Biography

Dr. Stephen Liben is currently a Professor of Pediatrics at McGill University, Director of the Pediatric Palliative Care Program. He received both his BSc in Neurophysiology and his M.D. from McGill University in Montreal, Canada.

Dr. Liben has published over 80 journal articles, published the book *MD Aware-A Mindfulness-Based Whole Person Care Course Guide for Physicians*, co-edited over 10 book chapters, and co-created core Medical Mindfulness curricula for incoming medical students of the McGill University Faculty of Medicine. His research interests are to reduce the suffering of children and families who are caring children with life-limiting conditions.

Interview Abstract

Dr. Liben credits his initial venture into pediatric palliative care to his experiences of witnessing “unnecessary suffering” during his career in pediatric critical care. Dr. Liben states that he was attracted to how much “promise” that pediatric palliative care held in addressing more than just the medical needs of children and their families.

He then recalls experiences he had with international leaders in the emerging field of pediatric palliative care. Dr. Liben describes how the field has evolved to be more patient- and family-centric while spanning across the intersections of pain management, chronic care, and complex care. Dr. Liben also discusses how he managed his team and developed integration strategies to become an established service in the hospital space. He recounts some of the initial challenges of educating other clinicians on what pediatric palliative care could bring to a health care team. He also reviews how much adult palliative and adult hospice have influenced and nurtured the pediatric care fields.

Dr. Liben then discusses his work in medical mindfulness with an emphasis on human connections and how he has experienced the “ultimate win-win,” with both healthcare teams and patients being happy with the connections and relationships forged. Dr. Liben concludes with his vision for current pediatric palliative care specialists to “teach ourselves out of a job,” and how he strives to cultivate the next generation of physicians in all specialties to have a holistic patient-first approach that incorporates his field’s mindfulness approach to care for more than just the physical, but also the “logical, spiritual, [and] emotional.”
## Glossary of Acronyms

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*The nature of suffering and the goals of medicine.*

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Today is June 20, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Dr. Stephen Liben over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Liben is in Montreal, Canada. Thank you Dr. Liben for joining me today. To get us started, could you tell me when your mind turned toward pediatric palliative care as a career focus?

I started off 1992 specializing in pediatric critical care or intensive care. I had just done a fellowship after my residency. It was in '95, so 1995 was the start date when I saw that there was a pediatric palliative care program just starting and I got interested.

I started off 1992 specializing in pediatric critical care or intensive care. I had just done a fellowship after my residency. It was in '95, so 1995 was the start date when I saw that there was a pediatric palliative care program just starting and I got interested.

What initially interested you in the palliative care program?

I was working in intensive care and I found that I was gravitating to the kinds of kids and families that were longer term, not sort of quick in-and-outs. They were staying there sometimes months and living with chronic, complex illness. I found myself being pulled towards wanting to get more involved with the longer-term problems, the less acute, critical care problems. Seeing that, that was sort of more my place than acute care, although I had been doing it for a while, and I still continue to do it. I saw an opening to do pediatric palliative care and thought, "Well this seems to be the kind of direction that pulls me, so I’ll give it a try." That’s how I ended up in pediatric palliative care in 1995.

Were there any particular moments or experiences or was it just a culmination of this awareness that you were being drawn in a different direction?

I think that there were specific examples and really it was examples of what I thought was unnecessary suffering that I was seeing in the pediatric ICU [Intensive care unit]. There’s a certain mortality, some kids die in the ICU. It’s nobody’s fault. It’s just a high-risk area. I thought that there were things we could do that seemed so simple at the time to make their care better and to have them suffer less, the kids themselves, but also their families. There was unnecessary use of technology that was inhibiting their personal contact.

To give you an example, if it’s a newborn baby that had a heart defect and needed cardiac surgery from the time of birth, the mom would often be sitting by the bed for weeks. Then the child would sometimes die and everyone would know that they’re probably
gonna die, but no one would offer the mom to hold her baby who she, in retrospect, probably never held in her arms. Just, I think, the power of asking the critical care team, "Hey, could we find a way to make this mom spend a bit of time in the chair with her very ill child? Even on a ventilator and all the rest of it."

Watching everyone rally for that. Then watching the mom’s absolutely important bonding with her child and cheerful—the beauty of just them touching them. Those kinds of things rang a bell in my mind that I think there’s more we can do than just having them hold their baby. There’s nothing wrong with that. It is a lot—there’s more that we could do. I thought that’s where pediatric palliative care held so much promise.

Do you think that the barriers to addressing that suffering to giving that care you were talking about, were those barriers related to lack of awareness from the doctors and nurses or lack of value of those things or fear of something else? What do you think were the barriers to actually having that mother hold her child or other things?

