



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 1
Episode # (8), 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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Today's episode features part 1 of my interview with Dr. Geoff McCowage, a Paediatric Oncologist at The Children's Hospital at Westmead in Sydney, Australia.

I love in this interview how Dr McCowage shares his love for the world of pediatric oncology, the dynamic healthcare teams working along side each other for the benefit of children and families and how much they are there to serve you and want to support you through this trying time. I hope you will find this interview as interesting as I did.

Today I am interviewing Dr. Geoffrey McCowage. Dr. Geoff is a pediatric 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 pediatric oncologist for twenty years. As Dr. Geoff, he hosts a podcast that is aimed at parents of children with cancer.

Laura: Thank you so much for joining us Dr. Geoff today. I'm really glad to have you with us.



Dr. Geoff McCowage: It's a pleasure Laura thanks for having me. It's morning here in Sydney.

Laura: Oh, right yes.

Dr. Geoff McCowage: It's mid-winter, it's bitterly cold. We're all suffering extremely its, you know, sixty degrees outside. We're really struggling.

Laura: Well, as a Canadian I can't relate as a Canadian.

Dr. Geoff McCowage: I'm sure you can. I'm sure you experience cold even as cold as this sometimes.

Laura: Yeah yeah We get to pass through that range of temperature every spring and every fall but it doesn't stay there very long.

Dr. Geoff McCowage: Okay. So I'm not going to get much sympathy out of you and your audience.

Laura: No. So hopefully there will be others in the south of the United States who can understand so.

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

Laura: So, I would love to hear more about you. What drew you to the field of pediatric oncology? And what is it that you love about serving in this area?

Dr. Geoff McCowage: Hmm, that's an interesting question. I get asked that one a lot and, I guess people imagine that perhaps when I was seventeen years old I had this dream one day to be a pediatric oncologist but really it's, in my case, I sort of got there stick wise. So, you come out of medical school and then you end up – in Australia you do a couple of years in adult medicine, and you know, I decided that wasn't really for me, and then ... so I went over and tried pediatrics, and I really liked pediatrics. And then in pediatrics you are dealing with dangerously ill children sometimes, and less dangerously ill children sometimes, but bit by bit you get part and part, part of the pediatric thing and, you find that it works for you, and you can deal with the dramas and the emotion, and you have something to contribute. And then I found myself doing a rotation through pediatric oncology and I don't know. I really just



loved it from the first time I did it. I think, a couple of things. One is that it's an area of medicine where one has a long-term relationship with patients and families. So rather than seeing them once with an episode of gastroenteritis and that's it, it's more a case of seeing the patients and families and having a long term relationship and working with them, and getting to know them and all of that settles that.

The other thing I would say about pediatrics is, you know, in general pediatrics you treat people with gastroenteritis for instance, and it might be a little baby, and they might be dehydrated, and you know what? they can be critically ill. And if they don't get a drip and an IV fluid started well, its life threatening you know they can die. So those are very important things to treat. And treat them we do. But at an intellectual and academic level it gets a bit, I don't know, a bit repetitive maybe, and a bit less intellectual and challenging. It's life saving, it's vital, I'm glad people do it. But I felt bad and, and I think I like working in the big academic center rather than being out in private practice and so on and so that appealed to me, and then as all the science in it as well. But I think more it was the emotion and the sense that these people are really in need. This is a terrible thing and I think that attracted me more than, you know, the DNA and the, you know, molecular aberrations and all that stuff. So that's sort of how you get there. It's more of bit-by-bit medicine, then pediatrics, then pediatric oncology and then here I am.

Laura: Mhm, so tell us what is it like to be working on the pediatric oncology unit? What's it like working with that team of doctors and nurses and other staff? And how is that different from working on other units?

