Biography

Dr. Ross Hays is the director of the Seattle Children’s Hospital Palliative Care Service, the chair of the Ethics Committee, and a professor in the Department of Pediatrics.

Dr. Hays trained at the University of Washington for his M.D., completed residencies in pediatrics, physical medicine and rehabilitation medicine, and a fellowship in birth defects. Dr. Hays has authored over 80 peer reviewed articles and abstracts, over 20 book chapters, has spoken at over 70 conferences domestically and internationally.

Interview Abstract

Dr. Ross Hays begins the interview by describing how he continued to pursue training after his pediatrics residency, transitioning to study birth defects, training in rehabilitation medicine, and finally training in bioethics. Dr. Hays was then recruited to become the principal investigator for a demonstration project by the Robert Wood Johnson Foundation titled Promoting Excellence in End-of-Life which finally allowed him to tie all his training experiences together.

Dr. Hays then describes his observations that pain in pediatrics was recognized, but there was a lack of urgency in clinical need to treat pain—maybe in part due to that lack of sophistication in treatment paths for pain in the early 1980s. He also recalls that psychological and social support of pediatric patients and families were not typically seen as a necessary duty to fulfill by the medical community and largely became the responsibility of the family.

The differences between primary and specialty palliative care are also defined by Dr. Hays as he describes how other hospital services met his palliative team with some suspicion and anxiety of his palliative service overstepping and usurping turf. He also explains that there will always be a need for palliative care due to the progression of medicine and more complex therapies available. When someone elects to complete these more complex therapies, they create the need for palliative care along their health care journey.

Dr. Hays describes the most looming challenge for palliative services to be funding, especially outside of wealthy institutions that can support a palliative service that generally is not reimbursed well. Dr. Hays also describes that the best thing about the palliative field now is the new generation of well-trained leaders that are stepping up to take the lead.

The interview concludes with Dr. Hays’ dream of having palliative services fully integrated and automatically consulted on every case of a leukemia or complex congenital heart disease or when a child goes on ECMO. He would like to see that palliative care professionals become viewed as integral parts of the medical team.
### Glossary of Acronyms

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<tr>
<td>CAR T-Cell</td>
<td>Chimeric Antigen Receptor T (T-lymphocytes) Cell Therapy</td>
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<tr>
<td>ECMO</td>
<td>Extracorporeal membrane oxygenation</td>
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<td>Heme/onc</td>
<td>Hematology/oncology</td>
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<td>ICU</td>
<td>Intensive care unit</td>
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<td>IPPC</td>
<td>Initiative on Pediatric Palliative Care</td>
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Today is September 3, 2019. I am Bryan Sisk. I am in St. Louis, Missouri interviewing Dr. Ross Hays for the Pediatric Palliative Care Oral History Project. Dr. Hays is in Seattle, Washington. Thank you, Dr. Hays, for joining me today, to get us started could you just tell me when you mind turned toward pediatric palliative care as a career focus?

Ross Hays: I believe it was around 1997 when my organization, Seattle Children's Hospital, was interested in competing for an award through the Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Program. These were demonstration projects that were going to be funded by The Robert Wood Johnson Foundation and a group at people at Seattle Children's drafted me to be the principal investigator on that project. I think that as a career focus, I suppose, that's where it started. I'll say that earlier on—I have additional training in bioethics. Around 1991 as part of a bioethics effort, was exposed to Elizabeth Latimer when she came to Seattle to give a lecture. She was the first person I really heard talk about palliative care as a clinical service. That was much earlier, that was maybe, around 1991.

Bryan Sisk: You have an interesting background where you studied pediatrics and then birth defects and then did physical and rehabilitation medicine training. How did all that fit into your career before ethics and palliative care came more of the forefront?

Ross Hays: Good question. It doesn't appear to be a logical connection, but in doing pediatrics and rehabilitation medicine, one of the areas where I gravitated and eventually specialized was in progressive neuromuscular disease. My clinical focus was children with spinal muscular atrophy and muscular dystrophy. In the late-80s to early 90s, or even before that, in the 80s I should say, the majority of those patients died at a young age. Spinal muscular atrophy. Type I patients usually didn't live through their first birthday, Duchenne patients didn't usually live to be 20, and so providing comprehensive care for them included some aspect of palliative care, even though we really didn't call it that. So that was my clinical focus. I had a very thoughtful chairman who first recognized in me that I had this interest in the larger view of this population. One time he told me, he said, "You agonize over these children. I think you need to learn
how to agonize more constructively." He introduced me to Al Johnson, who was the Chair of the Department of Bioethics and Humanities here at Seattle Children's, and that's when I started my bioethics training. The bioethics training and the experience in caring for children with serious life ending illness that I got through my rehab clinical work really was the clinical foundation for moving ahead with palliative care.

