Dr. Lynn McPherson:

This is Dr. Lynn McPherson, welcome to Palliative Care Chat, the podcast series brought to you by the online Master of Science, PhD and graduate certificate program in Palliative care at the University of Maryland. I am delighted to welcome you to our podcast series titled Founders, Leaders and Futurists in Palliative Care, a series I have recorded with Connie Dahlin to support coursework in the PhD in palliative care offered by the University of Maryland, Baltimore.

Connie Dahlin:

Welcome, everyone. This is another one of our podcast from our PhD program at the University of Maryland. My name is Connie Dahlin, and I'm one of the faculty at the University of Maryland. I'm joined by Dr. Lynn McPherson, who is the director of the University of Maryland graduate program, Masters in Palliative Care. Lynn?

Dr. Lynn McPherson:

We're very excited that literally any minute now we should be getting approval from the Maryland higher education commission for the first PhD in palliative care in the United States and I think only the fourth in the world. We're terribly excited about this, and I'm very grateful to Connie and the other faculty for their insight and wisdom and their great vision particularly in this first course in setting the stage and interviewing experts in the field such as our guest on this podcast and how this all started, where we now, and what is the future look like. Connie, take it away. I'm very excited about this one.

Connie Dahlin:

I am excited to introduce to all, Judi Lund Person. Judi is very well known in the hospice circle. She's been in the field for 40 years, has a perspective of the context before hospice was being totally formally created to the hospice benefit, to all of the places afterward of having to think about metrics, of having to think about regulations. Judi is currently the vice president of regulatory and compliance for the National Hospice and Palliative Care organization, where she's really been an amazing liaison with the Center for Medicare and Medicaid services. She actually started her career in the south, in the Carolinas, with working at the state organization. I think, again, for the students to understand, you may start in one place and you grow into other places or opportunities come and you realize that your passion will lead you in a different direction.

But I think, one of the things that Judi brings to us is learning from our past and understanding the future in terms of thinking about all of those regulatory pieces. Judi, thank you so much. I've only scratched the surface about who you are and what you've done, so I'd love for you to introduce yourself a little bit more and let the students know what your role was and how you came into that.

Judi Lund Person:

Sure. I often describe my first interaction with hospice as meeting a man on an airplane. I was very young, probably four years out of college, did not have a Master's degree at that time, and was going to, I worked with volunteer your programs and I was working in state government. Was going to some meeting in Chicago and I sat down in the middle seat, and there was a man at the window with papers everywhere and he was very irritated that I sat down in the middle seat, a woman on the aisle who is terrified. We're getting ready to take off, and I should probably also disclose I'm a social worker by training with a health policy masters, but the social worker part of it is important to the story.

Connie Dahlin:

Judi, that's a new fact I did not know.

Judi Lund Person:

See? You just never know. I see that the woman next to me is so scared, and so I turned to her and said, "It looks like you're afraid. Are you okay?" She says, "I've never flown before, I'm going to Las Vegas to see my son, and I'm just terrified. Her knuckles are like ... I turned to the man to the right of me and I said, "Please help me reassure this woman that everything is going to be okay." Her turns to her and he says, "Everything's going to be okay," and he goes back to his papers. We get there. We end up, he and I, we end up starting to talk.

He's going to one of the inaugural meetings of the National Hospice Organization quality and standards committee, where they are developing the initial and original standards for hospice care. We sit there and we're talking and he says, "Well, my job to bring to this meeting is to bring job descriptions for all the members of the interdisciplinary team, and the only one I don't know, I can't figure out what they do is I don't know what a volunteer coordinator does." I said, "Well, I know what a volunteer coordinator does because that's what I've been working on for the last four years."

Let's set the timeframe here. No email, no Internet, what we have is facts, and we had a thermal fax, so not fast fac or mail. I said, "Well, I have a lot of resources for you. I can help you develop that." He took some notes, so he would be prepared for his NHO meeting in Chicago. We kept in touch after that. He was the board president for the state association in North Carolina at that time called Hospice of North Carolina. They formed because they wanted to be like the Connecticut Hospice and have one hospice in North Carolina. Their very first meeting, 75 people showed up and said, "Oh, no, no, no, no. We all want our own hospices."

