Richard Hain Oral History.

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Biography
Professor Richard Hain, MBBS, MD, FRCP (Edin), FRCP, FRCPCH, is a Consultant and all-Wales Clinical Lead of the tertiary Palliative Medicine services for the Children’s Hospital in Cardiff, United Kingdom. Dr. Hain has cultivated a multidisciplinary academic background in medicine, pharmacology, education, ethics, and theology. As a trainee clinician, Hain integrated his long-time passion for pediatric medicine with his interest in closing the service gap for underserved children with life-limiting and complex illnesses to ultimately develop a multidimensional palliative practice model. Dr. Hain trained in and continues to develop his interests through research in end-of-life ethics, epidemiology, service development in pediatric palliative care, opioid pharmacology, pain and therapeutic symptom control, pediatric oncology, and pediatric hematology. He has co-authored over 50 research articles, several books, and many book chapters.

Interview Abstract
Dr. Richard Hain begins his interview by describing how his lifelong intentions of practicing in pediatrics developed into an intersecting interest in palliative medicine after hearing a lecture given by St. Christopher’s hospice. Dr. Hain then describes how he designed his medical school path to intersect at the disciplines of pediatric oncology, complex needs, pharmacology, and adult palliative medicine so that he would have the proper certifications to allow him the freedom to develop pediatric palliative to his vision: a multidisciplinary streamlined service with no barriers to access for those that needed the service. He says that while going through all that training would be “overkill now . . . it was well worth doing.”

Dr. Hain then describes how he began to form a community of like-minded healthcare providers in Wales that were able to develop and publish evidence of best practices for chronically ill and underserved children. This work eventually supported the discipline of pediatric palliative care becoming recognized as a subspecialty by the Royal College of Paediatrics and Child Health.

Early in his career, Dr. Hain was met with several resistant ideologies such as general disgust at the thought of administering children’s comfort care instead of solely cure-oriented care. Dr. Hain also described some discourse between clinicians that did not subscribe to recognizing pediatric palliative care “as a subspecialty within pediatrics and not a subspecialty within adult palliative care,” and some feelings from clinicians that pediatric palliative would take away from their practice rather than add another tool to health care. Dr. Hain also reflects on the role of opioids in palliative care, access and barriers to receiving pediatric palliative care, adult hospice and adult palliative care, the challenges the discipline has to overcome and the successes of in pediatric palliative. Dr. Hain then explains his future vision for pediatric palliative care; streamlined access to care where the clinicians fulfill a healthcare companion role rather than a sterile clinical relationship while also maintaining that the clinicians are the professionals with a knowledge base that continues to evolve with the discipline. Dr. Hain would also like there to be a larger community nursing infrastructure as well as simplified treatment methods of providing complex care at-home.
Glossary of Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>PCA</td>
<td>Patient Controlled Analgesia</td>
</tr>
</tbody>
</table>
Interview Roadmap

Beginnings

- Personal career influences ................................................................. 1, 3, 6, 10-11
- Colleagues, mentors, mentees, and other influential figures .......... 1, 2, 4, 5, 15

Pediatric palliative care

- Evolution and history of pediatric palliative care ................................. 1-4, 6-7, 14
- The multidisciplinary holistic approach .............................................. 2-3, 16-18
- Wales-wide palliative services .............................................................. 5, 12
- Pain, pain management, and opioids .................................................. 6-7, 10-11, 20
- Families ............................................................................................... 17
- Philanthropy and fundraising .............................................................. 8-10, 18
- Challenges and barriers ..................................................................... 6, 8-12, 15, 20-21, 23
- Successes ........................................................................................... 8, 19-20
- The future ......................................................................................... 8, 22-23

Reframing and rebranding pediatric palliative care

- Philanthropy ........................................................................................ 8-11
- Reframing clinician views ................................................................. 7, 11, 14-16
- Pediatrics vs. palliative clinicians ................................................... 14-15

Relationship to adult palliative care

- Separate and distinct practices ......................................................... 12-13
### Related Works and Mentions

<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baum, David</td>
<td>15</td>
</tr>
<tr>
<td>Goldman, Ann</td>
<td>1, 4</td>
</tr>
<tr>
<td>Liben, Stephen</td>
<td>5</td>
</tr>
<tr>
<td>Martinson, Ida</td>
<td>2</td>
</tr>
<tr>
<td>Saunders, Dame Cicely</td>
<td>1, 2</td>
</tr>
</tbody>
</table>
Today is July 8th, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Dr. Richard Hain over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Hain is in Cardiff, Wales in the United Kingdom. Thank you Dr. Hain for joining me today. To get it started, could you just tell me when your mind turned toward pediatric palliative care as a career focus?

I can tell you that quite relatively precisely. So, it was in 1984, I was a fourth-year medical student and I was approaching my pediatric block. I had always been interested in doing pediatrics and hadn't really expected to do anything else. I trained in medical school in South East London which encompassed St. Christopher's hospice. We had somebody come from St. Christopher's hospice to talk about palliative care. It was only one lecture, but it was one of those light switching moments. I thought, "Yep, palliative care is what I want to do." And I thought, "What am I going to do with my existing vision for doing pediatrics?" And then I thought about it and I thought, "Well what about palliative care in children?"

When I looked into it as part of my project, I discovered that there wasn't any pediatric palliative care in children at that time and so I thought, "Right, that's what I'm going to do."

So, before that had you been familiar with Cicely Saunders or any of that movement that had been developing? Or was this an all new flashlight, flash bulb moment when you were at that talk?

That's a very interesting question. I had heard of Cicely Saunders as many people in the U.K. and probably around the world had because she was quite a well-known figure. Interestingly, for one brief or a few months as a teenager I actually kept a diary. As it so happened, during that period I recorded my reaction to hearing a documentary about palliative care—about Cicely Saunders and palliative care and I was disgusted by the whole idea. The whole idea of spending your life caring for people who are dying was appalling at that time. But when it was unpacked for me in the way that I was taught at medical school, some four or five years later, it was completely different. I thought "I get it now." So, I did, but not at all in the same way. Interestingly, Cicely Saunders' response to my suggestion to children's palliative care—I had met her and talked a bit about it—her response to my wanting to do children's palliative care was very similar. She was horrified that anybody would want to spend their life doing that.

I've heard a similar thing from a number of other people that were early on in the development of palliative care—talking with Ann
Goldman, with Ida Martinson. What do you think it was for Cicely Saunders that turned her off to palliative care and hospice care for children specifically?

