



How to get the best help from your medical team when your child is first diagnosed with cancer

Laura Lane's interview with Dr. Geoff McCowage, Part 2
Episode # 9, Hope, Strength and Courage Podcast – Full Transcript

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Thank you for tuning into the Hope Strength Courage Podcast. Love and support for parents whose kids are fighting for their lives! A weekly podcast created to support parents and caregivers of children diagnosed with cancer, where you will find resources collected to help you face each day with Hope, Strength and Courage. From interviews with the top experts in their fields: doctors, psychologists, chaplains and inspiring frontline workers in paediatric oncology as they share their best advice, as well as day to day advice collected from other cancer moms and leaders in personal growth and development. From individuals who understand how hard it can be, I hope you will feel better prepared to cope with the day-to-day challenges of caring for your child. Hi, I am Laura Lane, and I am your host. My own daughter Celeste was diagnosed with cancer at the age of 12. In 2015 I wrote about our experiences in the book "Two Mothers One Prayer: Facing your child's cancer with Hope Strength and Courage". Since that time, I have dedicated thousands of hours to share with other parents and caregivers the resources, tools, tips, skills and strategies I learned that helped our family to stay happier, healthier and more hopeful. My goal is to share with you my interviews with experts to support you as you care for a child with cancer.

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Thank you for joining me this week for Part 2 of my interview with Dr. Geoff McCowage. Dr. Geoff is a paediatric oncologist at the children's hospital at Westmead in Sydney, Australia. He is a principle investigator for clinical trials within the children's oncology group. He has a particular clinical interest in neuro's oncology and sarcomas of bone and soft tissue. He has been an attending paediatric oncologist for twenty years. As Dr. Geoff, he hosts a podcast that is aimed at parents of children with cancer. Please join me as we continue our discussion on how to get the best help from our medical team when our child is first diagnosed with cancer.

In this part of the interview, I had asked Dr. Geoff, what was his best advice for parents and he talks about the importance of resilience and patience and the fabulous resource he put together for his patient families by creating his podcast "*Understanding Childhood Cancer With Dr Geoff.*" I hope you enjoy this interview as much I did.



Dr. Geoff: What else would I say? Well, so now we're going into this we're not feeling guilty we're not feeling angry except at the universe or God or something, or this lightning bolt that's hit your child. We're embarking on this big program. Well, what I would say is that treating childhood cancer is pretty all consuming, and if you can sort of believe me on that at the start, that'll help. You know, I think that just plan on your life being totally messed up this year probably. It may be a bit shorter; it may be a bit longer depends on the disease, it's going to be totally messed up. But it won't go on forever. I'd remind you that a lot of people have been down this path, people get through it, you know. People who are, you know, highly trained intellectual professionals, people who are regular people in regular jobs, all sorts of people, you know. They get through it, you know. The team's there to help. It is manageable. It might be a terrible time; it will probably be a terrible time. It won't be terrible every day. There will be moments of joy, moments of relief, there will be better days and worse days. So, you know, I think its best if you can adopt a mind set both, you know, we've got this mission to complete. We're going to get our child through chemotherapy. Think of it as a big project, a big mission. Think of it like an Olympic athlete thinks about those mixed Olympics, and you know, yep, I'll go to the movies sometimes, and I'll go out for dinner but it's a single-minded focus on that. Think about big exams. You're sitting to become a, you know, something at college or university, and think about it that way, this is this is what you're about for these several months, and you know, don't buy Bruce Springsteen tickets or Taylor Swift or, you know, lock in things, you're going to need to be flexible, able to change your plans and everything will go pear shaped, and you'll end up in hospital sometimes. It maybe won't you know, it's just sort of accept that this is your mission for this time. Now, that's easy for me to say, I know there's other kids in the families, there's husbands and wives, and you know, and they might live five hours from the major centre, and ten hours from the major centre. It's easy for me to say, you know, this is tough. I don't mean to minimize it but just accept that's how its going to seem a bit, and that this is my mission this is what we're going to do and then take all of the help anyone offers you. You know, so I don't know, Laura do you have much surf and waves in Canada?

