Frances Dominica Oral History.

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Biography

Sister Frances Dominica trained in nursing at The Hospital for Sick Children, Great Ormond Street Hospital and the Middlesex Hospital during the 1960s. She then entered the Society of All Saints Sisters of the Poor, an Anglican religious community, and was elected Mother Superior in 1977. After one transitional experience she had working with the family of a chronically ill child, Sister Frances founded Helen House, the first pediatric hospice in the world, to provide a holistic family care service for those who were caring for children with life-shortening conditions. Sister Dominica also identified similar care needs for young adults, to which she responded by founding the Douglas House, with the objective of providing respite care for families of young adults progressive life-shortening conditions. Her trailblazing work in developing the field of pediatric palliative care has been internationally acclaimed and her models of care adopted in many countries including South Africa, Japan, and the United States. Sister Frances Dominica is a Deputy Lieutenant of the County of Oxfordshire, an honorary fellow of the U.K. Royal College of Paediatrics and Child Health and of The Royal College of Nursing. Sister Frances now works with homeless people.

Interview Abstract

Sister Frances Dominica begins the interview by describing one particular experience early on in her pediatric nursing career that influenced her to found Helen House, the first pediatric respite and hospice house. Helen House implemented a comfortable, homey, and respite hospice model for chronically sick children. Sister Dominica also describes some of her guiding principles of having the children and the families take an active role in shaping their experiences at the Helen House, and eventually at the Douglas House. She then describes some of the early practices of pain management as well as the influence that others in palliative and hospice movements had on her development of pediatric hospice. Sister Dominica also recalled some of the generosity and support for Helen House that the surrounding community displayed. Sister Dominica then goes on to describe some of her international experiences. She concludes with her wish for the pediatric hospice field to reexamine and reinforce the role of family in the care of sick children as well as her recommendation of watching the BBC television series’ that depicted some of the stories of families and patients in the Helen House.
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>RGN</td>
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Today is May 20, 2019. I am Bryan Sisk, and I'm in St. Louis, Missouri. I'm interviewing Sister Frances Dominica over the telephone for the Pediatric Palliative Care Oral History project. Sister Frances is in Oxford, England. Thank you, Sister, for joining me today. To get us started, could you just tell me when your mind initially turned toward palliative care as the focus of your career?

Yes. Perhaps I should start by saying that I qualified as a pediatric nurse at the hospital for the sick children, Great Ormond Street. I suppose, along with a whole lot of other interests while I was there, I was interested in palliative care, but it wasn't really developed at that stage. I then entered an Anglican religious community and thought I might never nurse again, but that was not to be. In 1978—stop me if I'm going too fast.

Is that okay? In 1978 I had a telephone call from a young woman I didn't know, who said that her two-year-old daughter was critically ill in hospital having just had surgery for a cerebral tumor. This young woman said, "I need to talk to somebody outside the hospital and outside the immediate family." She said, "Somebody has given me your name and your telephone number. Can we meet?"

We did meet the next day. She told me that Helen had been a normal happy little girl, lively and intelligent, until a few weeks previously when she became a bit unwell. The family doctor was not unduly concerned. But as the days went by, she was less and less well and slept more. One Friday afternoon she went to sleep, and they couldn't rouse her. They took her immediately to the Accident and Emergency Department at the old Radcliffe Infirmary in Oxford. A few hours later they were told the devastating news that Helen had a massive cerebral tumor and that she needed surgery very quickly if there was to be any chance of survival. She had her surgery. She regained consciousness briefly. She told her parents that she loved them, and then she lost consciousness, and she never regained it. She lived to be 27 years old. She remained in hospital for approximately six months. Everything possible was done to try to help her to regain some degree of recovery, but it was not to be.

Five months on, her mother had to go to a different hospital to give birth to her second child, and so I stood proxy mum for a week. That was quite an experience. I saw how hard it was for the ward
staff who, for the most part were seeing the young patients recover from whatever condition they had been admitted for. I saw how, even though the consultant pediatrician was deeply caring, sometimes the ward round would pass by the end of Helen's cot without stopping. I knew that this was because there was nothing new to say. But, of course, when her parents were there, that was painful, very difficult. They longed for there to be something, some kind of contact, some kind of update on her condition. Finally, it was decided, six months post-operatively, that Helen should return home. Her baby sister was a month old. I think the ward staff thought that it would be for a trial weekend, but Helen's parents knew that in the circumstances, they would not readmit her to hospital. But at home she needed 24-hour care, 365 days a year.

