Biography
Dr. Ann Goldman, M.D. became one of first physicians in the world to practice pediatric palliative care. She pioneered a holistic multidisciplinary pain and symptom management model with her development of the Symptom Care Team in the 1980s at the Great Ormond Street Hospital, London, England. During her clinical career, she worked to get pediatric palliative care recognized as a specialty by the College of Pediatrics, was a founder member of the children’s charity Together for Short Lives (formally ACT), mentored many of the current leaders in pediatric pain and palliative care, has edited and authored numerous research articles, texts, and book chapters. She is currently an editor for the Oxford Textbook of Palliative Care for Children.

Interview Abstract
Dr. Ann Goldman begins the interview by identifying some early field experiences as an oncologist researcher and observing service gaps in clinical patient care that didn’t acknowledge the psychosocial needs of families with chronically ill children. As Dr. Goldman was attempting to find guidance to develop her idea of providing more holistic care, she was met with some unease by peers and a discouraging message from Dame Cicely Saunders to not pursue this notion.

Undaunted and driven by her innate knowledge that this idea was right, Dr. Goldman then describes her experience of being demoted in hospital hierarchy to “invent a job,” where she could establish a pain and symptom management service for pediatric patients with palliative care elements. She describes that she developed her team model from influences in pediatric pain and the adult palliative care field.

Dr. Goldman was met with several challenges to her pain and symptom service. For example, there were no training resources for her multidisciplinary team. She also noted the importance of the relationships she developed that allowed her to expand beyond the oncology department.

Dr. Goldman describes one of her proudest achievements being her role in legislative and public advocacy to help bring about the recognition of pediatric palliative care as a specialty and to develop training materials for providers globally through her charity work Together for Short Lives.

Dr. Goldman concludes the interview with her vision of pediatric palliative care expanding outside of resource rich countries and helping resource poor countries achieve a greater degree of accessibility and to reduce the gap between children who need palliative care and children who don’t receive it.
## Glossary of Acronyms

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Today is May 13th, 2019. I am Bryan Sisk, and I'm in St. Louis, Missouri interviewing Dr. Ann Goldman over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Goldman is in the Lake District in the United Kingdom. Thank you, Dr. Goldman, for joining me today. To get us started, can you tell me when your mind turned toward pediatric palliative care as a career focus?

I was doing pediatric oncology. I was involved in a research project which was looking at one of the early monoclonal antibodies called UJ13A. One of the things we were doing, having done some basic animal work, was radio labeling it and using it to try and target radioactivity to children with disseminated neuroblastoma. In the process of this clinical trial, I met quite a lot of families with children with very advanced neuroblastoma.

Two things were happening I suppose, in my mind; one was an increasing awareness that lab research with nude mice was not going to be my forte in life, and that I wanted to get back to clinical medicine. The second thing came to me I suppose through working with these families, that although most pediatric oncologists tend to have a special interest in a particular tumor, nobody seemed to have a particular interest in the needs of the children whose disease was so advanced that curative treatment and second or third line treatment were not going to be helpful or available for them. As I was thinking about getting back to clinical work, it seemed to me that this was a group of children I could be very interested in working to help. I've always been interested in, I suppose, people with serious disease but also psychosocial problems. That seemed to be exactly what these children had.

That was where my interest in palliative care arose, I suppose. There was no pediatric palliative care at all at that time, but there was adult palliative care. I had read stuff to do with Cicely Saunders and her setting up St. Christopher's, and I've read things like Elisabeth Kübler-Ross who was writing it around that time. That's where it began.

I see.

Does that help you?

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It does, absolutely. Clearly it was on the cutting edge. There wasn't really a lot of similar minds at that time. When did you start finding people that thought similarly about these things that you did?

There really weren't many people around thinking about it. I talked to our oncologist and he thought it was an interesting idea. I talked to Cicely Saunders. She thought it was a terribly bad idea. She wasn't interested in children at all and didn't think it was necessary. We had in the hospital at that time a system that we called Shared Care. Children who came from quite wide geographical areas to Great Ormond Street Hospital for care there; children with malignancies of whatever type, their care was shared with local hospitals. One of the things about the shared care was that it didn't work brilliantly. Often when families went back home, they felt very isolated and on their own. Hospitals we shared care with and their family doctors often felt very at a loss because they hadn't seen many children with problems like this.

