The Power of Pediatric Palliative Care: Equity, Access, and Hope

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Children's Healthcare Canada, pediatric palliative care, right sizing, equity and access, grief and bereavement, healthcare leadership, national alliance, Health Canada funding, family-centered care, virtual care, training and education, health human resources, advocacy, lived experience, quality of life.

SPEAKERS
Katharine Smart, Megan Wright, Denise Praill

Episode Transcript

Children's Healthcare Canada 00:03
Connected by purpose, driven by passion. This is Children's Healthcare Canada's SPARK: Conversations podcast series.

Katharine Smart 00:20

Welcome to SPARK: Conversations Children's Healthcare Canada's monthly podcast series. This year, SPARK: Conversations has dedicated our conversations to right sizing children's healthcare systems. We're grateful to the IWK Health Center for its ongoing sponsorship of SPARK: Conversations podcast right sizing series. I'm Dr. Katharine Smart, host for this podcast series, and today I'm delighted to be speaking with two wonderful women, Megan Wright and Denise Praill.

Megan joined Roger Neilson Children's Hospice in 2014 as the CEO and has over 25 years of healthcare leadership experience, mostly within child and family services. Megan has been a valued member of the CHEO Management team since 2003, currently serving as the Director for Palliative Care. Before that, she was the Emergency, Critical Care, Inpatient Medicine, Surgery and Oncology Director. Born and raised in Ottawa, Megan completed a Bachelor of Nursing at the Toronto Metropolitan University, a Master's of Nursing Degree at the University of Toronto, and a Health Leadership Certificate from Ottawa University. Before joining CHEO, Megan was a nursing manager at the Credit Valley Hospital and the Bloorview MacMillan Centre. She has served on numerous regional, provincial, and national committees, advancing the care of pediatric palliative care for children and their families. She is passionate about ensuring equity, accessibility for all families facing life-limiting illness and access to grief services for children and their families. Currently, Megan Chairs the National Pediatric Hospice Leadership Committee. Megan is also the Executive Sponsor for Canada's Pediatric Palliative Care Alliance, a new coming together of healthcare professionals, leaders, and families with lived experiences, working to improve equitable access to high quality pediatric palliative care. When she's not at work, Megan treasures spending time with her family and friends, escaping into a good book and riding her bike.

Denise Praill joined Canuck Place in 2013 as Chief Development Officer and was appointed Chief Executive Officer in April 2022. She brings more than 20 years of experience and success as a senior executive in the philanthropic, non-profit and private sectors in BC. Denise has helped build a diverse and talented team that brought a relationship-based fundraising models and other significant strategies to Canuck Place - doubling annual revenues from $9.1M to more than $18M. She has also been a key member of the senior leadership team, providing strategic vision and direction to the organization. Before joining Canuck Place, Denise held front-line fundraising and senior management positions with United Way of the Lower Mainland. She also has management, communications and public relations experience in the private sector. Denise holds her Certified Fund Raising Executive designation and is a long-standing member with the Association of Fundraising Professionals. She is an active volunteer in her community, currently serving on two non-profit boards dedicated to animal welfare.

So we have some serious power on the podcast today to talk to us about this really critical and important issue. As our listeners know, Children's Healthcare Canada is on a mission to right size children's healthcare systems. Such systems are meant to be accessible, equitable, connected and purpose, built to meet the needs of children, youth and their families and the highly specialized workforce that serves them. They are evidence informed and integrated with other health systems and services. In this episode, we are going to be focusing on right sizing child health systems for pediatric palliative care.

Welcome to the podcast Megan and Denise.

Megan Wright 03:55
Thanks, Katharine, it's a pleasure to be here.

Denise Praill 03:56
Thanks for having us.

Katharine Smart 03:59
This is such an important topic and very close to my heart, as I have several of my patients that are clients at the various palliative care services that they access. It's really transformative for youth and their families. And I think a lot of our listeners may not be you know, really that familiar with pediatric palliative care, and what makes it unique compared to what they might think about when they're thinking about palliative care experiences they've had for family members, perhaps adults. So I'd love to hear each of you perhaps share your experiences. You know, what is pediatric palliative care? Who does it serve? Why is it so critical? And what are the outcomes your programs are looking to provide? Megan, do you want to start.