[00:04:43]
Bryan Sisk: Are you still there?

Frances Dominica: Okay.

[00:04:51]
Bryan Sisk: All right. We were disconnected. But we are back together, and we're recording now.

Frances Dominica: Okay, good. She was back home and the center of family life. Is that where we got to?

Bryan Sisk: That is right where we left off, I believe.

Frances Dominica: Okay. Home was clearly where she belonged, but she did need 24-hour care and there was a new baby at home. She remained comatose. It became very, very exhausting for her parents, not just the physical exhaustion but the terrible grief of knowing that their beloved little girl was not going to get better and not knowing how long she might live. After some weeks I was so concerned about their exhaustion, not just the physical exhaustion but the exhaustion of grief—

[Recording Cuts 00:05:46-00:05:53]

[laughs] Okay. Well, I may retrace my steps a little bit, but that's better than leaving chunks out, I guess. She got home, and her parents were convinced that was where she belonged, and they cared for her with the kind of devotion that, I guess, only parents can. But it was exhausting, exhausting not just physically with a desperately sick child needing 24-hour care and a new baby with very broken nights, but underlying it all, the grief, which is the most exhausting experience. After several weeks when I visited quite frequently, I plucked up courage and asked them if they would trust me enough to lend her to me sometimes, and that was
how it began. I put up a cot in my room at home. She would come for a few days, a few nights, and her parents would catch up on sleep. They would focus on first one little sister and eventually another little sister. They would have a short holiday, or sometimes they themselves were unwell and would ask me to have her to stay with me then.

After I suppose about 12 months of this, it seemed to be working for them. They said it was like having a safety net—I was there to catch them if they were at risk of falling. I approached them and said I wondered how they would feel about extending our friendship, because that was what it was based on, friendship and practical help, to other very sick children and their families. They were enthusiastic from the start and were very important in the planning of the House which was to be called after their little daughter, Helen House. The model was to be home. The whole idea was to make it attractive, warm, friendly, a welcoming place—a big red front door. Families who came in the beginning used to say, “Oh, wonderful smell of home cooking,” and so on.

Referrals were slow to begin with. Pediatricians were reluctant to refer saying that the children either belonged at home or in a hospital. But it was quite often family-to-family referral. Quite often they had children with the same conditions like mucopolysaccharidosis or Duchenne muscular dystrophy or any number of conditions, very often genetic. There would be some families with two or even three children affected. Gradually it built up. We had staff with different backgrounds, obviously pediatric nurses, but also play therapy, physiotherapy, and all sorts of people. The most important thing was that they were fully paid-up, card-carrying members of the human race, making this a good kind of place for the children and their families.

We said from the start that the families could stay too, so we'd have mums and dads, brothers and sisters, and occasionally grandparents. There was one family where it was always the grandparents who came, and the parents took the other children off on holiday while the sick one and the grandparents were with us. There was a lot of laughter. There was a lot of music. But, of course, there were also a lot of tears. We had eight bedrooms for the children and separate apartments for families in the same building. They could take their children upstairs with them to their apartment if they wanted, or, if the child was very sick, they could sleep in the child's bedroom.

We had a ninth bedroom which could be kept very cold. It was just called the Little Room. When a child died, we invited the family,
when they were ready, to take the body of their child to the Little Room, and they could make it exactly as they wanted with things belonging to the child. There was one boy who was passionate about Doctor Who, so the whole room was decorated like a scene out of Doctor Who. His coffin was Tardis—are you familiar with Doctor Who? [laughs]

[00:10:30]

Bryan Sisk: No.

Frances Dominica: Are you still there? Yeah, good. Okay. We realized that it was very, very important in end-of-life care for families to do things at their pace, in their way. We were just there in the background to support them in whatever they decided was what they needed, what they wanted, what they believed was best for their child. The same applied when they asked for help with a funeral. It was very much how they wanted it from start to finish really. We were fortunate. In the same grounds we have a very beautiful chapel, and we were able to invite the families to have their funeral there if that was what they wanted. We had all manner of different coffins and services and so on, very much at the pace of the family and in the way that they wished.

But all this went on. I could tell you some amazing stories about some of the children who came. I'll just tell you one. It was a boy of 12, and he came a couple of times with his parents who had never left him anywhere. He had cystic fibrosis. A week before the third visit, he telephoned us and he said, "Sorry to bother you, but I'm bored at home and I'm fed up with my parents. Would you book me in for next week please, and they won't be coming with me." And so we did. They eventually left him rather reluctantly, but not before they said, "He doesn't know what the future holds, and that's how we want it to be." We said, "Well, we won't approach him with the reality. But if he asks us questions, there is one cardinal rule, and that is you don't lie to a child."