I sort of invented a job and an idea that we would have a team. There was certainly one nurse on the ward who was very interested in the idea of being able to be an outreach team from the hospital to help improve shared care. Our idea was we would have a team with medical and nursing input that would work with all the families who came to the oncology and hematology departments, not just the dying children. We called ourselves the "Symptom Care Team." We would be able to help with symptom management during treatment, we'd be able to help and do outreach work with the families when they first went home and with their family doctors and with their shared care hospitals, and that we would also be able to do outreach work with families when the child was entering end of life care and terminal palliative care.

We had the idea, but we had no money. The oncologist who was sympathetic to the idea helped me find a small charity that would fund myself and two nurses to start setting up the team, which is what we did.
stuff, I actually was out of work because I wanted to set this team up, but we didn't have the money. I went and I was a locum, a temporary doctor in general pediatrics for a year. Our health care system's different — it was like an attending consultant post, which is our senior level post. When we eventually found the money for me to go back to Great Ormond Street and set up the team, I didn't go back at the senior level. I went back down to being a junior, I think so they could keep an eye on me and make sure it was working with a good plan. I took a drop in status and salary in order to set the team going.

I think people were anxious because they always looked after their own patients, and wanted to look after their own patients, which is one of the of the differences from when Cicely Saunders was setting things up and she had surgeons who just abandoned their patients. The pediatric oncologists didn't abandon their patients, but I was just trying to say to them that I thought a closer focus would improve things. They felt maybe they were being excluded or perhaps that what they were doing wasn't thought to be good enough. I think that was an anxiety for them. They wanted to be supervising fairly closely, I think, just to start with, which they did.

*Ann Goldman*: It was okay. There were people I got on well with and have respect for. I think they appreciated what I was after as well.

*Bryan Sisk*: That's a tight rope to walk.

*Ann Goldman*: I don't think they had really thought about it in the same way. I think they thought they were doing a reasonably good job and hadn't really put together some of the things that we could learn from adult palliative care and the support that the families really wanted, if they wanted to be at home rather than in hospital.

*Bryan Sisk*: How many—

*Ann Goldman*: Most of them were not familiar with the sort of drugs that were beginning to be used in adult palliative care at that time.

*Bryan Sisk*: This was the early 80s then?

*Ann Goldman*: No, I think it was '74, wasn't it?
Bryan Sisk: I'm sorry, when you were starting this work.

Ann Goldman: I'm just trying to think. It'll be there in my CV. I suppose it was very early 80s.

Bryan Sisk: We've talked about—

Ann Goldman: It might have been 70s. It will be there in the docket somewhere.

Bryan Sisk: Yeah, it's in front of me here. I'll dig through it after our call.

Ann Goldman: If you look down the jobs it'll tell you.

Bryan Sisk: We've talked about how there are these gaps in the care and these challenges in the care, but how was the care most lacking at that time in the late 70s when you were starting to think through this stuff as you left the neuroblastoma lab?

Ann Goldman: I think the big thing that was missing was support for families who wanted to be at home. Also, people weren't focusing their mind on symptoms and improving symptom management, rather most of their focus being on ways of curing leukemia or lymphoma or whatever. But if you weren't curing it, then they hadn't put much energy and focus into thinking about the support people would need in the way of pain management and other symptom management, and psychosocial support at home.

Bryan Sisk: How effectively was pain managed back then?

Ann Goldman: I think it was managed very individually. There were people who were more confident in using stronger opioids in children, and other people who were less confident. There was certainly no standardized way of doing things. There was no use of subcutaneous opioids when I started, certainly in our department there hadn't been. I put up the first subcutaneous syringe driver.

Bryan Sisk: In terms of—

Ann Goldman: It was bringing in some of the ideas from the people who had been exploring in adult palliative care, I think, and having more confidence and experience.