Megan Wright 04:41
Sure. Thank you. And I think it is something that most people really have mystified background in and when you first talk about working in pediatric palliative care, people are all at the same time very saddened. Think that you have a very sad career, day in and day out. But also are really confused about what pediatric palliative care is. So thanks for highlighting this really important topic.

Pediatric Palliative care is not just end of life care. We really think of it as, you know, being with the family right from diagnosis right until the end of life and into grief and bereavement. And for some families, that can be 10 plus years long. For some families, it might only be several hours. But for some families, we really are working with them from the time that they get a diagnosis, either in perinatal hospice, really in utero, and then into that birth planning phase, into the birth of their child and into grief and bereavement. And then for families who are have children who have medical complexities, we really are with that family, right from again, diagnosis into symptom management. Really trying to improve quality of life, right throughout their entire life, and into grief and bereavement, and sometimes even really transitioning to adulthood. So often people think of palliative care as, you know, hospice care in nine days, end of nine days of life. Sorry, I'll just repeat that, the last nine days of life. And that's really not how it is most of the time in pediatric palliative care. So, we really try to wrap our arms around the family. What is the services and care that their children need. What are the services and care that the families need. And deliver that through a team-based approach.

Katharine Smart 06:34
Amazing. Denise, do you have anything you wanted to add from your experience?

Denise Praill 06:37
Yeah, no, I think Megan really highlighted it. It's really about improving the quality of life, the comfort. It's really about listening to a family's values and then tailoring the care and the resources and the approaches to that care based on, I guess, the guidance of the children and families. So it's really, really person, child-centered care. So I think Megan, you did a great job of defining the differences between adults and pediatric palliative care,

Katharine Smart 07:01
And I think that's so important, because, you know, in my experience, I've found sometimes initially families, when you introduce this idea to them, understandably, can be a bit hesitant or unsure.

Obviously, it makes the family have to really think about their child's diagnosis and the fact that it is likely life limiting. But once they engage with the teams that are going to work with them and serve them. I think what you ladies have described is so much people's experience. It just so improves the quality of their life, at their child's function, their symptom management. And you just see so many of these families really blossoming and really being able to focus on their child's experiences and really optimize their day to day. And it's, it's, I've seen it be very transformative in terms of people's experiences, as well as helping to coordinate their access to the healthcare system and the ongoing services those children that have medical complexity often need. These teams are really dialed in and really able to provide that to families. So I think it's, it's a really interesting part of medicine and healthcare that for people that haven't had the opportunity to work with those teams maybe don't really realize. So I'm really grateful for the work you do and the service you provide to kids and their families. So thank you for that.

Denise Praill 08:11
It's such great - sorry, Katharine, it's such great feedback, and I think we're focused on the *care* here. It really is about the quality and about creating memories with that time that we have left, and that's the non-care side, but I think that can be some of the most valuable time that we can give families.

Katharine Smart 08:27
Yeah, absolutely, I totally agree. So you know, as you know, we're talking today about right sizing, pediatric palliative care in Canada, and I think what we've learned from this podcast series is so many of these services for children. Just, you know, are, there's amazing people doing amazing things, but there's not always at the scale that's needed to really serve all the children's and families that would would benefit. Tell us a bit about what some of the national efforts are right now around rightsizing pediatric palliative care and that system of care. Denise, do you want to start this time?

Denise Praill 08:57
Actually, Megan's the leader. I'm going to pass right back to her.

Katharine Smart 09:01
Wonderful Megan, take it away.

Megan Wright 09:04
Great, thank you. So you know, this is something that our group of leaders across the country has really focused on over the last couple of years. And to that end, Roger Neilson Children's Hospice engaged with Health Canada a couple of years ago to receive funding to create an alliance for pediatric palliative care, bringing together all of the folks that are working on pediatric palliative care across the country. And there's 18 different teams. Some of them are hospice based, some of them are hospital based, some of them are community based. But really everyone with the same goal of trying to improve equity and access. The reality is that less than 1% of children need pediatric palliative care, and so we really aren't part of the conversation most of the time, which leads to lack of policy, lack of standardization. And so the goal of the Alliance really was to bring together the experts who are working really pretty much in silos, province to province. Even city to city, to come together to do really three things.

