

Biography

Ms. Ann Armstrong-Dailey, founder of Children's Hospice International, has devoted a lifetime of service to creating policy protections and ensuring that all ill children may have access to palliative services as they need them. Ms. Armstrong-Dailey was born in San Francisco in 1940 and experienced the loss of her parents and a sibling through war and illness. When Ms. Armstrong-Dailey lost her brother at sea in 1969 during the Vietnam conflict, she found she had no support from healthcare or policy. This drove her to seek action and investigate thanatology globally. Ms. Armstrong-Dailey then began to travel abroad seeking ideas and successful models of palliative care for dying children; however she was met with provider resistance and closed doors. She then formed the Children's Hospice International organization "out of sheer, unadulterated anger" so that there would at least be someone starting the policy work around patient and family advocacy for palliative services. Ms. Armstrong-Dailey describes her most important impact on the field of pediatric palliative care to be in awareness of the issue that children could have better care when critically ill. Ms. Armstrong-Dailey is still actively improving access to services for children with life-threatening conditions with Children's Hospice International.

Interview Abstract

Ms. Ann Armstrong-Dailey begins her interview by describing some early pivotal moments in her life that led her to a career advocating for palliative care. She first describes the memory of her and her mother fleeing kamikaze pilots and German submarines in Pearl Harbor, Hawaii and how that was a formative moment in understanding the processing power and tenacity of children. She then describes the circumstances of her brother's death and the lack of support she received as a transformational moment that empowered her to "audaciously" seek out the global leaders of the world and ask them 'why isn't there support for dying children?' Ms. Armstrong-Dailey then recalls two stories of children that were dying in a hospital and were blocked from receiving hospice care but were desperate to connect and support their parents and families as they died. She describes the momentous effect those deaths had on her and the urgency she felt to find a way to support better family communication and policy protections in pediatric healthcare.

Ms. Armstrong-Dailey tells how she built a supportive network of international collaborators who wanted to do better for dying children. She also describes instances where she rallied with this network to push ideas, legislation, literature, and healthcare models. Ms. Armstrong-Dailey describes some of her work exploring and dismantling some of the resistance she felt by providers and families with education and quantitative research. She concludes the interview by describing her dream of working herself out of business by integrating palliative care seamlessly into standard medical operating procedures. She also advocates for the continuation of investigations on how healthcare can perform better in communication with patients, families, and each other.

Glossary of Acronyms

Abbreviation	Definition
AAP	American Academy of Pediatrics
ACE Kids Act	Advancing Care for Exceptional Kids Act
CHI	Children's Hospice International
CMS	U.S. Centers for Medicare and Medicaid Services
HCFA	Health Care Financing Administration
NIH	National Institutes of Health
NHO	National Hospice Organization
ChiPACC	Children's Program of All-inclusive Coordinated Care

Interview Roadmap



Beginnings

Page

Personal career influences	1-5, 14, 20-21, 23
Influencers in field	13, 15-18
Early field practices.....	3-4



Pediatric palliative care

Evolution and history of pediatric palliative care	19-20
Bereavement and communication	3-4, 23-24
Thanatology	5-6
Reframing physician training and awareness	3, 11, 14, 21-22
Challenges	9-10, 11-12, 15, 19, 21-23
Policy success.....	7-8, 23
The future	15, 22-24



Children's Hospice International

Mission and values	6
Seamless integration of multidisciplinary healthcare services	6-7
Continuum of care	7
Finding support and marketing the issue	10-13, 15-16



Relationship to adult hospice care

Dame Cicely Saunders	6, 8-9
Children not welcomed in adult hospice care.....	11-12

Related Works and Mentions

<i>Mention</i>	<i>Page</i>
Bush, Barbara	13, 14
Bush, Pauline "Robin"	14
ChiPACC	11
Dole, Bob	13, 14
Dominica, Sister Frances	12
Hospice Care for Children	17
Grollman, MD, Rabbi Earl	18
Jampolsky, Jerry	17
Koop, MD, C. Everett	14
Kübler-Ross, Elisabeth	5, 15, 17
Lawrence, Melinda	20
Magno, MD, Josefina "Jo"	9
Martinson, Ida	10, 17, 18
Novello, MD, Antonia	14
Olsen, MD, Ed	10
<i>On Death and Dying</i>	5
Pell, Claiborne	13
Pizzo, MD, Philip "Phil"	14, 23
Reagan, Nancy	13
Saunders, Dame Cicely	6, 8, 9, 16, 18
Stepanek, Mattie J.T.	20
Stepanek, Jenny	20
Wiener, Lori	23
Wolfe, MD, Joanne	23

****Edited for grammar and content by Ms. Armstrong-Dailey. Additions and redactions indicated by brackets and ellipses, respectively.****

Bryan Sisk: Today is June 25th, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Ms. Ann Armstrong-Dailey over the telephone for the pediatric palliative care oral history project. Ms. Armstrong-Dailey is in Arlington, Virginia. Thank you, Ms. Armstrong-Dailey for joining me today. To get us started, could you just tell me when your mind turned toward pediatric, palliative, and hospice care as a career focus?

Ann Armstrong-Dailey: Oh, my goodness. Well, as a career focus, probably in the 1960s. Although, the root of my efforts and my work in this field really began during the aftermath of the bombing of Pearl Harbor, way back before your time. I won't go into detail about that, but just the bottom line—

Bryan Sisk: You can go into detail—

Ann Armstrong-Dailey: My father was a U.S. Army officer, and we lived at Fort Kamehameha, which is on the channel going into Pearl Harbor. It's also connected to Hickam Field and Schofield Barracks and was basically ground zero for the bombing by the Japanese.

