Ida Martinson Oral History.

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Biography

Dr. Ida Martinson, Ph.D., received her nursing diploma from St. Luke’s Hospital School of Nursing, both her Bachelor’s in Nursing Education and Master’s in Nursing Administration from the University of Minnesota, and her Ph.D. in Physiology from the University of Illinois at Chicago. Dr. Martinson worked as an Instructor in Nursing at St. Luke’s Hospital School of Nursing and at Thornton Junior College, an Assistant Professor and Chair of Research at the University of Minnesota School of Nursing, and Associate Professor, Director of Research, and Professor at the University of California at San Francisco, Chair and Professor of Nursing and Head of Health Sciences at Hong Kong Polytechnic University. She was the co-founder of the Children’s Cancer Foundation of Taiwan, President of Children’s Hospice International, won four American Journal Nursing Book of the Year awards. She has over 100 journal articles, over 50 book chapters, and one film. For the last ten years of her career, she went on to complete missionary and healthcare work in Asia. She enjoys skiing and reading.

Interview Abstract

Dr. Martinson recalls her career in children dying at home beginning after a backyard conversation with her neighbor and mentor Dr. John Kersey. Dr. Kersey had mentioned that a child with cancer was going to be admitted to the hospital to die. Dr. Martinson questioned the “common practice” of admitting patients who were actively dying to the hospital. After that conversation, she was drafted by Dr. Kersey to assist in the same child’s healthcare. Dr. Martinson then describes her experience with performing one of the first documented case studies of supporting a child to die at home with their family. She relates her motivation to help the child die with dignity at home to her own profound experience with helping her father-in-law pass at home surrounded by family. Dr. Martinson describes her early experiences with clinicians who offered some resistance and skepticism about allowing children to die at home, but she also states that she was supported by most physicians. Dr. Martinson continues by describing how she continued her work to allow other children to die at home and how she grew the practice of dying at home by making herself available for other nurses and health care professionals internationally. Dr. Martinson then mentions the complexities of maintaining and growing her research in the field of dying at home. She concludes with her vision of the field growing to incorporate community medicine and respite care into priorities for healthcare teams for children suffering with chronic diseases.
# Interview Roadmap

## Beginnings

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## Children dying at home

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Bryan Sisk: Today is May 14th, 2019. I am Bryan Sisk, and I'm in St. Louis, Missouri. I'm interviewing Dr. Ida Martinson over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Martinson is in her home in Bemidji, Minnesota. Thank you, Dr. Martinson, for joining me today. To get us started, could you just tell me when your mind turned toward the care of these dying children as a career?

Ida Martinson: Sure. Absolutely. John Kersey was my next-door neighbor in St. Paul, Minnesota, and one night he just looked sad. And he said, "Oh, I feel so bad. I have to admit Eric to the hospital tomorrow, because he is going to die." That hit me so, because only about a year or so earlier, my father-in-law died of cancer. And, it just—the flash, when he had said, "because Eric's going to die." I said, "Well, why admit him to the hospital, if you know he's going to die?" And he responded something like, "Well, that's what we do, that's the common practice." And I said, "Well, wouldn't it be better for children to be at home?" I had just finished a Ph.D. in physiology, so I immediately said, "Oh, we could do this. We could do a randomized clinical trial and find out if it's possible to let a child die at home with the help of parents and a healthcare professional." And, he said, "Well, that's something to think about, I never thought about it before." That was kind of the end of the conversation.

Well, I think it was the next day that he called me and he said, "Oh, listen, I've told the mother and the father that you'll come to their home Saturday morning and talk to them about keeping their child at home." And so, there I was. I think it was—so it either a Thursday or Friday, because Saturday was coming up and so I thought, "oh, my word, what in the world am I gonna do now." I was going to do this as a randomized clinical trial. What do you do when—I couldn't pull together a random clinical. At that time by the way, Human Subjects was not yet on-board—that came about a year to two later. The University of Minnesota helped develop this because of my work with the dying child. I ended up on their first committee, but that's beside the point. Well, anyway, I thought, "well, maybe I could do an in-depth case study."

In physiology, a lot of the breakthroughs in physiology was by a—there was an Indian that this one, I forget his name now of the physiologist, who studied as he gave the Indian different foods, what happened in the intestine. So case studies, in the history of physiology, have been a legitimate research approach. And, so I got to the home and I asked the mother and the father if they
would, especially the mother, if she would keep track of whatever I
did that was helpful and what was not helpful. That was to also
include emotionally, or physically, whatever the things that helped
and didn't. And she agreed that she would be willing to keep a
record, and so that's how it started. I myself will record as soon as I
leave the house. After that first visit, I stopped and recorded right
in their yard. I got halfway home, stopped again, did some more
recording. And when I got home, I did a recording again. It's
phenomenal what can occur in one home visit. That's how it
started.

When Eric did finally die at home, it was in only about 12 days. I
still remember a few things from that home visit. It's been written
up so that's probably, again, more accurate than I remember now.
I'm now 82. But I remember Eric saying to me, "I don't want to go
into the hospital." And I said, "Well, let's see. I'm not here to bring
you to the hospital today." I didn't make a commitment never to
take him to the hospital. And so I took his pulse and took his blood
pressure and all of that sort of thing. He was a bright kid and he
said to his mother, "Now you've got to let her teach you how to
take my pulse." [laughs] So, I got reassured he wanted to stay at
home. As a boy that was kind of one of the indications. And so, I'd
only made— I forget now how many home visits it was.