Before you were volun-told that you were going to be the PI [principal investigator] for this Robert Wood Johnson Foundation End-of-Life Excellence program, before that, had you already established in your own mind that, "I'm really interested in and going to focus on the suffering in this end of life care," or was it that you had an interest but it didn't become as apparent until you volunteered for that?

No, I think I had an interest before that. As I mentioned I was exposed to the concept of palliative care in general much earlier than that. I was also doing clinical work at the University of Washington Pain Center, where I was involved in pain and symptom management, before, primarily patients with chronic pain. I did that for eight years and I started that in 1993, and so, began to develop some of the fundamentals of understanding how to do pain and symptom management in that setting. I also had a chance there to meet another physician, Stu Farber who was then a Project On Death in America PDIA Fellow. That was a program started through the Soros Foundation. I think I got a healthy exposure to the field earlier on through Stu and through my opportunity to work with pain patients.

When you were starting out, let's say when you got to the late-90s and you were starting to PI this End-of-Life Excellence project, did you find a community of similar minds at that time?

Yeah, as I said I was sort of drafted for this project, and there were two nurses who became the managers of the project and were very committed to this. Other names were Mo Palmetto and Gerri Haynes. And Gerri Haynes in particularly had a lot of experience. She had as a hospice nurse, worked on the development of a free-standing hospice facility here in the Seattle area, and was very, very familiar and committed to that. She then was part of—she and Mo
Palmetto together were funded by an organ of our hospital, which was then called The Office of Children with Special Health Care Needs. As part of that, they did a statewide assessment of pediatric death in Washington State. They spent two years gathering data about how many children die in our state, what their most common diagnoses are, place of death, and then followed that up with a qualitative study where they interviewed bereaved families to find out what their needs were and that was sponsored by this Center for Children's Special Health Care Needs. They were very much committed to the idea of improving end-of-life care for children and became my closest colleagues.

Bryan Sisk: Sounds like Seattle was really ahead of the times at that point. Did you have a lot of colleagues at other institutions who had similar experiences?

Ross Hays: No, if you've been talking to some of the people, some of the leaders here, some of the leaders of our field, like Joanne Wolfe and Chris Feudtner. Chris Feudtner actually at that time was a Robert Wood Johnson scholar here in Seattle. He had done his pediatric residency here and went on to get an MPH through the program that's no longer available. But when Chris was here at Seattle at that time and got similarly drafted into this project. We worked together, we actually applied for PDIA fellowships together and didn't get one, but we worked on a number of other things. And then, as you know, he went on to Children's of Philadelphia and has established quite an important new national reputation as a palliative care specialist.

Bryan Sisk: Who did you learn from as you were focusing on end-of-life and what would become palliative care?

Ross Hays: [laughs] I think we kind of, had to all teach each other. In the beginning I think it was a matter of going to what we had in the literature and then our shared experience. I think in the beginning it was really an opportunity to be on auto didact. I mean we had to learn from each other. The American Academy of Hospice and Palliative Medicine was a very tiny organization then, and we would go to their meetings and you would gather information from that and, from wherever. Also being part of that larger Robert Wood Johnson Promoting Excellence and End-of-Life Care program, that program sponsored end-of-life opportunities for all of us to get
together. At least twice a year they would bring all of the PIs together and we would compare notes and we would learn from each other and so, there were opportunities like that. There was also, right around the 2000 or so, there was effort around called the Initiative on Pediatric Palliative Care, the I-P-P-C. They were doing a lot to educate people particularly about pediatric palliative care. I remember, I think it was in the spring of 2004, they sponsored a conference where they brought people who were doing this. I don't know if you could say leaders in the field, but people who were doing this altogether at a big conference in Massachusetts where we had an opportunity to kind of, learn from each other. There were a couple of organizations out there that were leading the way in terms of providing the beginnings of an academic foundation for the field.

