Kathleen Faulkner Oral History.

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Biography
Dr. Kathleen Faulkner is currently the Medical Director and a Hospice and Palliative Care Physician for the VNA Care Hospice and Palliative Medicine. In her 50-year career in palliative and care, Dr. Faulkner has served in many leadership capacities, such as the Medical Director for other Hospice organizations, faculty for Harvard University and Tufts School of Medicine, reviewer for numerous academic journals, board member of many domestic and international palliative and hospice organizations, author of over 20 peer-reviewed articles and texts, as well as winner of dozens of excellence in leadership awards.

Dr. Faulkner has consistently been a driver of change and was one of the first physicians certified in hospice and palliative medicine. Dr. Faulkner continues to contribute to the field of hospice and palliative care by giving frequent local and national lectures and authoring texts on clinical issues in hospice and palliative care.

Interview Abstract
Dr. Faulkner begins the interview by describing her early career experiences and how those shaped her journey into pediatric palliative care. She attributes a lot the success of her early career to her “nurturing environment” of like-minded clinicians. She then describes some of her experiences being a part of an early practice to make death a more natural and less isolated experience for the patient and family.

Dr. Faulkner then how she helped to evolve end of life care to become more inclusive for families, while also supporting improved communications between providers and family decision makers. Dr. Faulkner became involved with Children’s Hospice International and worked to develop programming for home-based care and natural death without aggressive curative treatments at end of life.

As Dr. Faulkner became more involved with hospice programming, she helped to develop best practices at the intersection of pediatrics and end of life care, and she also helped to integrate family support and family care into the health care plans of pediatric providers. Dr. Faulkner met some barriers such as providers not prescribing meaningful doses of pain and symptom management medicines to pediatrics as well as general lack of training of hospice staff in how to care for dying children.

Dr. Faulkner concludes the interview by describing some of the successes she has seen over her career in the care of sick children and her vision for providers to work together to follow family care plans and provide sophisticated home care services if that is what the family wants.
### Glossary of Acronyms

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<tr>
<td>AAHPM</td>
<td>American Academy of Hospice and Palliative Medicine</td>
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<td>ASCO</td>
<td>American Society of Clinical Oncology</td>
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<tr>
<td>CBC</td>
<td>Complete blood count</td>
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<td>CHI</td>
<td>Children’s Hospice International</td>
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<tr>
<td>E.T.</td>
<td><em>E.T. The Extra Terrestrial</em></td>
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<td>DNR</td>
<td>Do not resuscitate order</td>
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<td>IV</td>
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<td>LPs</td>
<td>Lumbar punctures</td>
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<td>MS Contin</td>
<td>Morphine sulfate controlled-release</td>
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<tr>
<td>NAD</td>
<td>Nicotinamide adenine dinucleotide</td>
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<tr>
<td>NHO</td>
<td>National Hospice Organization</td>
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<td>NP</td>
<td>Nurse practitioners</td>
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<td>OR</td>
<td>Operating room</td>
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Bryan Sisk: Today is July 22, 2019. I am Bryan Sisk and I am in St Louis, Missouri interviewing Kathleen Faulkner over the telephone with the Pediatric Palliative Care Oral History project. Dr. Faulkner is in Dover, Massachusetts. Thank you Dr. Faulkner for joining me today. To get us started could you tell me when your mind turned towards pediatric palliative care as a career focus?

Kathleen Faulkner: As a career focus. Well, I think initially I was interested in pediatric oncology and that was the career focus that I had. But in those days, which was back in the 1970s, you couldn't be interested in oncology without being aware of death because we had just started being able to treat the various cancers that children had. So often it was palliative care although there was absolutely no term like that or no term like hospice. So when I started, I went to Kansas University Medical School from 1972 to '75. Leukemia was being treated successfully but they were just discovering that if you didn't treat the central nervous system then many, many of the children would eventually relapse with CNS disease and at that point, were basically incurable. And also I remember that it was the very beginning that we treated the first patient with non-Hodgkin's lymphoma and that was such intensive chemotherapy for those days and we were so unskilled at giving it, that I am pretty sure that little boy was in the hospital for almost three months for his infection. So, it was very, very different time and place but from the very beginning I was exposed to a group of oncologists and others that really believed in this keen concept of treating patients and family.