One is create a comprehensive, evidence-based resource hub. So really creating standardized documents that everyone agrees on that this is how we want pediatric palliative care to be delivered across the country. Establish a network of folks who are working in this area, and so that team members know who to contact and who are the experts in their region that they can work with. And then sharing a created, shared, a share, creating a shared vision for inclusive care. And you know, equity and access is really important to us nationally, because there's only eight pediatric hospices in our country where the eighth one will open later this year. And that is a really small number of teams providing care across a national framework. And so for us, it was important to bring this group of experts together to work collaboratively. And so Health Canada funded a two-year project that we're really proud to be hosting here at Roger Neilson Children's Hospice, and really have all of the experts come together to create standards that every child and family should expect to receive, no matter where they are, in what province. And so our goal is really to continue that work - past the two years, we've put in another grant to Health Canada to ask them to continue to fund this work. Because what we've learned is there's so much work to be done this we've just really started to scratch the surface. And I should also mention that we are working with a number of families, partners with lived experience, in this project, and we're hearing from them that it is really very dependent on what province you're in, what standard of care you're going to receive, and that's not okay. Nationally, our children and families deserve to have the same standard no matter where they are.

Katharine Smart 12:01
So helpful too for people to know what to be aiming for, right? I think, you know, sometimes we just don't know what we should be doing. And it's incredible, I think to hear that there will be a standard so that it's clear about what's really what people should be expecting at this stage of their child's life and care. And it's wonderful, I think, to think about the positive outcomes we're going to see moving in that direction. Denise, is there anything that you wanted to offer in terms of your experience in BC and how this links to the work that Megan's leading out of CHEO.

Denise Praill 12:29
I think Megan you mentioned that there's only eight pediatric hospices across Canada, and it can feel like an island. Sometimes you cross the mountains, you lose touch with each other. So I think this alliance, bringing all of the expertise together into this Knowledge Hub, will really benefit the entire country.

Katharine Smart 12:48
That's great. So we're talking about the Knowledge Hub standards, really trying to elevate the experiences of children and families, making sure that it's equitable, accessible. Are there exemplars of right size pediatric palliative care systems right now in Canada, and if so, what are they doing, right and what should we be looking to take away from those programs?

Megan Wright 13:08
Yeah, I mean, I think one of the things that you know, I know that our team is really proud of, and so is Denise's team is really focusing on wrapping around the family. What are the family's values? What are the family's needs? And making sure that, whether it's care for the child, care for the sibling, care for

the parent, the medical care, the aftercare, the birth planning, the legacy creating. All of that is what we should be focusing on. It's not just that last few days of life. It is really that entire journey and to make sure that we're there to support afterwards from a grief and bereavement perspective. You know, families who go through the unimaginable of losing a child need our support after the fact, and it's one of the things that nationally is starting to get a lot of attention the area of grief and bereavement. And so I know that both of our teams are really proud that we are able to offer that full service to our patients. But again, we are two programs within a large country, and we need to be focusing on the fact that all Canadian children and families deserve that.

Denise Praill 14:19
Yeah, I think, I think Megan started us off on the right foot. I feel like Ontario and British Columbia may be ahead of many of the provinces, but I don't think any of us have mastered it yet. An important piece of our work in BC really is the location of care. So it doesn't necessarily mean you have to come to a hospice. Our expertise is exported. So we support children and families at hospitals, in communities, in homes across the province. We're delivering far more virtual care than we ever have before. So I think it is like, Where can we meet families, where they want to be met, and what is the suite of services that really helps along that journey? So like I said, I don't think. Any of us have mastered it yet, and I'm reflecting on it the with our with our initial introductions. Megan comes from that medical care background. I come from that nonprofit funding background, and that is another, I think, piece of the puzzle. Each one of our provinces have different healthcare systems, how these organizations are funded, and I think that's part of where the consistency needs to be put together. We certainly have consistency and alignment on our goals and how to support these children and families. How we achieve that care wildly different, depending on the province and the healthcare systems that you're part of.