He got rid of them as fast as he could, and then he approached the youngest, least experienced person on the team and said, "I've got cystic fibrosis. I've got it real bad. I'll probably be dead this time next year. What's it like?" Poor girl, I don't know what she said, but he was obviously satisfied with whatever it was she said, something like, "Well, yeah, with your kind of illness you probably won't live as long as somebody who doesn't have that kind of illness, but there's lots we can do in the meantime. There's lots of life to be lived."

He nipped back down the corridor and came back with a friend that he'd met on his previous visit, and they had planned to coincide
this visit. The other one had a cerebral tumor. They approached this poor young girl and said, "Will you take us to Blockbuster?" I don't know if you have Blockbuster in the States, but it was for renting videos. Off they went down the street to Blockbuster and came back a bit later looking pretty glum. I said, "Now what?" The 13-year-old said, "I wanted Texas Chainsaw Massacre, and they wouldn't let us have it." The 11-year-old said, "I'm not into horror. I'm into blue movies, and they wouldn't let us have that either," so two dissatisfied customers.

Helen House actually opened in 1982, in the autumn of '82. By 1995 or '96 we were really concerned about the number of young people who were living much longer than they would previously have done for all sorts of reasons that you would know about. Life expectancy was longer. By about '98, something like that, '99, somewhere near the turn anyway, when we did a head count there were 23 now over the age of 20, and one was 27 and six foot two and hyperactive. It felt like time to do something about it. At that stage there was nothing for this next older age group, but clearly there was a need.

We invited a group of them to a barbeque one evening. These were all guys over 20. After a glass of something nice, they became quite articulate in speaking to the architects of the new building about what they wanted. They wanted larger bedrooms than the ones in Helen House, so they could socialize in their big electric chairs. They wanted a long wide corridor so they could race. They wanted a jacuzzi bigger than the one in Helen House. They wanted a music room with really thick walls so nobody would complain about the noise when they were "jamming." They got that, but they never shut the door. Oh, one of them who hadn't said much up until now said, "Do you think we could have a bar with free drinks so we can relax in the evenings?" And so I have to say, they got that too. This was just really the next stage up. When we took these five who advised the architects to see the finished product, before we showed it to anybody else, they were speechless. They just said, "Wow. This isn't a hospice. This is like a really good hotel," and so they became known as the "guests."

Douglas House opened in two thousand and—I get this wrong—2004, I think. After several years we began to realize that even this wasn't sufficient, but enough is enough. We couldn't—we did make exceptions. If somebody was really very near the end of their life and they were over 35 years old, we did make an exception.

What happened as far as Helen House was concerned, very quickly other people came and said, "How did you do it? We'd like to do
something in our part of the country." The second one was actually in Yorkshire, up north. I went to talk to a conference of pediatricians from Leeds and York and all that part of the world. They said to me, "would I start another one up north? And I said, "No, but I know somebody who would." Martin House opened I think it was five years after Helen House opened. I think they opened in '87. Then they followed, thick and fast really, and we began to get quite concerned that there would be over provision. I'm not sure because I'm off the scene now, but I think some have really struggled financially.

Also now—I'm sure this applies in the States as well—there is a very different culture. It's all about safeguarding and ticking boxes. We wouldn't get away with a lot we got away with before. Those sadly are the things that the families probably valued most, the feeling that they were just coming to stay with friends and that they had as much control over the care of their child as they wanted, or they handed it over to us. It's a much more difficult climate here now than it was then. I think it's always been more difficult in the States probably. I've been many, many times by invitation to talk to different groups. Quite a number have said in different ways, "We just couldn't do that here."

However, it has caught on big time in Japan, in South Africa. There's one in Mumbai called Happy Feet House. In different parts of Scandinavia. The idea really has caught on. I would still say now, all these years later, the most important people to listen to are the families concerned. They will say what they're looking for, what place they would trust, and they should still be partners, as it were, in the care of their child. But that's a glimpse. But I'm very happy to answer any of your questions.

Sure. You had mentioned, initially I think when Helen was in the hospital, that there are really deeply caring physicians that didn't have anything to say technically about her care, so they would bypass the cot. What do you think it was that caused that?