Bryan Sisk: That's very interesting. That was a couple of years after Emil Freireich, but that was when the push really came "how can we create these kind of combinations and cocktails of chemotherapies?" And early on there was a lot of concern about toxicities, and like you mentioned, not knowing exactly what doses to give and how to manage them.

Kathleen Faulkner: What was going on, right.

Bryan Sisk: How was that viewed by clinicians on the ground—with fear, with trepidation, with excitement?

Kathleen Faulkner: So I think mostly it was excitement. I can clearly remember that part of my spiel was to tell families that, you know, what we were asking their children and them to go through—was really dramatic. It involved hair loss and lots of signs of critical illness. But that if they got through it, that they would then be cured. Because we had no idea of second cancers and no idea of long-term effects. So it was really kind of that "one and done" philosophy that I think filled us with hope and optimism frankly. But even at the beginning I was like—I was in school, you know, medical school in Kansas as I mentioned, but that was—you think that would be a very backward place, a very conservative place and it just so happened that I was there as a medical student the very first day on the oncology
rotation I was assigned to sit with a patient who was dying—a child dying in the hospital, but really in a peaceful environment with the parents at the bedside.

And I remember that was terrifying for me as a medical student. But it was really a team commitment at that time to have one of the team members physically present at every death for the duration—the whole vigil in fact, the oncology, peds oncology was actually that the interim acting head was a woman psychiatrist rather than an oncologist, because the two or three oncologists that were there, knew they were not very good at organization and Shirley Lansky had been helping them, you know, with the care of the families and the children. And in fact when I was there, published a paper on how much out of pocket expenses were caused by having a child with cancer. So it was a very nurturing environment and it was very committed to whole person care at the very beginning. The Kansas farmers from the rural communities knew how to take care of dying creatures, and they would want to take their child home if they could keep everything under control. That was back in the days when we were taught that oral morphine didn't work, because nobody had dared to give a large enough dose to account for the "first pass" effect, so we used oral methadone, which was available as kind of a PRN drug.

And that was really my first experiences, which then continued when I went out to Seattle first because it was a specific oncology fellowship, where again the hospital worked as a team and the families were taken care of as a whole unit along with their child. And often, because Seattle serviced a four-state area and because I was often dealing with bone marrow transplants which were just starting, we were often dealing with children and families who lived far away. And if we weren't giving them active therapy, I can remember having conferences, what would be called palliative care meetings now, with the child often, if they were old enough, with the family to really discuss their goals of care. So, I was lucky enough to be trained by people who were already joined on those concepts, and that made it easy.

And then when I moved to Boston to continue with the research fellowship that's the first time I actually took, physically took care of children dying at home. I was assigned to a small, chronic out-patient—people that were just coming in, but by that time, second cancers had started to appear. So, some of my kids were being treated. I started kind of, having a little bit more active clinical role, and that was the first time I actually got to go into houses, because there wasn't hospice at that point or certainly not hospice for children. And so, the physicians would also kind of be there at the end and be the one providing the hands-on care. Later I felt lucky to have done that, but it was very stressful, at the time but fulfilling.
**Bryan Sisk:** This working as a team in holistic care both at Kansas and at Seattle, did you get the impression that that was the norm or that you happened to land in exceptional places?

**Kathleen Faulkner:** I think it was becoming more the norm. And so I think that was the time we were struggling with communication with children. I believe—I'm going to guess on the name, there was a psychologist I think, Gerald Koocher is what I remember but I could be wrong, who was looking at how the hospital staff reacted to a dying child. And this was happening when I was a fellow in Seattle because I remember reading about his results which were that, the closer the child came to dying, the less time the hospital staff spent with him or her and the farther they stood away from the bed. And I remember that we talked about it as fellows and decided that we would start timing ourselves and being aware of that. So that if children were dying in the hospital, we'd would make sure that we spend as much time with them as we did with children that were there that had medically urgent issues.