Bryan Sisk: What do you think was the barrier to that confidence? Was it worry about addiction? Was it fear of harms? What was the big barrier to more use of strong opioids?
Ann Goldman: Again, I think it varied enormously. I don't think all those barriers have gone yet. There are still plenty people who are very anxious about addiction and worried about respiratory depression and overdosing. People are different. Part of the challenge was to try and work with colleagues and work out what it was that was stopping them or what they were afraid of and challenging that in a sophisticated enough way for them to believe that you understood what was happening and were capable of looking after things.

[00:13:48]
Bryan Sisk: What about the psychosocial needs that we talked about? How effectively were those recognized and managed?

Ann Goldman: I think in oncology there was quite a lot of recognition of the psychosocial needs of families. Most departments specializing in malignant diseases have psychologists who specialized with them. People like Barbara Sourkes who was doing it in Boston in those days. We had also people, competent people, who were helping families. I think the big change really, or one of the big things that we recognized fairly early on, was that this wasn't just oncology. That although adult palliative care was focused entirely on oncology, in pediatrics we wanted to focus on all children with life-threatening illnesses. I think the recognition of the needs of children with other diagnoses was much poorer than it was in oncology patients.

[00:15:12]
Bryan Sisk: Do you think that recognition of how broad the field of palliative care needed to be in pediatrics, do you think that started from the very foundations of pediatric palliative care, or do you think there was still outside of your group an oncology focus initially?

Ann Goldman: I think we started very early on because the first children's hospice Helen House was starting at very much the same time that I was starting, Helen House was a tiny bit before. There was a recognition by the pediatrician who was the president of the college of pediatrics, Professor David Baum, of the importance of palliative care. He put together a committee, which I was part of, and a number of nurses—a multidisciplinary committee, of people who were interested in, showing interest in palliative care. We put together the idea of having what's now the charity Together for Short Lives, which when we first put it together it was ACT [Association for Children with life-threatening and Terminal conditions], which you must have come across.

As soon as we started to do that, we put the criteria that we felt were important for people, those four ACT categories of diagnoses, the sorts of children who would benefit and sorts of
families who would benefit from the input of palliative care. We did that very early on. I know when I was interviewed for my job, when I moved from being a junior in the oncology department to a member of staff in the hospital, one of the things I said already at that time, one of my aims, was to move out of the oncology department and into the rest of the hospital. For me, and I think for pediatric and palliative care in the UK, it's been a very clear recognition right along from the very beginning.

Bryan Sisk: The adult palliative care movement really ramped up in the 60s going to the 70s, and the U.S. and U.K. and was really wrapped up into this strong autonomy movement and a lot of other social unrest that drove it from the outside in, but then there were also practitioners from the inside out driving it. What do you think were the main drivers for pediatric palliative care? Was it societal?

Ann Goldman: I'm not sure in the U.K. it was such a societal demand.

Bryan Sisk: Okay.

Ann Goldman: I think it came from practitioners outwards. I don't have any recollection of it being a sort of push from society.

Bryan Sisk: From the adult side it was primarily from physicians outward?

Ann Goldman: Yeah, I would say so. I haven't read deeply about it, but my recollection at the time was that it was an awareness that came from clinicians.

Bryan Sisk: Is that the same thing that happened in pediatrics?

Ann Goldman: I think so, yes. I think there were families who wanted to care for their child at home when it was not a very common thing to do and who tried very hard to do so. I think it was working with those families that alerted clinicians like me to realize that they needed more support, and that it wasn't being done well. I don't think it was parents demanding it at all, or society demanding it.

Bryan Sisk: Do you think society even recognized there was a need before clinicians started raising awareness?

Ann Goldman: I don't think they did.

Bryan Sisk: I wanted to go back. You had mentioned Cicely Saunders and how she was not a big fan of specifically pediatric palliative care as opposed to adults. Can you tell me a little more about that?
Ann Goldman: I don't think there's a lot more to tell. I went to see her and I said I was thinking about trying to develop more focus on palliative care and pediatrics. She said, "Oh well, there aren't really enough children with malignant diseases and I'm not sure that it's necessary," and "off you go," really. I think later she appreciated that we'd done a reasonable job and could see that it was a little bit different from adult palliative care, but she was never very interested in it.