Richard Hain: I think for people who don't care primarily for children, the idea of a child dying is so wrong, it goes against the laws of the universe so profoundly, that as caring adults they can lose touch, they can't bear to think about it. I suspect that if I had longer to talk to Cicely Saunders and several other colleagues, I think probably they would have started to get it. People who aren't working with children who don't see that children get sick and they die, I think their idea of childhood is a romanticized idea. And fair play, most of the time children are healthy and their lives are joy-filled. I think that the pain of considering that there are other children for whom that's not true and there maybe numbers of children who suffers as a result of a life limiting condition and ultimately die from it—just offends their idea of the universe. It's not deliberately denied, I think it's some subconscious protection mechanism.

Bryan Sisk: So, after you had that light bulb moment, what were your next steps? How did you move forward?

Richard Hain: So, I had to get my medical degree. One of the nice things, because I knew what I wanted to do—in those days in the U.K., I found it easier to organize my training. Many of my contemporaries—because at that time in the UK, although the training could be very good, it was a little bit haphazard. It wasn't the same structure as was happening in North America at the time. You didn't enter a fellowship scheme and stay there for two or three years, or much less a residency scheme. People would do a six months job here, another six months somewhere else and a year somewhere else. That was personally quite costly. You had to move around a lot. Less so in London where there were an awful lot of jobs that would come up, but even so you had to move around a lot. But what it did mean was that you had a lot of flexibility because you could cobble together whatever training you thought was necessary for what you wanted to do. For me starting out in a new specialty or aiming to develop a new specialty, that was extremely important.

I took advice from various colleagues including my father, who was a pediatric anesthetist who worked with pediatric oncologists. His advice was to specialize in pediatric oncology, which is what I did. So, I did my pediatrics and then went into pediatric oncology and I realized that wasn't really enough for palliative care because cancer is only one of the conditions that children die from. And
also, oncology training taught you a lot about curing cancer, it
actually didn't teach you that much about caring for children—the
one child in four who weren't able to be cured. So, I then added—I
did a Master's in opioid pharmacology which was really not
because I had a research interest in that, but because I wanted to
learn about those medications so I can be familiar with them in
clinical practice. And then I went and got some more experience
this time in what we call community pediatrics, which would be
caring for children with the chronic and complex conditions. And
then I was pretty much—

[00:07:00]
Bryan Sisk: Are you there? You froze up.

Richard Hain: Now I'm back yeah. I realized that the thing that was missing was
that I had done no training in actual palliative medicine. I then
went back and trained again, this time in adult palliative medicine.
What I had aimed to do and what the system at the time enabled
me to do was to get lots of different relevant trainings. I had the
general pediatric training, I had the pediatric oncology training, the
complex needs, the pharmacology, and now the palliative medicine
as well. Now, I think a lot of that wasn't necessary as things turned
out. I think somebody coming into this specialty now wouldn't
need to do all those things. But at that time, when I was coming to
a new field it was actually a really good way to do it. I've never
regretted it having done all those things because it meant that, for
people who were primarily palliative care specialists, I had the
authority of certification in palliative medicine and for
pediatricians, I had the authority of being certified as a pediatrician
and pediatric oncologist. So, it was well worth doing, even though
I think you could argue it was a bit of overkill in some ways.

[00:08:16]
Bryan Sisk: It sounds like you were a bridge between at least three somewhat
desperate fields where you had the adult palliative medicine, the
pediatric oncology that was very cure focused, the generalist
pediatrics, and then also your basic science understanding of
pharmacology and actual metabolism of opioids. What was that
experience like trying to pull all these different fields together?

Richard Hain: To me, they were three aspects of the same thing. They were three
aspects of what was important to children’s palliative care. So to
me they were all linked to children palliative care. I didn't see
them as three separate things really. I think—I mean there's this
inevitable feeling of course being you're the jack of all trades, at
the same time you are a master of none. Although I was a card-
carrying pediatric oncologist, I think I always saw myself as being
slightly out of my element. And as adult palliative medicine
physician, I was a pediatrician. I had gone into this, with no acute adult training at all—It was all in pediatrics. Oddly, that wasn't as difficult as you might imagine to make that transition. The pharmacology, I really enjoyed doing it, but I very much see it as having given me some basics and skills that were important to my clinical practice. I don't think I ever started to think of myself as primarily a pharmacologist. I sometimes refer to myself in a shorthand way, a pharmacologist, though I'm not a proper pharmacologist, I'm a clinician with a good knowledge of pharmacology.

[00:10:07]

Bryan Sisk: So early on, who did you interact with that was of a similar mind? Were you able to find a small community or did you largely feel on your own?

Richard Hain: As a trainee, I took lots of advice from lots of people, or I solicited lots advice from lots of people—I didn't always take it. Sometimes I regretted not taking that advice, sometimes I look back and thought if I had made the right call. I never worked with Ann Goldman, who was around at that time. I could have done that and there were lots of reasons why I did that, the main one being that I had the chance to come to the Hospital for Sick Kids in Toronto to do pediatric oncology fellowship. When I came back, I was then sorted for the next few years. I think there are many ways in which that would have been a good helpful thing to do. I did meet her many times and I used to go in several of her meetings to sort of see how things work there. What I would say is, as a trainee, I interacted with a lot of people who had relevant skills, but I didn't have much interaction with anybody who was doing children's palliative care. I think that was partly because I already had a fairly clear idea of how I thought things were going to unfold. What happened at that time was, most people who were going into it, like me, had their own vision and although the visions were similar, they weren't always the same. I worked in a provincial children's hospice where, at that time, they felt that the palliative care model should be a GP [General practitioner], a family doctor taking interesting in palliative care rather than being a pediatrician doing it. Their reasoning for saying that was that palliative care is part of primary care and it wasn't specialist territory. I didn't subscribe to that view at all, thought it was very important that I understood what that view was, if you see what I mean. So lots of people influenced me. Some influenced me to emulate what they were doing. Quite often it was the other way around, I looked at what they were doing and said ‘that's not the way I think it should be done.’ But none of them was doing exactly what I was doing. None of them was—except Ann Goldman, was a pediatrician
aiming to do specifically palliative care. That wasn't how they were doing it at that time.