Right. I think it was mostly the first one said, lack of awareness. I think people were focusing on what felt like the job definition. Our job is to keep patients alive no matter what. Somehow failing to do so was kind of a failure. When you feel like you’re a failure, I think you’re less likely to see what else you can do.

If you think your job is only to heal, not heal, to cure—if it’s only to cure, then you feel like a failure and I think they just weren’t continuing to see that this is all our job. I mean, how can we make this experience least harmful, most healing, as good as it can be? When you re-shift to that, questions such as holding the child naturally come up. I think it’s mostly lack of awareness, although not the only thing I’m sure.

How much do you think that has changed over time from when you started until now?

I think it has shifted in a positive direction. People are more aware. They’re certainly more open when you bring these things up to re-aiming what we’re doing and looking at bigger pictures than just cure and disease modification—looking at life enhancements and reducing suffering. There’s still sort of a narrow beam of attention that’s sort of people’s default in terms of what they do. That’s where having a palliative care team can be helpful, just asking the questions, "Hey. I don’t know how much time is left for this child but given that it
looks like it might be short—I hope we’re wrong. I hope it’s longer, but if it might be short, what are some things that are really important, not just for us, but for the mom and the dad? I wonder if we can have that conversation with them." Opening up that kind of question often re-shifts things.

[00:05:30] 

**Bryan Sisk:** When you were starting out back in the mid-90s with the palliative care work, it was still a really new field, nationally and in Canada. What was it like jumping onto something that not a lot of people had done before?

**Stephen Liben:** I think there’s good and bad things to being on the frontier of something. The good thing is that the expectations are low and so it’s hard to mess up. [Audio cuts out] Expectations are low is a good thing and you can try things. There’s a lot of positive in that.

The negative is that there wasn’t a lot of people around doing it. It wasn’t well-defined and you were struggling with each case to try and put together a care plan, whereas now it’s much easier to sort of see patterns and have some sort of operations heuristics for how you’re gonna work. It was making things up more on the fly, which both had its pros and cons.

[00:06:37] 

**Bryan Sisk:** Were you able to find a community of similar-minded people in the pediatric world?

**Stephen Liben:** You mean?

**Bryan Sisk:** When you were starting out.

**Stephen Liben:** Oh, very much so. I think there were a lot of other intensive care specialists. Not a lot, there were a few others. There was Marcia Levetown, for example. I guess we just saw that there’s more we could do than what we were doing and what the job was. It was a lot of like-minded folks. It was small groups of people, but it was very collegial. It was very helpful.

I don’t think I would have stayed in it if it wasn’t for the fact that it felt so supportive. I had a colleague in Halifax, Gerri Frager, who is retired now, who was supportive, and it was just great sharing of mindsets. We’d call each other up and share cases. It was very cool.

[00:07:27] 

**Bryan Sisk:** When you were finding these other people that were similarly interested and similarly blazing through this frontier with you, how did you become aware of them? Was it through publications?
Through word of mouth? Through meetings? How did you first develop this awareness that these other people were there?

**Stephen Liben:** Right. There were no publications. There was very little anyway. There was, there still is, the International Congress of Palliative Care that’s held in Montreal every two years. It’s been going on for decades. Headed by Balfour Mount, who was one of the sort of fathers of palliative care in North America, certainly in Canada.

At that conference, when I took over the job here in Montreal in 1995, I took over the pediatric palliative care part of the conference, which was very small. We just sort of sent invitations saying, "If you’re doing pediatric palliative care at all or if you’re interested, come and we’ll have an interest group and meet for lunch." That was sort of a way to connect up with folks from the U.S. and from Canada and was very helpful at the beginning. It was mostly through meetings, to answer your question.

**Bryan Sisk:** Given how there weren’t many publications and there weren’t a lot of people doing this work, did you have any doubt at the beginning that this field was gonna stick?

**Stephen Liben:** Did I have a doubt the field was gonna stick? What was the question? You’re asking the question 20 years later. Did I have doubts at the time? I don’t think that came up for me at the time. Probably like most naïve people starting off something, I was like, "This has to be done. We’ve got to do this."

I didn’t really ask whether—I wasn’t really worried about whether it was gonna stick or not. There was just such a need—there was so much unnecessary suffering. There’s necessary suffering and there’s unnecessary suffering. There’s only so much we can do to reduce someone’s emotional pain and anguish over losing their child. You can never take that away, but you can remove a lot of necessary suffering such as unnecessary physical pain, such as unnecessary separation of loved ones from their families, caring for them in better environments.