Bryan Sisk: I just want to take a second to go back a little further. You had finished medical school in '78 and then started your residency program at Brown I believe, after that. Around that time when you just beginning your clinical work, what were the biggest challenges that you observed caring for suffering and seriously ill and dying children?

Ross Hays: When I was a trainee at Brown?

Bryan Sisk: Just back around the late 70s or early 80s when you were first getting into this, what do you recall as challenges in caring for these kids at that time?

Ross Hays: That's a really good question. I think hematology oncology probably had made some headways in understanding the language of the hospice and palliative care for children, but it was relatively primitive then. Death in childhood is pretty unusual and the Brown program was really a generalist training program, so where we would encounter end-of-life would be in heme/onc [hematology oncology] and in the NICU [Neonatal intensive care unit] and rarely elsewhere. There wasn't a lot of sophistication in understanding things like incorporating family preferences into end-of-life care or understanding end-of-life care as a concept by itself. I think that those were really nascent at that time. I mean there was a lot of room to improve on the situation as it was back then.
Bryan Sisk: What about pain in children? How effectively was pain managed earlier on?

Ross Hays: Variably, I think. Probably not well and probably not nearly as well as it is now. Again, that was quite a long time ago and so there weren't as many choices in pain management as we have now. I think that people didn't really recognize the importance of managing pain and symptoms as much as we do. There wasn't much of an emphasis on it then as there is now. I don't think that we were doing particularly well. Joanne Wolfe published a paper in 2000. It said that although all children with cancer who died in the institution who treated for pain, only 50% of them felt like they've been effectively treated for pain, and that 80% of them had experienced suffering in the last few weeks of their lives. I don't think we were doing as good a job. I think it was we didn't know what questions to ask. I think we weren't educated. We were afraid of opioids. There were just a lot of reasons why we didn't do a better job.

Bryan Sisk: What about psychological and social needs, did those receive a lot of attention in pediatrics in the early 80s in your experience?

Ross Hays: I don't think they did universally. I don't think it was really recognized as part of what the medical community needed to offer. I think there were families that were very resourceful and found their resources and did a remarkable job. Then I think there were other families who didn't have those resources and didn't know where to look and didn't have a lot of help from the medical side, and so I think they probably suffered a fair amount. I think in those early stages, whether you got good social, psychological, spiritual support really was dependent on how resourceful the family was. It really wasn't seen as a responsibility of the medical team. I think it was much more the medical side was tasked with doing the best they could to treat the disease, but the larger picture of the whole human experience of end-of-life wasn't really—I don't think it was really understood to be a medical responsibility.

Bryan Sisk: Following up on that, did clinicians at that time have an awareness or you have the terminology of suffering when thinking about kids?
Ross Hays: I don't think anybody missed the fact that children were suffering. I think the medical providers were suffering too, it's just that I don't think we had the tools to be more constructive about it.

[00:18:29]
Bryan Sisk: You said earlier agonize more constructively.

Ross Hays: [laughs] Yeah, that was my chairman. He was very insightful.

[00:18:40]
Bryan Sisk: I also wanted follow-up on that, agonizing more constructively led you to bioethics. I am interested, has your continued role in bioethics and your role in palliative care, have those complimented each other or have they led to any tension?

Ross Hays: I think they're more complimentary than they are in opposition to each other. I think there are many, many bioethical questions that come up in end-of-life care, so having some facility with both I think is a helpful thing. I do think that if you're being a provider who is participating in both, so that would be like bioethics consultation and palliative care consultation, I think there is an important part about keeping those two separate. The big difference for me is in bioethics consultation, you want be as objective as you can be and often you're called to be a third-party observer in clinical disputes or in an ethical question where there might be one or two different factions or sides that are trying to influence a solution. And so objectivity is very important in bioethics consultation.

In palliative care consultation, it's sort of the opposite. I mean very often we find ourselves being advocates for the family, the patient and the family. And sometimes we have to insert ourselves into the clinical conversation to be sure that families have clear information and understanding about the choices that they're making and the decisions that they face and that in situations where there may be a bias that's inherent in the clinical treatment, that the families understand that they still have final authority to consent or not to treatment or to change the course of treatment. In my experience in palliative care consultation you forfeit your objectivity appropriately so that you can be a more effective advocate for the patient and family. So answering your question, I think the two of them work together. I think bioethics informs palliative care, palliative care provides a lot of clinical material for bioethics and so
they go together in that way. But when you're actually doing clinical consultation there are important reasons to keep them separate.