When I made another visit maybe just a week later, I remember
the father talked to me and he said, "Oh, my word, I carry Eric
downstairs and my fingerprints are on his body when I bring him
down for breakfast." And so, I tried to reassure him that was okay,
that didn't hurt the boy, and was more important that he, Eric, as
long as he could tolerate being downstairs, let him be with the
family. And, it was things like that that, they knew the child would
die and my goal was then to have him spend as much time with the
family as the boy could tolerate. So, maybe that's enough for—see,
this will be a long interview if all my answers are this long to you.
But, does that give you a sense?

[00:06:28]

Bryan Sisk: Yeah, it'll be a fascinating interview so let's keep that going.
[laughs] What were your experiences before that in nursing? Had
you practiced nursing previously?

Ida Martinson: Mm-hmm. Oh, yes. I was a nurse. For example, this is my crazy
life back then, I had a lot of energy. I was going to school full-time
getting my bachelor's and master's, I was a three-year diploma
nurse—we had intensive clinical work then. When I got both my
baccalaureate and master's, I also worked full-time in the hospital;
all my work clinically had been in the hospital. When my father
then had said to me in the hospital that he wanted to go back to the cabin, I was rather shook at that because all my clinical work had been in the hospital. I went to the physician and he said, "oh, that's where I'd like to be," and he even agreed to help me if I needed any help with my father-in-law.

That experience with my father-in-law, I was just amazed by it. We had children and his sister did too, and my husband's sister did, and these kids would go out and pick wildflowers and bring them in to their grandfather and he would just smile. He got to the point he couldn't eat much, but he would chew beets. He loved to eat beets but he couldn't swallow the beets, so we'd just let him chew and then he would spit it out. I did have a public health nurse come in like once a week there, because again, I was a hospital-based nurse.

This one day she said, "Oh my," she said, "he's really, he's slipping fast." And I said, "Well, then I'd better stay here all night." And she said, "That would be good." I think it was about two nights later, I then moved in to the cabin with my father-in-law. I got up, this is very interesting, and he was alert. He hadn't been alert for a couple of days now, and his arms and legs were both really cold. I mean, I couldn't believe it, and yet, this alertness. I woke my husband and he ran to get all the rest of the family members around the bedside and he said, goodbye to each member. He called each of the members around the bed, it was about seven or eight of us, called us by name, and said goodbye. It was quite a very, very moving experience. And, he died right there—his mother, they were Christians, was a missionary in China for many years and she said, "Do you see Jesus?" And, he said, "Yes." And that was the last word he said, he died in front.

Several months later I asked the family, well, what—my own family, and they said, "oh, the fact you got me, you had me there present and the fact that after the funeral home came and picked up the body, we sat and talked with him." So, this is kind of the first-time death had not been such a crisis experience. Instead it became a very powerful family experience. So, that was in the back of my mind as I thought of Eric and his family, how much better it is for the parents to be with the child if we can make it possible for them, and not to be too frightened by the things that can happen. Long story short, I even questioned, because that's how backwards we were in this area at that time, if I should even go to the funeral. Because I thought, if I go to the funeral, they're going think of this awful experience they went through. And, I said, "but I don't know that." It may be because of my research mentality, "how do I know
that that's what'll happen?" I tried to question everything in my mind. Did I really know that I shouldn't go? And I didn't, so I went. The sister of the father, when she heard who I was, she came over and hugged me and she said, "I was going to call you and scold you for what you were making my brother and his wife do, but," she said, "I see what a phenomenal difference it was to them." And so she thanked me instead. It just blew my mind. It was so unusual at that time, that this family even wrote a letter to the president of the University of Minnesota, talking about what I had helped the family achieve. I realized this could be a very powerful thing for families to go through, that it could get a family close, even though this difficult time.

**Bryan Sisk:** Did you have experience caring for children as a nurse before that? Or was this your first foray into pediatrics?

**Ida Martinson:** Well, it really was my first. I simply didn't know much about cancer at that time. Or pediatric cancer at that time. Of course in my nursing school, I'd had minimum experience in pediatrics. But no, I really thought I would be a—I liked the operating room, all the drama and excitement of that. I really had a lot to learn because it's not only the development of a child to learn, but also all about childhood cancer. I had to study quick.

**Bryan Sisk:** Who did you learn from?

**Ida Martinson:** Well, books, of course. I went through everything and then, John Kersey—he was an amazing physician. Interesting how I ended up at this. The boy, Eric, developed mouth sores, and I said, "Oh, my, I've gotta have meat sauced and non-spicy food," and all of these sorts of things. I mentioned to this John Kersey, who was my neighbor—whenever we would go to the University of Minnesota together by bus—that's how I kept John up-to-date on what I'm doing to the family. And he said, "Oh, now, Ida. Don't worry about that. He's going to die. If he wants to eat Italian spaghetti, you let him eat it." He was so good. He was more mature in this than I was at that time. And he was so right on that. I'm very grateful—we kept pretty close during those 14 days or so that I was involved there with Eric before he died. I had a huge learning curve and then I stayed in pediatrics. That kind of became my area, and of course, so many people told me, "oh, this was just one thing that can't be done," or because of my involvement in it, "it really wasn't nursing."