It didn't happen every time, I have to make that clear. It's just there wasn't something new to say every day, and she was there for six months after all. I guess there was pressure on them. There were new admissions, new situations, and Helen's condition really wasn't changing. Humanly speaking I can understand it, but I can also understand how parents would be hurt. The person on the ward who was consistently wonderful was a Caribbean orderly. At suppertime every day, if she was on duty, she'd come to Helen's parents and say, "Off you go. You go to the canteen. You get something to eat for yourselves. You have a break. I'll stay with
Helen." They'd come back after they'd had some supper, and she'd be singing Caribbean lullabies to Helen. That meant the world to her parents. It's the personal touch every time, isn't it, that counts really. The other thing they did was to put a photograph of Helen when she'd been well at the top of her cot, so that people could see that this had been a normal, active, intelligent, happy little girl.

[00:21:30]
**Bryan Sisk:** If you hadn't met Helen, do you think you would have gone into this line of work?

**Frances Dominica:** I don't think I can answer that question. I really don't think I can answer. I'm a great believer in things happening when they're meant to happen, and we just have to be on the lookout, as it were, eyes open and ready for anything. I look back over, well since 1980, and think of all the amazing families. We have a book. I think when Helen House was celebrating 25 years, we got in touch with as many families as we could—and most of them were still in touch—and asked if they'd like to contribute a page to a book, either writing something or a poem or a drawing or a photograph or whatever. It resulted in the most—one of the things I treasure most. It's called *Behind the Big Red Door*,¹ and it's an absolute treasure trove of memories of the children who came to Helen House and their families. Yes, it happened. I guess my philosophy is very much, "Who knows what today is going to bring?"

[00:22:56]
**Bryan Sisk:** I had read somewhere that when you were growing up your brother had a chronic medical condition.

**Frances Dominica:** Oh, yes.

**Bryan Sisk:** Did that have an impact on your wanting to care for children?

**Frances Dominica:** Yes, it did. I was five and a half when he was born. He was born with only one lung and had pneumonia on that one lung three times in the first year of his life. My mother really was very scared of illness in every way, so even at that tender age I did quite a lot of caring for my brother. The hospital he went to was the Hospital for Sick Children, Great Ormond Street, which is what firmed me up in my belief that that was where I was going to train to be a nurse. From the age of three I was going to be a nurse. By five and a half, six, it was going to Great Ormond Street. Great Ormond Street was a wonderful, wonderful experience, I have to say. It really was. It's unrecognizable now. The old part where we nursed is no longer. It's big and modern. Yes, I think we trained at the right time.

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Was that in the 1960s when you started nursing then?

Frances Dominica: Yes. My set was September '61, and we still have reunions. It was a really special time, amazing, and I—

Bryan Sisk: When you—go on, I'm sorry. Are you still there?

Frances Dominica: We were a set of 40 people, and 10 of us were fortunate enough to be invited to do a double training. In those days, if you went to Great Ormond Street, you became a Registered Sick Children's Nurse. But 10 of us were invited to do 15 months in a general hospital in the middle of our training, which gave us a double qualification of what's now called RGN and RSCN. I went to the Middlesex Hospital for that.

Bryan Sisk: When you were working in the '60s at Great Ormond Street Hospital, how was pain and other symptoms of these really chronic or life-threatening illnesses, how was it managed?

Frances Dominica: Sorry. When I was working there? What did you say?

Bryan Sisk: When you were working as a nurse before you entered the Holy Orders and before you started the hospice, how effectively was pain and psychological distress, all of these things, how effectively were they managed back then?

Frances Dominica: How did it affect me, is that what you said? Sorry.

Bryan Sisk: How effectively were they managed?

Frances Dominica: Oh, I see. Oh, at the time I think very well, and I think we were very fortunate to train there because there was a sensitivity to the anguish of parents and so on. As student nurses, yes, we were very involved. But probably around the time the child died or went home to die, it would be the ward sister or the staff nurses who looked after the families. Yes, I can still remember some of the children I looked after now, [laughs] who are probably grandparents-themselves by now, if they made it. There was a lot of support, mutual support among your set and the sisters. The ward sisters were a generation that doesn't exist anymore. They did it for life. I don't remember a single one of them being married. We used to wonder what they would do when they retired. They were totally devoted to it, and they were an amazing set of people with huge experience. Probably concerning the specialty of their ward, they knew at least as much as the consultant and probably more
than the registrar or the house man or woman. Yes, many of them
had done it for years.

Moving forward again to when you were first caring for Helen and
you made the decision to start Helen House, was there a
community of similar minds, or were you really out there on your
own doing this?