So there was a lot of research going on, even at that time, and the struggle to have to include families and children. That was when children started to be included in the conversation. In Seattle I worked with a woman Patti Trull who was an occupational therapist on staff and part of the oncology team. She was a survivor, an early survivor of osteosarcoma with—she had a lung metastases and was one of the first to receive Adriamycin. She could remember that when she was going through treatment, she was never told she had cancer and all correspondence was sent by mail to her father's work address so that there would not be any possibility of her finding out what she was being treated for. She had radiation to her leg, but then she was told it was going to be amputated and that was if you lived long enough without metastatic disease, they were going to give you a chance of cure, but being prepared for the amputation, that was when they found out she had lung metastases. And she remembered being glad that she didn't have the surgery because she didn't understand why she was going to have her leg cut off at that point and no idea what the implications were. But by the time I came along, that had really changed.

So, I don't know if it was exceptional clinicians, but people were starting to think about it for sure and trying to respond in a different way because the kids were clearly upset by the lack of transparency.

**Bryan Sisk:** So, I'm really interested in talking about where kids were dying at that time. You were talking about maybe, the mid-70s to late 70s, that's around the time that Ida Martinson was doing her dying at home or her treatment at home project in Minnesota. So was that, again, was that something that you were doing before you became aware of that research or was that something that people commonly held, that kids could go home to—
Kathleen Faulkner: Could go home, yeah, that question was actually specifically what got me interested in pediatric hospice. So, I’m here in Massachusetts—I finish my fellowship. I went out to UMass to start the clinical portion of their new pediatric oncology program with a colleague from Children’s Hospital who was doing the research portion of it. And I got married, had a child and I was one year too early, that UMass didn’t have any nurse practitioners, and I happened to want to breastfeed, like physically breastfeed because the pumps were pretty primitive there, and it was too far away. There were NPs [nurse practitioners] in Seattle and there were NPs in the Midwest, but there weren’t NPs in the Boston area. They just weren't used then. So, I basically left that position. And during the time I took off with those two kids, I became a friend of the people who had been dealing with pediatric oncology consortium which was the Pediatric Oncology Group. The Pediatric Oncology Group had—they were members, and it was Brown, and Vermont and Mass General, and RI Hospital that had small programs. I actually looked at—there was a tiny research study looking at the percentage of the kids when asked whether they wanted to die home, actually got to do that and what percentage asked.

As you would expect the vast majority of kids wanted to die at home. And most of the kids, except those with brain tumors, got to die at home. From these four places, which were again, not totally uncommon in my experience, but also in the forefront. So I presented that at, what I think was the first meeting of NHO [National Hospice Organization] and CHI [Children’s Hospice International], so the National Hospice Organization and Children's Hospice International had a joint meeting. I remember being struck by how good the audience was. I had previously presented at ASCO [American Society of Clinical Oncology], my research project, so it wasn't too far in the past, and to say that was not a supportive audience would be understating the issue. It just did not—I mean loved to present but that was not a presentation with questions and answers; it was kind of like one lab fighting with another. I don't know, but it wasn't positive, and then I presented this at this meeting. And Chuck Corr, whom I didn't know from anyone, came out afterwards and said such supportive things, "We were really happy to have a physician who’s interested in this issue. If I can ever be of any assistance here's my card." People were so interested because they were interested in having clinical data. They were interested in the patient and the families, not necessarily their own careers. Like Chuck didn't say to me, "I'm a famous person that has done a lot of research on this." No, he said, "Thank you for doing this. Can I help?" And that stuck with me. So, when I went back, I interviewed again at all the universities to see if I wanted to do oncology work, but people just did not seem happy, staff just didn't seem happy. In general, the people that I found in hospice were extraordinarily dedicated and passionate about their work. And so, I made the decision to switch and left university practice because of that.
**Interviewer:** Bryan Sisk  
**Interviewee:** Kathleen Faulkner  

**Bryan Sisk:** So, I want to talk a little more about pain management and other symptom control, because it sound like there was a lot of well-intentioned individuals but you had mentioned a little bit of the hesitance to give oral morphine in significant doses. What was the on the ground reality back in mid-70s of pain management? How effective was it, what were the barriers? What was it like?