The second child we found that was ready to go home to die was 250 miles away up in the rural area of Grand Forks, North Dakota.
I located a nurse who would be willing to do this. I guided her by phone and that child died at home. And they were wonderful experiences that she had, too. I mean, the second thing, that made me really realize that this could really be possible to do. I was back caring for the third child here in Minneapolis, Mary. I wrote a little story up about her and so did the father. And, they too were just so grateful. Anyway, over the next couple of years, I had seven or eight, I think it was eight. Five of the children died at home with really amazing things that happened in the family and three did not. And that was the basis I used. Being a physiologist, I kept track of everything, how much time on the phone, how much time going to the home and—you recorded, not by tape recorders, I guess I just wasn't thinking of that, but, by notes afterwards. That was the basis then that I used to write this grant that, ultimately, got funded by the National Cancer Institute. That was the feasibility and desirability of Homecare for the Child with Cancer.1 No one thought that I should say the dying child, but seriously, it was the feasibility and desirability of homecare for the dying child with cancer. But in the grant proposal, I just said child with cancer.

[00:15:14]

_Bryan Sisk:_ It's interesting how paths seem to connect over time. Getting a background, a Ph.D. in physiology, you would not think on the face of it is going lead you to homecare for the dying child project. How did that really help you to have that research background in that almost basically a science background?

_Ida Martinson:_ Yeah. Well, it was a tremendous thing, because it made me question what people thought was the thing to do. Like, when John felt he had to admit a child to the hospital, I questioned that. And, when I found myself, I maybe shouldn't go to the home after the funeral, yet I questioned that, "what was the evidence of it?" I think that my Ph.D. in physiology helped me question "what is a science-base in what you're thinking about." That also affected not only physical things, but psychological, emotional, and the whole thing. Everything became, "let's find out, is that true or is it not." I also knew that it was important for me not to be biased saying that, "it's got to be homecare." It turned people around to work with me to think of, "what are the conditions under which the child should be hospitalized?" It became a question, "let's find out." It was all that. So, that was helpful.

Having the Ph.D. in physiology, was immensely helpful in the signs and symptoms as a person was dying. I had my father-in-law

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with the cold limbs. But, here it was like when a child's leg would get cold and so I told the mother to watch it, it will either warm up—little leukemic cells clogging the vessels may have caused temporary cold. And if it doesn't, if it continues to get worse, you call me. That's how I ended up with all these things that they would ask me about. I always gave the answer and the parameters, what could be the best thing, and what could be the worst thing, and always ended with call me. [laughs] Not that I knew that much more than what I was saying, but I wanted them to really feel—that was a really important thing, I believed in then—that they needed to hurry up to get in touch with me. If they had a question at two o'clock in the morning, they should call me at two o'clock in the morning, never should they wait 'til morning light. I don't know where those things came from, but I just felt that was important.

[00:17:40]
Bryan Sisk: Sounds like it was just you, for at least the first--

Ida Martinson: Several, yeah. [laughs]

Bryan Sisk: --patients, so, what was that like, being the only care provider on call?

Ida Martinson: Well, it was different. Nurses weren't used to being on call. I think that's changed now, as we take on more professional responsibilities and we should always be responsible. I also knew I had to get other people doing it because otherwise it would say it was me. I really believed, in spite of the Ph.D. in physiology, the materials I was using was really what I'd learned from the medley in nursing. So, that's why I tried to keep getting other people involved. I stayed as backup to all the nurses throughout all those years. If they ever got into questions, they too had to call me in the middle of the night. So, it was just the way it was. I didn't get too many calls at night. I got a few from patients, mothers and fathers, and from different nurses who were out there alone, 200 miles away who would get worried about something. But I didn't find that too disruptive.

I was getting a little nervous as time went on because most of these families were caring for their child at home. Finally, I had this boy who had continuing seizures and I thought, "okay, this child has got to be hospitalized." Well, later on, we had a mother and a father who cared for a child with seizures and managed it at home as well as they could in the hospital. Then I thought, "well then, there has to be a logical explanation, there's got to be when you need to hospitalize." I know if we—if the parents were scared, then they should. But what else than that?
Then we have this boy, this is quite a powerful story, he had been an adolescent boy and really had trouble with his parents. He was on some sort of drugs, I don't know what kind of drugs at that time it was, and he wanted to go home. The mother and father talked to us and we got him home and were involved. I got a very experienced nurse working this time and he was independent at home.

One day he wanted to go to the bathroom alone, he fell, and of course, he had quite a bit of pain in his legs. I was funded by then, so we brought in the portable x-ray machine, an orthopedic surgeon, and his pediatric oncology physician. I had wonderful, wonderful cooperation from physicians in this study. The mother asked the orthopedic surgeon, "Would you do surgery?" "Oh, no. He wouldn't survive surgery." "So, what would you do in the hospital then?" "We would sandbag," and the mother went, "Well, can't they sandbag at home?" And that was a child that was hard on me, because in the middle of the night I would wake up in cold sweats. I thought I had made up my mind that, that under the conditions of a fractured hip, the child should be hospitalized. And the child died at home. And it was a very powerful post.