Katharine Smart 15:35
Yeah. And one other thing I'd just like to add to what both of you have said, based on my own experience of being a pediatrician, working in a rural area. I work in Whitehorse, Yukon. I have a patient right now who's actively involved with Canuck Place. It's not only is that family receiving incredible supports and it's incredibly accessible. They can call and people are there to answer their questions and guide them, which has been amazing. But it's a huge support for us as the providers in the community as well. You know, as you've touched on, these are uncommon things that happen in pediatrics. A lot of these children have rare diseases. There's a lot of medical complexity. There's often a lot of symptom management that's just part of their day to day. And it's not always something that as a general pediatrician in a community, we have a lot of experience with. So having this team to kind of walk alongside you, be there to support the child that you're caring for, supporting *you* as the provider, to make sure that you feel like you're doing the right thing. There to answer questions, help you navigate things to be considering - is really amazing. And it really, I think, allows that ability to bring that quality of care that you're obviously able to provide in your own facilities, into communities, even communities that are quite remote. And that's been certainly my experience as a pediatrician living in northern Canada, and I've been really grateful for that, because then I can feel like, okay, this child who lives in our community, whose family *wants* to be in this community, this is their home. They're not sacrificing the child's care, their experience, the support they're getting because of where they live, and that's, I think, really meaningful. And something that we don't always think about it - is just what that

experience is like for other healthcare professionals. So I just want to give a shout out Denise, to Cannuck Place and your team and and just how valuable that's been. You know, obviously the family first and foremost. But I also just really want to make sure we think about what it's like for providers too, to feel like they can do a proper job of care at these really critical times. So I think that that aspect of this is really, really important part of right sizing as well. Excellent.

Denise Praill 17:30
Yeah, partnerships are key. Yeah, partnerships are key to this work. It's not work we do alone, none of us.

Megan Wright 17:36
Yeah, yeah. I think equity and access is a big piece. I mean, you're, you know, the fact that there only is 1% of children who require Pediatric Palliative Care expertise across our country speaks to the fact that every community does not need, thankfully, a pediatric palliative care team right in that community. But if you are a Canadian who is needing that support, then you know you want to be able to know who to call. And really this resource hub and the website, which will have all of the tools and know who to call phone a friend, will really be very helpful so that we can keep families at home if they choose to stay there, and if not, then there will be a center where they can go.

Katharine Smart 18:16
Yeah, absolutely. And that's that information sharing. And again, it's another example, I think, of where virtual care can be really powerful and empowering. And it's, it's something that people are more comfortable leaning into. And I think it's really improved experiences in this area of care, which is fantastic as well. So, you know, we, as we've talked about, this is a limited resource. It's a high level of expertise that's not available everywhere you, both of you are using strategies to sort of scale and spread. But where are the gaps? What do you think is needed to right size palliative care systems for children across this country?

Megan Wright 18:52
Can I go first, Denise?

Denise Praill 18:53
Yeah sure sure sure. Yeah. I think, when I think about the gaps, of the obvious ones that we've already chatted about in terms of equity and access across the province, the vast geography of Canada. I think there also are the areas of education, training and research that could be strengthened. So, when I think about Canuck Place, we are a training site for UBC pediatric medical residents. We routinely support undergraduate nursing student education the rough clinical placements and teaching at Colleges. The Royal College of Physicians and Surgeons recently established the subspecialty and fellowship in pediatric palliative medicine with the first exam was in 2019 so it's still a relatively new area of medicine. Canuck Place is one of only two approved sites in Canada for training. So when I think about expanding training, that could be one of the gaps that could be covered off across other provinces.

Education. I know at Canuck Place, we provide training on the serious illness conversation guide.