Laura: We do on the coast.

Dr. Geoff McCowage: You know, okay well think about, I don't know, we do in Australia obviously. You know, the first few times you get stuck at the bottom of the big wave, you're getting totally pummelled and tumbled, and you know, all you can see is sandy water, and you look around, and if you do open your eyes, and you panic and you're freaked out, you know, what's happening here and so on but after a while, within reason, you learn this is going to be okay. And you just sort of roll with it. You just, the wave hits you, you think oh yeah, great here we go. You get tumbled, you get buffeted from side to side all over, but you know it ends. And you've been there before. Well, you haven't with childhood cancer chemotherapy but with waves, and you just sort of let it toss you around, and you know that you're going to come out the other side. So, now if the waves too big you won't I suppose. There are limits to this ... that sense of rolling with the ... letting it toss you around and that's



how it's going to be for a while. I wish we could change it. I wish we had drugs where you just took tablets and went back to school, and everything was good and maybe one day we will but ... For now, that's what I'd say and yeah.

Laura: I think that that's a great analogy of the waves. The first round of chemo for my daughter, when she did the high dose chemo and stem cell rescue for her pineoblastoma and that first round, yes there's just so much to get used to. The second time around, you know what's coming okay, you know the pattern, and you know okay, we have to go through this first and this next, and we're going to have the day where every fifteen minutes you have to get up and go pee, and you have to do that all night long. And you've got your day where you're going to be throwing up all day, and there's the day that they give you the stem cell rescue and it smells like cream corn in the room all day and you've got your transfer from one room over to isolation and you get used to the pattern, and it becomes a little easier that you become prepared for it.

Dr. Geoff McCowage: That's it, that's it. And then something comes out of left field that didn't happen the first time and you've just got to, you gotta say resilient somehow. Now I'll admit, I don't think normal human beings are built to handle this, okay? I think this is more than most people are built to handle but somehow, they do.

Which reminds me of another point is, social workers, you know. Paediatric oncology, you know, are normally well staffed with social workers. I don't know what the dynamic is in Canada or the US but I guess there might be a mindset that identifies having a social worker with, I don't know, someone who isn't thriving in life more broadly, let's say. Believe me you need a social worker. I don't care if you're the CEO of a multinational corporation, billionaire you need a social worker, alright. You've got emotions just like everyone else. They're not just here to sort out public housing or something. It's about support, emotional support and you know, the doctors can't always be there and the nurses, and plus the social workers know more about counselling and psychology and all that. You need a social worker. Don't be too proud to have a social worker.

Laura: We had a terrific social worker that she ... someone in the universe, God handpicked her for us that she was just terrific, was exactly what we needed to get through so many difficulties.

Dr. Geoff McCowage: So, you agree with what I'm saying

Laura: Oh yes, yeah.

Dr. Geoff McCowage: Special people. And you know they aren't getting the big bucks either but, uh they're just seriously committed. They're there for you.

Laura: Yeah, that reaching out and connecting and looking for those other resources are so important.

Dr. Geoff McCowage: Absolutely, that's right.



Laura: Yeah, so, any other advice?

Dr. Geoff McCowage: Hmm. I would, I'd be careful of the internet. There's a lot of people putting a lot of stuff on the internet. Some of it's useful. Some of it's not. Some of it's more about adult situations. Some of it is, you know, there are some sites you'll go to and sort of automatically will accumulate people where the treatment hasn't been successful and isn't going well, and people are seeking support from others and that's fine. But it would be wrong to assume that, you know, the dynamic you see there is the one that surrounds every child with cancer, or every child with your child's particular type of cancer. So, be a bit careful but by all means have a look, and you know, your doctors will be able to point you in the direction of I guess more reputable sites but so be a bit careful. And be a bit careful about people who'll, you know, give their advice, you know, too readily, give an opinion too readily.