However, I echo the comment you attributed to Stephen Liben earlier—when I was appointed as a consultant, the first thing I did was to gather around me a small group of like-minded people. I would absolutely endorse what Stephen said there. The power of that group was immense. What we did was, we met up—there were four or five of us. So, there was the head nurse of the local children's hospice, there was a lecturer in pediatric nursing in the university, there was a [indiscernible] nurse, somebody who works in the community supporting kids with chronic and complex conditions at home. She was in North Wales and she couldn't physically come to the meetings—we held them video conference meetings. That small group of people met every month for several years and the first conversation was, "How can we put together what we've already got? How can we make what we've already got work? How could we without asking for any more money how can we get stuff to work better than it does now?" Over time we came to develop a vision of how we thought it ought to work, what the Wales-wide service would look like. So, we're now talking the first half of the 2000s, so 2000, 2005. Then two things happened in quick succession. There were reorganizations of pediatrics in Wales and we were invited to submit evidence about palliative care as a specialty. The second thing was, the palliative care in Wales was reorganized and we were invited to submit evidence about pediatric urgent care as a specialty within that.

Because we had gotten this ready-made vision that we all agreed, we were able to submit quite detailed and consistent evidence to both of those two. As a result, there was some money that was made available and we were able to expand the network on the basis of that. Then once the network was in place, we continued to meet ever since. So I think if we haven't had those, if we hadn't been disciplined about having those very small meetings once a month for four years, we would not I think have been as persuasive in our evidence. When it came to the option of having the money there, that came from something. I was being paid to do palliative care, nobody else was. They were interested in it from different backgrounds; from nursing backgrounds, from the hospice background. It's interesting that most were nurses. I think an understanding of palliative care has never been so far from nursing understanding as it has been from a medical one, although perhaps in pediatrics it’s never been as far from medicine as it has been from some of the adult specialties.
Bryan Sisk: Sure. I wanted to go back to your early training when you were at medical school. Around that time, what were the biggest challenges you observed in caring for these suffering children?

Richard Hain: So, to say my project was looking at—well, I was going to say it was looking at exactly that. That's not true. I wasn't doing it as a philosophical study at that time, I was doing it as a practical one just to see what resources were available. The big problem that I noticed—so I was following up with patients. My project was built around a child who had a brainstem glioma. She came from a quite well-off family. As a result she was able to afford, when it became clear that she wasn't going to survive, her parents were able to afford to take her home and to pay for the 24-hour nursing care that she needed to be kept comfortable.

Now, in the U.K. as you know, people don't usually have to pay for health care. So this introduced an inequity that seemed to me to be inappropriate, that this family was able to do what was obviously the right thing for their child. In other words, caring for her at home for the last few weeks of her life. But they were able to do that because they had enough money to do that, and I thought that that was quite wrong.

Now, this particular child that I followed up with, as things turned out, in fact lost consciousness several weeks before she died. I think in terms of existential suffering, that wasn't a big problem for her. I think as it's considered a palliative care case study, she was relatively straightforward. I'm not even sure if she needed pain relief. Pain isn't a big part of management of brainstem glioma. But in the broader aspect of just being able to care for a child or support a family in caring for a child at home rather than needing to be in hospital, it seemed to me that this was something that we should be able to offer to everybody. It shouldn't depend on their income.

[00:18:12]

Bryan Sisk: And with your pharmacology understanding, looking back there's a lot of evidence at that time, at least in the U.S., of hesitance of prescribing opioids to children and up through the 70s and into the 80s. There were questions of if infants could even feel pain because they weren't able to have a cognitive experience. What was your experience at that time with how pain was managed for these kids?

Richard Hain: So, when you said that time, what period are you referring to?
Bryan Sisk: I'm thinking late 80s or early 90s when you were getting through your medical training and getting out more so into the field.

Richard Hain: So, in the mid to late-80s, I was doing my medical degree in pediatric oncology. In pediatric oncology for acute pain, I think acute pain was managed very well. There wasn't the same hesitation here. By the time I was working, people referred to those days when pain relief was withheld from children, but they referred to it with horror. Some of them said, “When I was training, we were taught this. We were taught that "infants do not experience pain. How horrible that was and I'm so glad we don't do that anymore." From what I've discovered since, I think the U.K. was a little bit ahead then. I think we did abandon that completely wrong-headed belief earlier than in North America. And in the '90s, I did quite a lot of my training during the 90s in North America, I was at Sick Kids then I did some training in Ottawa. Certainly at Sick Kids in the early 90s, there was some elder statesman, as it were, who still really believed that the children didn't experience pain. One of them told me, "that children are like fish, they don't feel pain." And he said it with a bit of sort of a smile, but I kind of had the feeling that he half believed what he was saying. He was slightly reluctant to stop that.

Certainly in those days, not now, but in those days bone marrow aspirates would still be done on conscious children. I don't know if that is still true. In the U.K. at that time, if you're having a bone marrow aspirate, you would have a general aesthetic where you would be anæsthetized for a few minutes for that. So my sense was the pain, that North America in particular, was really very cautious about—so cautious about the downside of pain relief that they would prefer to take the risk of a child being in pain because they were unlikely to die of pain, than the possibility they might overdose from the drugs and that was very uncomfortable.

[00:21:14]

Bryan Sisk: What about psychological and social distress as a component of a child's suffering or a child's problems, how was that addressed?

Richard Hain: You want me to compare the two now or just looking back at that period of history?

[00:21:34]

Bryan Sisk: Either way.

Richard Hain: Yeah. Okay so I think this is an area where I think in North America, which there is some data because there's more money flushing around than there is in the U.K. I think one of the things I really admired about the system in Canada was the access to child
life specialists—which there were very good play therapists in Britain, but it wasn't consistent. Whereas, what I could see, certainly in some places I worked at in Canada that wasn't true, but that was the expectation and that did make a huge difference.

I think there was a—so to stop now and to try to make transatlantic comparison, which I'm probably not qualified to make with any certainty—I think one of the things I do feel is very important is that existentially, the right place for the child to be, the place where the child would feel most secure and be best protected from existential types of suffering is in the home, in the house with the family where they grew up. It has always seemed to me that the default should be that the child is at home. Now I would not want that to be interpreted to mean that somebody's failed if a child dies somewhere else.

There are all sorts of reasons partly the fact that I've said that many families—what I've said is a generalization. There are many families for who it's not true. There are many families who feel much more comfortable on the ward and were the child feels more comfortable on the ward, so this isn't intended to be a universal assumption. But I think, if I could put it this way, I think one of the aims of care at the end of a child's life should be, the only reason for them not to go home is because that's not where they want to be. There should not be any practical barrier or economic barriers and we're not in that position yet and there are all sorts of reasons why we're not yet in that position. Until we are, until we're actually able to offer meaningful choice to all the children, all the families and all children, I think we haven't got to where we need to be.