[00:08:30]

**Bryan Sisk:** Are you still there?

**Stephen Liben:** Yeah.

**Bryan Sisk:** Sorry, you cut out for a second.

**Stephen Liben:** Sorry, okay.
We’ve been talking about suffering a little bit. How was suffering, at that time that you starting out, how was viewed? Was it viewed as individual symptoms? Was it understood as a concept? Can you tell me a little more about what that was like at the beginning?

I think suffering is still—we still have a lot more to learn. At the time, the most sophisticated academic investigation into it was being done by Eric Cassel in the Journal of Medicine article on the Nature of Suffering and the Art of Medicine and then in the self-titled book that he put out. There was very little—I mean, I don’t people even appreciate the differences between pain and suffering. Though, these statements were made about, and they’re still made to some extent, about how, "Oh this is just so much suffering."

When I was looking at a child who was unconscious, for example, on high doses of Fentanyl and midazolam, intubated in ICU, I think the question then is, what do you mean by suffering? I mean, certainly we looking at a child who is unconscious are suffering. Those questions weren’t asked. Everything was just assumed. When you make a lot of assumptions you run into a lot of problems. I think we’ve come a long way and we have a long way to go still on how we talk about these things, what we mean by suffering, what we mean, and that kind of—

When you were starting out, how did you learn what to do when there weren’t people doing your work before you started it?

What do you mean when there weren’t people?

Oh, how did you know how to care or how did you learn how to care for these children when there wasn’t a path or heuristic, as you were talking about, of how to easily address suffering, address pain, address symptoms, address psychological distress?

I think what I’m hearing is you cutting out at some points. You said how did move—do you hear me now?

I do. Yeah. It must have been cutting out a little bit. Let me ask you—I’m gonna pause.

There’s also a time lag when I stop talking to when you start talking. I think it might be a bit of you looking at your note, which

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is fine. I don’t mind that at all. It’s not a natural conversation. I’m allowing more time.

Early on, who did you learn from to figure out how to care for these children?

I was fortunate in Montreal that I had Royal Victoria Hospital and Balfour Mount just a half a kilometer away from me. The first thing I did was speak to my own department head and said, "Listen. I’m taking on the job but I don’t know what I’m doing. I need some help. I need to learn some stuff. My adult colleagues are gonna be the ones." I called them up and they were so generous with their time and so wanting to be helpful.

I spent time on the adult hospice wards, adult palliative care wards, and spent a month there, sort of being a trainee again and did that. Then I went to the U.K. [United Kingdom] to London, spent some time at the Ormond Street Hospital with Ann Goldman, who was one of the first physicians there to ever do pediatric palliative care. They had more advanced palliative care in general in the U.K. I sort of cobbled together my own little mini training program and learned a lot. Then I continue to learn on the job.

What do you think were the best lessons you learned from people like Ann Goldman and Balfour Mount?

From Ann, I really saw how much of the job is about communication and human relations. I had suspected that, but I hadn’t seen it in place. The way she worked her team was her, one doctor on 24/7, and there were a group of 3 or 4 nurses and they were such a beautiful team that worked together with such equality of purpose and lack of hierarchy between nurses and doctors. You saw that effected in really great relationships with the families that they worked with—I learned that from her.

Then from Bal, I saw—well I learned some of the expertise at what you actually can do to help patients. Again, with Bal, deeply humanistic caring and how much that makes a difference, both to ourselves as physicians who are doing this work and also to the patients. That’s what got deeply engrained and it sort of fortified or reified what I already sort of sensed. When I could it see in action, that was so helpful.

You had mentioned Geri Frager. I had interviewed her and she told me that you were the two pediatric palliative care physicians in Canada. When one of you went on vacation, the other one covered,
essentially, all of Canada for palliative care. Tell me a little bit about what that like being responsible for such a widely diverse and geographically far-reaching population.

**Stephen Liben:** It’s sort of a funny story because it is of course true and of course, in another sense, it’s not true in that people were doing the work they just weren’t calling themselves pediatric palliative care. Our hematology oncologists were doing the front-line work with those kids that were dying and doing it for the kids that are there. Everyone was doing the best they can and we weren’t that well-known. It wasn’t like it would be nowadays, it would be ridiculous to have one physician on-call for the United States for pediatric palliative care, right? I mean it’s ridiculous, right? When nobody knows what you’re doing or where you are, you could be on-call because people aren’t gonna reach out to you.