We interviewed, I think it was one month after the child died at home, and the mother said, "You know, he seemed like he didn't like me at all, but he said I served him on my best china, my best dishes, his favorite food, and I want you to know," she just stressed this for me, "that the day before he died he said, 'Mother, I never used to like you, but I sure love you now.'" And, wow, that hit me between the eyes. I mean, you can't measure love like that. I mean, wow, to think that—just think what better memories this mother has of that child and the death, that he could say that. If he'd been in the hospital and she might not ever have been here. Those are the things that kept me going. That were—I mean, it wasn't easy, because I had to teach—but, I must admit, this research project took most of my time and energy.

You had mentioned, initially, some skepticism where people were thinking that you couldn't do that. Who was offering types of resistance, was it nurses, doctors, parents?

Nurses. Yeah. Kind of everyone. I mean, mainly nurses and some physicians, but they weren't so much the pediatric oncologists. There was one physician, pediatric oncologist, who would not make a referral, which turned out to be good because then I could use the fact that when all his patients died, they all died in the hospital. And I could contrast-- even though it wasn't randomly
done, it showed how much more extensive hospitalization was. And then after, he finally made a referral and it was a tough one. But we handled that and the child died at home. It was like we were third year into the study when he finally made his referral to us. So, it was tough and the nurses were mostly afraid that I would get sued. I did have all nurses who worked with me carry malpractice. They had to get to drive a car, and they had to have malpractice. That was just to make sure that they would be covered if anything did happen. But there wasn't. The only other thing we had was a couple of neighbors who would say something like, well, "We don't want the child to die at home because then the family will move and we want them to stay here." Well, that was another one. So, I think that's the major, major ones that we had.

Bryan Sisk: What do you think allowed you to get past those points of resistance?

Ida Martinson: Oh, I think one was is my husband who was just really great. He would say, "Oh, ma," or "Oh Ida, kids always used to die at home." Which is true, so he got me kind of to laugh at myself when I would get all worked up that this is what's going to happen here, and all of that. And he would say, "Oh, kids used to die, what can go wrong." And then a patient's father said to me, "You know, if God's gonna perform a miracle, he can do it at home as well as in the hospital." Isn't that interesting what happens, I mean, the real life is quite something.

Bryan Sisk: When you were starting out, were there other people that were thinking about and studying these kids that were seriously ill and dying?

Ida Martinson: No one that I knew. I know Cicely Saunders, she was head hospice in England, she invited me over. She was very interested in how I was working the children—she just kind of excluded children for many years there. I went over it was because she felt she didn't have sufficient pediatric experience. And, here I was. [laughs] We had some wonderful discussions. She had me over a couple times talking—the British system was really easy to take up pediatric hospice care, because they already had nurses and physicians out in the community. Once they decided that they could care for children, it really became quite popular, even though they did develop Helen's House and things that were sort of an in-hospital hospice institution. But, many of those ended up caring more for the long-term neurological problems in children with cancer. So, I knew of no one. I'm sure they must have been some place in the world. I mean, there were, I'm sure, children dying at home that I
never knew about. But as far as systematically studying it, I knew of none. I did meet, oh my, the seven stages of dying, Kübler-Ross. And she wasn't working with children—she did some interviews with families later on with children. But I had some conversations with her. I was admitted to the international work group of Death, Dying, and Bereavement. I got admitted because of the work I had done with homecare for the dying child. I was pretty young at that time. I was maybe early 30s. I got to meet people like Cicely Saunders, Kübler-Ross and Wiseman, all the big names—Fulton, a sociologist from the University of Minnesota. I give thanks for all that type of wisdom that I got from the people in the area. They didn't know much about dying children at home, but they said they knew more about death dying from the sociological perspective.

It sounds like you found, after looking internationally, you eventually found a community of similar minds. Just nobody that was really focusing on pediatrics, and they were learning from you?

Yeah, that's right. Cicely Saunders was very open with everyone about how she was amazed what I did. And, the thing that made her most interested, she said, "You know, in England, because you were a nurse, you never could have done this." And, she herself found this. She was a nurse and she became a social worker so she thought she would have more power—one of the two, she was social worker, and then became a nurse. And then learned she had to be a physician before she should get enough power. She said, "And here you did this in Minnesota." I had the help from John Kersey and the physicians and at that time. I think Minnesota was being rather creative. I also had friends at church whose husbands worked with health insurance companies. I remember one man, John Tracy Anderson, and his wife was the secretary for my grant. She talked to her husband and he had me talk to claims adjusters, because we were always working on how in the world can we get this paid for? How can we get funded? So that after your grant money is over, this can still continue.

It was a very busy time. I sort of helped start the homecare at Children's Hospital in Minneapolis, University of Minnesota, and Children's Hospital in St. Paul. Now, the one pediatric hospice program in Minneapolis Children's is very well today—it's the best. University of Minnesota, I think they forget their roots—I don't think they remember that homecare started because of these dying children. St. Paul, people turned over, but now, pediatric hospice is more accepted, or, pediatric palliative care, I should say. I really supported palliative care because it gets the family in
earlier than what we were doing. My criteria were that there was no cure-orientated treatment going on, that the physician did not believe the child could live more than six or seven months, so really the end and things like that. My work was much more at that very end of life.

[00:29:47]

**Bryan Sisk:** When you mentioned talking to insurance companies, from reading through your papers and your archives, which I'm sure must be a strange feeling, but, I saw where you had interviews with the press, letters with insurance companies, letters to Senator Mondale, and then, my favorite thing I saw was, you had written a letter to 3M telling them that they needed to make a rectal suppository for long-lasting pain medication because your patients needed it.