My dad was goat hunting with the commanding officer at the time. My mother was pregnant with my brother. We lived right on the canal; our backyard was the beach. She started having contractions and she grabbed me; I was barely a toddler at the time. One of the physicians lived next door, so she was running across the yard to the physician's house because she thought she needed medical care immediately. One of the Kamikaze pilots that had been shot down saw us and decided he was going to take us out with him.

As he was crashing, he was shooting his machine gun. My mother counted the tracers. She threw me on the ground and threw herself over me. She actually was wounded, but it barely missed her, which was fortunate.

She would later describe how she looked back and she could describe his face and how he was smiling, which was horrifying. Then, he crashed into the water. An MP, who was in a Jeep, saw what was happening and he grabbed us, my mother and myself, and he took us to a cave, which incidentally was a storing place for munitions. Soon, other mothers and children started gathering in this same cave. We were there until we were evacuated.

They returned us to the mainland on a ship crammed full of officers and children while the men were sent off to finish the war in the Pacific. There was very little food, water, and milk. My mother was violently seasick due to her pregnancy and the motion of the ship. I was placed in a dresser drawer on the floor and told to be a good girl and stay there. All I really wanted to do was to crawl into bed, into the bunk with my mother and to be close to her, but I had to stay in my drawer.

It took 10 days to make the crossing to San Francisco because we had to zig zag, because German submarines were chasing us. According to my mom, a friend of hers was able to get some canned milk, twice, so I was able to have canned milk from time to time during the crossing. Unfortunately, even the officers' wives were fighting over the limited food and drink that was on the ship. It was not America's best tale of decorum under pressure.

There's a sense of isolation, abandonment, and feeling unloved, which is just the core piece of my involvement in the hospice field... The absolute most important thing, I feel, is that we... help facilitate communication between the child and the family and the healthcare professionals.

I often tell a true story about a boy named Tim in the 1970s. He was in a hospital on the west coast, a beautiful children's hospital with very well-trained, competent, caring staff. He had renal disease. While there was hope for cure, he was treated beautifully by his medical team. They were his best pals and together they were going to beat this dastardly disease.

When the time came where it was apparent that he was not going to beat the disease, that he was indeed terminal, he was moved to another room at the end of the hall. The doctors and nurses still would come in and do what they needed to do, but he sensed this difference in their approach. If we put ourselves in their shoes, they're trained to heal. The sense of failure and frustration is hard to deal with. That's the normal reaction to failure is to pull away emotionally.

Again, for understandable reasons, his parents would come every day to the hospital and would bring armloads of books and stuffed animals and things. They were physically present but not emotionally. Timmy had a lot of questions. He was 5 years old. He knew he was dying long before any of the rest, before anyone else wanted to even think about it or acknowledge it.

He wanted desperately to know what it was going to feel like to die. Would his grandmother be in heaven to greet him when he got there? Or his dog that had just died? Well, fortunately for Timmy, one of the pediatric residents that we was working with him reached out to him and would spend as much time as he could sitting by his bedside, even though he wasn't his patient. Holding his hand and listening to his questions, and at least, you know, even though he didn't have any answers, he listened. That meant a lot to this young man.

One of Timmy's last acts was to ask this young pediatrician for a piece of paper and some markers and he drew a big yellow butterfly and wrote across the bottom, "I love you, Mom." Timmy died soon after having drawn the yellow butterfly. Free from physical pain, thanks to superb medical care. However, he died yearning for the affirmation of his parents' love and blaming himself for having done something to have lost it.

This just shouldn't happen. It doesn't need to happen. To take it one step further, Timmy's death shattered his family. His father was a prominent lawyer in their town, a pillar of the community. The parents divorced, the father became addicted to drugs and was literally on skid row. The mother was addicted to prescription medications and was on public welfare. Timmy's sister was kicked out of every school she attended for disruptive behavior. And we know from experience that if only someone in that hospital, whether it was the pediatrician, the Chaplin, or a nurse, or even a volunteer could have helped the family understand that all they were going through was normal. And to let them know that there are people that can help you work through the anticipatory grief and the grieving process afterwards if Timmy doesn't live. To insist that pediatricians and nurses understand that it's important to continue caring for a patient even when cure is not attainable.

I know I'm preaching to the choir, but we have hundreds, probably thousands of stories like that, of kids who wanted desperately to communicate with their families and weren't able to.

There was another boy I didn't know personally. His name was Eric, but he was a patient of a colleague of mine in the Midwest. At the age of seven, he wrote a poem to his mother. He was an only child. He had leukemia and was on his third or fourth round of chemotherapy, and he just wanted to go home. He knew he was dying. Eric just wanted to go home, but his mother needed him to continue with his treatment, because she just wasn't able to cope with the potential loss of her child.

One of the nurses talked with Timmy and asked if there was anything at all that she could do for him. As a result, Eric wrote a poem for his mom. He wrote, *When I Die*, and he wrote *When W E N*, I think. “Wen I die. Don’t you cry. Because I will be with you in the darkness and the light, and I will be with you at all times. The end.” He gave the poem to his mom, and she cried and she held him, but she got the message, and she took him home, and he was able to die at home in his own bed with his dog, and to watch his friends play outside the window.

Again, and I know you know, it’s just so, so, so important that we assist in communication and education and training in advocacy on behalf of these kids and their families, and the healthcare professionals who want to do the right thing.