Dr. Geoff McCowage: Okay so, well I love it. It suits me down to the ground. So, what's the alternative? Well, you might be in general pediatrics, or I don't know what you would call it family pediatrics or general pediatrics maybe with a private room, or private surgery out in the suburbs somewhere with a secretary and a nurse and seeing patients after each other. And then maybe having admitting rights to the hospital and going up there and seeing kids with asthma, and seizures and meningitis and gastroenteritis. And I guess that's more how general pediatrics might work. On the contrary, pediatric oncology, so childhood cancer treatment is - is concentrated in the big academic medical center and we have a huge team of people all playing their role and so I quite like having all these other people around me. I quite like having all these junior doctors that I'm working with who are learning first about pediatrics and then it spills over about pediatric oncology. I like a bunch of nurses who are experienced and committed, and you know, have been there for years and years, and I rely on them enormously, you know, their judgements, and you know, something isn't right here, you know, and this isn't what we usually do. And, uh you know, very valued. We have pharmacists, and social workers, and phycologists, and dietitians, and whole lots of people, and uh, then we have very expert people in all the other departments, you know, the radiologists reporting the MRI scan, and I can go over there and look at the scan with them



and talk over it, and then go to pathology and hear what the biopsy shows, and you know, get a sense of the pathologists view of it, or is the pathologist worried about the I'm not quite sure what this is and do we have to do other tests? You know, the expertise is very important, but it's the relationships as well. You have to know who you're talking to, and they have to know you and they have to put up with your weird eccentricities and when they feel confident and when they don't, or you know, it's really a dynamic in a stimulating area, and you know, and also to be working with a bunch of people who are seriously committed to what they're doing. You know, none of them are there for the big bucks, you know. An awful lot of them could make a lot more money going out in a private practice and pulling on, you know, the knees of people with arthritis, you know, their MRI scans, you know, they're all there for a noble cause, I would suggest, and so it's great I love it.

Laura: So, it's that incredible sense of team and ...

Dr. Geoff McCowage: That's right, that's right. There is this great team thing and I guess, unashamedly, I'm sort of one of the bosses in the team, and well I quite like that, but it's not a dynamic way you can boss people around. A lot of them have expertise in their area that way surpasses your own and so while I have a leadership role in a department more broadly but in an individual patients care definitely, you know, you've got to be prepared to listen to them all and hear what they've got to say and, you know, let them tell you when they think you're wrong, and so on and yeah, a great team.

Laura: That's very good.

Dr. Geoff McCowage: So that's so what I'd say to families and to parents who, you know, just been told your child has cancer or leukemia or a tumor and, you know, they're going to embark on this treatment, well, I'd stress to them that there's a whole lot of people out there that are there to look after you and your child, and they're seriously committed people. From the you know, the head honcho professor to the ward clerk or even the porter, people get to know these families that get to know these children and, uh, they're all there for you. They're there to help, it's not like you know when you go to see a doctor I don't know, in Canada quite how it's like, but if I went to see a doctor, suppose I was just a regular person went to see him for my arthritis in my knee, you know, you have the appointment, and then you get the referral letter, and then you turn up, and you sit in the waiting room; everyone's very polite and then you get called, and then you see them, and then have the consultation and then you go, and it's all pretty structured and you don't, you know, feel like you can just turn up the next day and say "now what you were saying about my knee?" and "oh can we talk about that", well you know, that's sort of most people's image of going to see doctors, I think.



So, the dynamic here is a very different one. This is a team that's there for you. There are all sorts of people with their parts to play and they want to be there for you, and they want to be very flexible. You know, some of the treatments we have to use are pretty strong and toxic and have side effects and I want to know that the parents feel completely free to phone if something's wrong, if their child seems unwell, if they think their child's toenails look funny and they don't know what it means, I want them to call! I'm relying on the parents to be in touch with our team; tell us when things are odd and unusual and sometimes, we'll say, yeah that's not a problem, and sometimes we'll say, no, that's a problem. So, I really want parents to feel free to be in touch with the unit and to be talking us and at two AM if there's a fever, you've got to call; everyone's there for you, you know, we're all worried about the side effects of these drugs. We'll be nervous if we think you're not going to be in touch. So, you know, that's what I'll encourage. Think of it as a dynamic way you can call on help from various different quarters, and you know, most units will have, you know, a structure for who do you call, you know, who're you going to call when things are worrying, you know, whether it's the children's ward or the, you know, the consultant attending on call or the fellow who ... they all have systems - use them.