We really were on-call for our colleagues. It was fun to sort of sign over a whole province, which is equivocal to a state in the United States and say, "Okay, well in this province of eight million people, there’s a few patients." It was sort of funny to do so, but we weren’t really on-call for them primarily in the ways that we are now. The big change, that’s a positive thing, is that pediatric palliative care has gone from a "it’s nice to have" service, if you can call somebody, to a "we need to have this service to be accredited and to be considered a fully-fledged medical team hospital." From a nice-to-have to a need-to-have. That’s what changed. When Geri and I started off, it was nice if people wanted to call us, but it wasn’t anywhere near necessary.

[00:16:20]

**Bryan Sisk:** When you were beginning your work in the late-90s, what were the biggest challenges of launching a pediatric palliative care program?

**Stephen Liben:** There were several challenges. One of them was defining what we mean and what we’re doing, which to this day is still an issue just less so. What is pediatric palliative care and the crossover with chronic care, complex care, and pain management? At the beginning, it was just too much trial and error with pain and symptom management. There’s a lot we still need to learn about this for sure, but there are much more well-trodden research pathways on how to do this now. Pain management’s improved tremendously in 20 years. That was a big struggle, was just finding ways to keep the kids out of pain as much as possible as they were dying.
Bryan Sisk: Similarly, what worked really well from early on when you were developing this palliative care team?

Stephen Liben: I think what I found was that people were incredibly open to wanting to be helpful. Even if they didn’t know how to help, they were very open with that attitude. Sort of like in the ICU when everyone is saying, "The mom can’t hold the child. He’s on a ventilator. It’s too risky." You would just say, "Yeah, but are you sure we can’t find a way to transfer this baby carefully? Imagine how important it is."

Then you watched everybody rally around—once they sort of got it for themselves how important this is and if they made it personal, the rallying was just tremendous. My adult colleagues and adult palliative care were similar. They were just so open and trying to be helpful. They’d come over or they’d offer suggestions. There was an attitude of like, "Hey. We’re all in this together. Let’s reduce suffering. Let’s make things better than they are." That was very helpful.

[00:18:18]

Bryan Sisk: What was the role of the parents and the family in the conception of palliative care at that time?

Stephen Liben: Can you say more?

Bryan Sisk: Nowadays it seems like involving the parents in the care, involving them in decision making and effectively communicating with the family, thinking about the siblings, thinking about bereavement, all of those things have become part and parcel of what palliative care is. Has it always been that way or is that something that developed over time?

Stephen Liben: I think that has developed and continues to develop in terms of the definition of what we even mean by pediatric palliative care, in terms of including the families. Certainly, the parents are the major players always cause most of the kids, any of them, are too young, pre-verbal, or have intellectual deficits so that they’re nonverbal. A lot of the decision-making discussions are with the parents. We include the children, of course, when they’re able and the way that’s developmentally appropriate, but the role of the kids and the families has evolved and continues to evolve, all in a positive direction I would say.

[00:19:27]

Bryan Sisk: From my interviews with other individuals, I’ve heard that one tension as the field was developing was shifting concepts of if a child’s going to die, where that child should die. Where prior to Ida
Martinson’s work in the 60s and 70s it was if you have a child that’s going to die, they need to be in the hospital. Then there was a push to largely they should die at home to now maybe finding something in the middle. Have you experienced anything related to that as you were developing your career?

Stephen Liben: Yes. It wasn’t so much only the professionals, but to have a child die at, there was no support services whatsoever. It was very difficult in the early days to have a child die at home because it was just you personally that was gonna do everything. I mean go to the pharmacy, get the medications, draw them up, administer them subcutaneously. It was just one-person show the whole thing. We’ve evolved to the point where we have an expectation that nursing and others need to get involved in home-care also.

I’m grateful that the bias has swung sort of as you described from "it must be in the hospital" to now sort of an—earlier, you know, "it must be at home. They have to die at home." I mean, clearly for many families, it’s not the best place for them at home. Not everybody’s home is set up for that kind of thing. Plus, some parents just don’t have the resources emotionally, psychologically, financially to do it and don’t wanna do it and need the security of the hospital.

I’m glad to see that I think things have evolved to the point where we say, "Listen, we have three options. We have the home. We have the hospital. In places, including Montreal, we have a hospice. Actually, you can try them. See how they feel. You can be in one and then decide that it’s not working for you and transfer to another." There’s no limitations on that. It’s nice to offer people a range of options that can evolve with time. I don’t think there’s an expectation anymore that things need to be happening in a certain location for them to be right.