[B0:22:01]

**Bryan Sisk:** How did your clinical career develop? You started in rehab medicine and then you started in with more and more ethics, so did you continue doing rehab medicine overtime? How did that all progress?

**Ross Hays:** Pediatric disability or pediatric rehabilitation is the job that I was hired to do, so I continued to do that. But as the palliative care service began to increase, I did have the flexibility to gradually increase my palliative care clinical work and gradually decrease my pediatric rehab work. That was a luxury that was provided to me by my very generous institution, Seattle Children's Hospital—have the ability to give me that flexibility, and so it was a very gradual progression. I'll tell you that I only disengaged completely from the pediatric rehab department a month ago, or 2 months ago in July, so I continued to participate in that Department primarily as an outpatient clinic provider until this summer.

[B0:23:43]

**Bryan Sisk:** What do you think were the biggest challenges you faced as you started developing this pediatric palliative care niche?

**Ross Hays:** I think in the beginning it was establishing the legitimacy of what we did. I think that when you have new service that adds value to a system that already exists, then sometimes you have to state your case; you have to prove that what you're doing adds value. So for example, in the course of caring for pediatric cancer patients, the heme/onc providers who provide the clinical treatment for cancer would feel that they were not only experts at providing cancer treatment, but they were also experts at providing end-of-life care for their patients if their treatment didn't work. And so they already had that role and identified with it. Then when you come in and say, "We're going to provide palliative care," it would be very natural for the hematology oncology providers to say, "We're already done that. We don't need you. You're not necessary here." And if from our point of view, what we had to offer was a way to do it better, you have to be very careful about how you promote that. Because it's very easy for someone who's been involved in that aspect of care for a long time to look at any offer of additional help that would be an improvement as a statement on what they are already doing, if you understand what I'm trying to say. By saying,
"Oh, yes we have palliative care. We believe that we could add value to end-of-life," it could be interpreted by those who are already providing that care as well, "You're saying that we're not doing it well enough," and that puts people on the defensive. We often experienced that I would say to some degree from physicians, but really very strongly from our colleagues in social work. They really were often not appreciative of us trying to add on to what they were already doing. It was interpreted as a statement that what they were doing wasn't good enough. And we never, ever intended it to be that way of course, and it wasn't that way, but there is that possibility of interpreting that way. To answer the question, I think it was our biggest barrier. I think we just had to continue to do the work and to believe in the value in what we were doing and let the work speak for itself and eventually that resistance went away.

[00:27:36]

**Bryan Sisk:** What were your best practices, looking back the best things you did, that allowed you to get beyond that resistance?

**Ross Hays:** Sometimes it was always being supportive. If we got a request to meet with the patient and the family, we would always be diplomatic and explain to the referring team why we were there and what we were doing, and be very intentional about the fact that we were partnering with them and then we had no interest in competing for the family’s affections or trying to move the patient over to our own service and to interfere in any way to the relationships that had already been developed between the patient and the family and their providers. We always, always would bend over backwards to be cooperative and to be as open as and to communicate as effectively as we possibly could with the referring service. It's funny Joanne Wolfe used to say that, "50% of pediatric palliative care is diplomacy." And I really believe that, that is still true for us. I mean we are very respectful of the services their request us, whether it is in the ICU [intensive care unit], the neural muscular disease service, the hem/onc service, or bone marrow transplant team, whatever; very, very respectful of the fact that they asked us to come in and very reluctant to do anything that looked like it would interfere with that relationship. So I truly believe that 50% of pediatric palliative care is diplomacy. I was at a meeting Joanne and we were talking and I quoted that, and she said, "No, that's not right." I said, "Well Joanne how can you tell me that's not right? I learned that from you." And she said, "it's because it's 80%." And I thought, "Okay."
laughs] That is the way you have to do it. Often I felt what we were doing is enter into a situation, we'd recognize there was some deficiency there, maybe the pain wasn't being managed adequately or maybe the family was in the dark about some critical decision or the communication between the medical team and the family had not been thorough. We'd recognize something to be addressed and sometimes the best way to that was to find a way to put that idea in the head of the person who asked us to get involved. If it was the ICU attending who we recognized wasn't really communicating with the family and the family was not really getting what they needed, we would find a way to make that attending aware of the fact that she needed to do more in some kind of subtle way and then watch her do it and then congratulate her for being so thoughtful and being so proactive. And that was often the way you would make progress for patients and families. And it requires a certain amount of humility because you could just never take credit for what your work was, because you had to make it look like it belonged to somebody else.

