Eric Stephanson Oral History.
Biography

Eric Stephanson has worked for over 40 years as an ordained congregational minister, including in a bilingual French-English congregation in northern Quebec. He also served as an ecumenical university chaplain in Alberta, and in a variety of congregations in Victoria and Vancouver, B.C., including a bilingual Chinese-English congregation. Mr. Stephanson also worked for 20 years as the Spiritual Care Leader at Canuck Place Children's Hospice in Vancouver, where he was the first at Canuck Place to integrate spiritual services and support during events of family crisis.

Interview Abstract

Mr. Eric Stephanson begins the interview by describing his path into ministry and divinity and how that intersected over a lifetime, into a career in pediatric palliative and pediatric hospice care. Mr. Stephanson describes how spiritual guidance grew into the services offered at Canuck Place Children’s Hospice, the first free-standing North American children’s hospice, and how Mr. Stephanson took a chance opportunity to be on the first cohort of multidisciplinary professionals working to deliver palliative services to children in North America.

Mr. Stephanson then goes on to describe how his life experience as a minister helped prepare him to be “comfortable with being uncomfortable” as he approached families in crisis as their child became seriously ill. Mr. Stephanson describes his best teachers of whole human care to be the children themselves, their families, the nurses, and the social workers. He also describes the multidisciplinary model of health care at Canuck Place and how giving every team member, children and families included, a space to speak face to face and ask questions, resulted in people feeling they’ve received the utmost care and people would say “We just love coming to the hospice.”

Mr. Stephanson concludes with his desire to see that pediatric palliative care and pediatric hospice care become fully integrated. He also describes how holistic health care planning could better meet the needs of ill and suffering children by providing more freedom to switch between medical curative care and palliative care in a multidisciplinary model.
Interview Roadmap

### Beginnings

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal career influences</td>
<td>1-5, 17</td>
</tr>
<tr>
<td>Colleagues, Mentors, Mentees, and other influential figures</td>
<td>2, 8</td>
</tr>
</tbody>
</table>

### Pediatric palliative and hospice care

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evolution and history of pediatric and hospice care</td>
<td>2-3, 7</td>
</tr>
<tr>
<td>Multidiciplinary hospice teams</td>
<td>1, 3, 6-7, 13</td>
</tr>
<tr>
<td>Canuck Place</td>
<td>2-7, 11, 14, 16-18</td>
</tr>
<tr>
<td>Spirituality, suffering, and whole person care</td>
<td>3-11, 13-15</td>
</tr>
<tr>
<td>Religion versus spirituality</td>
<td>9-11</td>
</tr>
<tr>
<td>Challenges</td>
<td>8, 11, 16</td>
</tr>
<tr>
<td>Successes</td>
<td>6-7, 11, 14, 17</td>
</tr>
<tr>
<td>The future</td>
<td>17-18</td>
</tr>
</tbody>
</table>


**Bolding at the request of Mr. Stephanson**

<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Byrock, Ira</td>
<td>8</td>
</tr>
<tr>
<td>Eng, Brenda</td>
<td>2</td>
</tr>
<tr>
<td>Kearney, Michael</td>
<td>8</td>
</tr>
<tr>
<td>Mortally Wounded: Stories of Soul Pain, Death, and Healing</td>
<td>8</td>
</tr>
<tr>
<td>Saunders, Dame Cicely</td>
<td>2, 8</td>
</tr>
</tbody>
</table>
Bryan Sisk: Today is December 13, 2019. I am Brian Sisk and I am in St. Louis, Missouri. I'm interviewing Eric Stephanson over the telephone for the Pediatric Care Oral History Project. Mr. Stephanson is in Lake Cowichan, that's C-O-W-I-C-H-A-N, British Columbia, Canada. Thank you for being with me today. We already had a discussion, before. But now I would love to just get us started. Could you just walk me through your story of how you came to pediatric palliative care?

Eric Stephanson: Well, I would be glad to do that. I was ordained as a minister working in churches in the 1970s. And I wound up working northern Quebec in a French/English environment for a while. Then I was a University Chaplain for a while in Alberta, working in very interesting circumstances, a multidisciplinary team. And then I worked in a very large congregation in Victoria on Vancouver Island in British Columbia for almost 10 years, and another congregation then in Vancouver. Then, I went through a period of significant change, sort of a middle-age kind of trying to figure out which way I'm going. I worked on doing interim ministry, which is really quite this intervention in congregations, either that need palliative care or some tragedy or something has happened or some betrayal has happened. And so I worked in circumstances where everybody was angry with each for a number of years. And I realized that the work that I had done as a minister for all those years— as a minister you have an amazing opportunity to enter into these intimate circumstances with individuals or families at various critical life junctures. I mean I did, I mean, weddings are kind of fun, funerals are challenging. I find them almost more satisfying than any other kind of involvement. And so, at this stage in my life where I'm— within a month I'll be 70. I look back over 40 to 45 years of involvement, and I'm sure I've been involved in well over a 1,000 or 1500 funerals or circumstances like that.