Bryan Sisk: The one thing that’s interesting about medicine in general, if you look at the history in medicine, something will become the dogma that everyone does. Then everyone does it because it’s the dogma. Then, over time, somebody brings up the realization that that needs to change. Then that dogma shifts. You mentioned a little bit of it in terms of "we can’t hold very critically ill newborns because it’s not safe." Are there other examples within the palliative care community where we’ve developed a dogma that has subsequently needed to be overturned?
Stephen Liben: Great question. You’re asking kind of “how do I know what I’m not seeing?” You know, I have my own blind spots. My definition I’m not seeing them. What am I now assuming that will be proved later to be an assumption on not much? I’m not sure. The big ones, I don’t know what assumption I’m actually thinking that later will be—but what comes to mind as something that’s possible. It used to be things like after the death of a child, there’s way more divorces. That’s pretty much been debunked. There’s a lot of divorces as a baseline rate. If you even want to frame it that way. Make sure you keep track of the baseline. I don’t think it really makes a difference.

Long-term, I don’t have the data in front of me, but I’ve seen families where clearly it brings people together or it can be driving them apart when they’ve already been driven apart. Dogma. What else might be another dogma that we—I’m not sure Bryan. I don’t know. Do you have one in mind yourself that you’re thinking of?

Bryan Sisk: As I’m thinking, I didn’t know the answer until I asked it. Now I have an idea [laughs]. What does to come to mind a little bit is the process of communicating with the family about prognosis. Clearly that was in terms of the children, and largely in terms of the parents, you shouldn’t tell them and especially not the nitty gritty details, to you really need to incorporate them and include them, even if they don’t want to be to now—the real challenge of what is personalized communication and how do you actually meet the individual needs of the parent. Did your career come in after those transitions occurred or were you in the middle of any of those transitions?

Stephen Liben: I think medicine’s changed in general in terms of the role with the parents. The asking questions and trying to figure out what kind of styles actually work for people. I know some people like to hear a lot of information. Actually, that kind of conversation has evolved. I think my thinking on that has evolved as I’ve learned to do things better. That continues to be, how can we best connect with people? That’s what communication is. It’s connecting, I think.

That question remains not perfectly clear, as is evidenced by what goes on in the world every single day if you read the news as well. Medicine is not isolated from anything. We’re a part of a larger society. The way we communicate and don’t communicate is interesting. I think these questions are being raised more and more every where and it’s a good thing.
Aside from the professional challenges of developing and running a team, what were some of your personal challenges as you tried to develop this career?

I was fortunate to have—for myself, my own support, I need to have at least one person I can discuss things with. I had that one person early in my career. She was a child life specialist working in the ICU as a family support member. She’s since retired. Having somebody to do that with personally was—there’s no way that I could do this or I think I could do this alone. Alone in the sense of not connecting with someone else who thinks at least to learn enough to be unreactive and nonjudgmental when you talk with them. You can work with others and be lonely and you can be alone and not be lonely. Of course, the difference solitude and loneliness. The personal challenges were finding one or two people to connect with, and I did. That was very helpful.

Looking more globally at the development of pediatric palliative care as kind of its own field and eventually its own specialty, what do you think served as the initial spark to push that field along—to develop that field?

I think there was a cry of "We can do better than this. This is not okay." I was hearing at the beginning from the hematology-oncology wards in my own hospital. Balfour Mount did a study way back in 1988 that showed the distress from nursing and from allied health resources in terms of causing pain in children that everyone knew were dying and we were continuing to do things to them. I think that was a little microcosm in what was happening across North America and Europe too, that medicine was better interventions, but didn’t know how to use them wisely.

There is a time for a bone marrow transplant and there’s—well, no bone marrow transplants are gonna be done there. There’s a time for a bone marrow aspirate and there’s a time when that information is no longer of any help and is completely useless and causes pain for nothing, for example. There’s other examples. There was just a cry from people saying, "God. Medicine is so great, but it’s also so terrible. Can’t we do better?"

That’s the cry that I heard that was a spark that initiated the field. That’s personally the spark for me in the ICU. I felt like there were things we were doing that were just making some things worse sometimes, despite everybody’s obvious best intentions. The question, ‘what could we do to make this less awful or better’ was the driving force for palliative care for my point of view.
Bryan Sisk: Do you think that that initial spark is the same thing that pushed the progress along over these years or were there other contributors?

Stephen Liben: I’m sure there’s other ones, but that particular question kept being asked. I mean, the Joanne Wolfe study in 2000 looking at signs and symptoms of children at the end of life, what that really was, was just documenting what was already happening. You just see it on a nice, clear graph. The amount of misery, pain, and suffering that would be amenable, not all of it but much of it, to relief. You go, "My goodness, if that’s going on, we’ve got to do better."

Pointing with the problem is the first way towards a solution. I think that’s still a big part of it. Although as a field now, I think we need to move from describing how hard things are, to developing and testing interventions that we know are effective. This phase of research should be toning down the just-describing and we should be looking at, "We do this, this is what happens. We do that, that is what happens.” Which one do we wanna try doing?" How can we actually implement interventions that are evidenced based interventions?