[00:31:38] Bryan Sisk: Has that changed overtime or is that still the same?

Ross Hays: I think there is still an element of that. But you know there's this newer concept now that I think really came from Timothy Quill about specialty palliative care and primary palliative care. Specialty palliative care is what we're trained to do—it's more complicated pain and symptom management and it's a more aggressive way of recognizing ways to improve communication and provide continuity. I mean those are the things that a palliative care fellowship trains you to do, and so that's specialty palliative care.

Primary palliative care is basically the attitude of creating an environment that promotes better care at the end-of-life. So it is improved communication, it is a basic understanding of pain and symptom management, and it's something that everybody, every provider should have, and I know you're aware of this. I think what's happened over the last decade and so is that, there's been this development of specialty palliative care as a specialty, but there's been I think great improvements in the whole concept of primary palliative care too. I think the quality of care in both aspects specialty and primary palliative care has risen overtime and so. I think there are more people who are more thoughtful about the way
they are treating patients at the end of life and so, I think that our job is not quite as obvious as it was 20 years ago.

Looking more globally from your perspective, what do you think was the spark that really drove the development of pediatric palliative care as a specialty?

I think that palliative care in general, I mean I think we got to the point in the 90s where I think the whole medical community, really led by the Soros Foundation and the Robert Johnson Foundation, began to look at the way we managed end-of-life care and collectively said, "We suck at this." And that's when, particularly those two agencies, but others got on board and said, "We need to take this on. We need to make improvements here." And so that was in the early to mid-1990s, that was American health care in general. And we didn't have to look to far to find better systems. I think Canada was already ahead of us. I think the U.K. was ahead of us in terms of more enlightened hospice care and more attention to end-of-life care. So that happened in the early to mid-90s, palliative care in general.

I think in pediatric palliative care there were a few pioneers really who took this on and led the way. People like Pam Hinds in Washington D.C. and Joanne Wolfe certainly, but others; Ann Goldman in the U.K. It was individual people who recognized there was a need for this and I think because it was mostly in academic centers, not only did they initiate the clinical service, but they initiated an academic approach to it with research and education as being a component of the specialty from the very beginning. I think that's what happens when you have a brand new specialty that develops at this day and age. We know enough now to realize that you just can't go out and do the clinical work; you have to provide I think the academic justification for it at the same time, and so very thoughtful people did that. Bruce Himelstein was another person who took this on very early on. He's not doing it anymore now, but there were people, individuals I think, who were largely responsible for getting this off the ground.

You had mentioned the Robert Wood Foundation and the Soros Foundation, how important were these funders in the development of pediatric palliative care?
Ross Hays: Well I think they were very important legitimizing palliative care in general, not so much pediatric palliative care. Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Care, they had like 760 letters of intent from different organizations wanting to do a demonstration project and they chose 22 to fund. Each one of them was funded for three years and of those 22, only two were pediatric, so that was here at Seattle's Children's and at Cardinal Glennon Hospital in St. Louis. I think those agencies were very important in the development of palliative care in general, and hospice too and actually, I think in broadening the view of hospice. But I think pediatric palliative care wasn't the target of those agencies and it shouldn't have been. I mean when you think about it, pediatric palliative care is a tiny, tiny subset of palliative care in general. When do people die? They die when they're old, and so palliative care in general is quite big, but pediatric is a really small subset, it's a very intensely different subset. We're small compared to palliative care in general.

Bryan Sisk: And thinking more about palliative care in adult hospice, how much do you think the adult hospice movement affected the development of pediatric palliative care?