What happened over the first 20 years of that prime timeframe of my work as a minister is that a number of times I was involved in very tragic circumstances with children. I remember one for example 25 years ago, a child was playing with his parents, with his mom and dad in the evening he had a great time, he lined up all his toys on the edge of the bath tub as he was having his evening bath. They put him to bed. The father got up in the middle of night to check as they usually do— somebody gets up in the night, they always look at their kids. Everything was good and then they got up at 6:30 in the morning, and he was dead. And he had contracted meningitis overnight and he just burned up, he was gone. And the trauma that— this was a couple I did not know. I was asked if I would see them because I'd been involved I guess or shown up in that hospital through other work. And somebody just said, you know, "Call this fellow and
maybe he can be helpful." So I wound up—I was called to the hospital and when I got to the parking lot and entered the doors—it's a pretty large hospital, I could hear a woman's voice wailing down the hall. And this was the mother. And so I spent a couple of hours that day and then on the following day, and over weeks I extensively was to help them move towards a memorial service or a funeral, but along getting to know them.

And that kind of experience happened to me a number of times over 20 years. I mean, the drowning of a child, for example, in northern Quebec and how the family came apart because of that. Or another tragic circumstance where a mother took the life of her baby and then maybe a month later took her own life. I mean terrible, terrible circumstances that make everyone who hears about it feel wretched. Children with different kinds of diseases, whether cancer or coupled with spinal muscle atrophy. Accidental death, because there was a child who leaned on a screen window in the upper floor of a house; after somebody had come to put the screens on, they apparently left the window apparently open in a way that this little two-year-old or three-year-old child was just crawling around and got up on a chair and leaned on this window and fell out and then died.

So many experiences like that. I mean for me at any rate, it hadn’t been my intention to work with children dying, certainly. I'd expect there would be a few across the years, but by the middle 90s then, I was living in Vancouver and through a church where I was very involved, I met a young fellow who was a nurse and he was applying to be one of the first nurses hired at a new place called Canuck Place Children's Hospice. I've known people before who've worked in places with children and I myself had worked as an emergency room chaplain for some time when I was up in Evanston in Alberta. Mostly I was a volunteer because I was one of the university chaplains, but a fascinating experience.

At any rate I knew this young guy and he was so motivated, and he said, "Come and see the building." It was an old mansion in a very lovely area of Vancouver that was being absolutely refurbished. And it was a long story about how Canuck Place got established which was very fascinating and worth the research. But at any rate there was a board of directors who had been established through the work of a young woman name Brenda Eng, E-N-G, who was the driving force. She was a nurse of palliative care or a cancer specialist nurse in Vancouver working always with children. And she put herself through what was sort of a training program with Cicely Saunders over in England, looking at the hospices that been established there, and was quite struck that there were a number of children's hospices already in Britain at that stage. She came back to Vancouver determined to establish a hospice for children there, and over a period of years did.
So, this young fellow eventually was hired, within the following number of months, to be on staff—one of the first nurses at Canuck Place. I saw him once in a while. I wasn't very close to him. But the first child who came into the hospice was in November of 1995. They had one child for a month or two in hospice and then this child then died early on. And then at the turn of the year in 1996 they had more children. It was a very slow process at first, partly by choice and partly because medical folks were a little bit hesitant about a new medical facility in town. But by the spring of 1996 three different people said to me—one of them was this young guy, I guess, but three different people said to me in odd circumstances, "You know, they are looking for a chaplain over there. Why don't you apply?" And I thought, "I've got a job, thanks very much." [laughs] It was kind of funny in a way for me.

But what happened then was that this idea started to take root in my head. And I thought, "Why don't I at least explore it?" And so, over the course of a couple of months I did send in a word to try to find out what was going on. Because they were brand new and they were trying to establish a sort of a staff team accountability model from the very beginning so that the staff team who were going to hire a person to be a very part time chaplain at this hospice for children. So I sent in a few things and didn't hear from them for weeks on hand, and I thought, "Well, that's odd," and then I got a phone call saying, "Would you be willing to come to have a conversation with the four or five of us?" And I came. It was a most curious interview because, there as nobody identified as an eventual supervisor. These were all nurses, nurses and social workers and a couple of other people, and it was very conversational. But they wanted me to name the experiences that I had, had working with children.

Their big issue was they wanted to hire someone that they could work with. They wanted a collegial team of who would be, who would all have a similar orientation towards caring for children and so on. And, of course later on well, of course, if you are working in palliative care, it's always teamwork. And so why not start from the very beginning with the model that says the team is actually paramount. So, at any rate what happened over a period of months was that I was hired. I was asked to come on as a very part time chaplain. And then on June the 16th, 1996 I began work and eventually worked up to half time and then was at halftime for many years. It's called a spiritual care leader. And worked for 20 years and then stopped on the anniversary of the first day that I worked on June 16th, 2016. It was a fascinating experience. And that's a little bit about how I first got involved in it. And as you can tell I can go on and on. I should stop and give you a chance to pick up where you want. [laughs]
Bryan Sisk: No, it's my favorite thing to sit back and just have people tell me stories. It's a pleasure.

Eric Stephanson: Yeah, yeah. [laughs]

Bryan Sisk: One thing that struck me from the 70s on, you seemed to be the type of person that likes to put yourself in the middle of strife and suffering and crises. What—that seems to be what eventually led you to this hospice. So, where does that come from? How did you develop that sensibility by yourself?

Eric Stephanson: I would rephrase it. I don't think I like to put myself in situations of strife. But I've always made a joke about working in the church. There are a whole lot of people [in the world] who don't want to get involved what they call "organized religion." I would say that anybody who says that it's obvious they've never really got very involved with most churches. Most churches have a lot more going on under the surface than you can imagine. It's like that old joke about looking at the beautiful swans swimming on the water and it looked absolutely elegant on the top of the water, but you don't see how their feet are churning underneath.