**Ida Martinson:** [laughs] I'd even forgotten that, thank you.

[00:30:25]

**Bryan Sisk:** Could you talk to me a little bit about all of the different things that you did to advocate for those once it kind of got its hooks into you?

**Ida Martinson:** Yeah, it really did. Well, one of the things I wanted to do, and I eventually did—I spoke at least one time on this project in all 50 states. Alaska was my last one. I finally gotten invited up there, so I went up there. That was one thing I had to get word out, at least to one place. I also encouraged other people as much as I could to start that. And there was a gal, I think maybe married Lauer in Wisconsin, who kind of replicated the work there, and that went very well. I really thought it should be part of the hospice movement. There were some who felt that it should be special for pediatrics—I was president of Candlelighters with Ann Dailey who was the president later on. I did almost everything. I started speaking on the basis of the eight, before we even were funded. I had a lot of slides when I only had 32. Then the major work where we finished the first part of the study was the 58 children, where 80 percent of them died at home. Under these crazy things of almost a new nurse every time and a new physician every two times. We didn't have a stable team each time. It was always a new experience, but that was what kept me going—there was so much yet to learn. Then there'd be people who would ask about siblings, so we tried to follow-up siblings. I got funded by the American Cancer Society to do a ten-year follow-up of all these families, because people wondered what affect that it made, and basically, all those where the kids died at home, they were very grateful. Those where the child did not die at home, they wished they had.

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Even though I always tried to help them understand, it was partly we didn't know. One child died was admitted to the hospital because we had one nurse for two children—both parents called at the same time and she had to take her choice. Where she went, the child died at home, where she did not go, they admitted. A lot of that was for pain management.

Pain management was one thing we really worked hard on. The other thing that I found quickly—you've got to make sure the child is sleeping at night so that the parents can get some rest. The constant thing was to get the parents enough rest so they would not wear out. And they did not want a lot of people coming into the home, they really didn't. They wanted the team small, they didn't want a big team. With Alzheimer's patients, or these chronic, very complicated pediatric things, you almost need a whole team of people going in. But a child dying from cancer can be managed. You need to have somebody so that they can respond quickly. They tried to have all nurses live within 30 minutes of the home, and it wasn't always easy finding a nurse that close to the home of the child because Minnesota's more rural. We had rural—well, St. Louis, Missouri had some rural areas too. We covered that area. I would almost think "what didn't I do?" I don't know. [laughs]

**Bryan Sisk:** Knocking on the President's door.

**Ida Martinson:** [laughs] Yes, I did not go to the President of the United States, no.

**Bryan Sisk:** But I think you would have if given the opportunity.

**Ida Martinson:** Why, absolutely, [laughs] I'm sure I would have. Well, yeah, go ahead.

[00:34:39] **Bryan Sisk:** There was nothing before you started studying these kids. Did you—when did you start to sense a movement growing? Or studying—

**Ida Martinson:** Oh, it took a while. Again, I was grateful for John Kersey, who was so supportive. He first was the physician with every child I took on—he took over the medical management. And, finally, one day, he said, "Listen, Ida. You don't need me anymore. Why don't you work with different physicians so the family could keep their same physician?" And, of course, I agreed with it. In one way that's a very good move because then it got more mainstream among the medical community. I even spoke at a student medical meeting early on. That was close to the end of the funded study. I did speak at quite a few places, and that—you mentioned the newspaper, that
was the American Cancer Society, I was asked to talk five minutes about this and I couldn't believe it—I ended up in papers throughout the whole country. I thought, nobody should ever worry about it, if you're only given five minutes to talk, you can still do it. [laughs]

I have to give thanks—there's a reporter here in Minnesota, now, I can't remember his name, but he liked my work and he always did good write-ups. At the University of Minnesota, there was a couple of young news people who did a nice write-up too. This one child was from northern Minnesota, and he finally wanted to go home. He had been in bed and he knew this conference was going on down the road. He walked down the hallway, opened up the door and he said, "When can I go home?" Well, then they called me and said, "Listen, he better get home today, he's not gonna live long." I called up the president at the University of Minnesota, and we got the University of Minnesota private plane to take him home. [laughs] Wasn't I brave? I mean, I look back at this now, here I am—yeah, crazy. [laughs]

When you were beginning your work, what were the biggest challenges in caring for these kids that were dying?

Well, I suppose I was worried about would we get referrals. I had to be grateful that John Kersey believed in it enough that he made sure that was true. Sometimes the nurses in the hospital thought the child was too sick to go home. So, there was a little hesitance there. One of the biggest challenges was when I would get a call saying, "well, Dr. So-and-so has agreed the child can go home, the child's gonna die, and the parents are here now, and it'll take them three hours to get home, can you get us a nurse," I felt I had to get a nurse there in the home within the three hours before they got home so a nurse would be there in the home. Those were some of the real worries that I would have. I would worry about—sometimes I had no choice as to who the nurse would be, and some of the nurses on the phone would say, "You want me to do what?" They had never cared for a dying child before. But my husband said I should go selling things on telephone. He thought I would make lots of money if I did that. [laughs]

I'm sure less fulfilling.

Yes, but much less fulfilling. Absolutely. Yeah.

So, another interesting aspect of the history with dying children were the communication challenges and how from the 60s to the
80s, this transition from never telling the child, to largely telling the child. How does that history play into your development of this homecare follow-up program.