We've trained more than 900 clinicians across Canada, more than 150 internationally, on how to have those tough conversations with families. How to how to source what a family's values are, and then can we line up that care in accordance with that? So, how can we export the knowledge that's within these teams of expertise to other clinicians? And then the third piece would be research, because we're such a new, evolving part of medicine, and because Pediatric Palliative Care differs from adult care, the conditions for kids and families and as well as the trajectory of illnesses are different. So that research that needs to be focused on longitudinal studies, like with children with life threatening illnesses, maybe pain in nonverbal children, and what I'd love to see a study on is how the families go on following. We can't save every child, but our families tell us we're helping save them. So what is that long. I know it's a it's a really intense part of medicine for a very small number of people, but the impact is massive to those families. And if we can demonstrate, if we could demonstrate the survival of those marriages, those families, the siblings that go on to university, I think that's the I think that's the gift of pediatric palliative care is helping that family heal and carry on.

Katharine Smart 21:06
Absolutely. Megan.

Megan Wright 21:09
Yeah, I think I agree completely with what Denise was was saying. And there's two other areas that I would highlight. I think, you know, Katharine, you spoke about it early on. It's really about awareness. Awareness and comfort around these conversations. We do need to talk about palliative care in children. Denise is right. There are some that we cannot save, and those we cannot save, we really want to help support. But part of that is really the community being comfortable around the conversation around death and dying in children. It is a fact that we do need to be aware of, and one of the things that we're focusing on here is grief education, psychosocial education, for the generalist, for the next door neighbor, for the baseball coach, for the teachers who are then working with the siblings, or, you know, the the other community members after there's been a death. So that is something I think that we really ought to be spending a lot more time on.

And then the last one, I think, is health human resources. You know, there's a scarcity across every specialty. So when you start to talk about, you know, all of the opportunities that exist for healthcare practitioners across the country. And you know, as a graduate of almost 30 years ago now, when there was no jobs to now, you know, nurses who are graduating, there's so many opportunities and so many wonderful opportunities, and they're all as deserving as the next. But you know, you can imagine trying to sell for people who have never worked in the field pediatric palliative care. You know, unless we can really, you know, make sure that people understand it. And again, it goes back to that awareness. Then our health, human resources continues to suffer. And then the last piece I would say about Health Human Resources is really just that wellness, right? This work is challenging. It's tough. We have to be mindful and aware of the fact that, you know, we need to protect our team members as best we can and make sure that they're well enough to support the next family and the next family after that. And so it is something that you know, again, through research, as Denise said, you know, we can only learn how to do better and how to make sure that we're supporting the folks that are providing this great care.

Katharine Smart 23:20

Yeah, absolutely. You guys have highlighted so many important areas for growth. So when you think about an organization like Children's Healthcare Canada that I think is really doing an amazing job of bringing these issues to light and trying to set a national or pan-Canadian agenda for children's health, how can they help your work in this right sizing effort for these kids and families?

Megan Wright 23:41
I mean, I think that we've really benefited, The Alliance, has really benefited from the support from Children's Healthcare Canada. We were able to, you know, lean on Children's Healthcare Canada to piggyback off of their national conference this past spring and have a full day workshop where we were able to bring a group together who, it's about 100 people in the room from across Canada really working on something we're calling our Core Care Pathways. So that is, you know, really the standard of care that all children and families can expect to have. So that that partnership has been really helpful. I think conversations like this, I think awareness, advocacy, I think that you know, we really need to tap into Health Canada for them to understand that this is continued work, because it is such a small percentage of people continuing to work provincially is not going to make a huge dent in the work that needs to be done. We really need to have a coalition, and this alliance really is our best bet. So working through Children's Healthcare Canada, due to advocacy with Health Canada, I think, is really helpful.

Denise Praill 24:48
Denise, yeah, couldn't have said it better. It's really the sharing, the understanding, the awareness of the field, advocating for access across all provinces. And I think one of the most important things that Children's Healthcare Canada. Is bring that family voice and bring that family engagement piece to the fore. It's so powerful when our families speak about the care that they receive, and when they speak about it to other audiences, whether it's wider or other practitioners, or whether it is with our policymakers and decision makers within government and health systems.