Bryan Sisk: I've noticed from talking with some people who are in pediatrics and some people who are in adult, there seems to be a bit of a divide still about should it be palliative care with a continuum from children to adults, or should it be individual unique specialties that have unique skillsets that somewhat overlap? Is that a tension that you still notice in the field?

Ann Goldman: Yeah, I think that's probably true. People don't get excited in cardiology and expect there to be one field and a continuum. There are pediatric oncologists and there are adult. There are pediatric cardiologists and adult cardiologists and nobody objects to that. Everybody recognizes that the picture is different and you need people who can focus on the needs of the different ages. Everybody I think is aware that there is a continuum where children become adults, but that doesn't mean you don't need people who can focus on different things.

Bryan Sisk: For you, what were the biggest challenges once the supportive care team was launched? What were your biggest challenges in your early career moving that forward?

Ann Goldman: I think the need to spread out from oncology and help pediatricians and Great Ormond Street, which is a quaternary referral center. There's no child in there who comes in with straightforward illnesses; every child has got some sort of complex serious disease. There was lots of need for palliative care. I think it was trying to begin to move out of just oncology and help other people. That was one of the big challenges, really. Then of course there was just me. There was no training program, there were no junior staff, there was no training for the nurses particularly. It was beginning to get it recognized as a field and by the College of Pediatrics, by the nursing colleges, so that we could develop this into a specialty.

Bryan Sisk: When did it become an official specialty?

Ann Goldman: Oh gosh, I can't remember. I can't remember. It took a while. Must have taken 15 years I should think. Ten years maybe. I don't know.
Bryan Sisk: Were you involved in that process of moving it towards a specialty?

Ann Goldman: Oh yes. There was only me. For many years I was the only doctor doing it. I was involved in all of it.

Bryan Sisk: How did you advocate?

Ann Goldman: By going to college meetings, presenting papers, and by making a noise with the right people in the right places.

Bryan Sisk: Then you talked about how the charitable funding was really instrumental in your initial startup. How has the role of funders played a role in this development of pediatric palliative care in the U.K.?

Ann Goldman: I don't think I can really speak for the whole of the U.K. But most new developments have come through charitable funding. Then they become established and then they sort of get absorbed into the national health system eventually. That's what happened to us.

Bryan Sisk: Now it's all NHS [National Health Service] funded, or is it still a lot of charitable funding?

Ann Goldman: The children's hospice is almost entirely charitably funded. Children's hospices in the U.K. are hospice buildings. We don't call it hospice care, we use the term palliative care and then buildings are the hospices. They're still very much charitably funded.

Bryan Sisk: As your team was developing, we talked a little bit about how your colleagues viewed the team. How are the pediatric patients and the families viewing you?

Ann Goldman: When we introduced ourselves as the Symptom Care Team to newly diagnosed oncology patients and said that what we did was help with the transition to home and we would help with their shared care, but we never particularly stressed that we helped with palliative care. They seemed to cotton on. They understood very quickly that we also did that. Since we were doing useful things for them all the way through from the time of diagnosis, we got to know them and that meant the transition was relatively easy to make in the oncology department.

In other places I think it depended really on what those patients and their other teams had talked about. Also, the views of the other
specialists who called us into work alongside them. If they felt that we were the Angels of Death or the Death Squad, then that transferred to how the patients looked at us and thought about us. We often were brought in at times of transition and times when people were finding it difficult, particularly at the beginning. We almost always found ourselves being invited in when there was a crisis. In a way, by being able to manage those crises and being able to develop rapport with the families and with the staff, that we became much more a part of the hospital system and recognized as valuable.

When you were starting out, did you have pretty high confidence that this was going to resonate and stick, or did you have questions about whether pediatric palliative care was going to take root?

I was quite sure it was needed. I didn't have any doubts, really.