The sisters in my order, as it were, were very supportive because
my community was founded in 1851, and two of the main
objectives of the woman who founded it were the care of children
and the care of the sick. But this was the first time that the two
things had come together. I had wonderful support from the sisters
in the community. But of course, when it came to actually opening
Helen House, it needed people with the appropriate qualifications.
Some of the sisters would volunteer, but they were not actually
part of the team, although living in the in the same grounds as the
hospices. We also have a residential home for the elderly and so
on. We're very fortunate. We have four acres here in the middle of
Oxford.

I imagine as you started doing this, there was a lot to learn. Who
did you learn from?

There was a lot to learn, did you say?

Yeah. Who did you learn from as you started—

It mostly was the families who taught us because they knew their
child like nobody else did. For each child we made a little book.
This was in consultation with the parents. If the child was not able
to speak for him or herself, things like, "How is he most
comfortable to settle for the night," or, "Does he have favorite
foods," or, "How is it best to give her a drink," all these little
details that matter so much to families. Sometimes in a busy
hospital, I'll admit there just isn't the opportunity to share those
kinds of details. Time was of the essence. We always had to give
the impression that we've got all the time in the world to listen to
the family members. Some of the children who were aware of their
condition and of the future would express in the most amazing way
their concern for the rest of the family when they died, when they
themselves died. Would we look after their mum, their dad, their
brothers, their sisters? One little girl, she was seven and she was
dying with leukemia, and she said, "When I'm in heaven, please
will you make sure that my mummy and daddy see the Care Bears
movie because I think it will help them." [Laughs]
Bryan Sisk: Wow. What made Helen House unique from the other hospices that were popping up in the U.K. at that time?

Frances Dominica: What was the first bit of your question? Sorry.

Bryan Sisk: What made Helen House unique from the other hospices that were popping up in the U.K.?

Frances Dominica: Oh, I see. Oh, well, I don't know. I guess each person who's responsible for a children's hospice would think theirs was the best, wouldn't they? I wouldn't like to be so arrogant as to say ours was better than anybody else's, except in the ways in which the families had shown us how it should be done. They are the experts actually.

Bryan Sisk: How did it compare to the adult hospices?

Frances Dominica: Oh, interesting. Dame Cicely Saunders, you know the name I guess, who founded St. Christopher's Hospice and was the founder really of the modern hospice movement, she was the first person I wrote to when I had this idea of a children's hospice. I wrote a really carefully worded, carefully thought-out letter to this very famous lady saying, "could she give me any advice?" After about three weeks, I had a letter with three lines back just saying, "Don't do it. Children should die at home," And so I did it. [laughs] Years later she and I were on a conference platform together celebrating 21 years of hospices, I think. Being very junior, I spoke first, and I told this story. She came to the podium, and she said, "Probably what I said to Sister was what I would say to somebody coming to tell me they wanted to get married, don't do it unless you absolutely have to." That brought the house down, you can imagine.

In the end she became—she was a lot older than me, a lot more experienced. She was a co-founder of the International Work Group on Death, Dying, and Bereavement. She'd got years on me, but we became good friends in the end. I think part of it was that, as an individual, she was never comfortable with children. She never had any children of her own, and she wasn't comfortable with them. But she was amazing in her own field.

Bryan Sisk: How did that affect you when you got that three-line letter back?

Frances Dominica: Well, I'm sufficiently bolshy and arrogant to say, "Oh, never mind, we'll do it anyway." If you really believe in something, you have to go on and do it, don't you? It would have been nice if she'd had some good advice, but her field of work was so different from ours. She would say one of the most important things she did was
to control pain, with which we agree 100 percent. But it's not the only thing when it's children you're talking about. Yes, you do have to learn to control the symptoms, but it's also looking after the whole family.

[B00:34:28]
**Bryan Sisk:** Early on, what were the biggest challenges in caring for these children?

**Frances Dominica:** A long time ago. I suppose one of the biggest challenges was actually convincing pediatricians that we were there, and we could actually look after these children and their families reasonably well, and perhaps they needed to think again. The Professor of Child Health in Bristol wouldn't speak to me, wouldn't shake my hand at all. He just wouldn't. He was so unwilling to consider that this might be an option.

[B00:35:33]
**Bryan Sisk:** What do you think was the source of the hesitance?

**Frances Dominica:** What do I think—

**Bryan Sisk:** What caused them to be so hesitant?

**Frances Dominica:** I think he was so hospital orientated, and I think also he spent most of his time in his laboratory. I think he just couldn't envisage that we would care adequately for very sick children.

[B00:36:10]
**Bryan Sisk:** When did that view change?