Ida Martinson: Yes. Even with Eric, the first child, when he said to his mother to learn how to take his pulse, I began to say, "well, these children seem to know that there were two areas that I had to worry about— not only find out where the child was at, but also what the parents knew." The physicians would always say, "I told the parents that he's going to die." Well, I would ask the parents, "What is it that you understood the physician to say?" And they apparently didn't know the child was going to die. So that was kind of a touchy area there—how do I bring that conversation around, and so I didn't. I would go make a home visit and then start to explain how things could happen and all of that. It couldn't be a jolt. Then, eventually, the parents, someone would see, "oh, my, it's better the child dies, he's in such pain." Then we worked hard on pain, but it's just probably a 24-hour thinking process that went on. I did sleep, but I'm sure as soon as I woke up, I was thinking of the child. We usually had one or two children on at one time, but I could think about them.

That communication simply got easier as time goes on. I think now it's pretty well accepted—children would know. One of the cases I remember was, the child was only three years old, and he never would say "goodnight" to the parents. And here, this night he said, "Goodbye." The parents didn't think anything of it, but the child died in his sleep that night. And the parents thought of that first thing the next morning. So they asserted that he knew he was gonna die and he wanted to say "goodbye" to us. That turned out to be a fulfilling thing for the parents—that the child knew, and he could say "goodbye" to them. So, it was all those things that happened. I mean, I didn't think a three-year-old could sense that. What clued me on is kids would rest and not feel rested. They would sleep and they would wake up just as tired as where they—I don't think I even wrote that down any place, but that was one of my inner things that I thought about. If rest does not help them, there is something going on then more than what we can see. I felt that clued me in.

Communications is still important today. It's interesting when I talk to people in pediatric hospice care, some of these issues are still there. But at least we have a better drug treatment now. We ended up using methadone for a child because it's just a longer acting and it did relieve pain in some children that we used it on. I forget all of the implications on that, but I know we couldn't even
mail methadone in the mail. With my staff, I saw a box on the desk for the address of the family we were caring for and I said, "Oh, what's in there?" And they all said, "Don't ask us." Because they were mailing it, methadone in the mail. I thought, "Oh, no! I could get imprisoned." [laughs] I had some funny ideas, but I was trying to be obedient to the rules and regulations. But, good for you for reading through all that stuff that's in the—

*Bryan Sisk:* Out of ten boxes they have, I only got through about four, because I had about five hours to do it. But I found some gems.

*Ida Martinson:* Okay, I'm glad you did.

*Bryan Sisk:* What about when you did get referrals, especially as the project got a little bit bigger, did you get a sense that the physicians wanted to maintain that responsibility for the patient, or did you get the sense that the physicians were ready to hand the patient responsibility off because they were no longer able to cure them?

*Ida Martinson:* No, I didn't feel that way. I tried very hard to keep them informed. Like one physician told me, "My word, Ida, I know more about the child at home than when he was in the hospital." I think that helped the physician see. I would bring my worries or keep them up-to-date. I never felt rejected by the physicians, other than that one who didn't make a referral until at the end of the study. Some of them were hesitant in one way, but I think I had such an advocate with Nesbit, who was also chair of pediatric oncology at the time. He was a friend of John. Both were so in support that, that really helped. I know there was a Dr. Kennedy who was bigwig in the adult care. They even took me into see him one Saturday morning when things were really starting to happen, so that he would not speak against it. We tried to prevent that from happening. So, no, I was really pleased. Dr. Singer, he was the physician at Children's. He was hesitant at the beginning, but he came around. I really had felt I had a good relationship with the physicians.

*Ida Martinson:* [laughs] Well, I don't know. I think it was because of the satisfaction of the parents in this. When we go ten years back and the parents say, "well, the toughest thing," all they brought up was, "oh, trying to find parking at the University of Minnesota. Where can you park?"
Bryan Sisk:  Oh, wow.

Ida Martinson:  I thought it would be all the women—they watched at home. So I think the parents were a part, and they would speak on—I know I once got the American Cancer Society—we covered the whole university—whole state of Minnesota in speaking, and at every place we spoke, we were able to get parents who'd been involved in the project to be on a panel. So that, I think the parents made a difference.

[00:45:40]

Bryan Sisk:  Did others come to learn from you? Other clinicians who started to become interested in this?

Ida Martinson:  Well, this gal from Wisconsin, she'd heard me a couple times, and she said, "Well, Ida, I've been doing this a year now, I'd better tell you about what's going on." [laughs] And then some of the hospice that I—I did speak at a lot of hospices around the country. And, I usually did my very, very best to have them include children. I really challenged them if they did not and I think some of them did. And then, I think Ann Dailey was the candle—not candle lighters, Children Hospice Care International, maybe it is. Children, yeah, she did a lot. Candle Lighters is another thing, it was Children's Hospice International. She was not a nurse, but she had been involved. She got to President Bush—the first Bush had a child that died from cancer—and I know she worked with him. So they were these other places where things were starting to perk up.

