**Strength in the Storm: A Mother’s Journey Through Her Child’s Cancer Diagnosis**

**Narrator** 00:03

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**Dr. Bill Evans** 00:20

welcome to the cancer assistance podcast. I'm your host, Dr. Bill Evans. And today we're going to be talking about childhood cancer. And we have a guest who's had the personal experience of childhood cancer and has gained more experience by talking to others. And that's Samantha Taylor, and we're welcoming Samantha to our podcast today. And just before we get into our conduct conversation, I'd like to remind listeners to the cancer says podcast that is brought to you by the cancer Assistance Program here in Hamilton. And the cancer Systems Program provides a variety of free services to cancer patients, and include free rides, some free parking, equipment, loans, things like wheelchairs, emulators, commode chairs, nutritional supports, and incontinence supplies and a number of other important supplies that cancer patients may need. And these podcasts are actually made possible by a generous donation from the Hutton Family Foundation, and we're most appreciative for their support. We bring you these podcasts, both to educate people about cancer and its treatment and the supports that people need. And this is particularly relevant today when we talk about childhood cancer, something we haven't talked about a lot on prior podcasts. So I'm really happy to be doing this podcast today. With a Samantha or Sam Kelly, she goes by Sam. So a good place to start is just maybe a little bit about you and how you even got involved. Well, how cancer affected you because one of your children actually had cancer and I gather is going through treatment and is doing well. And which is good to hear. Yeah. But then that's opened the door to more conversations with people who are also experiencing children with cancer. So that's

**Sam Taylor** 02:00

right, our daughter was 10 years old in 2022. And she was starting to get this small little bump on her left cheek. We didn't think much of it. But it was growing and changing size. And we thought all right, you know, take her to her doctor, and we'll see if this is something to be concerned about. No one was concerned, her health was perfect, very, you know, energetic, she's plays on every sports team, like just a picture of health. So you're never going to connect the dots in that direction. But this bump kept to growing and changing. So she didn't like the way it looked. And we took her to a plastic surgeon and he removed it more for cosmetic reasons, as opposed to

**Dr. Bill Evans** 02:44

anyone think he was cancer, not at all. And

**Sam Taylor** 02:47

a couple of weeks later, we went back for just a routine checkup to see how our scar was healing. And he did one of those. Hey, Mom, can I talk to you out in the hall for a sec. And it was in that moment that something shifted. And as a parent, as any parent, I think will, will relate the air in the room changes. You don't know why, but an energy shifts. And you almost feel this like sinking sensation. And so he brought me out in the hall and he said Your daughter's biopsy came back a little questionable. We've sent it off for some extra tests. He didn't use the word cancer. But you just know something is not right.

**Dr. Bill Evans** 03:28

You're just trying to break the news to you sort of gradually, I guess you did unless

**Sam Taylor** 03:32

he was a plastic surgeon. I mean, this is not his domain whatsoever. Never before he had to he had to diagnose a pediatric cancer. So this was new for all of us. And a couple of weeks later, we got a phone call from him again, that it was rhabdomyosarcoma a soft tissue cancer, mainly found in children. And he had already set us up with a team at SickKids. And away we went. So we began the process very fast. So many layers to this process, which I'm happy to talk about whatever you want there.

**Dr. Bill Evans** 04:03

What was your initial reaction? And perhaps what was your reaction compared to your husband's reaction? Yeah,

**Sam Taylor** 04:08

great question. You know, I use this example a lot when it comes to a parents diagnosis story. It feels like one moment you are living on land, you are in your normal life. You are breathing air, you are communicating with your friends, your family, you speak your language, everything is very familiar and comfortable. And then within a split second you are thrown into the bottom of the ocean is what I compare it to where you can't breathe. You can't see you can't swim, you can't function you are completely at a loss and it's this fracture that happens so quickly. It takes families quite a while to adapt to their new surroundings. And this fracture or to me is very interesting because the way we respond to it, and what we do when we're thrown into the depths of the ocean is different for everybody. Yeah, and I think we can learn a lot from each other with how we've all learned to navigate it. But that's what it felt like it was a, it was a visceral feeling, it was a terror that I can't really put into words. It's a nightmare. It is like truly a nightmare. I mean, the word cancer has such a stigma, which, of course, you know, I mean, this is what you you have devoted yourself to as well. So, you know, the impact the word cancer has on a family that

**Dr. Bill Evans** 05:38

we sort of expected, perhaps in advanced years, you know, it's kind of, as you get older, there's a risk that you're gonna get cancer, and it's still a shock. But when it's your child, you don't really think about cancer, a very

**Sam Taylor** 05:51

primal thing happens, right? And you just, I equate it to like an armor just kind of like to kind of protects you. And we, as parents, I do believe we all have this, this reservoir of of strength that we don't really know exists, until our child is at risk until something scary has happened to our kids. It's that famous story, you know, parents who lift up a car when their child is stuck under it. It's that strength, right? And I think we don't know we have that strength. But we all do. So a lot of times when you're a parent carrying your child through treatment, you get told from everyone, you know, I don't know how you do it. I don't know how you do it? And the answer is, well, you could do I have nothing design different or special about me at all, I just have access to this reservoir that you don't know yet about.