[B00:23:48]

_Bryan Sisk:_
One thing I find interesting is you've mentioned a couple of times economic and financial barriers. I've spoken with individuals from the U.S., the U.K., Greece, South Africa—and everyone I've spoken to, either a large part or all of palliative and hospice care for children requires philanthropy and charitable donations. What do you think it is that led to that being an important source of the funding for palliative and hospice care?

_Richard Hain:_
I'm not sure that I would agree with that first position, at least in the U.K. In the U.K. we have a state funded health care system which means, if I'm given a salary and my job description says "you need to care for children with life-limiting conditions"—it was a bit more detailed than that, but it doesn't say it has to be in hospital or it needs to be in a hospice, the issue is that I treat the child wherever they are. So that gave me considerable freedom to develop a system that enabled me to see children irrespective of
whether they were in a hospice, at home or in a hospital or at school.

I think that a system that relied on a narrow contractual arrangements, I don't really know how the system works in the U.S., but a system where a doctor was employed to work in a hospital or something like that—that would be much more difficult to arrange because then they would expect you to do the work in a hospital or you would be paid go out and do something.

But it's all—there's a different economic model there and it is certainly true that philanthropists have made a big difference and often in the U.K., that's been through setting up children hospices. But I don't think the children's hospice model in the U.K. —so I'm using hospice now to mean a building—that model of care where the focus is on the hospice building, the inpatient building. They may have outreach services, but the focus is on that building. I'm not sure if that is the model that suits palliative care more generally.

It seems to me that we should be, in a sense—we sort of have no particular physical location. We see children wherever they need to be seen. It's helpful to have an office, and I in fact do have an office in a children's hospice, but that doesn't translate into a specific contractual arrangement nor does it translate into a specific care arrangement were I'm expected to prioritize the needs of children in a hospice, for example, over other children.

What I'm trying to get across is, philanthropists have been extremely valuable to the specialty, but I don't think that we should go with the idea that philanthropy is necessary for palliative care to work or even to work well, at least not where we got a socialized health system. I think outside that model, then that becomes more important because it's very difficult to prioritize. This perhaps comes to your question, why do some places have to rely on philanthropy? Well, because this sort of thing and the number of children dying is so small relative to the number of adults dying, that it neither costs you a large part of pediatrics nor a large part of palliative care. Therefore in order to make it important, we have to appeal to an individual's understanding of the needs kids might have.

I think I would be concerned if we overstated the important of philanthropy only because, we then characterize it as something that feels super arbitrary—it isn't something that the health system should have provide, it's simply something which people who got
lots of money can choose to help with, if that's what they want, and I don't think that's how we should be seeing it. This is actually—the number of children is small, it's not expensive. We should be providing this first-rate Rolls-Royce care for that small number of children and the families caring for them.

Yeah so that would be my key. There is one area I think that philanthropists have been extremely valuable, and that is to get things started. My post is paid for by the Welsh government which gets the money in turn from the Westminster government in London. But for the first three years, it was a charity that paid my salary and the fact that I was able to demonstrate in those three years that it was important thing to do and the government said "yeah okay, that's fine we get it."

I think another example of that, perhaps a more recent example, is academically. Children's palliative care clinically is low priority—academically, it's just off on the horizon. Whenever we've tried to get anything a serious academic off the ground, the only way to do that has been through philanthropy, through charities.

The other interesting thing about philanthropy and charity is that, it seems like you have to have a good message or a good pitch to people that are largely from the general public. And I'm struck thinking back about the diary you kept when you first heard the documentary on palliative care, and you were just totally disgusted. So, what has your experience been with trying to find ways to demonstrate the importance in a way that society will accept?

That's a very perceptive question. I think the main thing is improvement—things have got better and better. I do remember pitching a couple of academic projects early on, and one of them was to the Duchenne. I can't remember what it was called, but the Duchenne is the dystrophy charity in the U.K. I wanted to do a project to characterize the nature of the pain the boys with Duchenne muscular dystrophy felt. So the nature of it, including the incidence of it, because my sense was that we were seeing a lot of boys—much more people didn't think Duchenne was an obscenely painful condition and that the pain was under reported. I believe the boys themselves, wouldn't realize how uncomfortable they had become over time until you made it better and they thought "Yeah, I remember what this was like. This is what it's like not to be in pain." I was also interested that there seemed to be multiple modalities in the kind of the pain they have, and multiple causes behind it. So I thought that was a really interesting research
project here, talking to boys with Duchenne, getting to describe their pain, characterizing its incidence, its prevalence, and the nature of it. I still think that would be a really be a good project, but the Duchenne charity just wasn't interested because it wasn't cure oriented. As far as they were concerned the message, they trying to give people with Duchenne, was this is potentially fixable. If we have enough money we're going to cure for Duchenne, and they felt that my coming in and saying "you have to hang on, some kids are still going to die from it and we need money for that too, " that was going to undermine their basic message. That was the most obvious example, but I've had other similar sort of senses as well.

[00:31:45]

Bryan Sisk: Do you have any thoughts on best approaches to getting the concepts of palliative care out to the public?

Richard Hain: I think demonstrating is the most important thing. The most powerful witness to what can be done is when families go through this terrible experience and they're able to look back on it not only with sadness, but with also some satisfaction. To be able to think "Yeah I didn't want him suffering". That makes a big difference.

Certainly when it's come to my professional colleagues, when they've referred difficult patients, patients who they're worried will suffer at the end of their lives and we've been able to help out in such a way that their deaths were peaceful and comfortable. That stuff—people have talked about that among themselves and my colleagues have learned from that.

I think for the culture more generally there has been an overwhelming sense that "this shouldn't happen." And of course, they're right, it really shouldn't happen. Children aren't supposed to die—it's not the way the world was designed. Would you excuse me for a moment?

[Extraneous conversation 00:33:07 – 00:33:24]

So yeah, that makes a big difference. In the culture more generally, I think talking about dying is probably more important than talking about palliative care, because its the death bit of it that's taboo. Even then, we have to learn the skills of accommodating people's sensitivities. It's up to us, it's our job to enable people to feel comfortable talking about something that's difficult—they shouldn't have to change their approach for our sake. But I do think that we need to make institutions and health care people realize
that although death of children shouldn't occur in the universe, in reality it actually does occur.