And I think some of it was because of the work I—the one thing I still remember, I don't remember the physician's name, he was in Chicago, but he had read of the work, and he said, "Oh," he said, "I read of your work," he said. I realize that some of these children, he was not working with children with cancer, but with other children with diseases and he said, "we could have these children at home once in a while." So he thanked me for bringing out into the open the fact that parents can be quite capable at home. So that was interesting. And, just now, about oh last week, the University of Minnesota was celebrating the School of Nursing 110th anniversary of the first school of nursing within a university. And here was this physician there, he gets up and speaks and he had three stories to tell about nursing. And one of them, he used my name and I about fell off my chair. I never met him and he said just a day before he'd gotten a call, he was now doing bone transplants for children with cancer, and he said, "This mother, she called and wanted me to know the child needed a lung and a kidney transplant. And I remembered Dr. Ida Martinson's work," he went on, he said "that there comes to a time when we need to think
about what does it mean for the child?" And so, he said, "Because of her work, I told this mother that she should realize that that would not be helpful for her child." And I was just stunned. [laughs] So, I think in one way, word's gotten out in some medical communities, I guess.

[00:48:28]

**Bryan Sisk:** What happened after the funding for that initial study you did? What happened with the dying at home project?

**Ida Martinson:** Well, yeah, the project there, was really kept alive by Children's Hospital in Minneapolis. Let's see, what was her name? Betty, Betty, no. Her name is slipping right now. They just have gone on and now they do training programs for people from coming from all over in pediatric hospice care, or pediatric palliative care, they say. So, that was—they have kept on. And University of Minnesota, I really should check into that, I should do a follow-up. Well, but I'm old, I'm 82, I don't, can't do this anymore. I don't know what happened, for sure of the other two, but I think hospices have taken it up too now, in the state. So I'm not too sure what the statistics show on what the percentage of children who die at home. Of course, the treatment of childhood cancer has been improved too so that there's not so many children dying of cancer, but they will be if they will always be some that cannot survive. And it seems to me, it's also possible for some of the principles can be used for care of other children at home.

[00:49:46]

**Bryan Sisk:** When did the phrase, pediatric palliative care, when did that enter the consciousness?

**Ida Martinson:** Oh, goodness. At first, I was really surprised. I thought, "oh, my." It started out really from the medical community and I thought, was that just because nursing was too strong and pediatric palliative care? I had a little paranoia there for a little bit. And then the more I thought about it, the more I learned about that they were really trying to get in early on. I really appreciated that and so I now use both of them in either hospice or palliative care, I use them both. I know in England, they really, in the European community, they really jumped on the palliative care, so that's become quite, quite common. It must be at least—I think I first at least ten years ago, or maybe even more than that, because, see, I'm 82, 72, or yeah, I knew about palliative care before I was 72. I must have been in my 60s, probably.

[00:50:54]

**Bryan Sisk:** Think maybe in the 90s maybe?
Ida Martinson: Yeah. Must have been. Yeah. So, at my—first I was negative towards it but then I turned on very positive towards it. Have to be willing to change with the times, you know.

[00:51:10] Bryan Sisk: And your biggest negativity, what exactly were you concerned about?

Ida Martinson: Well, I was concerned that, was it going to be that they would continue treatment? Besides the fact they sounded like they wouldn't. I was just skeptical of, or was it sort of a denial of the fact that the child would die, because there was a lot of denial along the way that you had to deal with. But those fears weren't really grounded in fact, I don't think. I think it was more my worry that I thought hospice, everyone knew that was the end of life. Except I also understood the need because they wouldn't—in my grant proposal, they didn't want me to say homecare for the dying child. It had to be homecare for the child with cancer. So I thought, "well, palliative care maybe, it's less."—and that's kind of where my mind was willing to accept it. It didn't use the word hospice, which at that time had become really close to dying.

[00:52:15] Bryan Sisk: Did you have a lot of interaction with colleagues once this kind of palliative care movement started in pediatrics or was that towards the tail end of your career?

Ida Martinson: That was sort of at the tail end of my career. See, I ended up being head of a school of nursing and home con for the last few years. So, I kind of, there's sort of that period of time where I left the country and I really was trying to get care of the dying child or going more into some of the international affairs. I did speak in Greece and in China and in Taiwan and in South Korea, and in Hong Kong. And, Hong Kong has done pretty good now in that. So, I kind of was out of the American scene probably for a good ten years toward the end of my career.

[00:53:06] Bryan Sisk: You mentioned that, I don't remember if it was your parents or your in-laws, were missionaries in China. Is that where the China interest came from, or how did that come about?

Ida Martinson: Oh, yes, I think so. Well, when I married my husband—I met my husband, and that was over a Chinese meal, it's one of those things. [laughs] He didn't ask me if I could cook or clean, his one demand or he wanted me to be willing to learn Chinese. So, we got married in northern Minnesota, drove out to Yale and learned intensive Chinese. And, I couldn't understand the tone. Ma, ma, ma, ma, meaning mother, hemp, horse, or swear, swearing. All the same
sounds, but just different inflections. And, I failed. And then I finally finished my master's in nursing, and then went back again, and I could understand it, so learning Chinese became fun. And then, we went over and took traditional language study in Taiwan and then, went to Hong Kong. And we were missionaries ourselves there. As to grandfather, the story is his grandfather went to China in 1902, and so, his father was born in China and my husband was born in China, so. That's the interest in China. So, there's a lot of people over there.

Bryan Sisk: What role has your faith and your religious beliefs had in this work you've been doing?