Bryan Sisk: That was a beautiful series of stories. It’s unbelievable. I can safely say you are the first person I’ve interviewed whose story started with, “As I was being shot at by a Japanese kamikaze in Pearl Harbor.”[*Laughter*]

Ann Armstrong-Dailey: [*Laughter*] Oh gosh. Well you know.

Bryan Sisk: That, you described it as imprinting these experiences that really set off core values in you. When did the concept of focusing on palliative care itself crystalize for you?

Ann Armstrong-Dailey : On June 3rd 1969, 50 years ago, I lost my brother in an accident at sea, just a few months after having my mother die from cancer in November of ‘68, and my surrogate father had just died from a series of neurological diseases not long before that. Then my only brother, who was just younger than I am, was on the USS Frank E. Evans, [which was deployed in support of our troops in Vietnam]. They were in training with our allies in the area when an Australian aircraft carrier, the Melbourne sliced the Evans in half and 74 sailors were lost, including my brother. My brother was an ensign.

We didn’t have a body to bury. These guys are truly lost at sea. It’s different. He was younger than I, and I always felt like I was his protector, even though he always felt he had to protect me, because he was my brother. When you don’t have something to touch or to see, and to physically bury, it’s really hard to accept the fact that they’re really gone. On top of that, years later [when the Vietnam

Memorial was built in Washington, D.C.], the families of the lost 74 got all excited about oh, wow, how wonderful it will be to have a place to go, see their names, and just to visit. [But when the families of the lost 74 travelled to DC to see the unveiling of the Vietnam Memorial, they found that the names of the lost 74] are not on the wall. The Frank E. Evans families have been fighting ever since to get their names included. There's a bill pending in the U.S. Senate right now to demand that the names be added to the wall.

It just is a technicality. They'd been supporting our efforts in Vietnam and were pulled out of the 'war zone' for this Allied training, and they were going right back to the war, and the rest of the American ships in the exercise went to Vietnam. But because it was outside of the certain boundary, their names aren't on the wall.

With his death in '69, I just felt like I had to do something. I just had to. First of all, I realized that I wasn't going to live forever, for the first time, and that I really needed to do something. I got very interested in thanatology. A friend of mine gave me a copy of Elizabeth Kübler-Ross' book *On Death and Dying*, which was very useful. Not long after, my family moved to England where Dame Cicely Saunders had opened St. Christopher's hospice. I visited there and got excited, but they were not willing to accept children into their program at that time.

That was the first time it really hit me that even though people were comfortable talking about and supporting adults who were dying, that they just weren't with kids. There was a separate barrier that we needed to cross. The question was how do we address that? Where do we start? At first, I started trying to get adult hospice programs to incorporate kids into various associations that were already existing; however, my efforts were in vain. Out of sheer, unadulterated anger, I started CHI (Children's Hospice International).

Initially, we worked very closely with American Academy of Pediatrics (AAP). In fact, one of our very first board of directors included executive directors or presidents of the American Academy of Pediatrics, the National Association of Children's Hospitals, related institutions, hospice programs, homecare programs, et cetera. I sat down at my kitchen table and thought, "Okay, who are we going to need on our board to make this thing happen?"

We started with education and training. The first was a half-day seminar at the end of the AAP meeting in San Francisco in 1983; we then developed training materials for health care professionals and materials for the general public. *Approaching Grief* is a little pamphlet that was one of our first publications. It was designed for pediatricians just to have in their office about how to help parents understand how they can talk to a child, their child, about serious illness and disease.

It also became very apparent to us early on that it wasn't fair to ask parents to choose between hospice and palliative care and curative care—that they needed to be combined. CHI's mission from the very beginning is to so ingrain hospice and palliative care into healthcare for children, that it is not a separate specialty. It is just part of the seamless trajectory of the child's life.

Toward that end, we were able to get congressional appropriation to demonstrate whether our program -- the children's program for all-inclusive coordinated care (ChiPACC) -- is cost effective. In January of 1997, we started planning, and we pulled together people from all of the organizations involved, including the Health Care Finance Administration, which is now Centers for Medicare and Medicaid Services (CMS), to design the demonstration model.

We were trying to make certain that everybody would feel a part of it, rather than trying to feel threatened by it... We really feel strongly that everybody has got to work together.

We use the analogy of the wheel. That the hub of the wheel is the child and family. And equally important are all of the spokes, including all of the associations and the organizations from the physicians to the nurses and social workers and clergy and schoolteachers and volunteers and everybody -- hospices, home care programs, and the children's hospitals all working together towards the mutual support for our kids and families. CHI is simply the rim of the wheel, bringing everybody together to focus on these needs, and to together, develop programs that meet the needs.

Our children's program for all-inclusive coordinated care (ChiPACC) is something that we're very excited about. Our demonstration programs have proven that it works, by increasing quality of care for the child and family, from time of diagnosis, alongside curative care, whether the child's at home, in a hospital, at a hospice or other appropriate facility, that the services and the support is there.

We can show that we can do this and save federal government, state government, plus insurance companies' money. The Colorado demonstration program data is showing a savings of over \$300,000.00 per patient per year. That adds up.

We have a ChiPACC bill that's being reintroduced into congress, and we have bipartisan support for it. CMS [and CHI have worked closely together on this to] ensure the incorporation of hospice and palliative care from time of diagnosis, alongside curative care, [to provide the best continuum of care for children with life-threatening conditions and their families].