Bryan Sisk: What were the biggest challenges you faced early on when you trying to forge this career that hadn't been forged in pediatrics before?

Richard Hain: I think the biggest challenge, funny enough, was that the adult palliative care services didn't recognize that the pediatric palliative care service needed to be distinct. There were many adult palliative care physicians, especially because quite a lot had come from a general practice background, who thought that palliative care was for all ages, including children, and they thought that they would be better caring for children at the end of life than pediatricians would. Of course, sometimes that was true, but the idea that it would be okay for adult physicians to care for children remains, and always the remains for me an enigma. And so, trying to get support from them without colluding in the idea that it was part of the same specialty was quite difficult.

We did win that. I haven't told you the whole story. Around about 2009, we actually became a recognized subspecialty of pediatrics. In the U.K there's a real college of pediatrics and child health as you probably know. Once pediatric palliative care was recognized as a sub specialty by that college, that was there very clear—I didn't need to fight that battle anymore in the sense of training and the people who do it. There was still a political battle to be won. The strategy Wales-wide was still being decided by somebody who didn't know how little she knew about the pediatric specialty, about pediatrics. That was a battle. So oddly when I look back, the biggest battle I had wasn't with the people who didn't understand palliative care, but with people who didn't understand pediatrics.

Has that changed over time?

Richard Hain: It's got better because I think they've just stood back. Now we don't need their support quite the same way. I still work closely with them, but I think they've said, "Okay what you're doing it, you get you get on with it then," which is fine—that's what we wanted. So yes it is, but it hasn't gone away completely. There's still adult physicians who would see their expertise in palliative care as being so universally applicable, that the age of the patient isn't their consequence.
Bryan Sisk: How much do you think that the ability to have adult and pediatric palliative and hospice care as separate specialties is driven by available resources?

Richard Hain: So, I think it is a reasonable thing to think. I certainly think that aspirationally, there should be two specialties—they should work together, but they should consider themselves to be distinct. Pediatric palliative care should always see itself, in my view, as a subspecialty within pediatrics and not a subspecialty within adult palliative care.

However, there are clearly situations in which that's not practical. Interestingly, the resources issue wouldn't have been the first one I would have chosen, but again that's part because one of the great luxuries of working in a socialized health system is that's not a concern—that was not something I had to worry about.

What is more of a concern is sheer numbers. If you go to Scotland, Scotland's got six million people in it, but it's the same size as England which has 60 million. There are huge tracts of Scotland that are barely populated. You simply can't—there aren't enough patients to support the specialists in children's palliative care in every town in Scotland. It would just be a non-starter. So, I think there are many situations in which a good plan B is for a pediatrician to work with an adult palliative medicine specialty—you have two skill sets but you're bringing them together in a collaboration rather than in one person. That might be fine. I think that properly done and with good will on both sides and mutual respect, I think the child is well cared for under those circumstances.

But I think that everybody should be aware that it is a very good second-best rather than the ideal solution. I think what you're saying about some resources is more of an issue—I'm thinking now, I did some teaching in South Africa around Cape Town. Cape Town isn't particularly resource poor, but obviously the countryside behind it, the Hinterland is. There was so many children there needing palliative care, contrary to what I've just said about Scotland, that actually you could possibly not have pediatricians there to do that job. Instead that's actually done by primary care physicians, but these primary care physicians are seeing more dying children than I will ever see.

So, there are circumstances, alter cases as the saying goes, and there are many situations in which I think we do need an alternative model, but that shouldn't distract us from the basic
premise that palliative care for children needs is based on understanding the child as an existential being, and the more existentially you look at a child, the less they resemble an adult.

[00:40:48]

**Bryan Sisk:** One the concepts that come to mind, is something that you referred to earlier about having multiple different visions of what pediatric palliative care is or should be. That presumably was pretty common as the field was developing. Have these multiple visions largely coalesced or there are still desperate visions of what exactly palliative care should be?

**Richard Hain:** Both those two. I think we do have a much more unified vision than we did. The history of palliative care in the U.K. is very interesting because it's often located to 1981, 1982, when the first children's hospice opened in Oxford, Helen House in Oxford. That was a huge milestone, no question about that. What was interesting was when that started up—first of all, the medical input was from a GP, not a pediatrician at all. The pediatrics establishment at that time reacted with some alarm, and I think it's fair to say, some aggressiveness. Their concern was that they saw this an alternative inpatient unit where very sick patients would be treated without them knowing any amount of it because these are patients who would have pediatricians already.

So, the pediatricians were concerned that their sick patients would be admitted to this alternative facility and being given medical care of which they have no authority over or control. Put like that, that sounds like a reasonable concern, but what they hadn't understood was that the care that these kids were receiving in this hospice was not really medical care—it was respite care. It wasn't an alternative to a hospital ward, it was an alternative to them being at home. You wouldn't expect a pediatrician to necessarily to be going in everyday at home. So, there was a huge stand off and unfortunately, I think that set the scene for quite a lot for the divergence between two major visions. One which would primarily nurse-led actually, with minimal medical support from an interested GP. And on the other hand, this idea that pediatricians should be doing everything. But actually, to be fair the pediatricians weren't doing a great job at that time because most of them didn't know about palliative care—they didn't have that much of a clue about what it meant. So over time, I think what's happened is that each side—that persisted for some time. I would say 10 or 15 years that, that schism persisted. Possibly longer than 20 years, but what changed it was that both sides acknowledged that they needed the other. Over time, pediatricians have, as you've heard, pediatricians have increasingly recognized what palliative
Interviewer: Bryan Sisk  
Interviewee: Richard Hain  

care is and the contribution a specialist in pediatric palliative care can make.

At the same time, perhaps as a result of that, children's hospices have recognized the value of having a pediatrician involved. So many, by many means all children hospices now, will have some link with a consultant in pediatric palliative medicine. Others will have links with a consultant pediatrician of some other kind of interest. I think there aren't many GPs working in children's hospices now who would see themselves as experts the same way as those early GPs did, although there are still many who would not necessarily recognize the limits of the complexity of their patients sometimes. So yes, very much better, very much more unified vision and unified voice, but I think we still haven't completely resolved those different visions.

[00:45:05]  

Bryan Sisk:  
So, you talked about this standoff that lasted for maybe 10 or 15 years, how did it manifest itself? How was it apparent that there was a standoff going on?