There were simultaneous things that were developing primarily in Western Europe, primarily U.K., and then shortly after you there was some things developing in the U.S. When did you start to see more and more people pop up that who were of similar mind that were doing similar work outside of your immediate zone?

Outside of? I can't hear you.

Outside of your immediate area. When did you start hearing about people in the U.S. and people in different cultures?

People came to me. People who were interested came to me. People like Stephen Liben, Gerri Frager, a lot of the early people who started setting things up came and spent time with me first. John Collins from Australia. I don't know, loads of people would come and spend time with the team. People from Scandinavia came, people from all over the show.

There really are a lot of interesting parallels between you and Cicely Saunders. You started something and became the hub for people to come and branch out and make advancements in their own areas.

I think that's right. I think as far as I know I was the first physician who did this exclusively and called it paediatric palliative care. Other physicians—I think there were quite a lot more nurses doing very closely related things, but I was the first physician. Other physicians followed or contacted me to find out what we were doing.
Bryan Sisk: We've also talked about how you learned to some extent from the adult hospice movement and palliative care movement to pick up some of the skills and start to learn them in pediatrics. Were there any ways that the adult movement negatively influenced or hindered the development of pediatric as a specialty? Pediatric palliative care.

Ann Goldman: I don't think so. When I wanted to learn, because I didn't really know anybody in palliative care, I had to go to the adult movement. There was nowhere else to go except Helen House, which was doing respite care rather than medical palliative care. I did go to St. Christopher's. Cicely Saunders was happy for me to go and be an observer there for a few weeks. I did the same with an adult home care team in the north of London who were very helpful and supportive. I went to the adult palliative care shelf in the bookshop and bought the books, and then I just got on with it.

Bryan Sisk: Learn as you go.

Ann Goldman: Yeah. [laughs] In a way it was very easy because there was nothing. Whatever you did was a slight improvement. Now people get very anxious that there's a right way to do things, and have they been trained enough, and have they got the right qualifications? In many ways I think it was easier.

Bryan Sisk: How do you think the child suffering back then in the late 70s, early 80s, how do you think suffering was understood by clinicians? Do you think there was a holistic view, or do you think it was more focusing on individual symptoms?

Ann Goldman: I don't know. Suffering is not the word that I use a lot, and it's not a word that permeates into my ideal of doing palliative care somehow. I don't know. Very hospicey word somehow. I think clinicians were all doing the best they could for people, and very often did think holistically and did try and work with families. I don't think people were ever being neglectful.

Bryan Sisk: Another interesting thing historically is from a similar recognition of children with severe symptoms, a lot times in life threatening or life shortening illness, it spawned your work in the pediatric palliative care world, and it also seems to have spawned this pediatric pain medicine field. Towards the beginning it seemed like you were really straddling both of those worlds, but now it seems like they have become very discreet entities. Do you have any insights into how that developed?
Ann Goldman: I think that pediatric pain medicine began with anesthetists in acute pain, didn't it? I learned a huge amount actually from becoming involved in pediatric pain circles. I think probably more than I learned from any other field. I regularly went to the big pain meetings with people like Chuck Berde and Neil Schechter. The whole group of them—Maria Fitzgerald. The level of sophistication of science they had was greater than the case-history presenting we were still doing in palliative care.

[00:34:57]

Bryan Sisk: The acute pain services, did they end up consulting on similar patients as your Symptom Care Team did, or did you take over most of that pain management?

Ann Goldman: I can only speak for the hospital I was in. The anesthetists tended to be managing the post-operative pain and the intensivists were managing the pain in the intensive care unit, and we were doing other things around the hospital. I worked very closely in the end with one of my anesthetic colleagues and we set up a chronic pain clinic together, which was nothing really to do with palliative care, it was symptom management of pain and it was psychology support. It was chronic pain problems, really. Not the palliative care. It was a sort of sideline that we had together. I think they merged into each other. By getting to know each other it meant I could access my anesthetic colleagues for palliative care problems that initially I hadn't done. They could use us for problems that have more psychological issues that they weren't quite so interested and used to dealing with.