Laura: Yeah, take everything with a grain of salt.

Dr. Geoff McCowage: Well, that's it. If I just get a one liner email from somewhere and say hey, what would you do? I'd tell them I would gather all the facts, you know, I need all the data, right? Anybody who sort of too able to give their advice or an opinion on something without all the facts and seeing the scans maybe or hearing them described from a reputable source ... you've got to be a bit careful. So, you know, by all means ask your doctors, you know, can I get a second opinion, if you want. Now, paediatric oncologists by the way, typically being pretty academic types, they're normally in the thick of clinical trials which means they're going to conferences and meetings where, you know, people who live and breathe Wilms tumours are there. The people who are, live and breathe Ewing's sarcoma, you know, they're on trials, you know, mostly in the big academic centres you're going to find the treatment in one place and another place is likely to be the same. I don't think every patient needs to go out seeking a second opinion. Having said that, you know, if you want to do that you won't hurt your doctor's feelings. We've been asked a million times I'd like to get a second opinion, and you know, we know it's a family's right to do that if they want, and the best way to get a second opinion is with all the facts provided by your doctor right, you know. All the details, all the things that you might not be able to convey lay-speak, you know, you need to get said. Again, I don't want to encourage everyone go getting second opinions, but you know I can't buy a new golf club without getting seven opinions so, I get it. People might do that but if you're going to, you know, do it properly, with the cooperation of your team, you know, and you won't hurt their feelings, and if you do well, too bad. It's your right okay.

You know what else would I say? Hmm, I think I would say um, encourage you to sort of adopt a cooperative mentality in working with the team. You will find frustrations. There will be times where your scan gets cancelled because a more urgent one came up. There will be times where you sit around waiting for hours for someone and, you know, sometimes hospitals are just understaffed and under resourced, and sometimes the surgeon got stuck for four hours or ten hours, you know. Public hospital systems and, probably private ones, are fraught with complexity and demands. It's soul destroying. You're going to see your child



sick and vomiting, and you know, for some reason there's a delay in ordering the drug, you know, you're going to encounter all this stuff. I would blow my stack I expect. I'd probably be the worst, but I'd just encourage try to be patient with everyone, and speak up when you need to but, you know, really try a cooperative mentality. Like I said, these nurses are precious to us. We've all got vested interests here. I don't want too many of them burned out and leaving because they're ... when I get a call at two in the morning from one of those nurses, you know, they're precious. They've seen it all. They know this isn't right, so you know, we're all part of a big team and try to stay cooperative and level-headed but you know, you're got to melt down at some point, all right. We're all human and people in paediatrics have been there before - we've seen it all. Melt down, by all means, try to stay civil, you know. We don't want a scene. I think that's, they're my thoughts for now.

Laura: Well, terrific. So, I would love to hear more about your podcast. So, tell me about your podcast, what lead you to do it? and what has been the outcome or benefits of doing those?

Dr. Geoff McCowage: Okay, yes so, my podcasts. Understanding childhood cancer with Dr. Geoff, and you've got to spell Geoff properly, the sort of English/Australian way G-E-O-F-F. Not you know J-E double F, that's sort of the fast ballers in racing car drivers, in my opinion. So, G-E-O- double F. And you can get it in uh on iTunes and you subscribe to the podcast and there it is. Or you go to Sound Cloud that's a website the same thing you can find it, and it's free.