**Dr. Bill Evans** 06:43

So to some extent, you have to do it right for your child,

**Sam Taylor** 06:47

you have no choice, you have no choice. And that's part of that feeling of being thrown into the ocean, it's that you are now in a role. You want nothing to do with you know nothing about you don't want and it takes a while before you have to just succumb to it and get on track get swimming as essentially what you have to start doing get swimming, because, you know, you have to save your child.

**Dr. Bill Evans** 07:12

So what does swimming look like though? Yeah, great

**Sam Taylor** 07:15

question. For me, swimming looked like reaching out to as many other families as possible. I'm an external processor, my husband is an internal process gonna

**Dr. Bill Evans** 07:25

ask you about the difference. So talk about the external processor first,

**Sam Taylor** 07:29

for my Oh, for me, I needed to connect with other families instantly, it was very important for me to get context. What's it like down here in this ocean? What What are we supposed to do? How do we? How do we look after ourselves so that we can best support our kids? How do we deal with this excruciating pain and fear and terror, so that we can give everything we have to our child while this is also simultaneously going on inside of us? So there are lots of things you can learn from other families who, who have gone through it. And for me, that was the first thing to do was to connect with other families?

**Dr. Bill Evans** 08:07

Did you find these other families where other people you could connect with it? So children's hospital first? Or did you reach out on the internet?

**Sam Taylor** 08:13

What's interesting, the hospitals don't really have a system in place where they connect families, there are a few OPAC is excellent. OPAC is a group within some of the hospitals in Ontario, where parents can come together. But I found that the hospital environment was very siloed. Like every family was kind of in their room. And it was tricky to connect, because also we're all in these horrible, horrible places like no one's really in the mood to chat when their child is so ill and suffering. So it needed to be outside of the hospital environment. For me, it was really just pounding the pavement and reaching out to my community to find out if there was anyone who had pediatric cancer in their in their lives. There weren't many, but it was a start. And then I met some families and then they knew families and they knew families. So we grew this community very organically. But it took a lot of effort. And I think for people who don't have that external processing, ability, it, it would be too much work. It's a lot of work to do that. So yeah, my husband was the internal processor, who needed to just be head down. Let's do this one step at a time. Let's follow the treatment plan and pray to God we get to the other side.

**Dr. Bill Evans** 09:33

This sounds like the way men approach things.

**Sam Taylor** 09:37

Yeah, it's very common. I definitely don't ever want to stereotype or generalize, but it does seem to be the trend. Yes, the

**Dr. Bill Evans** 09:45

key person here is the child with the cancer. So how do you talk to your child and you know, what were those initial conversations like when you get a diagnosis of rhabdomyosarcoma over the phone after that conversation out in the hallway with A plastic surgeon, that child's 10 years old, they're reasonably aware and understand complex issues. And then somehow you got to communicate why did the doctor take mummy out to the home? Or why did you What did you hear on the phone call? And how did you deal with that?

**Sam Taylor** 10:16

And this is a great question. And there, you know, because of my daughter's age, you're right, she was mature, she knew what was going on. This wasn't a two year old with leukemia, this was a 10 year old, who was very aware of what was going on. So to be completely honest with you, we, we stressed about it for a while, you know, a couple of days, we had a couple of days until our appointment at SickKids. And so Oh, my gosh, we agonized. But to be honest with you, what happened was this, we sat her down, and I just opened my mouth, and words came out, and there was no way to possibly prepare, or write a script, or plan how you tell your child that they have cancer. If anyone does know, please let me know. I would love to hear how you did that. But for us, it was something we just had to cross our fingers and hope the right words came out based on how we know our child based on our relationship and the language that we knew that she would understand. Right? So we were we were factual. We didn't use words that, you know, we're, we use the words we said cancer, we said rhabdomyosarcoma, we said tumor. We said, chemotherapy, we said hair loss. We didn't know at the point at that time that we needed radiation. But we ended up having to go to Florida for radiation for a couple of months as well. So that original conversation, though, was devastating. It was a horrible, horrible moment in my life, I'll never forget it. The look on her face is burned in my brain forever. She knew right away what the gravity was of this diagnosis. And her first instinct actually was to get up and go for a walk by herself. It was August, it was warm, and she didn't have shoes on. And I just remember saying, okay, yes, do what you have to do. And I watched her from our living room window, just leave the house and walk barefoot through our neighborhood. And, you know, for our daughter that felt very appropriate. That is how she processes things. She needs to go and be alone and move and be with nature. So we were happy that she knew to do that. But then, of course, the conversations don't stop, right, they continue. And every single time we had to have a big scary talk, I just did the same thing. I cross my fingers. I opened my mouth, and I hope that the right words came out?