Also, in 2010, one line of the Affordable Care Act allows for concurrent care in a hospice and palliative care alongside curative care, but it's only for the last 6 months of life, and that just doesn't work for kids. So we are pushing for that same level of care from the time of diagnosis and throughout the continuum of care.

Our kids can be in and out of terminal phase over the long period of time. There's lots to be done. We're thrilled with the ACE Kids Act. That's another step in the right direction. We were able to get palliative care incorporated in that act. We had hoped to get even more, but you do what you can do. It's another step. Step by step by step. We're making a difference on behalf of the kids and families, and that's what matters.

Bryan Sisk: Absolutely. I'm interested in going back a little bit to explore your interactions with Dame Cicely Saunders.

Ann Armstrong-Dailey: Oh, bless her heart, yeah.

Bryan Sisk: I've heard, obviously, I've read so much of her work, and she's been mentioned by so many people as an influence. I've also heard from people who are instrumental in founding this field where, it seemed like she was hesitant or didn't understand the need. What was your interaction like with her, when talking about pediatric palliative care?

Ann Armstrong-Dailey: She was the first physician to honestly and openly say to me that "I cannot deal with a dying child."

Bryan Sisk: Wow.

Ann Armstrong-Dailey:

That was face-to-face she said that, but when I started CHI, I asked her if she would be a member of our international advisory council, and she's the only person that said no. [She acknowledged the need for children's hospice care but did not feel the need to incorporate it into the care provided at St. Christopher's.] ...

One healthcare professional actually told me in the 1970s that hospice and palliative care was not needed for children because they did not feel pain. I was completely stunned.

Bryan Sisk:

I'm sure that conversation went well. [*Sarcasm*]

Ann Armstrong-Dailey:

Cicely was the first person that owned up to her feelings on that. CHI regularly did exhibits at the American Academy of Pediatrics meeting every year. They hosted us. One time... this pediatrician came around the corner and stopped out in the aisle and he just held his hands up to his face. On the wall, we had three photographs of kids... He said, "I cannot cope with these—"

He ended up being a psychiatrist at a major Midwestern hospital. He told the CHI staff member that he had to send a social worker or somebody in to see them, because he physically couldn't do it. But he did acknowledge that there was a need and did find staff that were comfortable speaking with children and their families. You've got to give him credit for that. He was the second one that owned up to it. We've made some headway.

Bryan Sisk:

Early on, it sounds like your initial focus, after your brother died, and you were trying to dig into thanatology and dig into finding a purpose, it sounds like you were really trying to figure out how can we get kids into current structures that exist for adults? Is that an accurate statement?

Ann Armstrong-Dailey:

That's where I started, because I thought it would be the easiest, if I replicate, if I create another organization, if there's already one in existence kind of thing. When that didn't work, then, you either give up or you start the organization.

Bryan Sisk:

What were the reasons for resistance, do you think? What were the problems that you ran into?

Ann Armstrong-

Dailey:

Hospice in this country was organized in the 1970s when the National Hospice Organization (NHO) was formed. Dr. Jo Magno, who was a friend of mine, was the executive director. She was an adult oncologist, but she also understood the need for kids. She, herself, was not real comfortable with it but she certainly saw the need.

She encouraged me. At that point there was a bill being introduced into congress for support for adult cancer patients, for hospice care for adult cancer patients. That's where the focus was and they just didn't want to deviate from that.

When I founded Children's Hospice International, officially, Dr. Ed Olsen, who was the chairman of the National Hospice Organization Board, was on CHI's board of directors...

Gosh, I don't remember the year, but it was the 1970s when I began getting involved... Occasionally I'd get calls saying "I've got this patient", or "I've got this friend, and this is what's happening. Is there anything you can do?"

One example was from an ophthalmologist about people who called and said, "I've got a friend whose son has been diagnosed with adrenal leukodystrophy. He's going downhill really, really fast. Is there anything you can do?" At that time NHO's Standard 11 said that 'regardless of religion or cultural background or ability to pay, that a patient could have these services.'

So I met with this mom—the husband was from France and was with World Health Organization—and the mother, I met with her and her son and her daughter. I told them about hospice care, and what they could expect from it.

In my mind was Standard 11. I gave the parents phone numbers and contact information and everything. A few weeks later, the mother called me, and she was in tears. I'd given her the name and number of the local hospice program and she called and said they won't accept him because he might live longer than 6 months. That's when I took action.

That was just not fair. I went to the hospice. I met with the vice president of the Children's National Medical Center, Dr. Delaney, who was in charge of education at that time. The Hospice of Northern Virginia was the local hospice, and they said, "Well, we just can't. There's a 6-month limit."

The child was a patient at Children's National Medical Center at the time. Dr. Delaney just reached out, and he just took hold of my arm and he said, "We need your help. We don't know. We're not trained as to how to deal with these situations. We don't know how to talk to the parents. We don't know how to talk to the children. Help."

That's really what started CHI. It had to be. I just had to do something.

Bryan Sisk: Was that the first time that you realized that hospices were largely not open to children? Or had you had that awareness beforehand?

Ann Armstrong-Dailey: No, that was the first time. That was actually before I started writing the newsletters and stuff for NHO and doing the survey and stuff. Yeah, that boy was the first time. Yeah. The family's not comfortable with me using their name, so that's why I don't. The sad thing is that he died within 3 months. He didn't even last 6 months.

Bryan Sisk: Wow.