Well, what made me do it? A couple of things. One is people say I'm good at explaining things, you know. They all say you made that complicated subject, you know, interpretable so, that's what people say. Okay. Second things is, we talk to parents of diagnosis and we're going to talk about the big picture right, you know. What it is. What are our chances? What's our overall strategy, right? You know, is my child going to make it? You know, big stuff. We have to talk about practicalities too, you know. What sort of central line are we going to put in, you know? You know what's an MRI scan? What's an MIBG scan? All these sort of practicality things we have to deal with, you know. And from those sorts of initial discussions, I'd really like parents to go away with the big picture without me getting, you know, caught up in these minutiae. So, I'd rather talk big picture and then say now, we're going to need a central line, can you please listen to this and this, and you'll hear all about it and then we can talk about it. So, this way they can go away with the big picture. They can catch their breath, somehow put themselves back together and then listen to these few things I've said. Can you please listen to this and hear about it, and then we'll talk about it more, and the nurse educator will talk about it more, and we'll all talk about it more, you know, in the comfort of their own home or hospital bed. And also, it's sort of good for me because I sort of know it's a source I can trust and because I wrote it. Well, I didn't write it, I just talk it.

What else? You know, we've for a long time given written information to parents and a nurse educators gone over things in time. And I sort of feel like you need a bit of a something that



is slightly opinionated, it's a bit of a judgement, something you can convey with voice that you can't convey in writing. You know you never listen to side effects. These side effects are common but mild. These side effects are this but serious, you know. You can read all that, but I feel like with a voice you can give it some nuance, give it some perspective, reassure certain patients that this only applies in this situation. A whole lot of stuff that takes hours to go through and have to sit there, and you know that's another thing, after twenty years of explaining two different types of central lines to people, you know, you sort of think well why don't I just record this? So, there's that, and this is how modern people get their information these days in large part, this sort of thing, so all that lead me to do it. Now, it's been it's been quite fun you know, and I've got this program that tracks how many downloads, and you know, what cities it's downloaded in, and you know, it's being pretty well received, you know. There are people in Canada, people in the United States, someone in Iman, you know, Italy, all over the world is these people downloading these episodes, you know. It's not exactly going viral. I don't have millions, but you know, bit by bit, you know, and it's not like ... a normal podcast, you know, typically is a series, isn't it? So, episode one leads to episode two, leads to episode three, or else they're talking about current affairs or Hilary Clinton or Donald Trump, you know, and it's got a current. See, this is just more like a repository of episodes that're just there, and you can get ...

Laura: Yep, they're just stand-alones. It's sounds brilliant. It sounds brilliant. When you were saying before, when you get that first diagnosis, you're on overload, and you only retain a fraction of what's told you because you're still trying to process the first bit that okay. my child has cancer, and the next twenty sentences the doctor said is gone in one ear and out the other because you're still stuck trying to process that first information so having it where you can go back and okay, press play, press pause now okay I can only take it that much in the moment. OK. Now I press play again and play it over again until you really understand it, that's brilliant.

Dr. Geoff McCowage: That's it, I mean telling this family oh this child's got this tumor or something and we're going to use chemotherapy, and the next minute this doctor's talking about sperm banking and ovaries and central lines, and you know, ultrasounds of the heart there's all this chaos you know, exactly.

Laura: Yeah.

Dr. Geoff McCowage: It's been fun and uh for a while there I didn't really associate it with my hospital be cause I didn't want to I didn't want to get stuck in a bureaucracy that has to, you know, check everything and send it to legal and you know. The other thing I've done is I've deliberately sort of avoided really controversial nuanced areas. All right, you know, this is the basic information you need. Not the fine details of should we give this dose or that dose. Firstly, well it's too hard, you know, I have to become a super expert on super detailed areas of everything. I don't want to do that. Also, I want you to get that from your doctors, this is sort of general resource.



Laura: Yeah, he knows your child.

Dr. Geoff McCowage: That's right. In context and is aware of, you know, maybe your child has another condition some abnormality in their kidney's or something, and that's why they're giving this drug and not that drug alright. Or you know some other, some other reason for things. So, I don't want to say this is what you've gotta do. I want to say this is what doctors might talk about, you know, and provide general information.

Laura: Yeah, well that's great, that's awesome, thank you for everything you've been sharing. My last question for you is what website can we send our audience to so that they can learn about more about you, and your podcast, your work, where would you like people to go to learn more?

