need an oxygen mask.

**Lizette:** So as a parent, how do you work through that guilt though because you feel so much guilt that you're going to take care of yourself before your child, and you want to take care of child before yourself; their needs before yours. How do you work through that?

**Dr. Hemphill-Ruden:** That is such a good question. It's such a good question and it's so hard. I don't know if there's a simple answer to this but let me give you some ideas. One thing I notice is there's guilt because there's a feeling almost like you're responsible for your child's difficulty. And I want to say really clearly your child, even if they're upset and mad and worried because of your cancer, you did not cause them that pain, you did not cause them that upset. So that's something that I think is important. It's not like you made it your plan to do this. You are both struggling through something that has happened to you.

So even if your kid is dealing with tough feelings around this, please remember that. I think that's a really important point 'cause then they'll listen. And there's no guilt. You can feel empathy for your child for going through something difficult, but it's not something that I would argue, sort of unfairly to yourself, you know, and in a way that doesn't give you the kindness you deserve, are saying to yourself, "You're to blame." So, I think that's important.

I think it's important, again, to have this community that tells you and reminds you it is okay to prioritize yourself in this situation; and it's not even okay, it's needed. I know you guys one of the questions you had for me was about being a supermom or dad 'cause that is something that I mentioned also in this talk at CancerCon. I talked about what does a great parent look like when you're going through cancer. And, actually, we mention in The Feather Foundation being a supermom or dad to kind of shift the thinking from you have to do it all, to it is okay to not do it all. And so, the quantity of time, quality of time to tell parents with cancer remind them again and again, "It's okay to say, 'I can't do more.'" In fact, sometimes that's the wisest move.

So, in one of the tips sheets we have for The Feather Foundation, we actually go over what does being a super parent with cancer look like? It looks like taking care of yourself. What else does it look like? It looks like actually thinking ahead and maybe getting some other people on board to help your kids get picked up from school and go to soccer and do all the things that they normally did. So, you're not just, doing it by yourself, but you are being the essence of a good parent there because you're making sure your, your kid has it. And it doesn't have to always be provided by you and sometimes it can't be provided by you.

So I think in terms of dealing with the guilt and processing the guilt, it sometimes comes down to hearing a totally refreshing and different view, which is, you know, "Please don't do it all yourself, please say no sometimes to some of those old parenting responsibilities you used to put on yourself, get other people on board, and focus on

quality of time with your kids and making that attentive, loving experience rather than every moment of the day trying to provide everything for them.”

**Lizette:** Sure. And you mentioned before that every child is different and, you know, that’s how you would speak to your child about cancer, you know, really trying to figure out what’s best for each child. I know that some folks don’t feel comfortable telling their children that they have cancer. So, is there a right way or a wrong way or is it really dependent on somebody’s situation or, or the personality of your child?

**Dr. Hemphill Ruden:** I’ll be honest, to begin with, I followed a lot of the literature saying, “If you can, use the word cancer and do that as soon as possible.” And I really thought that was the best way to go about it because it, it got rid of ambiguity and avoided situations possibly in the future where maybe your kid is in class and another child mentions, you know, something that they’ve heard, that they, you know, and says the word cancer for the first time. Something like that. So, I thought I could avoid possible situations in the future.

Having said that, I have spoken to more and more parents about seeing the other way. Like thinking about their child’s associations with the word cancer and whether they, might have a negative association with it and, therefore, they just want to talk to them about their treatment more and the goals of their treatment. So, them thinking that this allowed their child to process and understand their cancer without using the big C word.

And, you know, I think there could be a reason to not use that word. You know, maybe you have a fairly early stage diagnosis, and, frankly, part of your self-care is wanting to focus on your own ability to get through this. And if you know that your child is grappling with something that all of a sudden, they think is bigger than it in fact is that will make it harder for you. So that can be an argument for talking to them but maybe talking to them really about the logistics of care and not talking about the diagnosis in medical terms.

so that is what I mean by knowing your child and what they can handle and what they need. But I think it's important to also acknowledge that part of this decision-making mix might be your own feelings and, and adjustment to the new, the word cancer and your, and your grappling with that and your comfort with that. So making sure you're not making a decision for your child based on your own, you know, totally understandable difficulties with coming to terms with your own diagnosis.

**Lizette:** Sure. And also, the child's age has a lot to do with how much and how you speak to them, correct?

**Dr. Hemphill Ruden:** Oh yeah. You know, if you have a 3-year-old, They may not even understand if you give them a lot of information upfront, but they certainly will notice if you lose hair or if you have a mastectomy; something that's a physical change. So maybe that's the information you share with your 3-year-old. If it's a 15-year-old you'll give more information, you'll give more context. So, yeah, age matters a lot.

You know, understanding matters a lot too. If you have a precocious 5-year-old, you know, even though the, another 5-year-old might not want to know medical jargon, your 5-year-old might want to. So, age does matter, but it also matters, you know, sort of what you understand about your child and what they'll want to know and truly anticipating it as best you can.