**Kathleen Faulkner:** It was, I would say fairly primitive. I think that the first handicap was that none of us really knew about oral medications. So, if we had a chance, we would often use IV meds, it was a little hard. In Seattle there was the bone marrow transplant. There was—you know Dr. Hickman was there. And so the Hickman Catheter actually came into existence during my training. He was a renal guy, but he had a lot of kids—he told me he needed to make money. [Laughter] So, that was the first kind of access where you could disconnect and be reconnected. For that some children that had a Hickman, you could teach the parents to administer medication IV, and that was actually done fairly often. We also used oral methadone without a whole lot of specific training. It was really kind of trial, not too much error, I might say, but we were all learning. I had never seen a completely natural death in my training as a medical student or resident, because almost everyone who died got coded. There was no such thing as a DNR [Do not resuscitate order] initially.

When I was at UMass we tried to do it. I tried to do with this one child whose mother didn't have a home that was set up large enough, there wasn't enough resources to care for him at home, but wanted to give this child with widely metastatic disease a comfortable death. And so by word of mouth, we asked him not be coded. And I remember driving home and getting paged, there were no cell phones then, so you'd get beepers, which were tremendous improvement and then you'd have to go find a pay phone. And then I found out that somehow the communication system has slipped and he was being— the child was being coded. And so, I ran back to the hospital. One of the nurses who knew the mother's intent basically, set up a curtain program like you would have in the OR [operating room], and she and the mom were at the head and they were playing his favorite music. Maybe from *E.T.*, that was a very popular one in those days. And then they were doing the code through lines in the feet. Of course, they did manage to bring it back that day, but the residents rocked that child with mom, until he passed several days later. So natural death was almost unheard of. We all had to learn what symptoms were associated with it and what you could do. It was very primitive, but the parents were so grateful to have the child at home that often you got away with a little, maybe a less optimum treatment because you were there or you had presence with them on the phone.

[00:20:27]  
**Bryan Sisk:** When you are talking about the pain, was this at a time where it was still largely treating pain as needed, or was this a time when transitioning towards anticipating pain?
Kathleen Faulkner: That's a good question. Not initially it was definitely as-needed. I think that's why we got away with using methadone the way that we did. Then somewhere in there, and I'm not going to be able—I may not be able to give you the decade, it became more routine. I can't remember when the MS Conti [morphine sulfate controlled-release] first became available. I think that was quite a bit later, but that was probably—by that time we had established you could use oral morphine and with the long acting form, then it was kind of a dosage thing but we lucked out a little bit because kids metabolisms were so good that they actually handled, what I see taking care of adults now is a relatively high dose of opioids, very well. I remember when the fentanyl patch came out, it was a blessing. It was wonderful to use, but it was difficult because you'd get the kids feeling well and they'd go outside playing then so much of the patches would slide off. There were definitely some issues. I think one thing we did is stop treatment sooner. There were a number of salvage therapies. So when kids were ready to go home to die, so to speak, they actually had a fairly better quality of life than what they had right now, when they've been through three or four lines of therapy. So they were able to do things like play, and go to Disney World, and all the other things kids like to do or did like to do.

Bryan Sisk: One thing I've heard quite a bit about is, the things that the kids were put through in the name of their treatment, whether it be from the medications themselves causing disease, mouth sores and other types of pain and discomfort, the disease itself causing a lot of other problems, and then also the pain from procedures that were insufficiently sedated or insufficiently given pain medication like bone marrow aspirates and LPs [lumbar punctures]. From an on ground perspective was that some the pain and discomfort wasn't recognized, or was it more so that it was just accepted as kind of, the nature of the game. What was the reality?