Laura: From what I'm hearing from you there's two things – one, the parent should not say, oh I don't want to bother anyone because –

Dr. Geoff McCowage: Absolutely, absolutely. You're not bothering anyone. We get bothered when people don't contact us when something was wrong. When we hear the child had a fever in the night of thirty-nine but he looked all right, we didn't want to bother you, that freaks us out totally. We want to hear about it. Now do I personally need to hear about it every time? No, I want the unit to hear about it and to respond and everyone's drill and knows how to respond. So, none of this "I don't want to bother the doctors or the nurses or the anyone". We want to be bothered.

Laura: Right.

Dr. Geoff McCowage: Sorry, you had a second thing.

Laura: Yeah, so then the second thing was don't try and figure it out yourself, let your team make the decision on whether it's good or bad. If you think it's different just let them make the decision.

Dr. Geoff McCowage: That's right, that's right. And you know, there's limits of course. You know, someone with a mosquito bite you don't need to be in touch but, yeah, things that



seem odd, you know, these are very complicated medical situations we find ourselves in, where we're treating a cancer and, you know, very often we have the cancer improving and shrinking or going into remission but we're still throwing around some, you know, pretty strong drugs with complicated side effects and uh you know, I don't expect the you know, the general doctors in the emergency room department to have very good familiarity with these things, so very much I don't want parents sort of dwelling on it and googling it and trying to work out oh what should we do? You know, call on the experts and if three-quarters of the time we say, oh it's nothing don't worry, that's okay. Don't feel oh I disturbed them for no good reason, okay.

Laura: Yep terrific. Okay, so my next question for you is what key advice would you give to parents of children with cancer? What are the things that they should be doing, the things just important information that you think they should know?

Dr. Geoff McCowage: All right, so let's imagine that we're right at the start and a child has just been found to have cancer or leukemia. OK, worst day of your life undeniably; terrible totally shell shocked, totally devastated, and that's why we're going to tell you the same things five times over in the case that one time you'll remember it. Well, so we're going to embark on treatment for this cancer or leukemia, and your doctors will need to advise you about whether this is a form of cancer where we should be being optimistic that eventually we'll cure the disease, or is it one where you know we can't be as optimistic or even is it one where we can't be very optimistic at all? So, you'll need to get that from your doctors. This is not one to google and look at.

First off childhood cancer is a totally different thing to adult cancer. They're totally different cancers and even when they've got the same name like lymphoma, childhood lymphoma is different to adult lymphoma so you really need to get that from your doctors. We've all, but keep in mind, you know, something like 80% or more of children with cancer will be cured, if you're looking at sort of the developed world - Canada, Australia, the US, Britain, France, you know, all those countries. It's over 80% that will be cured but, you know, you've got one child and you don't want them 80% cured, you want them 100% cured so get the information from your doctors. But in any event, we're going to go down a path of treatment, and almost always that involves chemotherapy and some tumours there will be an operation, or there may be radiation, but there will be chemotherapy usually, and I've got to say it, you know, we achieved this 80% plus by using chemotherapy, and we throw it around in pretty solid doses; pretty high doses, and we expect to get all sorts of side effects. In fact, you know, if we didn't have many side effects, we would probably put the dose up until we did because higher doses very often are the key. So, you know it's going to be a rough ride most of the time. Again, get your doctors to tell you is this going to be this sort of minimalist chemotherapy, or something medium, or is it going to be full on acute myeloid leukemia, bone marrow transplants things like that. But whatever it is, it's going to be a way worse time than you've probably ever



experienced. It is going to be a tough time. It's probably going to be the worst year of your life, alright? So, I would be honest and say that and if you can adjust to that then I think maybe you can handle it better.