[00:36:39]

Bryan Sisk: We had talked a little bit about your role in developing ACT. Could you tell me, what are the biggest accomplishments and biggest wins that ACT had? Also, you said that it turned into Together for Short Lives, isn't that correct?

Ann Goldman: Yes because originally ACT was a broad overview on all children with life threatening illnesses. Then there was a separate organization that was the Children's Hospice Association. Eventually we merged the two and called it Together for Short Lives. I think it's quite a powerful advocacy group, really, speaking for and working for all children and families with palliative care and being available to both professionals and to children and families. They've done lots of valuable things I think over the years. Practical things, care pathways, run conferences, brought together multidisciplinary colleagues. I think advocacy is probably the single thing that nobody else was doing that they had done and raised the whole profile of palliative care in pediatrics.
Bryan Sisk: Was that advocacy to the public? Advocacy to legislature?

Ann Goldman: Sorry? I can't hear you.

[00:38:38]

Bryan Sisk: I'm sorry. Was that advocating to the public, or advocating to the government? What type of advocating were you doing?

Ann Goldman: To the government, particularly, but also to the public in general.

[00:38:54]

Bryan Sisk: When you look over your career, what do you think have been the biggest changes from when you were starting to where we are now in the care for these children with this life threatening, life shortening illnesses?

Ann Goldman: There are huge numbers of people doing it now. I think that's far and away the biggest change. That it is recognized as a need and a special interest in medicine, in nursing, in psychology, with special skills and knowledge. That we train people.

[00:39:40]

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

Ann Goldman: Let me think. I think the group of patients who are much more difficult to manage are the non-oncology patients. I think that they still have a lot of complex needs. I think we've got better at managing pain. Not perfect by any means, but I think a lot of the other symptoms, particularly children with neurodevelopmental problems have. I think there's a lot of scope for improving that. People who are involved in research and palliative care I think would be fairly unanimous in saying that the level of research that we do is still fairly basic, really, and that we could be a lot more sophisticated and that would improve the way we care for people. I don't know, what else?

[00:41:12]

Bryan Sisk: What do you think are the strongest things in the field right now?

Ann Goldman: I'm not actually clinically practicing anymore and haven't really done for about ten years. I'm not sure. I'll tell you what actually the biggest need in the field is to move out of the well-resourced countries into the poorly resourced countries. That is far and away the biggest need because there are huge numbers of children with all sorts of illnesses and could benefit across the world. If you look at the WHO [World Health Organization] figures, they're very clear about that, aren't they? They say that 90 percent or more than 90 percent of the children who could benefit from palliative care
are not getting it. There are loads of countries that still won't really allow anybody to have opioids. There's a lot of scope in the rest of the world. That's answering the question before last. I can't remember what the most recent question was.

[00:42:35]

**Bryan Sisk:** What do you think is the strongest area of the field of palliative care?

**Ann Goldman:** I think just that it's there and that we're trying to get out into the rest of the world and the rest of the illnesses. That it's multidisciplinary and team-working, which again is something that so often medicine is not very good at, but it's very fundamental to palliative care. I think in many ways a lot of what we do is just very good clinical care. Some of it is quite specialized, but a lot of it is good holistic clinical care. We can be seen and I would hope that we would act as a beacon to other clinical medicine to go back to that concept of good holistic clinical care.

[00:44:00]

**Bryan Sisk:** Well actually, I'd love for you to just dream aloud, if budget and politics and all of the other potential obstacles, if they were not an issue, what would you want care for these children to look like in another ten years?

**Ann Goldman:** I think I'd want it to be much more widespread, like I say, globally. I think we would have to train a lot more people, we would have to make opioids available to a lot more people. It should be that it's not something that is available to just one or two people, but to anybody, and it's coordinated and organized for them.

[00:44:56]

**Bryan Sisk:** Absolutely. Those are all the questions that I had, but do you think there’s any areas of this history that I've missed in our conversation?

**Ann Goldman:** I don't know. Nothing that's leaping out at me.

**Bryan Sisk:** Wonderful.

[End of Audio]