Katharine Smart 25:18
Yeah, absolutely, learning from people with lived experience, I think, has been one of our biggest lessons in the healthcare system over the past few years, right? Is let's listen to what people have to tell us, and so often what they're thinking about or sharing are maybe not things that we've considered. So that those perspectives, I think, can be really transformative. And the goal, I think, that we all share, which is providing family-centered wraparound services to people when they need it. Okay, well, you women have shared some incredible wisdom with us today, I think, really inspiring the work that you're doing. It's so important. And again, for many families, it spans years of their life with a child who does have medical complexity, and I know like I've already shared, it's transformative for those families.

So I want to give you both an opportunity to give a pitch. Denise, I'll maybe start with you. What would be your 30 second elevator pitch to policymakers regarding the uniqueness, impact and value of prioritizing and focusing on children and their health and healthcare, specifically right now, when there's so many competing issues out there.

Denise Praill 26:21

So true. Well, I would first start by saying pediatric palliative care, it does affect a relatively small number of children and families each year, but the impact of that care is massive, and I just have to hang on to that statement. It is about keeping these families whole. It is about providing quality for what people deem the imaginable. It's like we want you to imagine our family's experience, and let's walk the path together so. And I think Megan, you said earlier on, it's difficult to say that children die, and there is a pushing away of that we really need to embrace, that this is part of life. And thank heavens, there are people like Megan's team and others across the country who are delivering this care for families. We invite our policymakers to think about that and be inclusive. So how can we fund pediatric palliative care effectively so that it is inclusive, it is accessible to everyone across the province, no matter the communities you live in. So it's about accepting that reality.

And then I'll add a little dose on top that we do get the feedback like It must be really difficult in your field. It certainly is difficult to witness. But I also would say we get to witness the best of humanity. These people are displaying love on a scale like you've never seen. I mean, there's just such a massive upside to the work of what we get to witness every day. So I would ask the policymakers and decision makers funders to stick with us. It is difficult work, but it has such, such an impact on the families that we are able to care for and support throughout their journey.

Katharine Smart 27:53
Wonderful. Megan, it's your turn for your 30 second pitch.

Megan Wright 27:57
Yeah. Denise said it really, really well. I think the thing that we all know is that children are minority already in our country. Pediatric palliative care, children are, you know, less than 1% and so that makes this topic in this population, deprioritized, and really then less resourced than it ought to be. The impact that this work can have I see day in and day out. Right now the kids are doing a magic show right outside my office. The volunteers, the staff, the therapy dog, everyone is really providing, you know, a wonderful couple of hours here for these kids, these 10 kids that are here with us today. And so every child deserves that. What we have right now is a national standard for pediatric palliative care that hasn't been updated to since 2006 that's way too long. We have limited training and unclear roles, and we really want to make sure that the people who are coming into this work have all the supports that they need to do the best job.

We have unequal access due to geography. And as we've highlighted here, BC and Ontario may be in the lead and, you know. But there are people who are doing great work in every single province, but they are maybe one or two people in an entire province. And that is not only exhausting, but it's not fair to those clinical teams, and we need to, we need to do better.

And then lastly, I would say that, you know, if we don't wrap our arms around these children and families, families are less left to coordinate this care themselves. In our Alliance work, we've had over 1000 conversations with partners with lived experience, and every single one of them has shared with us how without pediatric palliative care, they would be left not only caring for their dying child, but also coordinating their medical care. And I don't think anybody in Canada would think that that would be okay.

Katharine Smart 29:53
Thank you both so much for sharing your passion for this really important work, your leadership across the country in terms of making sure that this care is equitable and accessible for kids and families, regardless of where they live. And just for the passion that you bring and the teams that you're building to ensure that we can get this care where it needs to be. So, I really appreciate you making time to share that vision with us today, and I think anyone who listened is going to have really benefited and learned a lot. So thank you both.

Megan Wright 30:21
Thank you for discussing this really important topic and thanks for having us.

Denise Praill 30:25
Yeah, it's lovely. Thank you.

Katharine Smart 30:28
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