**Dr. Bill Evans** 12:59

Well, I think the general recommendation is just to have those open, common calm, honest conversations, and then a level of language appropriate for the age of the child. Right? Absolutely. So if the child is you know, two years old, and not going to have the same level of comprehension as a five year old and not the same as a teenager, and for each of them requires a different level of sophistication, I guess in the conversation, more detail. But and also anticipating different reactions. That's interesting, your daughter's reaction of an older teenager might react with anger and upset and much more outward expression of their emotions. So I think one of the issues is if there's an uncertainty here, you can't really anticipate but you have to be honest and, and not try and camouflage. What you're, what the gravity of the issue is and what they're going to be facing. Otherwise, they won't trust you in the future. Exactly.

**Sam Taylor** 13:59

Exactly. And it's interesting, use the word uncertainty because, you know, look, it lifestyle was uncertain. We never know what's going on. Right.

**Dr. Bill Evans** 14:09

But I don't tend to think that way. Exactly. We think we think we can

**Sam Taylor** 14:13

make plans, you know, what's that saying? Man plans God laughs Right. Like, we we are under the illusion that we do have a set idea. We make plans for you know, vacations, we make Christmas plans, we make summer plans months in advance, and we're used to doing that. But when you get a diagnosis of cancer in your family, the word uncertain, really takes on a new meeting, because everything is now officially out of control. You don't have control. You don't know what outcome and it forces you to really live in the present moment, which I'm not saying there are silver linings. I'm not a silver linings person. I will never say, you know, yes, my daughter had cancer, but I learned some grit, no one I take back all the great things I've learned because of my daughter's cancer just for her not to have cancer. Yeah, of course. Of course I would. But the fact is, when you have a diagnosis in the family, the lessons that you learn about life and about relationships, and about what really matters are some of the most important, valuable, profound lessons, I think that we can learn. And that is why I wanted to open up these conversations so that I could have them with other families, other parents, and learn about what profound important lessons that they took away from their experience with their child's cancer, because, you know, we have all been forced to look at life through a whole different lens now. And not all of its bad.

**Dr. Bill Evans** 15:47

So I want to get into that in a moment. But before we we go there, just tell me a little bit more about sort of the trajectory of her illness. And then, because there's sort of stages of, of an illness and reactions and difficulties you encounter as a family coping with those stages. I don't know whether she spent a lot of time at hospital. If you're living out in the middle, somewhere along the Lakeshore, I guess and traveling into Toronto, which is a big pain to try and do. So there's a lot of challenges of commuting and time commitments. And that totally changes your schedule. And so what did that trajectory of illness look like? And how did it impact you? And a corollary question, maybe too much to ask one simple question, but had another child. Yeah. So that's another issue. You're trying to manage a family not just one person with an illness or managing a family. So yeah. Can we delve into that a little more is?

**Sam Taylor** 16:49

So yeah, very layered, very complicated. But I think the short answer to that question would be, you are suddenly living in a very reactive state, you can't plan like I said, there's no planning, you can't be proactive at all. It's everything is reactive. So we have an appointment, we go, we have a symptom, we go, we have a fever, we go. So you're constantly waiting for the next shoe to the next, you know, thing to happen. But to answer your question more, in terms of her prognosis, she needed eight rounds of chemotherapy, 20 rounds of radiation, and she had five surgeries in total. So this all took just under a year for her treatment. And like I said earlier, the type of radiation that she needed is proton therapy, which we don't have in Canada. So Sick Kids sent us down to Jacksonville, Florida, where we spent just under two months for her radiation. Excellent experience, by the way, it was, it was you know, it was bittersweet, let's call it you know, there was a lot of wonderful and a lot of not wonderful. And then we returned to Canada after her radiation and finished up chemotherapy here. So she was not she was not impatient, except for times when she would get a fever. And we'd have to, of course, go to the hospital. And she'd be admitted for that. But she was able to be an outpatient patient, and we would go once a week for chemo. And the rest of the time. Manage life, like I said, very reactively that included raising our son as well. Our daughter didn't go to school at all for the entire year. So my husband and I, I wish I could say there was some kind of formula or some kind of like, great schedule that we figured out but absolutely not. We were we were just flying by the seat of our pants with our daughter's health as the driving force. So whatever she needed, We accommodated and anything else just would either fall by the wayside, or we'd figure it out or our incredible community. Well,

**Dr. Bill Evans** 19:12

you're gonna ask about that. Because, yeah, first of all, you can't just ignore the schooling for her. Totally. So she didn't go to school for that time, or you didn't communicate with what did you do with the school system, he must inform them that she was ill and couldn't attend, and so on so forth. We can't ignore your son's schooling. So he's got to stay on schedule and presumably stay in activities that he enjoyed, I mean, sports or whatever extracurricular activities that maybe you would like to be involved in? What happened to those things.