As a young boy I was extremely introspective. I look back now, and have for many years, on my childhood and my youth particularly, as very active and busy but extremely self—anyway, I was introspective, I was shy. I mean I was just really hesitant So, in my teenage years I stuttered so badly I didn't talk to people. My wife says now I'm making up for it, I guess. [laughs] So, it was not anywhere near my target to work with people in circumstances of difficulty. But it was true these experiences that have happened—I mean if you are working in a church, for example, when you get a phone call that says "Somebody has been tragically killed, we need you to come right now," there isn't anybody else you can refer to. You go and you stumble through it. So, most of my learning was in the crucible of those circumstances. What I discovered was, I wouldn't have named it in this way at the moment, the first 10 or 15 years or so, I discovered that I could be comfortable being uncomfortable. And that to me is kind of the watch word about working with people at the end of the life. The other phrase that I use with the staff at Canuck Place over, over and over; part of my role is to be with the family, but a lot of it also was to support the staff. We had a staff team of like 60 or 70 altogether because it was the full complement of nurses and doctors every day. There would four volunteers per shift, per day, so 12 volunteers at least every single day and time. So we had 400 volunteers, 60 or 70 medical staff, plus a bunch of other people raising funds and doing other things.
And when I was there, between 130 and 350 families on our list every year coming and going. So, it's a constant—a whole series of concentric circles of communities all called Canuck Place, beginning with the children. But I discovered that I could be comfortable in this way at Canuck Place. I tried to encourage the thought particularly, just to remind ourselves when we feel like we are not up to the challenge of the job—honestly I began doing this every day, saying, "I'm going into a room and I have to accept as I go that there is nothing I can say or do that's going to make a material difference in the life of this parent or the life of a child." I say that because everybody says, "Well, you'd probably be a comfort in someone's journey." But if you are in my shoes—I grew to accept that by coming into the room I was offering something else. So, in other words I don't have an answer. I don't have something to fix the circumstances of the child. I don't have wisdom necessarily to share. But I'm willing, if someone sits there and if they cry, I often will cry, or I'll just sit quietly. And so, over the years I grew to accept that I could be in these circumstances, and it wasn't my plan to work in churches that were blowing up or falling apart, but I did work in a few like that. I found working at Canuck Place in the children's hospices by far the most satisfying, fulfilling involvement I think in my whole life. It's just an amazing experience. I'm going off in all directions. I need to pause again and say, "Where are we now?" [laughs]

[00:15:47]

Bryan Sisk: You came in certainly with skills you'd acquired as a minister over 20, 30 years. Was working in the hospice like more of the same in terms of the skill you needed, the experiences you were in or was it something that was qualitatively different for you?

Eric Stephanson: I think it would be on a different spot on the continuum. But in different circumstances—if you work in a congregation you are essentially accepting that you have 100, or 200 or 300 bosses. And everybody has a different idea what you can do and how you should operate and so on and so forth. But you are a little bit like a CEO of a company, where you are hired by the company and you therefore have to give direction to the company, but at the same time they can pull the rug out from you at any moment and say goodbye. So, it's kind of a balancing act. And a lot of times in the congregation, there's many occasions where you are with individuals and you can say and do things that are helpful to them. But it's not as often when you are in a circumstance where the parents—the very first time you ever meet the parents, they've already accepted or they've already been told the worst news any parent could ever hear. So your introduction is most always kind of awkward. The day of diagnosis for most parents is almost the worst day then the actual day of death of their child.
So, it's qualitatively a little further along in the continuum of care perhaps. But at the same time then, on my side of the relationship with these folks, I realized pretty quickly that you can never depend upon prior experience to help you in these circumstances. You have to be alive in your shoes at the moment and listen, and pay attention and be patient and be cautious not to jump to conclusions, or the way that my wife says, "we both jump to contusions." And so the whole business is you're there as a companion potentially at the pleasure, as it were, of the parents or the child. And if you decide you are in charge, then the thing is over; it won't work. So, you have to be, you have to bring the skills that you have, the person that you are, the past experience that perhaps you have; the hopes and fears are all that's left of us, of course, what human life is all about. So bring that as kind of a toolbox that's represented in your presence, in your very person. Because nobody wants you to pull out a piece of paper or a book or something else. They want you to be there and then try to figure out what actually makes the difference. And there are some circumstances where you have to bold and suggest something that hasn't been said. And lots of the training for actual care that's done in hospitals have such a strong emphasis on a kind of Rogerian pattern of listening and then mimicking back to the person what they want. And then very early some of the people said, "Don't just reflect back to me what I just said." They don't want that. One person said to me, "Just be real with me. Don't be professional."

In theological circles, you are here to be pastor above being a professional. By that they are just trying to draw a nuance that they want you to be a person. So then there's always a paradox. I think palliative care involves teamwork, but it also involves paradox that you have to be vulnerable, you have to be willing to make mistakes. You have to be willing, perhaps even willing to share things even in your experience that are difficult to share. But you only do that in the context of a relationship developing over many times, many years. And so the paradox is that there's vulnerability and there's boldness that's required. I don't think that you can find preparation for this work in a book. I think you can find lots of starting blocks, let's say, but I think you actually learn best from your mistakes. And it's trying to be helpful to people, to be present with people; it makes a difference.