Kathleen Faulkner: I think it was recognized—by the time I was in Seattle for my fellowship, we actually used hypnosis on the kids. That provided excellent coverage for procedures. But we were taught that. I was actually in charge of teaching him self-hypnosis to the hemophiliacs, because that was before the days of manufactured aid—you never wanted to use unless you absolutely had to, because if they became immune to it, then it was over. So I remember my job was to teach them how to stop their own bleeding. At least by the time I got to Seattle, which was probably '79, I think '79. I mean there was treatment, but the only other thing that was considered an option was actually surgery, not surgery but anesthesia. And it felt like that that would just take so much time, we would only do it for children that were inconsolable—if they were really, really tired. But then it would be—they would have to come in like the night before or very early the morning of. Most offices were the night before those days, and then they'd have it in the OR and then there would be this recovery afterward. So, it was considered that it took too big of a chunk out of the kids lives, but we paid a lot of attention to it. We weren't allowed to do a procedure unless you knew how to do it. It was a little tough, but we had the bone marrow transplant where to
teach fellows, because the person donating the marrow was under anesthesia and needed multiple aspirations to get it enough. So we tried really hard to do it, but we did it more with non-medical means. And that's what I did when we came to UMass and started that, and nobody else was interested in those days. So, I was the only one doing the clinical work with one highly trained person and using hypnosis or distraction. It worked amazingly well. I didn't have too many kids—they didn't have a bad experience, so they didn't get quite as afraid.

Another thing that you mentioned was the shifting roles that parents were taking caring of their kids. So how did, when you started out how did the role and the involvement of parents evolve? When was it when you started and how did you see that change?

Kathleen Faulkner: Well, I think the parents certainly be—they were never excluded from the discussion, but I think they were included more and more as those years went on. Even at the very beginning when I was in medical school and during my pediatric residency, we had those fold out chairs, sofas that allowed a parent to sleep in the room. All of the rooms were set up that way for all the pediatric patients, but the oncology room is where they got a little bit bigger ones and a little bit more comfortable. So, there was definitely some attention to that. The fathers often were the ones to get excluded, it was much more a mother and a father. We were in Kansas; we were unaware of diversity [laughs], and the fathers were often working. The mothers were often very involved and the grandparents were often taking care of the other kids. I think what we became aware of is first the father and then the siblings—that you really, really had to treat the entire family.

I remember one case that stuck in my mind when we were treating a little girl. She got relapses, but really wasn't completely end stage. This was at UMass. So, this would have been fairly late in the 80s. Her sister, actually her older sister, became pregnant and without it being recognized by the staff at the hospital or her parents. The first sign of it when she had her seizure from the eclampsia, and she came a hair's breath away from dying. I just remember being totally and completely appalled that we could have missed something like that. To me that was a game changer. We had to do better.

So, I think people were starting to be more aware of that. So again, that's the 1980s. But we definitely had family conferences and we definitely were aware—I was taught to be aware of what we call "practicing". So, even at the first conference, you were asking the family and child to go through something very difficult, but it was worth it because there was this chance for cure. I was taught to say, "But there may come a time when that chance for cure isn't there and then we wouldn't necessarily ask so much of you and your child." So, we would talk to you about what's most important to the child and to you at that point. We were always setting the stage, because even on a good day it was maybe 50% cured.
and 50% died. I don't know. I was just trained by people who were aware of that and that's how we always practiced.

Bryan Sisk: When you say that parents were engaged, and increasingly engaged, was that primarily in decision-making, or was that on the hands-on care, or was it across the spectrum?

Kathleen Faulkner: I think it was across the spectrum. I think the big chance came in urging the parents to pay more attention to their child's wishes. That was often the sticking point, where the child was aware and because of the way they felt—totally understood death was near. Our work was often helping that child have a voice in the family spectrum of decision-making. We talked about things like open communication patterns in families and closed communication patterns with families. We were always trying to promote the open and not the closed. The parents were often, what I would say, overly involved in the medical aspects of the care. Many of them felt that they could control—if they knew the CBC [complete blood count] results and they knew the medical jargon and lingo, that, that would protect them and make sure that their child got good care, et cetera, et cetera, and to shift the focus to the important things. But even then, if you give a parent permission to be a parent, they would often take that and go with it. They were willing to give medications but they didn't necessarily become fixated on the meds at the expense of what they needed to do as a family.

In my experience, crisis in most cases really brought out the best in families, rather than disaster. Although obviously sometimes families couldn't cope with it and ended up divorcing afterwards. Things that we wouldn't want to see—that we didn't want to see.

Bryan Sisk: When did you first become aware that the palliative care was a profession? When did that enter your mind as a career?

Kathleen Faulkner: Well, I think after the conference presentation, that was when I was first aware that there was such a thing as hospice. Palliative care didn't exist. And I think except maybe, who was the guy in Canada? In Canada, hospice had a negative connotation. And there was one, maybe I'll think of it, he was an adult—

Bryan Sisk: Balfour Mount?