**Sam Taylor** 19:44

We bubbled the four of us bubbled and explain bubble. We didn't care about anything else, except for LEDs.

**Dr. Bill Evans** 19:55

So the whole family Correct? Yeah. 20 or so that's all in the same team. That's right. Okay,

**Sam Taylor** 20:00

so yeah, of course school and activities and social and life, those things are all very important. But nothing is as important as her health, nothing. Right? So when that becomes your focus, everything else becomes sort of what do you what can you fit in here? So our son did continue school, except when we went to Jacksonville, he came and he was part of that experience with us. Absolutely. I can't imagine leaving him at home with who, you know, friends that know like he needed to be part of this with us, we did it together. And she needed him there. And we all gain strength from each other. So we were enormously privileged, enormously privileged to be able to go as a family to Jacksonville, we do not take that lightly. We are very aware of how lucky we were to be able to do that. Many families can't. So when it came to her school, no, we really didn't. We tried. I tried tutors here and there. But it didn't matter. You have one focus, and it's your kids health. And like I said before, your lens completely changes. Regular childhood stuff does not apply. When a cancer diagnosis is in the family. It just doesn't to us anyway. So I know a lot of families who do try to keep their kids active and engaged in in school, and the siblings the same, we just didn't, we couldn't, it was too much on our plate to figure that out as well, when all we cared about was her survival. So

**Dr. Bill Evans** 21:36

I guess it's just different strategies for different families, what works for them?

**Sam Taylor** 21:41

Well, it's the same with anything cookie cutter, nothing's cookie cutter. Right? Nothing's cookie cutter

**Dr. Bill Evans** 21:45

as you do in the time between our treatments. So it's weekly treatment. So you got, you know, six days, what do you feel? How do you feel that time and as a family supporting her like, what's it look like? Well,

**Sam Taylor** 21:58

she was really sick, you know, she was really sick. So most of our time was focused on her care. And it was all consuming. It wasn't just like, we would go for chemo and come home. And then you know, play video games, like it was a full time job. She also because like we've said, was old enough to know it was going on, there was a whole mental health aspect to it as well, that I was not prepared for I had no clue what to do. So I again, with my external processing, brought in a lot of different therapists, and, you know, people who could support her emotionally and mentally as well, her her hair loss was a big, big, big problem, big problem, I would say, for her, she would look back probably on this experience, and say that it was the toughest part. Because again, at that age, being othered is very painful and hard to make sense of. And so we had a lot of work around that for her for, like I said, for her mental health and her attitude, needed a lot of work. So cancer is a all encompassing experience, I think when it comes to a child, and you can't predict how it's going, what the ripple effect is going to be. But like I said, you just react. So what would happen on a Tuesday would be what happened on that Tuesday, what would happen on a Saturday would be that Saturday, there was no planning. But as I was saying, our community was incredible. So we had a ton of support as well from friends and family that made the experience a lot more. I don't know, smooth,

**Dr. Bill Evans** 23:48

maybe smooth, but maybe more supportive or helpful. Guys, or read about these things, you see that, you know, encourage people to kind of make up a list of things you need a shopping, taking someone to an appointment, whatever to try and offload yourself of trying to do everything and you give yourself a break because one of the things that happened to parents is they get overwhelmed and exhausted physically, mentally. And unfortunately, sometimes that leads to a schism in the parents, you know that two different approaches and not a few divorces have occurred over childhood cancers. Absolutely.

**Sam Taylor** 24:23

Well, what I found happens is that parents get through treatment and it's when their child rings the bell that they start to fall apart and that they start to crumble. And this seems to be the pattern so like I said that reservoir of strength carries parents through their treatment, not always but it's quite often you are working at a level of like hyper your your nervous system is just shooting your fight or flight you are all systems go And then when your child is starting to God willing, come back to their, you know, I'm not gonna say normal because there's no such thing as normal after a cancer diagnosis, life is completely different. But as your child starts to discover their new existence and their new place in the world, and their health starts to improve, that's typically when a parent, you know, in my case, it was like a fetal position, complete collapse, not knowing how to function for quite a while because it destroyed me, it completely wiped me out, carrying her through that it was a really difficult experience, that

**Dr. Bill Evans** 25:41

you've clearly bounced back. So I appeared back, I made this judgment, but you seem to be full of vitality, and you're certainly not in the fetal position.