So, in the circumstances of Canuck Place, I would say that my teachers were the children number one, the parents' number two. The parents are just amazing; they are losing their children over time. And then I would say the nurses. The nurses are the most astonishing, because they all, I would tell them, they are all spiritual care workers. I said, "You've got some medical skills and gifts and so on and so forth, but what you are doing is you are paying attention to the whole person you are with. That is spiritual care. You are not just looking after disease or symptoms. You
have to do those things too, of course. But you are trying to pay attention to the person. What does this mean for them? What are they feeling? How can you be present in such a way that some of the moral distress or the spiritual fear, whatever it is they are going through, can be alleviated or witnessed in a way that's positive or healthy?" So, I found that nurses and a couple of the social workers and so on, to be the best companions for me on this journey because I—when I began working there, I just thought, "I'm the beginner. I don't have a clue." But it was only years later that realized that, "well no, I actually did have some experiences before that I can impart here that I can draw upon." [laughs] But I didn't think of myself a person who was skilled in palliative care and that kind of thing.

That was a lot at the beginning at any rate for me. And I was just delighted to realize that the team that hired me—and there were a few changes of course, but it felt like you become intimate friends with people, that there is a form of intimacy professionally working together, I think, that's unlike most other things. You are standing in that crucible spot where children are dying, people are falling apart, it's very difficult and you're present, and then you are present to one another in that way. I learned a lot from the nurses in that particular experience, spiritually.

[00:22:55]

Bryan Sisk: Was there a community of chaplains outside of Canuck Place that you knew that were doing this type of work? Because in other areas of the development, nurses and doctors are reaching out to other people who were starting to do this. Is there anything similar with chaplains?

Eric Stephanson: No there really wasn't. I mean from my perspective. I mean it could the other chaplains would say that I'm not being very insightful or something. Canuck Place was the first freestanding children's hospice in North America in 1995 when they opened. Over the years I went to a number of conferences across Canada, down in the States and so on. Ultimately, I was able to visit some children's hospice in Britain as well. And I realized people used to say at Canuck Place, even in the 90s when we were doing pioneer work. I always thought, "Let's not take ourselves too seriously." [laughs] But then 10 years later, we are doing pioneering work. The truth is, I heard this from the doctors as well, "find a titrate of the drug and find out where you could go with it." They're constantly looking for counsel from others who've been there. What if you are at the end of—you are giving the maximum amount that's supposedly allowable and it's not working, so where do you go then? And unfortunately, lots and lots of people would say, "Well, that's all we can do." But at the same time when you are in a circumstance like this and children are suffering, I've worked with doctors that said "we're actually on the cutting"—I mean they
wouldn't say this in these terms, but they were actually saying "we have to try something more, we have to take another step."

I grew in respect for people who were willing—there's a certain kind of risk there, but it's sort of a calculated risk. We are stepping forward to care for children. We are not in the business of medical assistance in dying, that's not our work. But we are trying to support them and alleviate, palliate the symptoms. So, it was a great opportunity to learn and grow together. And at the same time, I mean I did seek out some of the chaplains in the hospitals around. Most of them looked at me as though somehow, what was I doing in this work? And I'm sure you might have heard of this yourself, there's a little bit of a sense of palliative care work or hospice work is just at the foot of the edge of medical care. I've met people who said, "Well, that's after all of our medical initiatives have failed, that's where you go." [laughs] And I think that added to its presence. I've met people who work just as diligently in hospital settings who I have great respect for, and yet who say, "I could never work in the environment you are. I couldn't go there." Or on the other hand you would have people who would say, "Well we care for children who are going to recover," as though somehow that would—[laughs] Anyway.

So, I didn't find a lot of mentors. I did read. I read a number of different people—I enjoyed them all. I read some stuff from Cicely Saunders, the positive care doctrine in the States, Ira Byock, she wrote a book a number of years ago that was great. Michael Kearney in Ireland wrote some very interesting and helpful things, a book called Mortally Wounded. I've always found myself drawn towards those people who have identified a paradox, because I feel like that is a step into this work. If you don't accept living in a paradoxical situation, I feel like you are holding yourself aloof somehow. Because that's where the children and their families live. So, they are trying to learn what is it like to be living with dying, honestly. So, my best teachers were the families, the nurses. I listen to chaplains of course and I did some reading but it was mostly on the job kind of support from work along the way.

And how well within the team of the hospice... how well was the role spiritual care and chaplaincy accepted and appreciated?

Eric Stephanson: [laughs] I think it was very, very suspect at the very beginning, honestly. I mean, one moment I grew close many years later, very Scottish, lovely hilarious woman. I remember an earlier experience—I told her about this years later, and she said, "I didn't do that!" I said, "Yes, you did." [laughs] I just had the distinct impression when we were chatting and I was trying to offer some things. She gave me a look; I teased her about her Scottish
look. Said something to the effect of, "Don't call us, we'll call you if we need you. We are not sure we want all of your religious ideas here." That kind of stuff. And I think there is a legitimate confusion in the mind of lots of these people that work in these areas. And so what is religion, let's say, and what is spirituality? And I would have been just as confused in the beginning. But then over the years significantly—I mean, British Columbia is one of the most secular of provinces. You get more and more secular the further west you go across Canada. And so, the great majority of people in British Columbia who claim to be spiritual but not religious. And so, it's one of my jobs is to do training sessions with the volunteers. And I did a few of the staff as well, trying to help people. Like, what if the family said to the nurse, "Would you pray for us?" Or, what if you get into a conversation where you honestly feel like you are ill equipped to participate, or you just don't want to, what do you say?