Kathleen Faulkner: Yeah, he liked palliative care. I think he, I'm pretty sure he was the first one to use that term, but that was really late in my language. It was hospice at that point. And so, I became more involved with Children's Hospice International, which was in many ways the leading organization at that time, promoting the peaceful death of children and death at home if that's what they wanted. They had an alliance with Helen House, I believe in England, that was I think it was maybe the first pediatric kind of in-patient hospice, and I started going to CHI
conferences very regularly. They were the ones who really, Ann Armstrong-Dailey, really, really promoted the field, made it more visual. I think one of the contributions, if I've done any, for the pediatric hospice and palliative care movement is to gently steer it into the mainstream. There were many people who felt the children's care was so different, that it should be a separate entity from adult hospice care. I really tried—I tried for a while to actually have a job at just doing pediatric hospice. I was here in Boston. I tried through a grant from Children's Hospice International to see if we couldn't get a four-state coalition going that would promote pediatric hospice. We got the State of Massachusetts, the legislature, really interested in a pediatric hospice program, which they actually continue to fund to this day. But it is not exactly pediatric—I would say it's more pediatric palliative care, it's layered onto something else. There were a lot of pediatricians who just really were unaware of the adult hospice movement but felt instinctively that it probably would not serve children and their families well.

But I just have the feeling that we'd never be able to get a critical mass for a homecare base without using hospice, and that we would deny kids and their families support from trained staff if we tried to isolate it. Even though there was no hospice benefit at that point. All of it was usually given for free by the hospices. So I kept, I think, just pushing that we stay in the eyes of the National Hospice movement as it evolved. It really makes me very proud and pleased to see Joanne Wolfe, head of AAHPM [American Academy of Hospice and Palliative Medicine] now is nice. I think that although there are unique differences, we need the strength of a larger movement to bring the pediatric voices to the fore.

So, when you started your work with CHI, were you still practicing as an oncologist?

Kathleen Faulkner: So I did not go back to practice as an oncologist, I switched to hospice. That was because of a random friend that I met at a conference. I was going to a symptom management conference at Memorial Sloan Kettering, and it was shortly before I was ready to return back to work. And I happened to meet a person, an internist, who was a hospice medical director, and he was just ready to go on a six-month leave. He was going to the hospices of England to study. There wasn't a lot of information in adult hospice at that point. Often it would involve this kind of travel to England to see how they did it, because they were ahead of us. And maybe one paperback book by Robert Enck had some useful information in it. He asked me to cover at the hospice as acting medical director when he was gone. I was absolutely terrified to be taking care of adults. [laughs].

The very first question that a nurse asked me, at my very first team meeting—it involved a patient who had difficulty falling asleep. They asked what I used asked what I used as a sleep aid. In my mind, my first thought was my own
children and how they breast fed, and thinking, "Well we don't use drugs." I was completely and totally at a loss. I had no idea what she was asking or what to answer, so I determined clearly [laughs]. But in those days no hospice medical director ever saw a patient. It was just, you just sat at team meetings and you would occasionally, rarely, get a call in between because the patient's physicians were the ones that were still actively involved. And so the only time I'd be called is if the physician refused to give a patient morphine at home, which we had happen even in the Boston area fairly routinely for the first decade or so when I was in hospice. They just, either didn't believe in it or didn't think that adults should die at home. So, I made the decision to switch to hospice medicine to retrain in adult medicine. There wasn't—there weren't fellowships there, so I ended up going to every conference that I could and reading what two books were available at that time, and include the care of children and part of that practice. So that I tried to work and was generally successful—I tried to work in a hospice that had a strong interest in pediatrics and it was really quite fulfilling, you know, it was good, and that's what I've done ever since.

Bryan Sisk: So that was probably late-80s then when you came back and started to work in hospice?

Kathleen Faulkner: I'd have to look at my CV, to tell you the truth. When you get old, your CV gets too long. [laughs] It was probably the 90s I would say, right?

Bryan Sisk: Yeah, actually, it looks like you came back in '93 and became acting medical director at Hospice of Cambridge.