**Sam Taylor** 25:52

I'll tell you, though, I needed to be in the fetal position, I needed to go into a pretty dark place to begin a healing experience for myself. And part of that healing, like I've said, has been to reach out and talk to other parents about their experience and how they've also come through this. And I haven't met one parent yet, who hasn't spiraled into a very dark place. Usually after their child's treatment, and no one talks about it. No one addresses it. Caregivers are typically not brought into the conversation, because the focus is and should be all on the patient. No one's debating that. Of course, it should be. But the caregiver has a very important role that requires a certain level of support as well. And I really want to be someone who starts that conversation. Well,

**Dr. Bill Evans** 26:46

it seems absolutely essential because of the health of your daughter and son are dependent on a healthy parent, or parents. And if the marriage falls apart, or, or your solo, emotionally traumatized that you're not an effective parent going forward, then that's going to negatively impact the growth and development of your child. So when you think about holistic care, it really means we do have to broaden it out to support and help for the parents. And as you say, I it's not something I've ever heard anybody expressed before, before today, and I didn't read about it either, in kind of preparing for this. So I think it's a very important points you're making to bring up now. Just a couple of questions. Just to wrap up about your daughter's situation. I gather, she's recovered physically from the treatments and how far out is she now? And is she doing well? And physically and mentally? Yeah,

**Sam Taylor** 27:41

thank you. She's a year passed out of treatment. We are still in a three month scan cycle. So she goes for an MRI every three months. And we will do that probably for the next three or four years. And then when she turns 18, she'll transition into the adult program. So cancer is still part of your life. And it is still, you know, something that will always be in our midst. But yes, she's doing well. She's back at school. Her hair is growing back. She is starting to be just a regular, I guess we call them tweens. She'll be 13 in September. And it's been it's been very helpful to see her health improve. It takes an enormous stress and anxiety off of my husband and myself. So she's doing well. The care we had was incredible. Absolutely incredible. I am so grateful. We live in Canada. I'm so grateful that we had access to sick kids, I would drive 10 hours if I had to, you know, we were lucky enough to be close. But it was a phenomenal, phenomenal experience on the medical side. We were very, very lucky. Yeah. Oh,

**Dr. Bill Evans** 28:55

good to hear that. She's doing well. And so she continues well, we're going to take a brief break here. So heavy conversation. Probably need a break, but we're gonna hear a message from the cancer Assistance Program and we'll be right back with Sam Taylor.

**Narrator** 29:09

We'd like to take a moment to thank our generous supporters. The Hutton Family Fund and Banco creative studio who make the cancer says podcast possible. The cancer Assistance Program is as busy as ever, providing essential support to patients and their families. We remain committed to providing free services for patients in our community including transportation and equipment loans, personal care and comfort items, parking and practical education. These services are made possible by the generosity of our donors through one time gifts, monthly donations, third party fundraising, corporate sponsorships, and volunteer opportunities. Visit cancer assist.ca to see how you can make a difference in the lives of cancer patients and their families.

**Dr. Bill Evans** 29:51

We're back with Samantha Taylor talking about her experience of having a child with cancer and as you've heard from the first part of this call recession. It's a really rough road. And in her case, in her husband's case, they just lived in a bubble and focused entirely on their child and drew their one other child into that same bubble bubble and just focused entirely on, on trying to get your daughter well. But that journey, being rough isn't just physically rough. It's mentally rough for family and mentally rough for the child. And maybe you can talk about how, how your daughter experienced those mental challenges and what helps where they're actually available. And if there weren't, what did you do about it?

**Sam Taylor** 30:40

So, you know, obviously, a cancer diagnosis is a medical, it needs medical attention, right. So the medical system was excellent. Like I, like I said earlier, her physical care was excellent. But there wasn't really a bridge that took us into the same kind of support when it came to her mental health. It, it doesn't, it doesn't fully exist. I don't expect it to exist within the medical framework, because they're doing their job. And as we know, a lot of these different, you know, ways to support a person, they don't all communicate there isn't really like a system where, you know, mental health, physical health, emotional, like they don't all work together. So we had our physical health checked, great. But it became very apparent to me during my daughter's treatment, that she needed mental and emotional support as well, as did I. But of course, like I said, She's the priority. So how did I support her? There are some excellent, excellent therapists who are who are also in our, in our area, they're local, who support kids. Ice I reached out to wellspring. Wellspring is a fantastic Cancer Support System. And they provide pediatric oncology support, not only for kids, but also for parents free, you get a couple sessions with this unbelievable therapist who can get you started on a bit of a path to make sense of what's going on. So I sought that support. And while spring also does a parent, a peds support group for parents as well. So that helped for me, I had to find private support for my daughter, who wasn't really open to talking. My daughter's cancer was something that she was actually very ashamed of it embarrassed her. Like I said before it other had her so much. So she really struggled with seeing her friends and being with her friends. And that was part of the reason she didn't go to school because there was just so much shame around this illness. Again, did