Dr. Geoff McCowage: Okay, yeah. I don't have a very well-developed internet space but I have a Facebook page. So, if you go to Facebook and then you just you know you just search for the new contacts and you search for "*Understanding childhood cancer with Dr. Geoff*" G-E-O-F-F, you'll find the Facebook page. And that's sort of where I announce there's a new episode out there and invite people to comment, or say if they like that episode or not, and I get a little bit but not a huge amount. That would provide the place where you can then find the episodes from that Facebook page.

Laura: Perfect.

Dr. Geoff McCowage: Again, if you just wanted to go and get these podcasts, so if you went to iTunes - if you look on your iPhone it normally comes with an app called podcasts, purple app, click it and you need to activate it in setting sometimes and search for "*Understanding childhood cancer with Dr. Geoff*" and then subscribe to it, well there you'll find all the episodes and then or else you can go to a website just google Sound Cloud and then look in there for "*Understanding childhood cancer with Dr. Geoff*" and you'll find it. And yeah and then listen to it now the, it's sort of back to front, you want to listen to the very early episodes first because they're going to - it's the later episodes where I'm sort of, you know, I'm running out of content, talking into less basic stuff that may or may not be relevant to you but it's those early episodes, you know, central lines, why the doctors are obsessed with fevers, what to do about vomiting. You know, side effects, you know, different drugs. That's what you'll find in the earlier episodes.

Laura: Oh brilliant. That's brilliant. So, we will make sure to put that link at the bottom of this interview when it's posted.

Dr. Geoff McCowage: Oh, well thank you, Laura.

Laura: So that would be great, thank you so much

Dr. Geoff McCowage: Alright, well thanks again for having me it's been fun I look forward to seeing the project when it comes out and it'll be exciting.

Laura: Well thank you so much.



I would like to reiterate what I said in last week's episode: that was so refreshing to hear such down to earth, behind the scenes advice from Dr Geoff. His reminder to have patience, put things into perspective and recognize that like an Olympic athlete we need to focus and brace ourselves for the year ahead, that it is all hands-on deck and while we might be in for a bumpy ride we can get through this. You are not alone; you have a team to support you. And that team has a great deal of experience. They can be a great resource for you if you let them.

I hope you will join me next week when I will be sharing my interview with Reverend Kevin Ross of Unity Sacramento as he shares the importance of surrounding yourself with community during this challenging time.

Before we end our show today, we have one last segment. Over the last few years, I have asked other cancer moms what advice they wish they had known when their child was first diagnosed. I have compiled that information and will be sharing their advice each week. You can download the top 101 pieces of advice that I put together as a mini E-book at www.twomothersoneprayer.com

Today's advice comes from Shelley who says: You are not alone! Once we were going to clinic and meeting other families going through the same thing it was such a huge burden [of] relief. I felt so alone and terrified. It was another mom who found me crying in the hallway who gave me hope even more than the doctors and nurses. And to ask for and accept help. You don't have to be strong and take it all on yourself.

Thank you, Shelley, for sharing that.

If you have advice you have learned along the way that you wish someone had told you weeks, months or years earlier, I invite you to fill out the contact form on our website www.twomothersoneprayer.com and I will be sharing your advice with our listeners on future shows.

[Music begins lightly in the back ground]

Thank you for taking time out of your busy schedule today to listen to the Hope, Strength & Courage podcast. I look forward to sharing more experts and advice with you again next Wednesday. Please remember to take a minute to subscribe to the show. Thanks also need to go out to our Hope, Strength & Courage production team which consists of my wonderful assistant Tracey Ogilvie-McDonald, Andrew Braun at Braun Audio and Audio Geek, music by Fiz Anthony, social media support by Marife Constantino, and graphic design by Amy Hosmer. To learn more about myself, Laura Lane, and to order my book, please visit www.lauralane.ca.