However, having said that, you can't anticipate it all. So, to a certain extent, you have to go with the flow and just be ready to answer those questions that they might have. So, it's useful sometimes to have in your mind an idea of what you will talk to your kid about and how you will navigate questions and even rehearse that beforehand. I think that's always a really good idea but also you have to be a little bit prepared to think on your feet because it might be a week or two weeks later that you get that question that you were expecting the first time.

**Lizette:** Sure. And what if as a cancer patient, as a parent, you're in the hospital away from your child, or with blood cancers, there's many patients that get stem cell transplantations that maybe have, may have to be away, how do you still stay connected to the rest of the family?

**Dr. Hemphill Ruden:** We actually have a tip sheet. And we actually have a tip sheet on this at The Feather Foundation's website, [thefeatherfoundation.org](http://thefeatherfoundation.org), and it's about staying connected, exactly what you said, while in isolation. And it is really, thank goodness we live in a time of FaceTime and all of that you can stay connected to a certain extent. You can't be with your kid in person, but you can certainly talk to them, throughout the day. And maybe you can even talk to them not even like a phone conversation downloading your day but watch a movie with them via FaceTime, so to have that sense that you're with them and you're present there. So, you can stay connected that way. You can write each other notes and letters. You can, ask to be part of just the news of the everyday things in their life. You could send them little care packages of some sort. You can read them a bedtime story. So, I think you could create rituals, either new rituals or you can repeat old ones even remotely and that's a way to stay connected for sure.

But it's totally a, understandable that you might feel regardless, disconnected from your child. It's not the same as being in person. And to that I would say, "It's normal, it's understandable. Acknowledge it, feel those feelings, and know that this will be something that you will go through and can be a chapter in your life and in your child's life that won't at all define sort of your sense of connection with them overall." So, I think that's a fear, like that you feel disconnected and that feeling of disconnection will continue on. No, this might be something that just is for now and it is for now for a good reason.

**Lizette:** Sure. And I know that you mentioned some of the questions that you hear from, from parents. Are there other common questions that you hear?

**Dr. Hemphill Ruden:** Oh, my goodness! there are so many questions about really how to talk about bodily changes, a lot of questions about those, you know, and preparing for things like hair loss and mastectomy. There's a lot of questions about how to describe to a very young child that the reason for the hair loss might be actually because the medicine is doing, it's job and to explain that bodily changes don't actually mean you're getting sicker but actually might be getting better.

And to that I would say there's some great children's books out there. You can just look online to check them out. There are ones that give great analogies that help explain how it can be that something that's medicine can make these changes in your body but are a sign that the medicine's working. And I think that's really sort of, that's a common misunderstanding young children have that parents ask me about. So, I have it about, questions about that.

I have questions about also if your cancer gets worse. So, you prepare your child for a one round of treatment and your doctor says unexpectedly another one's needed or even just that your cancer has advanced. How do you then have this conversation again with your child and say, "Actually things have changed"?

And to that I would say it's the same sort of thing. First of all, how are you doing? How are you feeling about it? I love this Mr. Rogers quote, "Anything that is mentionable is manageable." So put words to it. Say what's going on if you, if you can because when you put words to it, you give it the potential to be manageable.

**Edith:** I love that Mr. Rogers quote. Like he's truly.

**Dr. Hemphill Ruden:** A wonderful human being.

**Edith:** So, we covered a lot in this episode, but is there anything you feel we didn't cover today that you think is important for our audience to hear?

**Dr. Hemphill Ruden:** One thing that I'd like to also mention is I think anybody who is going something like cancer treatment and is a parent will feel, and it's

understandable, is that their cancer diagnosis and treatment will mean that there are losses that are incurred with sense of connection with their child or there will be bumps along the road. So, there are challenges and there are losses that happen if you're a parent with cancer.

But one thing I want to mention also is I think there's a huge opportunity to grow as a parent and for your children to grow here too. And how does that happen? It's just simply in really focusing instead on trying to do it all but actually thinking a lot about how to be attentive and for your child right now. Think about your child as an individual and what they need.

Sometimes in the busyness of our lives, we don't think about that kind of stuff. But when it comes down to it, I think that's what's most important, so it might be something that really makes you focus on that quality time in a way you haven't done for a long time and in that way you can grow together. So I just think it's clear that I have that hopeful outlook that The Feather Foundation's all about, but I really do believe that it's not just about losses and challenges; there might be something beautiful that comes out of this as well.

**Edith:** Thank you. Very well said. And thank you, Meredith, for joining us today and sharing your expertise with us and our listeners.

**Dr. Hemphill Ruden:** Oh, you're so welcome. Thank you for having me.

**Lizette:** Thank you so much. Appreciate it.

**Edith:** For more information about The Feather Foundation, please go to [www.thefeatherfoundation.org](http://www.thefeatherfoundation.org). And for those who would like more information about LLS in general, you can contact our information specialists Monday through Friday, 9 AM to 9 PM Eastern Time by calling 1-800-955-4572 and they can provide support and educational information.