**Dr. Bill Evans** 33:02

she feel shame about it? Like was this because it's on her face and visible in surgical scar? And so it wasn't something you could easily I perhaps it part

**Sam Taylor** 33:11

of it, for sure, yes, she has a big scar on her face now that she will always have and she had to wear this like horrendous wig that looked ridiculous on her. And she was aware of that as well. But again, you know, it, we have to go back to that age, right. And I remember it very, very well. I remember feeling like anything that was different about me, would be like, there's the spotlight all of a sudden, and everyone would be staring and I would be so insecure and so uncomfortable. And I mean, I think every teenager had something that they feel was, you know, really difficult to process about their childhood, whatever it is, in this case, le le shame was about it being different. And also, you know, being sick having an illness. I think at her age, she thought it was something it was something that was wrong with her like it happened to her like, maybe she thought people would think it was contagious. Maybe she thought people would want to not want to talk to her because they could catch cancer. Two kids don't have conversations about cancer. It's not something that we have brochures about in you know, the classrooms, so no one really knew it was going on, but

**Dr. Bill Evans** 34:23

you think perhaps she'd done something wrong, because that's exactly right off. 100%

**Sam Taylor** 34:27

And why wouldn't she? You know, we don't grow up having conversations with our kids about anything like this ever happening. So this huge big bomb drops in your family and we're all struggling to figure it out. And when all the focus is on the physical, the mental and the emotional gets sort of forgotten about but because therapy for me has always been such a vital part of my life. To me. A therapist is like a trainer at the gym. I just have never not had one I think It is so important to have a therapist the same way you would go to the gym the same way you work out your mind. I mean, it is they go, they're completely aligned to me. And so it was a natural response for me to find someone for my daughter to speak to. I wasn't the right person for her to talk to. I was struggling with my own, you know, stuff at the time. So I found a woman who lives in Burlington, and she has about 25 years in palliative and bereavement. And all in the cancer world, she worked at Princess Margaret for years. She's a social worker, and she works with kids. And she was instrumental in Ellie's, Ellie's making peace with what was going on in her life. She used a lot of art, a lot of drawing a lot of painting a lot of ways to express her feelings that way, and really just sat with her. I was not in the room. This was all between my daughter and her therapist. And it seemed to really help. It also helped for parents to have some kind of a dialogue as well with their kids. So I needed to be trained on that as well. And I needed to learn a whole new way of communicating with her that would draw out these big feelings that I knew she had inside.

**Dr. Bill Evans** 36:23

Can you share some of that? What are some of those learnings? What do you need to communicate to your child?

**Sam Taylor** 36:29

And it's a great question. It all, it's always age dependent, right? So you really do again, like need to know what your child's language, what language they understand. So in my daughter's case, and in my daughter as a person, right, they're all so different. But for my daughter, what mattered most was just having me physically near not talking all the time, just being there. So that she felt if she wanted to talk she could. So that meant I was not sitting on my phone. It was I was not, you know, in the kitchen doing something I was present with her lying with her massaging she had a ton of neuropathy from one of her chemos it gave her extreme pain. So I would just really sit and I would massage her feet and her legs, and we'd be in silence. And sometimes just that physical connection that she felt calmed her a lot enough to get to a place where she could open up about something that was eating her up inside. She didn't always have the words for it. But together, we would articulate what some of these feelings were. And I got that guidance from the therapist as well. So, you know, we were really it was like Wild West, to be honest with you. I didn't know what I was doing. She didn't No one knew what they were doing. But we worked together with very basic primal skills, touch, love, presents, you know, food, she didn't, she had no appetite, of course. So getting food into her was impossible. So I made it part of our time together to come up with food that she could eat, and I would help her, she would help make it and we would make it sort of I don't want to say game. But anyway, we came up with things we could do together, that were very simple and basic that would calm her butt. It really was it really took an enormous amount of attention to be able to navigate it.

**Dr. Bill Evans** 38:25

I'm sort of thinking you're a very proactive person. And you had the experience, I guess of having use therapists over time. So it was kind of a natural thing. But the vast majority of people I don't think would be absolutely fine to do that right. And points, really a shortcoming of the health care system. It's not a physical care system. It's meant to be a holistic system, to help people who are maybe struggling with a physical problem that but has psychological overtones and issues that have to be managed as well. And it just sounds like a terrible shortcoming of our system that we don't do this part better, particularly for children.