Richard Hain:  
I think there are lots of answers to that question. I think on an individual level there were many hospices whose experiences were that some pediatricians would never refer patients—that they just pretended that hospices didn't exist. They were possibly discouraging of families who wanted to go to hospice. That by no means was universal. There were many pediatricians who were extremely supportive. David Baum if you've probably heard in the course of your history taking. David Baum was in Oxford at that time and in fact he was one of the pediatricians who defied the trend at that time and supported the idea of children's hospices from the outset. He got what it was all about. There have been so many honorable exceptions but so many would just be critical. I think many of the hospices, and the GPs working in children's hospices, considered that because they were working in children's hospices, they were already by nature doing that, they were already experts at palliative care. I certainly knew one GP who had very little time for pediatricians coming into it because he felt like palliative care was a primary care skill, it wasn't a skill that pediatricians could muster and he was quite critical at conferences and things so it's that kind of thing. More obviously, I think you could stand back and say well we have this profusion of children hospices between 1981 and 2011, 30 years later—53 hospices in the UK opened and only one of those I think involved a consultant pediatrician from the outset and that was one of the early ones in fact in Leeds. Now that doesn't mean to say they were always
treated with antagonism that's not my point. My point is that they didn't consider that they needed to build in the idea of specialist pediatric input from the outset. That wasn't the way that they saw it.

And I think the third evidence is that even now in some children's hospices, including the one that I'm linked with, the number of oncology admissions to the hospice is disproportionately low and I think that's because the systems that were in place managed children at home were always very good and there's been a sort of attitude, "We can manage this very well thank you, we don't need a hospice." Most of the time that is true but sometimes it isn't true and when you look at the numbers of referrals of children with oncology needs into hospices certainly needs some statistics disproportionately low which I think is still evidence to the same thing.

[B00:48:16]

**Bryan Sisk:** Looking back from your perspective, what do you think is the spark that set off this movement towards pediatric palliative care, developing and becoming a specialty? What was that initial spark that really got this going?

**Richard Hain:** To be honest, I think it was the example that the adults were showing us. I think the hospice model in adults which is—it's good to say the hospice probably in adults is quite different from the one in children. The hospice in adults did start as a medically led new idea. It was doctors uncharacteristically recognizing the need for a holistic and multidisciplinary approach and creating an environment in which that could happen and calling it hospice.

So the adult hospice model, the model of care that, that represented I think presented pediatrics with an example and demonstration of something to emulate. You know pediatrics is already fundamentally more holistic in that sense than the adult medicine is because part of the reason why it took long to get the idea because actually this was something that pediatricians aspired to do and whereas the adult physician, the adult oncologist might say yeah you're right, I can't do this. I can't provide holistic model while my patients are dying let me refer them to you.

I think pediatricians would say, "I understand that. I got a holistic model." A lot of what I feel I should be doing anyway and if I may this kind relates to your previous question. Many would see the very existence of palliative care or hospice model as an implicit criticism, "I'm not doing the job I should be because if I were, the hospice would be unnecessary we wouldn't need palliative care."
Bryan Sisk: So, we've talked a bit about how other physicians viewed this development of palliative and hospice care for kids, how did patients and families view it at the beginning?

Richard Hain: Well, so I've never had anybody come to me, anybody who's in the situation say, "What on earth are you doing this for? What is palliative care all about?" I think it comes back, I think to what you were saying how do we get the message across and I said by exemplifying, by demonstrating it, by illustrating it.

And I think by the time families are introduced to palliative care, their life experience, their life situation is such that they understand the need for it. Now that isn't to say they aren't alarmed by the words, because they are. And that is to say there's some families who can never adjust to palliative care is what's on the agenda, what's on the menu. I think on the whole, most families that I've been able to work with, by the time I'm introduced, I'm dealing with to needs that already recognize that they have. Interestingly quite often that's to do with soluble problems, so I think families find it a little easier for palliative care to get involved when our care is built around a specific problem, commonly pain. People say, "This is my colleague Dr. Hain, he's good at managing pain." And little Johnny has some pain, and they say, "Oh that's great." And so we come along and we talk about pain. Then it's a natural progression to talk about pain in the context was going on in somebody's life. It provided a point of entry into that wider discussion. And that's to say why that discussion typically flows very naturally because families are already experiencing the sort of things we're talking about.

Bryan Sisk: Over the last maybe several years to a decade or so there has been a growing debate about generalist versus specialist palliative care and getting back to this question of what should be the role of the primary team versus when should the specialist team be called in, what are your views on how that debate has developed and what potential solutions might be?

Richard Hain: So, I think the danger of the debate is that it dichotomizes one model against another, and neither of those representations is true. It is neither wholly a specialist field nor can it be adequately done by generalists alone. It is good palliative care for the child; lots and lots of different levels of expertise, including of course the general expertise of all the day-to-day care of the child by the family, by the parents or by nonprofessional caretakers in the home. And then you got all the nursing aid who helps, and then you've got the
general nurse who helps, then you got the special pediatric nurse who helps, then you got the pediatrician that helps her, and then you got the specialist pediatrician who helps them; you can't do without any those so I think the debate is fundamentally misconceived.

If you were to ask me the question, "Can palliative care be done adequately without the existence of a specialty called palliative care?" My answer is no you can't. You need some people to specialize in it because there are some things that you need to be done that you can only get good at doing if you're seeing lots of children. You can only do that if that's your specialty. Sorry—lots of children needing palliative care and you can only do that if that's your specialty. So, I'm equally outraged by the idea that we don't need generalists as I am by the idea that we don't need specialists. We absolutely need both and all the ones in between and they all should be regarded as equally valuable in the care in providing this meaningful care and choice for an individual family.

[B00:54:55]

**Bryan Sisk:** So, one thing I noticed from looking through your CV was that in 2000 you awarded that first academic pediatric palliative medicine post in the U.K. So, was that what you were talking about was primarily funded initially from charity for those few years?

**Richard Hain:** Correct.

[00:55:12]

**Bryan Sisk:** So how did that come about?

**Richard Hain:** Well, so I—actually this was linked to what we were saying earlier. I was at the end of my training in pediatrics which had encompassed oncology, complex chronic pain, and pharmacology, but hadn't encompassed any adult palliative medicine at that point. An advertisement came out in the *British Medical Journal* for a consultant specialists job in the U.K. in Wales. I wrote back and I said, "I'm not ready to apply for this yet but I'm just interested to know what is it that you're looking for. You've advertised for pediatric palliative care specialist. What are the skills that you are looking for?" And the person wrote back and said, "Well obviously they will be a palliative care doctor and we would give them six months training in pediatrics and then they would be a pediatric palliative care doctor."