I've tried to develop some ways to speak about this that would be comfortable and affirming of the actual lived experience that people have. For example, I did, and most of these things that I stumbled into because like you I was looking for books, resources, ideas, and I felt so many of that just didn't, they weren't, they didn't go far enough. I felt like they were—it was like looking for a university textbook, and finding something written for kids in grade five. I don't mean to demean anything, but I just wanted something with a little bit more luster in it or something.

But at any rate, I wound up playing in sort of a playful workshop way, working with volunteers. And one of the very interesting experiences I had is—I just wrote up the word religion on the top of a huge piece of newsprint. Then I'd say to a group of 20 to 30 prospective volunteers, "Just name every word or feeling that comes to mind when you see the word "religion."" And of course, there would be all kinds of nice, fuzzy, warm words that would come up about love and one thing or another. And then eventually somebody would say something about hypocritical or the wars of religion. Essentially, they would simply be reflecting on the fact religion is a difficult topic for lots of us. And about a third of the words that would come up in the free association would tend to be very pejorative about religion. And so, I'd take another sheet of newsprint and write the word "spirituality" at the top, and guess what? We'd have lots of similar words but then different concepts as well. But never once in all the years that I did this did anybody ever throw up a word that had any negative or pejorative connotations about spirituality.

So after doing this I left two pieces of paper up on the wall, and I simply asked the question, "How would you explain the interrelation between these two thought realms to anybody who is asking you, "What is the link
between religion and spirituality?" Well, I got some fascinating answers. I mean I remember one young woman said, "I think one is inner directed and the other is outer directed." I thought that was quite insightful. And a variety of different kinds of insights and perspectives that people have. And there was some fellow who had been very quiet in the group, said something to the effect of, "I think that religion is the roadway or direction for a path that you are going to follow, and spirituality is a description of your experience in traveling." I like that a lot because I think religion is something you can study and the world's religions or any particular religion has an intellectual construct underneath it. I'm sure that's the case with spirituality. But the limit today is that word "spirituality" has in mind experiment with the newsprint, it's a huge container that is all positive for everybody because everybody puts their own meaning into it. What puzzles myself, if a person identifies themselves with one particular religion—like I would often get asked that—we have a lot of Muslims in Vancouver, a lot of Asians and so on and people and some Hindus, and so lots of people from other religious backgrounds. At any rate people would ask me the question, they'd say, "You work in a church, you must be Christian. How do you work with everybody who's different?" and then I try to talk about religion and spirituality. And I realized I needed a little shorthand phrase.

The truth is that there are, some people are religious, but everybody is spiritual. And they look at me, and I said, "Because spirituality is the word that we use to refer to what makes our lives meaningful. Spirituality is meaning making." And I thought over and over and over when I would say these things in the group, so that when we come to these conclusions collectively, that there would be almost like everybody with their wrinkled brows would sort of relax, and people would say, "Oh, of course! That's comfortable then." We all have a different way of seeing and experiencing things. And some of us interpret our spiritual experiences through religious frameworks. But lots of us don't, most of have our own independent frameworks or frameworks that are collection of ideas from lots of different places and whatever, whatever. But the bottom line that is if you accept the spirituality as meaning making, then you can actually talk to anybody about whatever is meaningful to them.

For me that was great step forward in my own experience that I get through the actual work and being with children and the families, but the nurses particularly and then my own kind of struggle because I wanted to speak with integrity to people. I don't want to mouth words that I don't believe or that just don't fit. It's sort of circumstantially; you have to invest yourself in the risky process of making mistakes in order to actually take a step forward in life. So I learned a lot.
Bryan Sisk: So how did that process go from initially the staff around you being a little suspicious of chaplains in spiritual care? How did that get further incorporated over time? What changed?

Eric Stephanson: Well, again, I would say the first two or three years I was a little bit hesitant because, you know, this was a brand new organization. And in fact, within three years we went through an organizational crisis, which you know, you only figure out later after the fact, that a lot of new organizations that require a huge commitment to get started, the early initiators are not the people who take it on to maturity. There would have been a wholesale change of leadership. And we went through that and it was a crisis situation. Several of our key leaders left under difficult circumstances. But people were hesitant trying to name, "Well what's your role as a chaplain?" because I had worked in circumstances, I had done training in hospitals and psychiatric places and so on and had worked in the church and lots of hospital involvement over many, many years. I had a certain sense of what was appropriate, but again those are my interpretations and my experience. And the truth is that Canuck Place, people there didn't have other experiences. This is the first children's hospice, what are we going to say. It's not quite the same as an adult hospice. Most adult hospices get people for about six weeks or involved for up to three months. Whereas we have children that were involved with some of us for many, many years from their date of diagnosis.

So, I think what changed over time is that the team grew in self-understanding. I mean I think there is a lot of sharing. We've made a lot of workshops. I offered a lot—there's other kinds of things. I mean they were active participants. I tried to get to know people as well as I could and to demonstrate that I was not interested in "converting" somebody from my perspective, but rather to support people in discovering what was helpful for them. And of course, so people say "Well, what would you say if somebody said, "Would you say a prayer for me?" Well, I'd always say yes. But I would say yes in the context of like "do I know these folks?" And if somebody was to ask me the question, "Why do you do this work?" Or "How did you get to be here? What does this mean for you?" Or "What about your spiritual self?" So I would talk about that and I would always confirm to myself that we were stepping onto a platform where there was a mutual regard here. I wasn't in a situation where I had authority or power or instrumentality, taking somebody down a path where they didn't want to go.