**Frances Dominica:** I don't think it ever changed in him, but gradually one pediatrician after another came around to seeing that this was a way forward and that it was safe to refer their patient to us either for respite care or for symptom control from home or stepped discharge from hospital or end-of-life care. All of those things developed over the years. We had eight beds, and we always tried to keep two for emergencies of one kind or another. An emergency wasn't necessarily that the child was more sick, but perhaps a mother had, I don't know, hurt her arm or her leg or something and couldn't carry the child, and that was an emergency, so we would take the child for as long as was needed. I do remember on one occasion the head nurse, who was a lovely woman, had three teenage children of her own. She came to me and she said, "Frances, have you got any good ideas of how to fit nine children into eight beds?" [laughs] I don't remember now how we solved it, but that was the sort of situation we met with once the thing had really got going and got a reputation.

[B00:37:41]
Thinking of the other side of the challenges, what went especially well when you were first starting out?

What went especially well? Do you mean with Helen House?

When you were starting Helen House.

To start with, we couldn't have done it without people's generosity. It became the charity of the region. It was fantastic—people giving in huge sums. But also, we never forget, every Friday after lunch we would walk back to the front of the House to the office. There would be a one-pound coin on the doormat, and we never knew who it was until, oh, a couple of years later. We came out of lunch early, and here was this little old man coming and putting his pound coin through the letter box. That was as important to us as the person who gave us a million pounds. The support, the local support was fantastic.

The time when Helen House was developing was also around the time Ann Goldman was starting her palliative care team and palliative care, and Ida Martinson in the States was starting her palliative care study.

Yes, yes.

Your hospice and you, how did you interact with the other aspects of the pediatric palliative care movement that was developing?

Ann and Ida became very good friends of ours. They were doing different things. I think Ida in the beginning, she wasn't quite sure about the whole concept of children's hospice the way we did it. I hope in the end, the three different patterns complimented one another. Certainly Ann, she became a very good friend of mine. She and her team did an amazing job, absolutely amazing, mostly focused on cancer, of course, where Helen House wasn't. We did have children with cancer. I suppose the majority had these rare—what's the word I want—genetic conditions, mucopolysaccharidosis and all that big group. We did have several children with Rett's Syndrome. But in the end, it's very difficult to say what the life expectancy is of a child with Rett's, isn't it? It became more and more difficult to find beds for all the people who wanted to come.

From your perspective, what do you think drove the development of pediatric palliative care as its own specialty?
Frances Dominica: Well, children are not just small adults, are they? Children have their own particular needs. Even just with the administration of drugs or the prescribing of drugs, you don't just give smaller doses of what you might give to an adult. I think the whole concept of death in childhood, that's the hardest thing anybody can face, the death of their child. Although I know the death of a spouse any time can be very hard, but you don't expect to be burying your own child. It was as much care for the parents, the siblings, the grandparents, as it was caring for the sick child.

Bryan Sisk: Do you think the fuel, the motivation to really push this field forward, was that driven by parents and families, by clinicians, by society? Who recognized the need and was really pushing?

Frances Dominica: At what stage do you mean? Sorry.

Bryan Sisk: In the late 70s or early 80s, when all of these ideas were swirling around?

Frances Dominica: Oh, no. No, no, no. I don't think families at that stage, other than Helen's family. I don't think they dreamt of something like Helen House, as far as I'm aware, because there wasn't a model anywhere that we could find. We looked hard enough. There had been going to be something in New York State actually, and I visited. But by the time I got there, it wasn't trying to be hospice. It was much more recovery from head injuries and that sort of thing. I'm trying to remember the name of it. Could it be Bayside, New York?

Bryan Sisk: Possibly. I'll have to look it up. I'm not sure.

Frances Dominica: Yes. I can't remember very much. I did visit, and it was mostly children recovering from head injuries. Bayside, New York, rings a bell.

Bryan Sisk: We talked about how the adult hospice and palliative movement was different than the pediatric movement because of the unique care that children need. What were the different ways that the adult movement influence the development of the pediatric movement?

Frances Dominica: Do you mean once we were on the road?

Bryan Sisk: Mm-hmm.

Frances Dominica: Not very much, I think. Perhaps that sounds really arrogant. It wasn't the adult hospice movement that guided us. It was very much the needs of the children and the families and listening to them.
Other than getting a terse three-sentence letter, were there any other negative influences of the adult hospice movement on the development of pediatric palliative care?