Ross Hays: I think minimally. They had enough on their plates already trying to improve care for adults at the end-of-life, which is again, that is the industry. I think it was a few enlightened individuals who really emphasized pediatric hospice care. We here in Seattle were lucky there was a visionary person in our hospice community here who recognized that there needed to be a dedicated pediatric hospice program and she really made the case and found a willing sponsor and developed a dedicated community-based pediatric palliative care and hospice program. And so, we've had that here in Seattle for probably 15 years or so, but that's not the case everywhere else. I mean even in large Metropolitan areas, like in Boston, Philadelphia and New York, there aren't dedicated pediatric hospice programs. There are hospices that provide care to children occasionally and it's a continual issue for them because those hospices who have nurses primarily who are familiar with adult hospice and very comfortable doing that, don't feel very comfortable taking care of children, and so, they really rely on organizations like the palliative care programs at Children's of Philadelphia or Boston Children's or Seattle Children's, to provide the extra expertise that they need to be able to
do this. So pediatric hospice care, it's just really small, and so there are relatively few pediatric programs. Trinity Health in Los Angeles is a great example of one that's been very successful. The Steppingstones Program here in Seattle is the one that I mentioned, is 15 years old now and is really quite successful, but it really took a visionary person to make it happen.

Bryan Sisk: How has interactions been between hospital-based programs, especially in pediatrics, and the community-based programs?

Ross Hays: I think in my observation good, generally. We share a mutual need, which is the best interest of our patients. Palliative care programs within hospitals are anxious for children to be able to spend their final days in the setting that's most appropriate for them and for many of them that's home. And so, it's our responsibility to allow them to have that experience. We have a vested interest in getting those children out of the hospital and home where they want to be and to have them cared for appropriately once they get there. So we have a strong interest in promoting community-based programs. And the community-based programs, at least in my state, are mandated to take children. The Certificate of Need for Hospice in the State of Washington includes a clause that says that, "There could be no discrimination based on age." So that means a hospice that takes 99% older adults is required to take a pediatric patient if it's referred in their catchment area. So they often look to us for support and help in how to manage these kids. I think the we mutually depend on each and our shared goal is to try to create the best outcome for our patients and their families.

Bryan Sisk: Looking over your career from the late-70s to date, what do you think have been the biggest changes in care that we provide to these kids that are suffering and dying?

Ross Hays: [laughs] Wow. Well I think that the fact that we do have pediatric palliative—well, between the 1970s and now, the fact that we have pediatric palliative care at all. It did not exist obviously, when I started my training or even when I stared as an attending physician. So the biggest change is that we have this specialty with all of the expertise and experience and authority and education that it has. The answer to your question would be simple. We have this specialty that makes a difference. To dive in a little deeper, I think that children
die differently now than they did in the 70s. I think back then, children would often die in the hospital, it was pretty rare for them to die at home. I think we had less ability to prognosticate and to plan for end-of-life care. I'll just give you an example that came up recently.

In the late-70s when a child was born with hypoplastic left heart syndrome, which is a fatal congenital cardiac condition, the babies would be born, they would be okay for a few hours and then they'd start getting sick. There would be some kind of emergency work up. You would realize, "Oh my gosh, this baby has only one ventricle." And you would gather up the family and say, "Oh, we're so sorry there's nothing we can do." And the baby would live for a day or so. And that was hypoplastic left heart. Well now in 2019, number one, those children are diagnosed at 20 weeks gestation. They're diagnosed long before they're born, and then there's an opportunity to plan for their delivery. They're delivered in a high-risk center and then there are a series of three very complicated surgeries available to the family. So the family can be counseled, "Yes your baby is going to have rough road ahead, but it's certainly not going to be fatal, and the likelihood is your child is going to live, and maybe live through these three surgeries and maybe on to have a heart transplant and end up in college and beyond." So there are those kinds of developments that create an entire need for palliative care.

I mean if you define palliative care broadly, which includes multi-disciplinary supported continuity of care throughout the trajectory of the illness and assisted decision making, than pediatric palliative care for that child with hypoplastic left heart begins about five months before that baby is born and then continues on through all of those different phases of treatment. It's an entirely different ballgame. Now again, back in the 70s, if you were treated for acute lymphoblastic leukemia and then you relapsed, often you'd die. Now if you’re treated and you relapse, then you go on to a more intensive chemo therapy regimen. And then if you relapse again you go on to bone marrow transplant. And then if that fails, then you usually have a second bone marrow transplant. And if that fails then you're referred on to CAR [Chimeric Antigen Receptor] T-Cell therapy. And so these diseases that were once quite short and fatal are now
prolonged and variably successful and so they create and entire need for palliative care along the way. So lots of changes.