OK, now there are a few things I've tried to discard right at the outset; some of the negative emotions that you might carry with you. So, first off is the question of why did my child get cancer? You know, often parents feel guilty, you know, their child got cancer and it's something they did; it's what we fed the child; it's what we, you know, smoked when I was pregnant; or I drank or, you know, its TV; its where we live; it's ... you know, I've got to say I struggle to think of a single lifestyle factor that is associated with childhood cancer. Okay? Smoking and adult cancer definitely, you know, not enough fiber in the diet, you know, drinking ... pretty much anything that's fun in adults seems to be linked to getting cancer. But in childhood, it's not about lifestyle, its nothing you did. It's not from anything you did. It's not your fault that the child has cancer. And it's no one else's fault either. It's not what your husband or wife or partner did. It's not their fault. It's no one's fault. Be angry at the universe. Be angry at god if you'd like. Be angry but don't be angry at yourself or at others. Don't harbour that emotion.

The next thing to say is, well you might be angry at the doctors. You know, the doctor that you saw, and you saw, and you kept going back and you said something's wrong, and he said ah, it's just a virus and then, you know, eventually you find it's a tumour. You know, we hear this story all the time, and you know, I don't hold it against those doctors. Childhood cancer is rare, if family doctors mention cancer every time they saw a kid with a virus or a fever or a sore bone, I think their practice would dry up very quickly because it's rare, and the symptoms of cancer they're often what you call nonspecific. They're not, they're not things that, you know, cry out this is cancer. They're things that cry out this is a kid with some sore legs, probably, I don't know, growing pains, virus, something, okay? And you know, also that delay in diagnosis that you get it's not clear that that's going to impact the chances of treating the cancer, right? It's not like if they got to it sooner we would have found that before the tumour spread to the lungs or something. I don't really think of it that way. More likely it's a tumour that's going to be one that spreads to the lungs from the outset, or it's not. It's not because the doctor took three months to work it out and then it spread.

And you know, ultimately what it's going to come down to is do the drugs work? That's what it'll come down to, so don't be angry about some delays in diagnosis and, you know, it's not desirable and the child might be in a more parlous state by the time they get to you, maybe sicker or more unstable, but you know, we get through that and then it comes down to do the drugs work? Can the tumour be cut out sometimes, you know? And all those things. So, I wouldn't come into this feeling guilty or angry or feeling blame, and you've got to discard all those things.

The other thing you might worry about is wow! my child has cancer. Well, it must be in the family, you know. What about the other kids? What about the cousins? The nephews, the nieces, all of them? And this is an area of very active research and I've got to say that, you



know, it's only a small proportion of patients where there's some, you know, some hereditary component to it; something you inherit from a parent or something that made them more likely to get the cancer. This is rare. Now, you know, as DNA exploration happens its, we're going to find more examples of it I suppose but, I mean a big paper in a New England Journal 2015, they looked at this in great detail, and I think they found about 8% of patients had some genetic abnormality, I mean hereditary type abnormality that, um, made them more likely to get the cancer. 8%, and you know, so that's the sort of figure, even that may be higher than it really is. So, don't freak out, oh my goodness, all my other children need to be checked, and the cousins, and the nephews, and the nieces. Okay, so that's getting rid of some emotions at the outset.

That was so refreshing to hear such down to earth, behind the scenes advice from Dr Geoff. To have that reassurance that our child's medical team is there to support and serve and that we are not a burden to them and they are just as concerned about our child's welfare as we are.

Please join me next week for Part 2 of my interview with Pediatric Oncologist and Podcast Host Dr Geoff McCowage as he shares his best advice for parents, and he tells us about the podcast he created specifically to support parents when their child is first diagnosed with cancer.

And in the meantime please check out Dr Geoff's podcast *"Understanding Childhood Cancer With Dr Geoff"* on your favourite podcast player.

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 echoes one of Dr. Geoff's comments. This mom said: It isn't your fault!! Her in-laws blamed her at one time for her daughter's leukaemia at one point.

If we recall what Dr. Geoff said, childhood cancer isn't about the food our children eat, it's not about watching television, it's not where you live. It's not your fault and it's not anyone else's either. So be angry at the universe or at God, if you must, but don't be angry with yourself or others.

Thank you 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.