Ann Armstrong-Dailey: The good thing, because my meeting with Dr. Delaney at Children's is that he did become aware of that patient personally, and saw to it that he had additional support from the social workers and the chaplain and things like that. He bumped up his level of support within the hospital on a voluntary basis because they couldn't be reimbursed for it, obviously..

Bryan Sisk: Did you get a sense that that was unique to the U.S. with a regulatory framework, or was it a problem worldwide, where kids weren't regularly welcomed into adult hospices?

Ann Armstrong-Dailey: Well, I really thought, initially, that it was a U.S. problem. That it was because of the stringent 6-month laws that we had in this country. I learned soon after that, that it was just not so. I became very close with Sister Francis at Helen House in Oxford, England and others around the world that were struggling with this.

There was no question that we were going to make it an international organization... Actually, before I started CHI, there were three early children's hospice programs: St. Mary's in Bayside, New York, Edmarc in Virginia, down in the tidewater

area of Virginia that actually predates Helen House or St. Mary's in Bayside, New York. Those are the three earliest programs.

We were involved in Helen House and St. Mary's. We were not involved with Edmarc.

Bryan Sisk:

Simple question, but how did you know how to do any of this? How did you know how to build a non-profit when you decided that's what needed to be done?

Ann Armstrong-Dailey:

... My mother had always told me, "If you want to do something, start at the top." When this all came down, I just thought 'okay, this is what we need to do, who do we need to do it?'

We needed a law firm, because we needed to develop bylaws and articles for the corporation and all this stuff, and an accounting firm and all. We had nothing. We literally started with nothing. Blessedly, our international law firm called Arnold and Porter with offices here in Washington D.C. took us on as a pro bono client. We've been a pro bono client of theirs for 36 years. They have provided us with millions of dollars of pro bono services on a level that even if we'd had a lot of money, we wouldn't have been able to hire staff of that caliber.

Arnold & Porter then got Price Waterhouse to accept us as a pro bono client, and they set up all of our financial stuff. Arnold and Porter literally have held my hand every step of the way. Honest to God, we could not have done what we'd done without them. It basically was just sitting down with a yellow pad and just saying 'okay, this is what we need to do. Who do we need? What do we need to make it happen? We have no money.' [*Laughter*]

Bryan Sisk:

How did you develop the clout and the credibility such that you could call the vice president of Children's National, and they answer you. Or you can reach out to the leadership of the AAP and they agree to be on your board? How did that come about?

Ann Armstrong-Dailey:

I just called blindly and just said who I was, what I wanted to do, and we needed their help. That was for the board. With Dr. Delaney, I think I called the CEO's office and they put me off onto him. There was a patient of theirs involved and I felt that might have made a difference there...

I just knew it needed to be done and I sat down and picked up my phone from my kitchen table and started making some calls.

Actually, the first person that I called was Senator Bob Dole. I knew that he was very involved in World War II, obviously, and a wounded veteran, and very interested in these kinds of issues. I asked him if he would be on our honorary board. I also invited Senator Claiborne Pell to serve on the honorary board. From the beginning, I knew it would be really important to be bipartisan in everything that we do.

Then we asked Mrs. Reagan who was the First Lady at the time, but she didn't respond. When President Bush was elected and Barbara Bush was First Lady, I asked her social secretary to ask Mrs. Bush and Mrs. Bush said yes.

It was Bob Dole, I had his commitment before anybody else's and so I could use his name, [which added credibility to future requests.]

Bryan Sisk: Oh my gosh. I was going to make a joke like, "Well, I guess the only person you didn't go on knock on the front door was the president," but actually, you did. [*Laughter*]

Bryan Sisk: That's remarkable. Obviously, the Bushes, they had lost a daughter to cancer, so they probably had a—

Ann Armstrong-Dailey: Yeah.

Bryan Sisk: Was that something that you guys ever discussed?

Ann Armstrong-Dailey: Yes, Robin. They actually were in a video that we did. It was Mrs. Bush, Bob Dole, and Claiborne Pell. Surgeon General Koop was also supportive along with Antonia Novello who replaced him.

Yeah, I think when you get really angry, your audacity level goes up, or something. [*Laughter*] When we were evacuated from Pearl Harbor, we lived with my grandparents on their farm. Then they moved to this very small town and my grandfather was mayor of the town. I learned at his knee the importance of bipartisan support and fearlessly going after what needs to be done. That's part of it, too.

Bryan Sisk: Wow.

Ann Armstrong-Dailey:

Just an odd combination of stuff. Anyway, as I've grown old, I've lost some of the audacity, so I leave it to others.

Bryan Sisk:

When you were starting out, obviously you ran into resistance that we talked about with the hospices, but were you able to find, early on, a community of other similar minds?

Ann Armstrong-Dailey:

Yes, it grew. It grew. It started with a very small nexus. One of the first things we did was to hold that seminar in conjunction with the American Academy of Pediatrics. We felt that our first step was to help, to empower pediatricians, to continue caring when cure is not available; to help them become aware of the nature of the kids and families. From that, actually I got—did you ever know or hear of Phil Pizzo? He was a pediatric oncologist at NIH for years and then he was dean at Harvard and at Stanford.

Bryan Sisk:

Yeah, I think he's one of the authors of the main pediatric oncology book.

Ann Armstrong-Dailey:

Bryan Sisk:

I'm doing the ethics chapter for right now.

Ann Armstrong-Dailey:

Oh cool. One of Phil's social worker's husband was a pediatrician and they were at that meeting in San Francisco. Phil called and asked if I'd come out and do grand rounds, and I did — three times. I just adore that man. I absolutely adore him.