Bryan Sisk: Thinking about research in the late ‘90s, were the people that were developing this field and doing this work, were most of them writing it up as research or were most of them with their nose to the grind stone doing the work but not writing it up?

Stephen Liben: A lot of people were just putting out fires all day long, clinical fires, people suffering, and weren’t writing things up. That emerged with time and the first was written was very much descriptive, narrative, which needed to be done. It still needs to be done to some extent, but we don’t need to repeat the same kind of stuff. Most people were actually just doing the clinical work. It was very hard to do everything at once.

It was your both looking out for the patients, trying to advocate for why you needed to exist at all as a service, trying to publish something to show that this stuff actually needs to be out there beyond your own local place. There was a triple threat of academic, teaching, and research. It was quite the challenge. It still is to some extent, but less so.

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**Bryan Sisk:** From your experience, what has been the role of philanthropy, government funding, other types of funding that aren’t traditional healthcare funding in developing this field?

**Stephen Liben:** There are big differences between the U.S. and Canada. Canada is a public health system, so it’s been easier to have hospital-based pediatric palliative care teams as part of a global budget of the hospital. I know there’s different in the U.S. where philanthropy has come in is in terms of the pediatric hospices and also the adult hospices. I actually don’t really understand why an adult or pediatric hospice has to get only part of its funding from the government and the rest of it privately. We don’t ask emergency rooms to get part of their funding from taxes and the rest of it from philanthropy either.

Somehow, it’s not seen as important or as an extra. It’s the one thing that everyone goes through, certainly for adults, everybody dies. There’s gonna be a need for that for everybody. It’s still an evolution, but the role of philanthropy has been less important in Canada than in the U.S. from a pediatric perspective.

**Bryan Sisk:** When you developed the team and it was starting to launch throughout the hospital, how were you viewed by your clinical colleagues?

**Stephen Liben:** I’d like to hear what they have to say [laughs]. I don’t really know—you never really know—you only know what you think how other people look at you. I think we were a bit of a threat to some services that felt like, "Hey. We’re doing this. Who are you to come in? What are you actually doing that’s new or helpful in addition to what we’re already doing?” There was that bit of a threat. We had to show that we were an additive to a service and not taking over anything. We didn’t have the capacity nor the desire to take over anyone’s chair anyway. I guess that was mostly it.

**Bryan Sisk:** What were steps that you took to address that threat and to alleviate those concerns?

**Stephen Liben:** One of the things I noticed, because I came from the world of pediatric intensive care, that the intensive care units, the NICU, the neonatal intensive care unit, the pediatric intensive care unit, PICU, emergency rooms, each ward has its own mini culture where people feel there’s sort of an in-group and an out-group. The in-group being people you see every day that your work with and
the out-group often being people that you consult. In the PICU, if you have to consult a specialist, it’s a different feeling than if you were actually consulting somebody who’s already on your team. That kind of tribal, cultural dynamic, I thought of a way to incorporate the palliative care team so that we’re part of the tribe instead of someone you have to consult outside the tribe.

What I did in the early years, and I still do, was one of us attends ICU rounds every week on the long-term care patients, because they have one-hour rounds on those patients. We’re there whether we have a consult or not, partly to hear what’s going on and to give our input for patients who we’re not formally consulted on, but also to become part of the tribe of the ICU. The same in the NICU on the wards, we try and have—actually, we do that for oncology also, where we attend on a regular basis so that we’re not seen as outsiders who have to be called in from time to time, but rather we’re part of the team.

[00:33:56]

_Bryan Sisk:_ Speaking about that culture, within palliative care one of the big cultural elements from the beginning has been multidisciplinarity and lack of hierarchy where a psychologist, a social worker, a nurse, a nurse practitioner, and physician all have an important stake in the care of children. I’ve heard from reviewing this history that some people have perceived attention between the big tent concept of palliative care and the growth of palliative medicine as a physician-run specialty. Have you been aware or have experience with that tension?

_Stephen Liben:_ In palliative medicine and palliative care?

_Bryan Sisk:_ Yeah. There’s some concerns I’ve heard of that there might be a waning of the multidisciplinarity that’s at the heart of palliative care and that might be an increasing of hierarchy.