**Bryan Sisk:** Looking at your career what is your favorite contribution to this field that you've made?

**Ross Hays:** [laughs] Survival? Maybe survival would that be it? The thing that is most gratifying is that when I started, it was just kind of an uphill struggle. You knew you were doing the right thing but half the time you really had to devote your energy to convincing somebody else that it was the right thing. I don't really feel like we face that anymore. Now, we have a new generation of bright, young, well-trained physicians who want to do this work and they're not having to blaze the trail anymore. I think the pathway is already there, they just now really get to do the work, which I think is a great thing.

**Bryan Sisk:** What do you think are the biggest challenges that still face the field right now?

**Ross Hays:** Well we're in a medical economic system that doesn't value what we do. And you can say that about all kinds of different aspects of health care, we don't get paid for what we do. I always say if we could provide palliative care consultation and colonoscopy, then we'd be great because we would have a well-compensated procedure and then we would never have to worry about money. But palliative care programs, they add value but they don't generate revenue in our system, and so they are variably precarious. I'm fortunate here at Seattle Children's, we have a very generous hospital that recognizes the value of what we do, and the fact that we don't bring in enough money to offset our expenses has never been limitation or hasn't been a big limitation, and you work with adjusting. At St. Jude it's similar. They have the economic wherewithal to support this, but it's not true everywhere and there are other programs that really are struggling and are very precarious because their administration doesn't recognize the value and they don't have the resources to essentially support a loss leader. And so I think that in our present system, the biggest barrier or the biggest threat or the biggest challenge is to have a robust reimbursement system that supports this everywhere, not just at wealthy children's hospitals like at St. Jude's that can pay for almost anything.
Bryan Sisk: Looking at the whole field again, in what areas do you think the field is the strongest?

Ross Hays: I think it's the strongest in the commitment of this young generation physicians who are doing the work. For over 10 years I was the only palliative care doc here. Now there are eight at Seattle Children's, and the other seven are all a generation younger than I am. And they're well trained and they are interested in making a contribution and they're getting additional training in methodology and research experimental designs, statistical analysis so that they can improve the value of what we do. And so I think this generation is by far the best thing that can happen to pediatric palliative care.

[00:52:16]

Bryan Sisk: And then the last question, I would really love you to dream aloud. So if budget, politics, reimbursement and all the other things that we talked about weren't an obstacle, what would you want care for these children to look like in another 10 years?

Ross Hays: I think I want it to be a seamlessly integrated system where pediatric palliative care is recognized as one part of every bone marrow transplant, one part of every complex congenital heart disease, one part of the care for all children with leukemia at relapse, so that you really don't require consultation anymore, you are just part of the team. We don't apologize for the fact that we have a dietitian on the leukemia team, that's just assumed that that's normal. We don't apologize for the fact that we have a physical therapist on the cancer care unit or that we have a social worker attached to the brain tumor unit. We don't apologize for those things because we've all recognized they are a necessary part of the team, that they have a role to play, and they really don't require any justification anymore. In my ideal world, pediatric palliative care, we have that same status. I really think I’m not exaggerating when I say that after 20 years at Seattle Children's we're pretty close to that. We're just integrated into the care these high risk groups, we have an automatic seat at the table for all the high risk leukemia admissions, we are consulted for every bone marrow transplant. We are automatically consulted when we have a child that goes on ECMO [Extracorporeal membrane oxygenation]. I think, at least at our place, we're close to realizing that goal, but I don't think that's true everywhere. The ideal state would be where pediatric palliative care is recognized as a necessary treatment for any child who has potential life limiting illness. It
doesn't require consultation, it doesn't require justification, doesn't require anything. We're just part of the game.

[00:54:53]  
**Bryan Sisk:** Those were all of the questions I have, but is there any area of this history that you think that I should dig into deeper in the future?

**Ross Hays:** I don't think so. I'm going to be really interested to see what you come up with because I suspect that you're getting different stories from people at different places, which I think should be quite interesting.

*End of Audio*