There were some invitations that came from that first seminar that really were on that level, which was very good. From then, we decided we would start doing an annual World Congress, and so I think our first one was here in Washington DC in conjunction with National Children's Medical Center. We did several in DC with them.

It just grew from this tiny, miniscule number of people that were interested, and then it just kept magnifying itself. I feel like we're into about the seventh generation now. My mistake is that I thought if we could train this first core group, and give them what they needed, that they would train the next generation. What I've

learned is that each generation wants to rediscover it for themselves.

It's kind of like having teenagers. They want to do it themselves. They don't want help. Yes, it's been—we started with a tiny, tiny group, and it just constantly grows. Which is wonderful.

Bryan Sisk:

Who did you learn from as you were starting this out?

Ann Armstrong-Dailey:

Elizabeth Kübler-Ross became a really good friend and a supporter. In fact, our very first donation came from her. She did a lecture at Ford Theater for us in 1983 as a fundraiser for CHI and she also did some other lectures in D.C. at that time, and she just turned over all of the honorary checks from her speaking engagements to CHI, which was very, very generous of her.

I probably learned some audacity from her, too. I knew her when she was still married to Manny, her husband, and I met both of her kids, and they were just really wonderful. I learned a lot from her. I also learned a lot from Dame Cicely Saunders...

She struggled early, I don't know what her reasons were for having challenges with kids, or that psychiatrist that I met at the AAP meeting, at our exhibit. I think people are well-meaning and want to live up to their very best, but often don't know how. For some reason or another, just have to close down emotionally.

I mean it's human nature that when something that is fearful or threatening, you shut down emotionally. What we're asking is people to go beyond that...

Bryan Sisk:

One thing, I'm going to jump ahead a little bit, to follow-up on this concept of kids dying is sad. One of the big challenges for advocacy is growing public awareness. How have you navigated that where the general public probably doesn't want to think about kids dying, but they need to know about it so it can gain the importance in public discussion?

Ann Armstrong-Dailey:

Well, [one of our greatest achievements is the establishing the Children's Program of All-inclusive Coordinated Care (ChiPACC), which was kicked off with over \$4 million in federally funding demonstration models. These demonstrations proved the the ChiPACC model of care can both save money and improve quality of care for these children and families. The

ChiPACC model of care provides comprehensive, compassionate, coordinated care for children with life-threatening conditions and their families from the time of diagnosis alongside curative care in the most appropriate setting based on the family's choice.

More recently this has culminated in the creation of the ChiPACC Bill (aka Mattie & Melinda Bill), which will allow states to receive reimbursement for ChiPACC care services.]

A lot has changed over these past 36 years, [but CHI has been paving the way since the beginning in 1983]. Going back to the very beginning, we started that with that world pamphlet called *Approaching Grief*, and it was for the general public, but we targeted it for the pediatrician's offices. We've always involved parents.

We've done a number of publications and videos for the public. We didn't have email, internet, or all of those wonderful avenues early on. It was slow. Slow going. We have a number of congressional tributes and we're in the Congressional Register multiple times, just trying to keep everybody involved and informed.

Today it's easier, you've got websites and you've got internet, and you've got social media. Initially it's through printed materials and newspaper, it's various newspaper articles, *60 Minutes* did a piece featuring Melinda Lawrence, and *Parade Magazine* did a piece, *Reader's Digest*. We did not approach them, they approached us, which was interesting.

Then, local things, but we've never had a budget for public relations and communications and that kind of thing. Whatever we can do, we've done. I don't know if you've noticed, but I think we were the very first book on children's hospice and palliative care that Oxford University Press published. So we did three editions for them. The first one was in the 80's; Oxford University Press was very proud of the fact that they published this book, is what they said. I mean, that helped with a specific set of population.

Bryan Sisk: Looks like it was in 1993.

Ann Armstrong-Dailey: 1993.

Bryan Sisk: When the *Hospice Care for Children* came out.

Ann Armstrong-Dailey:

Is that the first? Okay. We were working on it in the 80s. We've been trying to take advantage of avenues as they came up.

Bryan Sisk:

Could you tell me a little more about that CHI, the World Congress in San Francisco that you guys held in 1983? What happened at that? What actually happened, and what were the outcomes of that meeting?

Ann Armstrong-Dailey:

Oh, it was great. I'm trying to think of—and forgive me if I don't remember all of the speakers, but we drew on the small cadre of people that we could find, as speakers. It was with Kübler-Ross. I think Ida Martinson came. Jerry Jampolsky who did several books on working with kids and artwork. Art Kohrman who was the chairman of our board. He was a pediatrician. He was the executive director of La Rabida Children's Hospital in Chicago, and a professor of pediatrics at the University of Chicago Medical School.

We had several speakers. We just reached out and said, "Look, this is what we would like to do, are you available?" We didn't pay any honorarium, or anybody's travel or anything, but they came. I know Ida was invited. I can't recall for sure if she actually presented or not.

Bryan Sisk:

When you were starting out, were there other people doing similar advocacy? Or when did you start to see other groups that were trying to follow this path?

Ann Armstrong-Dailey:

When we first started, no. We couldn't find anybody. Ida Martinson had written her manual for nurses, for homecare for kids with cancer. That was the only thing we could find when we first started back in the 1970s.

Then people became aware. St. Mary's actually reached out to me and asked about my interest in the field. I guess they picked up on one of the articles I'd written for the NHO newsletter or something, or the survey or something like that. They asked if I would be willing to meet with them?