I thought that's not my vision of this at all. You can't turn somebody to a pediatrician by giving them six months experience with children, that's just not enough. So, I wrote back politely
saying it's a very interesting, thank you and I didn't contact them any further.

But the person who had written to me I think carried on thinking about that and when I came to finishing my, I was about to finish my training, I had gone back to Canada and I did adult palliative medicine fellowship and I was expecting to comeback to a consultant job in the U.K. and this person wrote to me and said, "Why don't you come back to Wales and finish training in adult palliative medicine as well so do another two years training and by that time we should be able to set a job up here in Wales," and that's what we did. So, in this particular instance at that point I had persuaded this person that what we needed was a pediatrician to do the job.

[00:57:19]

**Bryan Sisk:** So, we're getting close to the end of the interview and looking more broadly over the span of your career, what do you think have been the biggest changes in the care that we provide to these children suffering with serious illnesses?

**Richard Hain:** So, I think, so one of the things I think is interesting you put it like that, that is I think we have, they've come higher up the agenda than they used to be. We talk about these kids. We're caring for them in this wider multidimensional sense is something that is matter of fact now, whereas I think it would have sounded flakey 30-40 years ago.

I think people understand now that it can be relevant to be involved in the care of somebody even though that person isn't going to be cured. Again 30 or 40 years ago, I think that was something that people didn't get. Doctors try to cure people, when they can't do that, they had nurses and nurses had the nurses who do the caring of the child as they die and or even the parents. And I think nowadays we take it for granted why that should be case. Why shouldn't doctors have the role in helping to care for children as they're dying too?

I think that has been reflected in the gradual change in medicine where we recognize that getting along side people in their suffering is an important part of what we can and should be doing. That is reflected in other areas too; chronic pain and teaching management of these “psychosomatic conditions” that we very often can't fix, but we can still do something, and we found that families still value our input. The number of times that I've spent 45 minutes with somebody, written no prescriptions at all, made no changes to their medications, but I'm aware because of what they say as they
go out that, they're feeling very much better than when they came in, in a much more realistic way than if I had actually written a drug. So, I get the fact that we can do lots of wonders, but we can't efficiently do both is now built into the way that we think pediatrician. We have managed to get the idea that children die out of the realms of the darkened subconscious and to a certain extent onto the public agenda. Recently the U.K. government announced it was giving £25 million to children's hospices across the U.K.

So, I think we are winning that particular battle—people are more comfortable talking about this terrible thing. And I suppose the other thing is I think we are better at managing pain in children. What I understand in the States, you're about to face the opposite backlash because of the worry about the addiction epidemic and I really hope that doesn't happen. My hope is that we're seeing an oscillation around a reasonable mean.

In the U.K. we didn't have the same problem with over prescription of opioids; it's not been great but it hasn't been as bad and I'm hoping we won't swing back either. But at the moment what I said to families 20 years ago, "I would like to start with a low dose of morphine," their faces would drop in horror because I was saying something outlandish; I'm talking about an addiction and I was talking about all sorts of things. Nowadays that's not what happens. People say "oh yeah okay, okay." They will talk about their worries and they understand that morphine has a place, even for children who were going to recover and survive, and certainly that morphine, in small doses, is a good pain killer without being dangerous.

Bryan Sisk: You've had contributions in many different areas and many different ways and continue to have different contributions with your new degree that you're pursuing. What do you think is your biggest or favorite contribution that you've given in career to this field?

Richard Hain: Oh gosh.

Bryan Sisk: That's always least people's favorite question [laughs].

Richard Hain: So I was very pleased to have got palliative care recognized as a subspecialty. So, I was the chair of the committee of the Royal College of Paediatrics and Child Health that got that through, and it was a lot of work. So that's one thing. I think that did make a difference Once it was done, we no longer had to fight this battle of saying that this needs to be a pediatric job.
We were able to set down standards of what people—you can't just set yourself up as a palliative or pediatric there are certain things that you need to be able to do and this is what they are. So I'm proud of that. And I think leading up to that, in order to do that because of my experience in the adult field, I knew that in order to justify being thought of as a specialty, we already had to show that there was a canon of knowledge that could be identified as pertaining to that specialty, which basically meant a textbook. We had to have a textbook that contained information that was relevant to the specialty and so we did do that. So with the Oxford University Press, we got the hospice and palliative care in children\(^1\) which has gone into two or three editions and that would be the other thing that I'm most proud of.

So what I've done, being a consultant in Wales, the services have been expanded and that's been great and I've loved my part in that. But to claim that I was being the sole person who did that would be simply wrong and the passage of time had a lot to do with it as well. But those other two things I felt if I hadn't been around, I'm not sure they would have happened, so I suppose I'm proud of it.

What do you think is the biggest challenges that remain for the field of pediatric palliative care?

I think one of them is that there's always a risk when the specialty starts to think of itself as more important than it should. So, I think the view that nobody should be caring for dying children other than the specialists in palliative care; that would be wrong in my view. I haven't heard but I've articulated but I think it's a danger that we could come into. It tends to be the way of specialties. If you've got a hammer, everything looks like a nail and that's not the way I see it. There are some patients that we need to take over their care, but most other patients actually we're already working alongside colleagues who were already involved. So that's one danger.

I think there's a danger—first generation people who go into a new specialty, driven by a vision and they've got the enthusiasm. Once it's already there, you're much more likely to go into with less than a passion. I think that could be an issue. And I think one of the ways which I've noticed that is the people are willing to let their knowledge wither a little bit—

\(^{1}\) Oxford American Handbook of Hospice and Palliative Medicine and Supportive Care.
They're just not right or else they're incomplete or they're ill thought through. That's not good enough.

We're supposed to be the highest level of expertise in this field. We need to know better than that, and that does worry me a bit. But I do I wonder whether everybody that's ever been in the excitement of a new specialty looks at the next generation. And of course amongst those people are some absolutely superb people and I've have been privileged to see some of those because they've been my trainees and I would see some of those I guess it's good hands.

What do you think are the strongest areas of the field, the brightest shining lights in pediatric palliative care right now?

People do you mean, or do you mean ideas?

Ideas mainly.