_Stephen Liben:_ I see. I haven’t seen that here. One development that I see as positive is that in Canada it’s become an official specialty. The American board has had palliative care as a specialty for a while, but in Canada it’s taken longer. By having it as an official specialty, it does create some hierarchy and some more administrative elements, but it also confers legitimacy to the field in that it’s less seen as kind of part of an open book, anybody can call themselves that. Now you have to pass certain hurdles and there’s sort of rigor and intention being placed. I suppose that can have deleterious effects, but I haven’t seen that here. Also, I’m a physician, so I have my own lens on things. We’ve had a music therapy service, for example, that’s actually now part of the whole
hospital not just the palliative care team. We’ve had a broadening of services, not a restriction, where I am anyway.

We’ve talked a little bit about Balfour Mount and some of your interactions and learning early on from the adult hospice and palliative care specialists. How much did the adult hospice movement affect that initial spark that drove palliative care or influenced that initial spark?

There wasn’t really a hospice movement so much in Canada. There’s quite a distinction in the U.S., of course, between hospice and palliative care. Here, palliative care, I think the term was coined by Bal. I’m pretty sure by him, but it was hospital-based in the beginning here. He and that service was absolutely—I don’t think we would have existed without that service starting. It just was such a powerhouse of a movement.

We were both that rose with the tide of that emerging awareness through Dame Cicely Saunders. Then that first textbook—the first Oxford textbook of adult palliative care came out and the one co-editors was also here in Montreal. For me, adult palliative care was absolutely essential to what I was starting off to do. I had no pediatric—I didn’t have any resistance in pediatrics, but nobody knew really what we were talking about. They were helpful, but not in the same way that the adult palliative medicine folks were helpful, and still are to this day actually.

How has that relationship developed? Is there a lot of close collaboration between pediatric and adult palliative care specialists and cross-pollination of ideas? Have they developed into kind of distinct separate entities completely?

I’ve seen different models. I’ve seen the Dana-Farber model where they bring the adults and pediatric groups together more often. We don’t very much here. I think there is much to be gained, but I also think there’s very much a separate—I mean the core concepts, for example, if we’re gonna explore what suffering means, clearly it’s gonna be helpful to do that as a group.

There are other issues that are much more specialty dependent, pediatric dependent. I think there’s a need for both collaboration and the separateness and overall to be bit more niche and specialized. I think that’s often the natural evolution things as they get more mature, as the field gets more mature, but I don’t see it as necessarily a negative thing.
Bryan Sisk: Looking over the span of your career thus far, what have been the biggest changes in the way that we care for children who are suffering or dying from these serious illnesses?

Stephen Liben: Better at pain and symptom management; We’re more aware of family meetings and communications that, that is an intervention, that the family meeting is the equivalent of a palliative doctor being in the operating room for a surgeon; and that we have a much more structured approach to discussions and conversations that are not just—that the role is not just to elicit what people are thinking, but to help them think in other ways than they currently are thinking as well and to come to solutions that are emergent. They’re not that they’re already there, the family knows what they want, they know exactly what they want. We’re an emerging phenomenon once there’s an interplay of what’s available, what’s possible. I think that’s what’s really advanced the most.

[00:39:31]

Bryan Sisk: Following up on that, what do you think are really the strongest areas of the field? What are the things that are going the best?

Stephen Liben: I think the psychosocial research is going very well. I think we’ve done a lot. We need to do better. You’re asking what’s going well. That’s going well. I think the other thing that’s going well is recognition that pediatric palliative care has a place within the wider spectrum of pediatrics in general, that it isn’t a nice to have but a need to have.

Bryan Sisk: What do you think are the biggest challenges that still remain?

Stephen Liben: Biggest challenges, let me think. There’s still a need to build enough of a core structure for what a palliative care team is. To have it staffed in numbers that sufficient for long-term well-being of those that are providing the care. It still often seems to be, where I’ve travelled, where there’s a few people carrying the load with a lot of call and lot of responsibility. I still see a lot of places where there aren’t people, like four physicians covering for the physician aspect of it. There’s often one or two and they’re on-call a lot. I don’t that’s sustainable in the long-term and I don’t think the newer generation will tolerate that kind of long-term stuff. I do think that’s an ongoing struggle, to bring it to an expectation that you can’t just have one or two people on-call.

[00:41:23]

Bryan Sisk: One other thing that has really in medicine over the last 20-30 years is an awareness—a thing that goes by multiple names, burnout, moral distress. I know that you’ve got a particular interest in mindfulness. I’m wondering how much of this awareness and
appreciation of the emotional toll of this care on the care providers was born out of palliative care?

*Stephen Liben:* I think a lot of it sprang from that. Not all of it, but much of it. Before Balfour Mount retired from palliative medicine, he founded the Center for Whole Person Care here at McGill. The idea being a very simple one. The kinds of things that we do in palliative care ask the question, "Why aren’t we doing them for almost all of medicine?" When is pain and symptoms management not important? When is the whole person, logical, spiritual, emotional, when is that not important in medicine?