Kathleen Faulkner: Yeah.

[00:40:54]

Bryan Sisk: So at that point, how open were hospices to caring for children?

Kathleen Faulkner: With almost no knowledge and lot of just plain commitment. It was, even the way children died was different. I can remember being called by a nurse and we had a baby who was dying. And the nurse was describing all of these symptoms, what was happening, and what should we do. Even before I could kind of wrap my mind around it, in the first sentence or two she said, "Oh, the baby just passed." So I think we were learning that—also adults usually stop eating for a period of several weeks and then they die. Children would stay much more kind of metabolically active closer to death. And so, even the basic kind of signs and symptoms of death changed. We had to relearn that. It just took a lot of joint visits, a lot of phone calls, a lot of learning from every single patient that you took care of, in both adults and in pediatrics, to really build up the field. And it wasn't always perfect for the families. If it wasn't perfect, I would say, "I really, really learned from this experience, and I'll know what we can do little bit better next time. But I want you to know we tried as hard as we could and I think things
went very well, "you know, something like that. And it was true. It was really individual-based learning.

So thinking about pediatric palliative care, and you've talked a little bit about whether that should be hospice and palliative care for children, or pediatric palliative care as its own sub-discipline. What do you think was the spark that really drove the development of the focus on pediatrics, of the development of this discipline?

Well I don't think it was the pediatric hospitals. It could have been that pediatric hospitals promoted the home based care for children dying, but I didn't do that anymore than adult hospitals did until they were, really almost literally, forced. I think we missed the opportunity for a continuum of care. I think here in Boston, for instance, I didn't have any direct contact with the board. But I knew Phil Pizzo when he was here for a while from Boston Children's was really—apparently, talked to the board about creating an out-patient based program that would include the continuum of home care and hospice. But the feedback I got was that they really didn't want to have the hospital associated with death. It had been the place that had discovered the treatment for Leukemia and they really didn't want to draw attention to "any failure", right. So that was upsetting.

So, to me, I think the movement was driven mostly by people who were doing hospice work in the community, and those who were willing to consider caring for children. It was case by case, you know, some hospices would, and many hospices would not. It was also a very informal network.

There was a time when I was getting random calls from people around the New England area, "We have this kid and we have them on this much," and they were all hospice nurses, that I even—you know Paul Thayer and I, who's a play therapist and social worker at one of the hospices that I worked with. We would really take the message of pediatric hospice out to the hospice conferences, the adult conferences. So our names were fairly well-known; and we get this call from some nurse in Vermont who wanted to know how to handle the symptoms of a child that was on service, and I gave it. You know, that, in today's medical legal [laughs], the atmosphere I don't think we would, just freely offer knowledge over the phone randomly. But there were so few people on those days, that we all just felt compelled to try and jointly care for every single child. It got better.

How much do you think the adult hospice movement, Cicely Saunders, through the 60s and 70s, that I'm very sure you're familiar with. How much do you think that impacted the development of pediatric palliative care?

I think it definitely helped. I think it was—even in the stages of death. The hospice movement and Kübler-Ross' publications, they made the normal public aware of death. The fact that we were able to do resuscitation, that was relatively
new, to be able to resuscitate. So, it went from being able to do it, to having to do it. Even in times when it seemed kind of crazy, to this kind of anti-medical movement. So, I think it did help having adults who want to die at home, that allowed children to die at home. Because in order to die successfully at home you have to have people who can come to you. I tried to do it over the phone. We would do the best we can, but sometimes it's much better if you have a physician or a nurse, or a psychologist or someone who can actually support the family physically, be there and help them through it. And so, you needed people in the community that were willing to take care of dying people first, and then dying children.

Kathleen Faulkner: Do you think there were any negative influences or any barriers that having this robust adult movement had on the care of pediatric patients?

Bryan Sisk: I'm not aware of that. I may not be thinking of something, but no, I don't think so.

Bryan Sisk: A couple of questions to wrap up. When you look over your career, and granted you mainly, you've run organizations that primarily provide care for adults but also provided a lot of care for children, what have been the biggest changes in the care that these kids suffering and dying from serious illnesses get? What are the biggest changes you've seen over your career?