A couple of times early on, I would try to deflect people. Kids are pretty huge in their insight. I remember a couple of people who said, "Listen, I understand that you are trying not to influence me, but I want to know what you think? How do you cope with being with children who are dying
all the time? What are the resources in your faith?” And so, then I'd begin talking about that, and what that means to me and for me personally. If you are Christian, you live in the midst of a religion that encompasses the most profound paradoxes. We follow a god who was crucified. So like whatever. How does that help you in your everyday—? Well, the truth is life is a little bit like the crucifixion. I mean you learn as you go along. You have to learn how to cope with losses. And so, I try to be myself and grow and learn. If I made mistakes, I would speak to people, and if others made mistakes, I would try to put myself in circumstances where we could talk about it. And I think, over a period of years, I think people recognized in me, an open heart, a sort of open mindedness somehow, a willingness to actually be a team player. I think that made a big difference.

[00:39:54]

Bryan Sisk:

Being in such a secular area, how were you received within the hospice by people who were atheists or other religious backgrounds? Did they often seem to seek your insights and inputs as a chaplain, or did they seem to be more hesitant?

Eric Stephanson:

Both. I mean it comes down to individual, personal choices. Some people were very comfortable within their own perspective, but were genuinely interested in having somebody to talk to outside of their normal circles. And there's lots of people in the world like that. They say, "Oh, you're a minister," or "You're a chaplain, could we have a few minutes?" And it's very clear that they don't really want an opinion from you, they want you to listen. And the response is, they want to have somebody who will listen well enough to be able to either validate what they are saying or just to give them the opportunity to be heard. And then if you are successful in demonstrating to them that you are trustworthy in what they say to you, then the conversation can go several different places. And sometimes it goes much deeper, much more personal. I think it's pretty much the same across the board with somebody, everybody. I mean, everybody is a little bit hesitant to speak to somebody unless the somebody they are speaking to is willing to share at the same level or at the same risk, let's say, as they are taking on. And so one of my premises, quite quickly I realized that I'm in a situation where I go home to a family where our children aren't dying every night. They are giving us the fears perhaps, but not the same pain. And these are families who are—they are really in the midst of the fire, as it were, so I want to be available to them and helpful to them, and therefore to be cautious in presuming that I know or that I understand what's happening. So, I try to embody that actively in the way the way that I sit, in the way that I speak or the way that I would listen to people.

I always made a practical example. I mean it sounds really trite in some ways, but it seems differential if you are coming into the room with somebody who is in a bed, and you stand above them, it's quite different
than if you draw a chair up so your head is at the same level as theirs. But since, you can say a lot by the way in which you smile or don't smile, whether you look at them or don't look at them. If you react in a shocked manner when they say something that is shocking, or whether you just simply stand and can't take it or whatever. And I think that that is a lot of the business of palliative care. I think when you see the slogans and conferences, "being there, don't do something just be there." How do you be present with people, and as you can tell because I use too many words, I still struggle to put it into just nice, neat, short sentences. It's hard work for real.

[00:43:19]

Bryan Sisk: When you were starting out, what do you think were your biggest challenges when you were starting out in the hospice?

Eric Stephanson: I think just finding balance was a huge thing. Finding a way to navigate expectations of people. And realizing that, I remember at the very first, if I was meeting with a couple whose child was in difficult circumstances, inevitably there's nurses coming and going all the time. Some nurses, you know, we would have a primary nurses assigned to a family, so they would be with that particular family whenever they were in the house. They would develop a much closer relationship. And what happens then is, if I'm in a situation talking with the mother or the father or a child and the nurse's present and I'm being as honest and direct and you know, making, kind of leaning into the integrity that I have as much as I can, I'm going to say things that are quite vulnerable. And the result is, I think that pattern, I mean the I think because nurse had told me, really encouraged them to accept their own vulnerability or to accept the fact that we don't have all of the answers. Or that sometimes, if you break into tears, it's not a bad thing. Oftentimes those moments of weakness or brokenness or whatever, they really let the family feel a kind of bonding with you as a caregiver. If nothing else, it would create—I mean it would be goofy to go into a room planning to cry. I would never do that. So you just simply recognize these parents are under the most vulnerable circumstances in life, and if you are not willing to match that level of vulnerability, I think you ought not be there. You are too damaged.

You've probably heard the phrase "iatrogenic suffering," suffering caused by medical staff. I think there's a lot of that. And certainly we've heard a lot of that, and to hear it coming into the hospital before they got over to the hospice. And they talk about things that have been said to them by a doctor, or a nurse or somebody, and sometimes you are just astonished that people would say those things. At any rate, trying to find ways to support them where they are without being predictive or pushing them one way or the other, that's really important. The challenge on balance, of growing and
learning both for myself as a person and then in a team and then living into this paradox of needing to be bold in some circumstances and risk saying things that you are uncertain of or that might seem a little bit of a step too far, or presumptuous, at the same time that you are attempting to embody that boldness in kind of a humble package. I don't really presume things of people, but sometimes somebody needs to say the thing that everybody is thinking. And a good family team meeting for example, we are proud to have a family team meeting with every family at least once a year. It's just necessary because they are coming and going across several years. They would be in the house two, three or four or five times a year. And depending upon the circumstances of their child, when they have a family team meeting much more often during the year up to once or twice or three times a day, if they're staying in house at the end of a child's life. And a family team meeting can be called by the physician or by another staff member, a nurse, a social worker, a chaplain, whoever. It can be also called by the parents, they can say "We need to have a meeting."