People don’t come to hospitals and to doctors become everything is going great and they say you just wanna touch base. People are suffering, whether it large or it small, in some way. Addressing that suffering and reducing pain and symptoms and getting a location of care that’s important, all the things we say that are important in palliative care, you just draw a line and you could say, "Well that’s important in all of adult medicine or in all of medicine as well." Sorry, I lost track of the question now.

[B00:42:52]  
*Bryan Sisk:* I was asking about also the concept of mindfulness and self-care in preventing burnout in clinicians. How has that developed over time and how much of that is tied to palliative care’s development?

*Stephen Liben:* Right. A lot of the people that do the kind of mindfulness work are the ones to come from palliative care, so I don’t know how much of it is attributed to it. What I am seeing is an increasing awareness of the importance of when you talk about whole person care for the patient, it’s the same for the physician. The things that make patients unhappy, people not connecting with them, not listening to them, that also causes burnout for physicians. Physicians are humans too, healthcare professionals also.

There’s nothing more resilience building than making a human connection. It’s not so much a matter of draining your battery down at work by giving all day long and then charging the battery by going on vacation or on a weekend. Rather, in the work itself, doing and knowing that you’re making a difference with people and connecting with them, that’s a huge charge. That is the ultimate win-win in that you as a clinician feel enlivened and encouraged and charged up that you made a difference and the patient is happy and the patient’s family that you’ve actually connected with them and made a difference.
That is becoming increasingly recognized and there’s overlaps there about—the question then becomes, ‘how do you that? How do you connect?’ That’s where mindfulness comes in. It does bring sort of a state of consciousness where that’s much more likely to happen. You create the conditions for human connection in ways that are helpful to both peoples involved to improve.

Bryan Sisk: I’ve only got a couple of questions left. This one’s a hard question for most people because it forces you to tell me what you’ve done really well. What do you think is your favorite or most lasting contribution that you’ve given to the field of palliative care over your career?

Stephen Liben: I’ve co-created a course for medical students called Mindful Medical Practice. It’s now in its fifth year. At our medical school, myself and my colleague have made it a mandatory part of medical school. Every medical student has to take this course to graduate med school. It’s not an elective. It’s not about becoming a meditator or becoming a mindful whatever. It’s about clinical skills, but it does use contemplative practices in the course. It’s very much labor intensive, small groups of 20 students at a time over 7 weeks, 2 hours a week. Its 14 hours of direct instruction with 1 teacher. We have a whole cohort of teachers and teacher training program.

We’re publishing a book about the course this October so that other people can use that material to create their own courses if they want to as well and embed within medical school the idea that how you pay attention is as important as what you do. How you do things is as important as what you do. For me, watching these students, watching the lights go on for some of them going, “Yes. Yes. This makes since. This is good. I wanna learn more how to do this.” For myself and for others, that’s been the best charge for me, to watch that evolution take place.

Bryan Sisk: Lastly, I’d love for you to dream aloud. If none of the barriers that we talked about with staffing or budget or politics or any of that stuff existed, what would want care for these children to look like in another 10 years?

Stephen Liben: I’d like to see that palliative care becomes a specialty that’s needed sometimes, but not often. The principles that we talk about and espouse as being important are intertwined into the essentials of medical care so that everybody’s being greeted as a whole person. Clinicians at all levels are addressing all these issues to the extent that they’re comfortable and they have the skills to do so in ways
that mean you actually need palliative care specialists less than you do now, because the baseline assumptions and baseline knowledge would be so good that you’re average oncology team, which is already doing a very good job and has gotten better, would get even better at addressing the whole person and be given the reserves to do that and that basically we teach ourselves out of a job. I’d love to basically [laughs] teach myself out of a job where only from time to time is there sort of an expertise needed for something really difficult, but that I know its going so well, that the kids are getting such great care that you just need an occasional nudge of people and not so much a direct intervention.

[00:47:43]

**Bryan Sisk:** Anything else about this history that I haven’t hit on or that you think I should know about?

**Stephen Liben:** You probably already know it, but it’s the adage that don’t underestimate what a small group of people who have a really good idea can do. I think the power of good ideas is definitely underestimated in the world. We’re seeing the effect the now of the power of good ideas and the power of bad ideas that are pressing buttons that we’re biologically built for as well in politics and elsewhere. I think a more sophisticated understanding of the power of ideas, good ideas and bad ideas, and how to communicate will be part of the evolution of palliative care and we’ll continue to be the evolution of, I think, all of medical care.

*[End of Audio]*