Yeah, I was going to say that's going to get a bit personal [laughs]. The biggest one would be the one that I've already alluded to. I think the idea that doctors can and should be prepared to get alongside patients and be more than just a fixer. We should recapture that much more ancient tradition of healing, which was sort of just being somebody, helping them through something, accompanying them, being as a knowledgeable friend along the way, that's very important.

I think one of the things that's going to be important is—this is opening a whole other field—we're living in an age where certainly in the west, the tradition has arisen that doctors look to parents to make decisions about their child's medical care at the end of life. We've started to believe it so strongly that we assume that it's a fundamental ethical principle; that what the parents want for their child should happen. I think it's very important that that isn't taken uncritically to be the case.

Actually, parents don't have a right to say, they don't have a right make a decision about what happens to their child. They have the right to express what they think is right for their child and we have to listen, we should listen and there needs to be a dialogue between the two. It's that dialogue that I think I'm coming to because I think in order for the best thing to happen to a child, it's not enough for doctors to make a decision nor is it enough for parents to make the decision—there has to be an ongoing dialogue and I think the ongoing dialogue in the kind of context we're talking about can't
just be a five or ten-minute conversation while the child's oxygen levels are falling in front of you. It has to be on the basis of a relationship that's already in place.

A trusting relationship. A relationship in which end of life issues are on the table and they're being discussed in an open and honest way where each part needs to respect, even if they don't necessarily agree with and it only holds fast to things that are really important. So in other words what I'm saying is the role of palliative care in brokering and being part of those difficult sensitive, but very, very important conversations for ensuring that children aren't denied intensive or invasive interventions when it's appropriate, nor forced to endure them when it's not appropriate. If we get to a on point either of those extremes, I think the place of palliative care is going to be very central and I think that's going to be one of its biggest challenges in the next 10-20 years making clear with that and ensure the right thing out for the child at end of life.

So lastly, I would love for you to just dream aloud and if politics, finances, and geography and everything else that we talked about as barriers to effective palliative care, if none of those existed, what would you ideally want the care for these children to look like in 10 to 15 years?

So, I sort of hinted that this support should be available. First of all, I think families should be able to care for their child in any environment that they feel most comfortable in. And so that means that we need to be able to provide for every single dying child, the option of dying at home. A hospital too, but the home is the hardest of those to manage. That means a number of things. First of all, it means that we would be teaching skills to families so that they don't feel completely at sea when it comes to managing gastrointestinal tubes for example. It means finding new ways of managing symptoms that don't necessarily mean intravenous and all those tubes; ways that can be managed in a home environment that are less complex then they are now. I think we need to have systems for delivering medications that are more user friendly, more intuitive and I would see that—I'm sure the remote controlled through apps I have a way to do that. I think that's particularly important because one of the other things is that we need to be able to record things more accurately so that we can feel confident that parents are being supported and are able to care for their child.

On top of that layer, I think we need to have adequate community pediatric nursing infrastructure; so we need to have enough nurses
trained to work with children in the community to be able to go out there if necessarily once or twice a day, or even 24 hours a day if that's needed, to, if necessary, to attend to a syringe driver for example, to make sure the PCA [Patient Controlled Analgesia] is working. Something like that, so that even kids whose symptom control is complicated can still be offered a place at home.

I would want all of those to be supported by a local, not only the local pediatrician who knows the family but also by a local pediatrician who's got a knowledge of and interest in palliative care; so somebody who's just down the road and can come just see the child at home if necessary. We still do home visits here in the U.K. and my understanding is that doesn't happen much in the U.S., is that right?

[01:12:17]

_Bryan Sisk:_ Not much.

_Richard Hain:_ Yeah so here that's still an expectation of primary care of GPs. It's not usually an expectation of pediatricians, but I can't see why it shouldn't be. But then I think those local pediatricians should always have other resources at their disposal including the opportunity to consult with a specialty pediatric palliative care nurse and a specialist pediatric palliative doctor who may or may not be local to the child, but who can provide remote support and on occasion would actually come out and see the child as well.

I think that combination of things means you've got combinations of somebody who's seen lots of palliative care, but doesn't know this family very well necessarily, combined with a team that knows the family very well, but doesn't necessarily see a lot of palliative care, and working together I think they've got the perfect team around that child. And the family in that situation that I described would I think feel more confident in caring for their child at home if that's what they wanted. They should also then have other resources such as child's hospice if that's what they want. What I've said about parents caring for their child at home should also be true of teachers caring for the child at school, so if necessarily the child carry on going to school for as long as they feel comfortable with.

So for me it's a question of not having to sacrifice specialist skills in order to deliver care locally or put it in another way not having to sacrifice care locally in a home in order to obtain specialist skills which all too often is the exchange skills that children find themselves having to make.
**Bryan Sisk:** Phenomenal. So those are all the questions that I have. Are there any major areas that of this history that you think I've missed or glossed over that I should think more deeply about?

**Richard Hain:** The only thing that I would suggest is—initially when you were talking about what are the challenges that we face. There was an interesting debate here a few years ago about the term “life limiting condition” and it was the philosophy behind that debate that was interesting for me, because to me "life limiting condition" meant it was a condition that would limit the lifespan plausibly within childhood, so a child who wouldn't survive into adulthood.

But people I found were using it in a different way. They were using it to suggest that the child's activities during their life would be limited and of course that extended the constituency of kids that we're talking about to include any child with a significant disability. And I found myself in a difficult position because I think there's a danger in extending that far because if you extend that far then you lose the particular needs of children who are going to die as children.

On the other hand, I'm also aware a lot of what we said about the lack of priority given to children who are going to die is even more true for children who really have disabilities so I wanted very much to support them but I didn't want that term "life-limited" to lose its power. I think we've move on from that, so I think life-limited is more often used now to mean somebody who's going to die in childhood. Those people don't use it in that broader sense, but I noticed you use the term of long-term illnesses and people are using complex chronic condition and I think it's wrong to consider those synonymous with life-limiting conditions.

Now clearly, they overlap. Most life-limiting conditions are simultaneously chronic and complex, but not all chronic and complex conditions are life limiting. And while we shouldn't regard them as utterly separate. I don't think we need any inflate and we don't regard them as synonymous. If we do, then I suspect that the special skills that are necessary in like the care of a dying a child will become diluted or lost in more general concern and that would just be one point on there.

[01:16:47]

**Bryan Sisk:** Wonderful. Anything else?

**Richard Hain:** No, I've really enjoyed talking to you.

[End of Audio]