I realized years into it that I felt that a successful meeting is one where everybody left the room knowing something that nobody knew at the beginning of the meeting. Because a lot of meetings like that at the bedside are kind of like computers downloading into each other. One person knows something and so they share it with the others. The other person has asked the question and so they respond. But in a meeting where you are paying attention to one another, you can certainly see for example, a little flash of emotion in somebody's eyes, and if you are patient and just pause at that face, sometimes they'll take the opportunity to speak, and sometimes you can say "Is there's something else there?" And all of a sudden, they risk saying something that is caught in their throat. And then you suddenly see it in a way that you never have before. You happen to nod that they have a perspective like that, and they hear your response, and suddenly it's like a transformative meeting instead of just downloading information back and forth; there's an actual meeting of persons of hearts and spirits and minds. And the result is the family feels cared for and a little more integral with one another, and they feel so well supported by staff, over and over and over. We've had experiences with families just telling us how much they love to come to Canuck Place. It's a strange thing for the family to say, "We just love coming to the hospice." [laughs] But they do. Yeah. You're going to talk me into going back to work.

[00:49:04]
Bryan Sisk: [laughs] Do I get a finder's fee?

Eric Stephanson: [laughs] Yeah, yeah.

[00:49:10]
Bryan Sisk: When you look over the trajectory of your career and think about your personal experience, but also other chaplains you've spoken with...
throughout Canada or throughout the States or wherever, do you get the
sense that chaplaincy has been viewed in palliative care as an essential
component? Or as like a nice icing on the cake? What's your sense?

Eric Stephanson: Well I think it's a little bit like the way religion is viewed in our society in
lots of ways. It's okay for people who like that sort of thing. [laughs] So, I
think the chaplaincy—and that was certainly my experience with this
Scottish woman. She was like, "Well, whatever. You go ahead and do
whatever the mumbo-jumbo is that you do." Well, I later grew to be so
close to her that she eventually asked me to do the wedding for herself and
her fiancé. She had a second marriage and she announced to me—she's
very Scottish. She announced to me, only she says, "You're gonna' do my
wedding you know." And I said, "What do you mean? That's not the way
to—" [laughs] She was very, very skeptical of my involvement. Sorry, can
you rephrase the question again. I just went off on a tangent I realize.

Bryan Sisk: In palliative care and hospice in general, for kids, do you think that
chaplaincy is often viewed as central as kind of nice if you have it, but not
as essential?

Eric Stephanson: I think it was depending on the person. Some people—I've met a number
of people who felt that it was sort of a nice add-on. I've also met other
people who feel the chaplaincy—I would prefer to use the term spiritual
care—the perspective that's brought in spiritual care is special and
essential. It is with palliative care is, it's spiritual care. It's caring for the
whole person even if they are radically broken and in pain and falling apart
and dying. There's a whole that is underneath all of that, that we have to
pay attention to because they are human beings. So, I believe that lot's
people are drawn, I think most people that work in hospice are drawn into
it, like a calling of sorts. And I'm convinced most people—for some people
it's a challenge to figure out something in their own lives, a pain or a
wound, or a sense of mystery or something. And for other people, it's just a
conviction, that this is the place that they can be useful and helpful in the
lives of others. And my own conviction is that in the last 20 years, like 25
or 30 years, I think I've met more and more people that seemed too "get it"
that their spiritual care is not an incidental on the side, side dish, but it is
rather everything we do, everything that we say, everything that we are, it
is the way that we approach people, the way that we listen to people and so
on.

You can see the difference if you are sitting in a meeting. I think one of the
challenges that is certainly in the children's hospice, so I presume the same
for adult hospice, although I don't have at all as much experience with
them now, but it was a constant temptation to fall back into a medical
model where we are speaking about symptoms and diseases and incidentally the person who had the symptoms and the disease.

I've got sympathy for them, I understand that, because the medical folks and the nurses, everybody comes out of a medical model situation and you have to focus on those things, because your hope is you are going to make the person well and they'll go home. But when that eventuality is already off the table in a hospice setting, that's not part of the goal, you're not going to "heal them" unless your sense of healing is something beyond what's merely physical. But if you begin with that perspective, that there is wholeness in this person no matter what else is going on in their lives, or for example, children who are nonverbal and radically broken from birth, there's a way that you can be present and whole with them that is precious and important it seems to me. So, I think pediatric palliative care is getting that message. And again, some of these books that I mentioned, I think it's seeping out into our society, people are recognizing that good medical care begins with the basics and it includes the whole person.

Bryan Sisk:

When again, looking over your career, what do you think, from your observations, are the biggest changes in the way that we provide this care to children that might be suffering or dying from terminal illnesses?

Eric Stephanson:

I feel a little bit like, you know, I don't have a great expansive experience. I have a lot of intense experience in one circumstance, and then visiting other places across the country, but I don't think of myself as an expert in the field certainly. And I think the challenges that I see are the kinds of the stuff I've been trying to talk about, the importance of valuing the person as a person, certainly there's a huge challenge about getting enough money to offer this kind of care. And that's a big, big, big issue. I mean Canuck Place is an independent children's hospice. So what that means is we have built the foundation board that raises several million dollars a year to create the circumstances where the clinic can run. So, any child or family who come there are never presented with a bill, they don't have to pay anything, they have all their meals, we do their laundry. Everything is provided and it's never even talked about that there would be a cost to it because it's all provided. And the government of British Columbia was asked to be a partner at the very beginning. And they began at around 20% of the total cost, because they thought that this was valuable and clearly it would take some of the pressure off some of the hospitals. And now, I think the government is based on, there is up to 35 or 40% because they can see this work is actually spreading through the province. But I think the challenge of just finding your place on the spectrum of care that has been a really big problem.
Bryan Sisk: Now that you think back—this has been one of my favorite questions ask because it often makes people uncomfortable. If you had to overthink the whole course of your career, what's your favorite contribution to this field?