**Sam Taylor** 39:03

I completely agree. I also do want to mention that we did have the support of Pogo, the pediatric oncology group of Ontario, we had an interlinked nurse who came to our home. And she provided great resources that were not only for Ellie, but we're also for my husband and myself. So one of the one of the resources that she provided us was wellspring. And there's other things that families can access. Pogo is free, you are entitled to an interlinked nurse if you're in Ontario. And if there's a family who is looking for support, definitely reach out to Pogo, they will send someone to your home, which by the way, is like a total gift. And this person is a nurse, she knows the medical side, but also knows all of the different resources available to a family, which Yeah, there aren't a ton, but there are some and I think It's slowly growing, because this awareness is of course increasing of the need. And

**Dr. Bill Evans** 40:04

you've become a resource to families, I gather through your podcasts and tell me a little bit about how that grew. It sounded like very organic. Gradually, more and more people are gravitating to you and to the podcast to share their experiences.

**Sam Taylor** 40:18

Yeah, I found that a lot of families after treatment, do one of the few things a lot of families get on the fundraising train, so they run marathons bike, Athens, they, you know, do all of these different types of ways to raise money for their child's type of cancer or for pediatric cancer in general. There's parents who, you know, create things and sell them. And there's parents who get on boards of groups, I mean, parents coming through treatment, have this urge to give back and it's not for their children, their children already have cancer, it's for the kids yet to be diagnosed. It's like we have this, you know, obligation almost to help the families yet to be in this club, the same way that parents have been helping people like us for years, right. So there's this need to give back. And it is a deep, deep seated need. So I had it. As soon as I got out of that fetal position. My first inclination was okay, how do I give because, of course, let's not forget that that feeling of giving back is also, you know, a huge healer. And it's a wonderful way for us to mend our wounds as well, right? So what am I good at? am I great at marathons? No, am I great at Vika Don's node. And so I had to come up with what my way of what I was good at and what I could do, and so not sure if you've picked out but I love to talk to people, I love to have conversation, it is something that really fuels me. And like I said, during treatment, it was a very lonely and isolating place for a parent, I couldn't talk to my friends, what are they going, they just all would look at me and cry. I didn't have a support group who knew this language. So I thought, well, let's create one. And with the families who I slowly were piecing it with piecing together during treatment to reach out with I thought, you know, let's record these conversations. I'm sure there's families out there who will want to hear them as well. Because I don't know about you. But one of the greatest ways that I have found to heal is when someone else is explaining or expressing the exact same thing that I'm feeling in that moment. And I go, Oh, my gosh, me too. And all of a sudden, I feel connected. And I don't feel so alone anymore. And so all I wanted to do was have conversations for parents out there, the internal processors who don't know how to, you know, tap on shoulders in line at the pharmacy and say, hey, you know, does your child also have cancer, which I did many times. But, you know, for the parents who don't know how to articulate the parents who maybe their English isn't their first language, or this isn't the country that they were born in, and they don't have the community, they don't have people to turn to. I wanted to have conversations, where they could listen to them and go, Oh, my God, I'm not alone. And so that's how I started the podcast.

**Dr. Bill Evans** 43:18

And so how many families have you engaged? No. And are they all these external people? Or some of them? Great.

**Sam Taylor** 43:26

Great question. You know what it started out with? Mainly external processors, the moms who really liked to chat, and parents, sorry, I shouldn't just say moms, dads, as well, everyone, we've talked to everyone in a family. But after a few episodes, I started to get emails from the really quiet ones, the parents who are sitting currently bedside, in a hospital room with all the beeps and all the noises and their child is sick beside them. And they've just listened to an episode. And they write me and they say, thank you for that conversation. I have never felt more seen or more witnessed. I want to share my story too. But I'm really nervous. And I'm really scared to do it. I've never opened up I've never shared, but I now feel compelled to do it. And so with those families, those parents, we usually have a couple conversations just as first. And we kind of draw it out of each other. We come up with what they'd like to share, and then we record it. So to answer your question, it's everybody. Everybody has a story, right? And I also just want to make something sort of clear, talking about childhood cancer all the time. Sounds like it would be a really sad conversation. Right? And it would be I mean, it is a very sad conversation, but that's not what the podcast As the podcast is what we do how we respond to our child's having cancer. And that's when stuff gets interesting, right? Because now we're talking about all of the different brave and courageous ways that parent is lifting a car off of their child, right? And those stories are endless. And that's where I think we can really connect the most is to hear, Oh, how did you do it? How did you do it? How did you do it? And now suddenly, it's that old ritual of people sitting around a fire, talking about their life experience, cancer becomes something in the background, it's now talking about human experience, which to me is the most fascinating thing we could talk about.