No, I don't think so. The adult hospice movement was doing, and continues to do, an amazing job. Of course, it's a bit different here from the States. I think the States is mostly—adult hospice care is mostly done at home, isn't it, or a lot of it at home.

Yeah, largely it is.

I suppose increasingly here, the support has a lot of it been at home. But if I think of our own adult hospice in Oxford, Sobell House, people used to come in towards the end of their life and die there. There's less of that now. More often they will come in for symptom control, go home again, and the outreach team will look after them at home. But, again, it depends on circumstances. If it's somebody living on their own, that's different from somebody with a family around them.

In the U.S. there are children's hospices, but there's a lot fewer of them. What do you think was the biggest difference between the U.S. and the UK and divergent development?

I've been many times by invitation to talk to groups who got all enthusiastic and nothing happened. George Mark in California, that's been a success I think, although it partially closed at one point because it ran out of funds. Are you familiar with George Mark Hospice?

No, this is new to me.

California—and Ryan House—I'm struggling to remember which state it is—but Ryan House I believe is doing well. That's a family who used Helen House a lot before they went to the States. They've modeled it on Helen House, Ryan House.

Why do you think there were so few in the States? What were the barriers?

[laughs] I don't know. I used to get quite frustrated because I was frequently asked to go and talk to groups in the States, and it was just like we spoke a different language somehow. There were a lot of people who were too sentimental about it, I think. That's not meant to be rude, saying, "You're so wonderful. We couldn't do that here." We didn't understand that really. I think fundraising in the States has been more difficult than it has been here. Yeah, I just
don't know whether it's to do with pediatricians in the States. I have no idea. But I am told that Ryan House is a success, and certainly George Mark is a success, so those might be worth looking at.

_Bryan Sisk:_ Sure.

_Frances Dominica:_ When you think how huge the States are, it's extraordinary really. I think there might be a mindset which says—and this is not meant to be disrespectful—there might be a mindset which says if you hook children up on enough sophisticated apparatus, they'll get better. There's a very good children's hospice in Canada, Canuck Place in Vancouver, and that was modeled on Helen House. There was a young woman who came over and spent seven months with us and took the concept back and set up Canuck Place in Vancouver.

[00:48:36]

_Bryan Sisk:_ Looking over your career, there's obviously been very big changes in the care that's provided to these children who are suffering and dying from serious illnesses. What do you think have been the biggest changes from your perspective?

_Frances Dominica:_ In our profession.

_Bryan Sisk:_ Mm-hmm.

_Frances Dominica:_ I hope it's been listening more to the real experts, who are the families of the sick children. I think there's a lot more of that now than there used to be—listening and working in partnership with the family.

[00:49:26]

_Bryan Sisk:_ What do you think are the biggest challenges that remain today?

[Distorted audio 00:49:30-00:49:32]

_Frances Dominica:_ It's funding. Definitely funding is one. But the other is the change in culture. Everything is about inspections and ticking boxes and Care Quality Commission and all this. There's a very real daily [laughs]. For the first three or four years of Helen House's existence, nobody came and look at us officially. Then one Christmas Eve at 5 o'clock the doorbell rang. Our head of care went to open the door. This woman said, "I've come to inspect Helen House." Poor Edith, she wasn't quite sure what to do. But, anyway, the woman spent three hours and on the way out, Edith said, "Well, I hope you have a happy Christmas," and she just looked at her and said, "Probably these three hours will be the happiest bit of Christmas I will have." That was our first inspection.

[00:50:43]
**Bryan Sisk:** The administrative burden, inspections, and quality assurances that you talked about, how do you think that particularly impacts the care these kids are getting?

**Frances Dominica:** How does it impact—I'm sorry.

**Bryan Sisk:** The care these children are receiving.

**Frances Dominica:** Well, it still depends a lot on recruiting the right people. I don't know how it is in the States, but we are increasingly short of healthcare workers of any shape or size. It's getting to be a crisis point, and it's very difficult to recruit pediatric nurses at the moment. Not helped by this Brexit thing, but we'll leave that out. [laughs] We used to be so relaxed and have such a lot of fun, as well as a lot of tears. It was a very natural way of trying to do our best for these families. And now, to a certain extent, everything has got to be documented. Everyone is concerned lest they haven't done something right. I'm not now talking about administration of drugs. I think in this country we've lost the relaxed approach. You can do that and still be professional, I think, in my book. People are scared.

[00:52:43] **Bryan Sisk:** On the flip side, what do you think are the biggest strengths, the biggest pillars that are supporting this field?