Ida Martinson: I think that has been probably a strength for me. And, in that I am—my husband, I think was part of that strength that gave me going when I would get depressed—but he also used some Chinese figures for me. He talked about Guan Yin because I said, people wonder how I—why do I stay in this field, why do I keep on when I wouldn't have to. And, he tells the story of Guan Yin—she could have left, but she chose to stay. Somehow that story helped me realize that I have a choice to leave, but these families do not. They are dealing with this day in and day out. They cannot get away, but I could. And just sort of a maybe it's an educational, a logical thinking, I could always leave, if it gets too much for me. And then, if you know you can leave, then you can handle it. And then I took that thought to the parents and I would always tell them, "We can always take your child into the hospital." And then, that allowed them to keep the child at home. So, I used that principle of giving them options that there is a way out if it gets too much for you. Does that make sense?

Bryan Sisk: It makes perfect sense.

Ida Martinson: Oh, good.

Bryan Sisk: We talked about Kübler-Ross and Saunders. Another beacon of the adult hospice movement was Florence Wald, and I noticed several letters back and forth, so what was your relationship with Florence Wald?

Ida Martinson: Oh, yes. Well, Florence Wald had me come out to Yale to speak about the dying child. She was working too, again, only with the adult, and I, of course, challenged her, why doesn't she include the child? And, so I knew her, yes. I should have mentioned her earlier on. She took me in the United States, she did some wonderful work at Yale there. And, she, at one time, was Dean of the School of
Nursing there, and I think she stepped down to be able to work more in this area out at Yale. And I knew her husband, they were—and Florence Wald was also part of this international work group on Death, Dying, and Bereavement. But yeah, she was a gem.

Bryan Sisk: And then, a lot of these people we've been talking about, a lot of them were nurses, or at least not physicians. So who really drove this field, initially, what type of professionals?

Ida Martinson: Oh, I think it was nursing, really. I don't ever say that though, publicly. I could not have done it without cooperation from physicians, there's no way. And, I always feel that when physicians and nurses can work together, that's where you can do the most creative and the safest type of care. See, in America's system here, we don't have social workers available. So, for me, I didn't mean to exclude social workers, or any other membered team, but at that time, nurses were kind of ubiquitous, we were all over in the country. We had many, many nurses, and we had more nurses than physicians. So that you could get one physician with you, they could help you with several children, but then, as our problem—as our project evolved, we kept using the physician they had in the treatment of the medical center.

Bryan Sisk: Getting towards the end here, over your career, what do you think have been the biggest changes in the care provided to these children that are suffering from serious illnesses?

Ida Martinson: Well, I think this—when I think there's been a realization that now, even though we can cure most children now in cancer, there are still children that do need intensive care. I think there's been more acknowledgment of that. I think symptom control is much better than it used to be. I still believe that it's easier to control all the symptoms in the home than you can in the hospital with all the distraction. At the home you have this child and the parents. I think we still need to work more yet with siblings. I think I kind of neglected siblings. I still have a memory of a few siblings that, after I'd go making these interviews or go see them after the child died, I can remember seeing a couple siblings who had watched me, and I didn't—I thought, oh, I should drive—I can turn around and go back and see what was bothering him, but I did not do that. So, it's one of my regrets, that I didn't pay enough attention to the siblings. But I think they do a better job on that now. I think the healthcare is coming along, we just need to pay attention to the family members. I think they're pretty good. And the family members, if they're in the hospital, the children at home need to be
kept informed somehow or another. But, people, they don't keep—
show anybody in the hospital very long now, do they? No.

*Bryan Sisk:* Not too long.

*Ida Martinson:* No, no. So, no, I think there's more resources available. I do hope hospices or palliative care teams keep up being open to children. There's a bias that children are too hard for people to care for, but I don't think that's true. I think, when you've got such loving parents, or parents—not all of them are so loving I suppose—are directed as what they can and cannot do, they can do a lot more than you imagine. It's always it's an ongoing thing to stress. In other words, I wouldn't want a system where there's not nurses and physicians involved in a child being at home.

*Bryan Sisk:* Well, lastly, I would just love for you to dream aloud. *[laughs]* If there were no issues with budget or politics, or any of the other things we've been talking about, what would you want care for these children to look like in another ten years?

*Ida Martinson:* Oh, another ten years. Well, that's a seamless system that if they can be in and out of the hospital and that somehow. I think we do need more nurses out in the community involved so that, when you're dealing with distances, any distance beyond 30 miles, you really cannot expect the hospital nurses to go to the home. But there should be a way—and the same with physicians, that physicians should have an easier seamless system to the local physician. Rather than the local physician get totally excluded. But, somehow, we need to have better communications from hospital to community nurses and physicians. I think that would be my ideal. That there is a loop that's—they know that these kids aren't being forgotten, and I don't think they should be or would be.

What else would I like? To continue on symptom control, I think sleep is still an important one. People tend to forget that—respite care, respite care. I know, England does much better—Britain, Great Britain does better in respite care, but I did not find— because I was in so late, I was only in most of the families within the last 30 days. I think if you're coming in with palliative care, maybe it needs to be a respite care within. And, let's see, yeah.

*Bryan Sisk:* Well, is there anything else from this history you think I've not hit on that I should know about?

*Ida Martinson:* *[laughs]* I can't think of any that you've—I think that's amazing, you read four books—I mean, you got through that library there.
Bryan Sisk: Well.

Ida Martinson: I still have more stuff I need to get over there.

Bryan Sisk: Yeah, send it to me.

[End of Audio]