**Dr. Bill Evans** 45:40

Well, there may well be people listening to this podcast, who are the quiet ones who haven't stepped forward yet, but it would benefit from having a conversation with you and perhaps a future podcast. So here's an opportunity for you to do a shameless promotion for your podcast tell us how they would get in touch with you. What's the name of the podcast? Where is it available to listen to,

**Sam Taylor** 46:01

it's called the deep sea, the letter C, not S, E. A, the letter C, the deep sea podcast. Of course, like I said earlier, it is based on that feeling you get when you're thrown into the depths of the ocean, and you need to learn how to swim. So the deep sea is, I think, a place where we all get from, and you can find the podcast anywhere, the same places we can find your podcast. And you can find me by emailing me at the deep sea podcast@gmail.com I have an application process that's in the works. I've typically been communicating with every family myself, but that has become its whole own full time job, which I adore. And I love but I know there's a way to manage it a little better. So please reach out. We also have an Instagram account that I post all of the upcoming episodes on so you can get an idea. You can hear a little clip, a little blurb about the episode coming up. And there's a lot lot more to come, the month of May will all be brain cancer stories, because May is brain cancer awareness month. So you'll hear from different families whose children have come through brain cancer. I have two parents who are bereaved whose children passed because of brain cancer. And we talk about the incredible ways that they have integrated the loss and what they've done with it.

**Dr. Bill Evans** 47:21

As a man I'm interested to, you know, bring in a male perspective how your husband process things that was much different than yours. I'm imagining it was but I'm just guessing you can

**Sam Taylor** 47:33

listen to our episode because I have one with Him, actually. And he will tell you that he was he felt like it was his role to be the stoic, strong. Like I said, before, head down, let's get through this role. But what was really interesting was that he was our daughter's most physical support. He was the hand holder, he was the head stroker. He was beside her for every poke every injection. Every chemo long chemo day, he was the one beside her holding her hand endlessly. While I was the one out there, trying to make sense of what was going on meeting all the right people talking to the right doctors, and so on. So he kind of encompassed all of the roles I think that a parent could could really encompass for a child. And he was incredible. Yeah. Look, any parent would do it. Right. Any parent would do it. We all have this very primal need to keep our kids safe and healthy, and nothing will stop us nothing. And my husband would say the

**Dr. Bill Evans** 48:50

same. Great to hear. And you're both doing well together. are both doing well together. Yeah. Also good to hear. Thank you. Now I'm doing the podcasts. And this would be my last question. Maybe what are the top three things you've learned from having these conversations with others who've had the experience of a child with cancer?

**Sam Taylor** 49:12

I'm going to tell you the top thing, because it's really important number one, two, and three, it's one, two, and three. The darker the dark, the lighter, the light, the darker, you go into the pain and the terror and the fear. That's where you then get access to the lightest light. And what I mean by that is, you can't know one without the other. And when I said earlier that there were silver linings about a pediatric cancer diagnosis. What I meant by that was you get a new lens on life, and when you've been to a really dark place, you then bounce it into a really bright place. It does come. And I think the main conversations, the main topic of conversations that I have with families, bereaved families who are in relapse, families who are ne D, whatever stage you are on your cancer journey, every single parent will tell you that the new lens they have sees more light in the world than ever before. Nothing, all the silly stuff goes away all of the nonsense, all of the noise disappears. And suddenly, you are living a rich, meaningful life. Now, I do not mean for one second to say that those rich, meaningful lives don't also include grief and pain. They absolutely do. But with that deep pain also comes deep joy, and they can't exist without each other. So that is something that I've learned from every parent that I've spoken to. So we come out of that fetal position, we don't stay in it. And we actually come out of it with a whole new way of looking at life. That is, for some of us, quite beautiful.

**Dr. Bill Evans** 51:10

That's a great way to conclude, you've provided not only the practical ideas about how to cope with this terrible situation of a child with cancer, but some really deep wisdom. And I think that's going to be incredibly valuable for people who listen to this podcast, to whom this topic is relevant. And I know there are people out there who will be relevant to so I really want to thank you for for sharing that. And also, just to remind our listeners that you can listen to this podcast or prior podcasts to cancer assistance program that we've done, covered a lot of different cancers, a lot of different supports that cancer patients can benefit from, whether it's a physiotherapist, a Child Life Support Worker, librarian, we've covered a lot of different topics, but take advantage of these things. Because I think information and other people's experiences can really help you through the difficult journey of cancer. So I just want to thank Samantha Taylor for this wonderful conversation. I think it's really been, as I said, wise and very helpful to those who are approaching what is a very, very difficult time in their life when the child has cancer. So thank you very much, Sam,

**Sam Taylor** 52:19

thank you so much. Thank you.

**Narrator** 52:24

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