**Frances Dominica:** The biggest strengths.

**Bryan Sisk:** Yeah, the biggest strengths of the field.

**Frances Dominica:** I suppose the biggest strengths have got to be when you have the right person in the right place at the right time. There are still people who speak the right language, who do understand what is needed. At the end of the day it's about people. I recently was in South Africa and I was invited to go to celebrate the 20th birthday of Sunflower House. It's a children's hospice. You don't say, "How many beds have you got," because if another child is brought, then you just find a cot from somewhere or a bed from somewhere. The happiness, just amazing really, because all the children are HIV [Human immunodeficiency virus] and all the parents have died, so granny is looking after the sick children.

One day I was invited to go out into the township with the outreach nurse. She'd been doing it for 26 years and she has huge experience. We went to these shacks, very often no windows, no doors, and the temperatures were below zero at night. That outreach nurse has got it. She's the support of these grandmas looking after their sick children in place of the children's own
parents, who all died with AIDS [Acquired immunodeficiency syndrome]. That was a very, very moving experience. It shows how hospice care can be given in very difficult circumstances. But the love and the laughter and so on was wonderful.

Bryan Sisk: Speaking of HIV, did HIV play a big role in the development or the history of Helen House?

Frances Dominica: No, it didn't. We thought it might, and all sorts of provision was made in London, in Edinburgh, and so on. But in the end, there was very little incidence actually, remarkably so. In all the years, I think we only had one child who was HIV positive.

Bryan Sisk: Was that just because there wasn't a high incidence in the U.K. or that they were going somewhere else?

Frances Dominica: No, they weren't going somewhere else because everybody had the same experience. They'd prepared to have these children, but they didn't come. I don't know. I really don't know. I didn't get involved except to know that they weren't coming to us, and they weren't going to other children's hospices.

Bryan Sisk: Lastly, I'd love for you to dream aloud for me. If budget, politics, logistics and administration, all of the things we've talked about as obstacles, if those didn't exist, what would you want care for these children to look like in another 10 years?

Frances Dominica: A children's hospice in 10 years, is that what you're saying? Sorry.

Bryan Sisk: How would you want the care of children with these complex serious illnesses, even thinking outside of hospice, how would you want it to look in 10 years?

Frances Dominica: I would want to go with what the families wanted most because that's what we did in the beginning, and we've tried to do over the years. It would be in consultation with them, "What would be most helpful to you? What would you want for your child?" I wouldn't want to make the decision for them. I would want to make it with them.

Bryan Sisk: Are there any other parts of this history of your story that you think we missed out on, before we close, that we should touch on?
Frances Dominica: I can't think of anything. Have you been made aware of a book that Helen's mother wrote called A House Called Helen?²

Bryan Sisk: I just learned of that as I was preparing for this interview, and it's on my to-buy list.

Frances Dominica: Okay, okay. Yes. That's really well worth reading because it's from her point of view. We had an amazing experience a few years back. A television researcher came to see us and said would we consider—he had very good references. We said, "Well, let's try it and see." It ended up with—let me count—I think it was 11 half-hour programs. It really, really spelled out what Helen and Douglas House are about. They were so sensitive. The fact that the BBC funded a team of people, three or four people on the team, to be here for 11 months to make those programs. They were ultrasensitive. They became part of the team. The families loved them, and families queued up actually, to be part of the program. It included everything like the transplant team coming in to talk to a family whose child was just dying. Would they consider allowing a donor organ? It included the service that we used to have once a year for all the bereaved families who wanted to come, with lots of tears and lots of music. Yes, some of them came year after year because it was so important for them to have their child remembered. It was just an amazing documentary really, for which I am very grateful. I could let you have a copy if that would be helpful to you, but I don't want to give you too much material.

Bryan Sisk: Oh, that would be wonderful. I'm of the mindset there's not such a thing as too much material.

Frances Dominica: Right, okay. I will see if I can find a spare copy. I think I probably can. What I would ask is if you would be so very kind as to return it when you're finished with it. There is no hurry at all. There are two DVDs actually. One is The Children of Helen House,³ and the other is the Children of Helen House Revisited.⁴ They were made in 2007 and 2009. I can mail them to you. But, as I say, I'd be most grateful if you could mail them back when you finish with them.

Bryan Sisk: I would certainly be happy to do that. My vow has been recorded on this transcription, so it will be done.

Frances Dominica: [laughs] You can't get away with it then.

Bryan Sisk: That’s right.

Frances Dominica: Perhaps you’d be kind enough to email me your postal address, and I will get those in the post to you.

[End of Audio]