I then became aware of Helen House. Actually, I think I became aware of them through Dame Cicely Saunders, but I'm not

positive. And then, Edmarc Those were the first groupings of people that I knew that were interested in the field.

When we held our first CHI World Congress, we drew on that along with the staff at the children's hospital that hosted it. After hosting the World Congress, it was an opportunity to promote the concept within their institution and their city and their region. For example, in Sydney, Australia, they did a whole week-long event around the city, in conjunction with the World Congress. Singing events and all kinds of things just to utilize the fact that it was being held there as an opportunity to communicate with their own general public for the need for children's hospice care.

Every time we hold a World Congress, there's the mushroom effect. All kinds of wonderful things will grow out of that.

Earl Grollman was another one that was involved very early on. He's a Rabbi. Are you familiar with him?

Bryan Sisk: No.

Ann Armstrong-Dailey: He did a lot of work in the field and became a personal friend. One of his quotes that I use a lot is "to lose your parent is to lose your past, to lose your spouse is to lose the present, but to lose your child is to lose your future." Very powerful.

Bryan Sisk: What do you think were the biggest challenges you faced early on, as you were developing along this trajectory?

Ann Armstrong-Dailey: The taboo of that children aren't supposed to die and that you can send your child to Children's Hospital and there'll be a magic—there will be a miracle. The child will be cured.

Bryan Sisk: From your perspective, what do you think was the spark that really drove the development of pediatric palliative care as its own field?

Ann Armstrong-Dailey: I think from the minute we considered Earl Grollman's statement – to lose your parent is to lose your past, to lose your spouse is to lose the present, but to lose your child is to lose your future, CHI built upon that. We were able to get congressional funding for four years, for children's hospice demonstration model programs. It was very interesting to see what a motivation that was to all of these

organizations that we've been working [who support these children and families.] ...

Our ultimate goal is to put ourselves out of business. When this gets into the mainstream of healthcare, we feel that we've done our job... [The ChiPACC program and the ChiPACC Bill help us achieve that.]

Bryan Sisk:

Following up on that, what's interesting is the United States is largely the exception. Around the world, philanthropy plays either a major role or the *only* role of funding for children's hospice and palliative care—from the U.K. to Canada to South Africa to Greece, why do you think it is that there's such a necessary role for philanthropy around the world for these kids?

Ann Armstrong-Dailey:

Again, it comes back to the fact that, I think, people don't like to think about, to admit that children die—that they're in need of special help. It's uncomfortable for people. Either if you've lost a child or you have a sick child, you instantly understand. If you have a healthy child, you're almost afraid to be involved, because maybe your kid might be sick. Or, on the other side of that coin is, let me support your cause so that my child doesn't get sick.

From my perspective, there seems to be a lot of emotion involved in either why people support it, or why they just aren't comfortable supporting it.

Bryan Sisk:

Mm-hmm.

Ann Armstrong-Dailey:

I think over time, more and more people are getting comfortable in talking about it, in seeking support for their child. Oh, that's the whole—can I go on a tangent?

Bryan Sisk:

Absolutely.

Ann Armstrong-Dailey:

One of the mothers that we worked really closely with, Jenny Stepanek, who doesn't mind me using her name or her son, Mattie Stepanek. Mattie's become very nearly famous and has written a whole series of heart song books that are *New York Times* best sellers. When we first met Mattie, he was 3 years old. He has a form of muscular dystrophy.

Mattie's mother, I met them at an Association for the Care of Children's Health, which sadly no longer exists. I had attended one of their meetings to present. Jenny was there giving a workshop. She had lost three of her four children to this disease. Mattie was the youngest. We got to know Mattie and Jenny well, they lived here in the greater Washington D.C. area.

Later, Jenny developed the adult form of the disease. She's still alive today. Mattie died 15 years ago, I think. When Mattie was three, his next oldest brother was still alive. His name was Jamie, and at Jamie's funeral, Mattie talked about how Jamie and Mattie used to play hide-and-go-seek, and they just loved it. When he went into the funeral, and he was told that his brother was inside that box, he knocked on the casket and said, "It's okay Jamie, you can come out now." He said, "I didn't realize that he was dead."

To cope with the loss of his brother, he started writing poetry, or dictating poetry to his mother. She would write it down verbatim. These poems became really important to Mattie. When Mattie was 12, he was at Children's National Medical Center and was very close to dying, they really thought that this was it.

One of his wishes was to get his book published, and so it was, his first book. Then he ended up being an Oprah favorite and on Larry King Live, and even in Cape Town, South Africa. When CHI did our World Congress there, the banquet manager knew about Mattie Stepanek.

Bryan Sisk:

Wow.

Ann Armstrong-Dailey:

Jenny is a very intelligent woman. Had her PhD in education and understood the disease trajectory of her youngest son. She'd already gone through it three times. She knew that she needed help. Mattie wanted to be at home. He didn't want to be in the hospital. Jenny wanted him at home; she was living at the hospital, in a sleeping bag, sleeping on the floor in the waiting room at night.

We were able to find a hospice program in her area that would provide round-the-clock home care for him at no charge to them, at all. She emotionally could not take advantage of that opportunity because to accept it meant she was giving up on his care and on the fact that he might live. Mattie died in the ICU at Children's National Medical Center after being there for months.

It was because of this reflection that “if I accept hospice and palliative care, I am giving up hope for a cure.” As a parent, she could not make that decision. We see that a lot. That’s one of the reasons neither hospice nor palliative care are in the title of our children’s program for all-inclusive coordinated care. Because it’s a barrier, unfortunately.