Eric Stephanson: That's a good one. I like to joke, I guess. I think that coming up with these little phrases that honestly have arisen in my mind in self-defense, were self-descriptors that helped me. "Palliative care is willing to be comfortable being uncomfortable." I've said that a lot of times and have people suddenly sit up straight, smile and shake their heads positively. So, saying things that they already know, but in a way that people say, "Yes, that's right. That's who I am!" I think I've enjoyed that. And I think that's one of the roles that I had at Canuck Place when I was there. I was the first person there, essentially hired to be a spiritual care person there for 20 years, worked through the crisis area. I've tried to learn and grow myself and offer support to people throughout it, so that kind of thing. Another one that I used to use at the very beginning is that "with spiritual care," — how do I say this? "Good spiritual care is loitering with intent."

[00:57:51] Bryan Sisk: [laughs] You are right. Those are good.

Eric Stephanson: Every time you offer something like that to a conference of people who work in this realm, they always had that little momentary pause and then they laugh. But it's a laugh of their recognition of "Yeah that's right! That's what we do. We are available to help you to make a difference in your life. But you have to take a move, you have to take some of the initiative." So I think I'm a person that tries to sympathize and make sense of things. That's certainly—when I look back that's why I got into ministry in the church is because I had arguments and struggles with my own faith as a boy growing up, as a young man. And I realized that I wanted to work through it. I also think I began to realize that other people also have lots of issues and that this might be a realm in which I could make a contribution and it'll make difference for me. I think back over positive times and exactly the same thing that, what had made me feel best is when I've been able to encourage somebody in a way that it affirms their experience and it's kind of validating. If somebody says something that you thought, but you haven't been able to put it in the concise phrase or you hear it in a different way. I think I like to encourage people bottom line, I guess.

[00:59:25] Bryan Sisk: This has been phenomenal. I've got one last question, and this is another one of my favorite questions. But I just want you to dream aloud. So, if every budget, politics, leadership transitions, all of the things that we talked about were no obstacles, what would you ideally want care to look like for kids in 10 years, who are suffering and dying from illnesses?
Well, I think the biggest challenge; we talked about integrating palliative care into the lifelong continuum. I talked a little bit about how I think that hospice palliative care is different care, meaning that hospice and palliative care is spiritual care. We also talked about how we can flip from a palliative care model back into a medical model where we are paying more attention to the symptoms and the disease and the person. But all this kind of stuff is incredibly costly. The amount of money that has to be raised to keep a bed open in a hospice for a year is quite high. It's probably not quite as much as what is required in a hospital, but it's still high.

If I were to dream big I would love to see a little fledgling network of children's hospices that are out there, as a real network. And for the sense of shared community, that I think all of us have known at Canuck Place, to see that work its way around the world in different ways. I think hospices have, it's like they're—I can't think of the phrase—hospices are hidden gifts in our societies because it helps people too focus on the reality of living with dying, or coping with suffering, of being real in circumstances where you would like to run away and being present with people who are going through the worst of life that sometimes offer. And the truth is we are all are going to be in those circumstances someday.

And so, a hospice has a huge gift in its very presence to the larger society around, because it kind of percolates by osmosis; it helps people to be valued, and it helps to validate the importance of caring for one another, caring for our souls. The biggest challenge I think is just the cost. But it's like everything else, if you value something, the money is always secondary. If you really value something, you'll find a way to raise the funds. And what's happened with Canuck Place in Vancouver is that, I think that all of the families that have come and gone there have just spoken in all of their communities across the province in ways because they've done fundraising projects themselves. It's the most common way for families to want to give back somehow through the things that they've experienced. And the result is that Canuck Place is now two different houses in the province. It's pretty much doubled or tripled the work that it did 10 or 15 years ago. So that there's many, many, many more children and families involved and so on. I think sometimes we've even joked that maybe we'll be the tail that wags the dog of the medical system in our province. That we will help people say, "This is important work, this is valuable." And caring for one another along the continuum of life, it's really worthwhile. I mean I think those of us who are involved in that work grow and learn so much. But I think society benefits as a whole as well.

Bryan, I sort of want to apologize because I think I go off in so many directions that I lose my pathway, but you are very patient and I appreciate
it. But for me it's been a way thinking through a little bit of what my own experiences have been. I've kind of enjoyed it. Thank you so much.

[01:03:40]

**Bryan Sisk:** Absolutely, I assure you no apologies needed. Those are all my questions. Is there anything that you think I missed out on or that I should dig into more in the future?

**Eric Stephanson:** Yeah, I think, that's a great question. I guess I would love to hear a little bit from you, if you are talking to 30 or 40 people all over the place about their experiences, what are you learning about the condition of palliative care for children or hospice work for children today in North America and what do you see to be the challenges. What do you see things going on and so forth? And then beyond that I'm just curious to know about your own hope, because I would say even if you are working as an oncologist, years of experience and the perspective into what you are growing right now I think with this kind of work that you are doing, I'm sure it's going to inform your work in a lot of different ways. I think that's a really good thing.

[End of Audio]