Kathleen Faulkner: Well I think the course of the children's illnesses has gotten to be quite a bit longer. As improvements in therapy and the development of alternative therapy, when the disease has relapsed and oncology or support of children with severe neurologic illness receive. So I think that children are often are more presented as having more chronic illness just as they do with adults—more chronic illness rather than acute illness. And now that does have an effect on the child and the family, a lot of it is good. They have achieved milestones, they've had the opportunity to live long enough to develop their personhood. But it also means that the family has lived with the illness for many years. And if the child does die, the adjustment is much more difficult then say when a baby would die, but it would be in the first weeks of life. So I think improving the survival has had obviously overall benefits, but it also makes it more consuming with the children and the family.

Bryan Sisk: And we touched on this earlier, what is your favorite contribution that you've made to this care?

Kathleen Faulkner: I think what other things that it does help to be kind of a constant presence. So I think my enjoyment of teaching at conferences, developing curriculum, what I guess curricula would be the appropriate actual right word spreading the word and encouraging people in the same way that I was encouraged. I think that's something that I feel quite positive about. And I just have been lucky enough because I've been in the field for so long, that I cared for an amazing number of...
incredible children and their families. So it's very, very reinforcing to do the work, when you do get to see good outcomes follow people. Now I'm in communication with people, the remaining family members of kids that I've cared for decades and decades ago. You can even see it them passing down to the next generation, the siblings. So, I think I have a much—it allows me to kind of see a lot more of that circle of life and death and how it can be a positive impact, as well as a devastating one.

[B00:52:20] 

**Bryan Sisk:** What do you think are the strongest areas in the field in the care of these kids right now?

**Kathleen Faulkner:** The strongest areas?

(B00:52:29) 

**Bryan Sisk:** Yeah. What's the brightest light? Not the individuals, but the brightest light in the care that we are providing for these kids?

**Kathleen Faulkner:** I think they improved the symptom management has got to be right up there. We have medications to work with, we understand more how to use them. There are a constant fine tuning going on, so I would say that probably more sophistication in symptom management in both palliative care, especially palliative care and then hospice, seems probably the brightest light that I have seen.

(B00:53:13) 

**Bryan Sisk:** What do you think of the biggest challenges you still face field?

**Kathleen Faulkner:** Well I think luckily there, hopefully always be relatively few children dying compared to adults, and so it is with a small field that's very dispersed over the large geographic area that's the United States. So I think there will always be a challenge. I think we will always have to work—those in the field, really have to work very hard to connect with one another, and to work together with the advance of science and the psychology of the movement.

(B00:54:01) 

**Bryan Sisk:** Then given that there's this very strong community-based hospice infrastructure, and there's also been this strong growing in-patient palliative care, specially structured in pediatrics. Has that that led to collaboration what has that led to confrontation? How has that relationship been in-patient development?

**Kathleen Faulkner:** I think in my experience most of it has been collaboration, I think that when I see the conflict might be too strong what time, it often seems to arise from the parents who are quite willing to give up being in an academic world where they can reassure themselves that they are giving the absolute best the world has to offer to their children. But I think the actual participants in the field from all disciplines in my area at least really make a commitment to do with each other in a respectful manner that encourages completion of the family's care plan. It's impressive, actually.
And lastly, I would just love for you to dream aloud. If budget, politics, turf, and all the other things we were talking about were no obstacles, what do you want care for these kids to look like in 10 years?

I would like to continue to support the education and development of people in the community who feel comfortable and are competent in caring for children. I think many of the illnesses that children have are going to necessitate them going in much of the country, in going longer distances to receive treatment. And I would like all kids and their families to be very comfortable in going home and knowing that they are going to find sophisticated support in their home communities, if that's what they choose to do.

Those are all of my questions. Is there any other aspect of this history did you think that I really missed out on that I should dig into further?

No, you are, I'm impressed. [laughs] Thank you for doing this. Like I said, Oh my god, I couldn't possibly do what you are doing. But you are very nice to be doing it. I think it's a good thing.

I hope so. I'm enjoying it. I'm certainly learning a lot. Hopefully a lot of other people will too.

[End of Audio]