Bryan Sisk:

That would be something that probably still needs room to grow. When you’re looking back over your career we’ve been talking about, I mean really, from the-the seeds of this, as early as the late 60s and into the 70s, until now, what have been the really big changes in the care that’s provided to these kids that you’ve noticed?

Ann Armstrong-Dailey:

Well, I think more and more institutions have stepped up to the plate, you know? The hospices, the home care programs, and the children’s hospitals. I think more pediatricians are aware of it. The quality of care is not always the same from one program to another program, which is a challenge.

However, we still see reluctance. Unless there is full reimbursement for the services so that we don’t have complete dependence upon philanthropy for covering the cost of the services, we still see a reluctance. Hopefully that’s changing with the laws in congress that are changing, and the policies at CMS which are changing. I mean it’s little bit by little bit by little bit, but there is movement in the right direction.

Bryan Sisk:

What would you say is your favorite contribution to this field that you’ve made?

Ann Armstrong-Dailey:

The first word that came to my mind is awareness. Although there is still tremendous need for awareness. And maybe tenacity.

Bryan Sisk:

I picked up on that through the interview.

Ann Armstrong-Dailey:

One time, in a small hospice, and I don’t even remember where it was, they had asked if I could come and present to their board of directors or something. The medical director asked if I would be willing to be a guest at their home. I said, “Well, yes.” Over breakfast the next morning, they each said, “I have one question for you. Where did you get the audacity to do this?”

I just remember looking—feeling like my mouth fell to my chest. I didn't have an answer for him. I'd never thought of it as being audacious.

Bryan Sisk:

That's probably where it came from. *[Laughter]* What would you say are the biggest challenges that we have in this field right now?

Ann Armstrong-Dailey:

Public awareness. Getting the laws changed, congressional support, and support from the people in this country who can—we know that the money's in the system. With our system, there's no new money used—it's saving money. It's broadening the silos at CMS in order to allow these services. That, unfortunately, has to be done by law, by congress.

I think continuing to work together is important, because the children and families deserve it—to look beyond our turf issues between the hospices, the children's hospitals. All of these are critical to a continued program of care for the child and family, from time of diagnosis. The child is going to be in and out of the hospital, they're going to be in and out of the hospice, and at home.

In order for it to be successful for the child and family, it needs to be a cohesive, continued, coordinated effort. That can be a challenge.

Bryan Sisk:

What gives you the most hope? What's the strongest area of the field right now?

Ann Armstrong-Dailey:

I think the fact that more and more people are getting involved—I mean Joanne Wolfe, such wonderful work. I could go on and on with the wonderful people that are in the field now. Laurie Weiner is somebody I just absolutely adore. We met her through Phil Pizzo when he was at NIH. There are so many wonderful people in the field that are researching and educating and advocating on behalf of this patient population that's very, very exciting, and very encouraging. We need more, but it continues to mushroom.

Bryan Sisk:

Well, lastly, I would really love for you to dream aloud for me. If budget and politics and turf wars, all of the things that we talked about were not an obstacle, what would you ideally want to care for these children to look like in another 10 years?

Ann Armstrong-

Dailey: Oh, that's easy. Take Timmy as the example. From the time of his diagnosis of his renal disease, we would like to see that the pediatrician would've sat down with his parents and talked with them. It comes back to communication—'this is what the disease is, these are the things that we can do. We hope for success, but success is not guaranteed. Therefore, it would be really important to meet with these team members who could provide you with anticipatory grieving.' I mean, just the fact that your child is diagnosed with a life-threatening condition is traumatic to a child and traumatic to the families. Just to help them to work with that trauma and to talk about what their options are. Involve them in the decision process and include the child and the siblings in that. The healthcare professional, the family, down to child, we're all working together toward cure, while at the same time preparing for the potential impacts of the loss of the child, if he isn't cured. All simultaneously. That it would start from the very beginning of the diagnosis.

The overall arching care for the child and the family and oversight for all of this project would be overseen by someone who—whether it's in the hospital or on the state level, or whatever, would be head of the team to ensure that all the medical, psychological, social, and spiritual issues of that child and family are being addressed. Let alone the practical issues of insurance, schooling, and all of these other things.

Bryan Sisk: Wonderful. This has been absolutely phenomenal. We've touched base on a lot of the history. Are there other areas of this history that you think I haven't hit on and I should know about?

Ann Armstrong-Dailey: Oh gosh, not that I can think of at the moment. I had a very late-night last night. We were at the Capitol Hill Club, but it was on behalf—I was representing the Frankie Evans Association, and working to get my brother and the other names on the Vietnam wall.

Bryan Sisk: Mm-hmm.

Ann Armstrong-Dailey: But I can't thank you enough for your interest and the fact that you're coming at this from the point of communication, because I honestly agree with you, wholeheartedly, that it begins and ends with communication. Whether it's medical, psychological, or practical communication for the healthcare professionals, the child and the family, and their friends and associates.

Oh, there's one other point that—and I forgot who did the study, that showed that for every child that was diagnosed with a life-threatening condition, that at least 200 people were involved. The kids in school, the neighborhood children, the kids from their church or synagogue, aunts, uncles, cousins, et cetera. That's a large number of people.

Bryan Sisk:

Absolutely. Great.

Ann Armstrong-Dailey:

Anyway, bravo to you, because I really think you're taking—you've got your finger on a red button, and that's communication.

[End of Audio]