The state organization became the helper to get all these organizations around the state to develop hospices. Early on, the work of that group was traveling to nighttime meetings with community citizens and doctors and nurses who had seen bad deaths all over the place. They were so committed and so completely passionate about how do we make sure that we provide, develop some care for patients, so they have a better death than what we're seeing now. It was a very exciting time. The thing that was about, amazing about it, is that it was all volunteer. Each of the hospices in North Carolina at the very beginning had one employee. Everything else that was provided was provided by volunteers. The one employee was always a nurse. The one employee coordinated all the other volunteer nurses, coordinated all the other volunteers to do other things, they had huge fundraisers, but hospice did not start as a medicare benefit. If I am inking about it, I am thinking about how incredibly different the start was for hospice than for most Medicare benefits, so quite something and I think as we think about the beginning of hospice care.

Connie Dahlin:

Judi, when you ... I think nobody ... that's the part that I think a lot of people don't know, the history of how many years it was a volunteer process, and then the Medicare benefit. Talk to us a little bit about, so this started, people have been invested because they see care for the dying is wrong. We've had different speakers talk about the context of, we didn't talk about it in America, cancer was automatically a death sentence. We were having this birthing movement, so then people thinking that, so we laid that, but I don't think people understood. You have this development of a volunteer part and then talk to us a little bit about the evolution about what even happened that the Medicare benefit was even put forth as a possibility.

Judi Lund Person:

It's also such an interesting part of our history. We've got care being provided. I was on the board of Hospice of North Carolina during when the first hospice patient in North Carolina was served in Winston-Salem in 1979. There's a lot to do about that. In the first, they served their first patient I think in September, October. By the end of the year, they served 27 patients, they were so proud. They were so proud. If we think about it from that perspective, it's small numbers of patients because you couldn't do all of that with just volunteers. I think there was a lot of pride at being a volunteer movement that we didn't expect money for this. We didn't expect for the government like the government Medicare or whatever to pay for this care. What we really wanted to make sure of is that we had the opportunity for care to be better for patients and patients to be supported and their families to be supported. It was completely passionate about that being the end goal all the time.

As we started to think about this a little bit more, we were looking at, "Okay, we have more people that want this care, but we're dead tired. We were so exhausted from trying to make sure that all this gets done. We don't have the structure in place yet. We have great fundraisers, but is that going to be able to sustain us?" A small group of us started meeting in Washington. Ann Morgan Vickery from what is now Hogan Lovells, was a young associate at what then was Hogan & Hartson. She got interested in this and got some other colleagues at Hogan & Hartson to also be interested. Then we have two young whippersnappers from Florida who were also very, very interested in this. Don Gaetz and then Hugh Westbrook.

We started meeting with a few people, like in the conference rooms at Hogan & Hartson to say, "What would it look like if Medicare would pay for this?" We're all like, "Yeah right. This is never going to happen. It's a dream world we're in." We can't imagine that this would be something that people would be excited about, and nobody wants to talk about death. That's the other big piece of this. We kept on meeting. Don and Hugh said, "We're going to put together a grassroots movement, and we're going to figure out how to cover the country with advocates." I ended up being an advocate for the Southeast. I think Virginia, West Virginia, maybe the Carolinas, maybe down even further into South Carolina and Georgia. We had people just like me all over the country. Again, remember, we have no email, no Internet, none of those things except of the phone and the fax.

Then we decided we started meeting like once a month in Washington to say, "Okay, what are we hearing here, and how do we make sure that we get some interest from this part of the country or that part of the country?" We have two things going. We have a group of advocates that I was part of who said, "Okay, how can we talk about this with Sen. Heinz from Pennsylvania or some of the other members of Congress? Bob Dole, for instance, on the Senate side and then on the House side, Leon Panetta from California? How do we to them about this?" Once we started talking, people were very interested.

Then we're like, "Okay, how do we get?" I remember the conversations with the Blue Crest Blue Shield Association. Are they going to be interested in this? Is this something that a Blue Cross Blue Shield plan would pay for? There's a whole discussion around that. Meanwhile, back at the ranch, back amongst all the hospices who were like just little fledgling organizations all over the country were like, "Oh, no, no, no, this is going to change hospice. We like this volunteer thing. We don't want rules and regulations. Medicare dollars is not the way to go." We had, at ne meeting while we're in the midst of this whole discussion around the Medicare hospice benefit, we had a meeting at the [inaudible 00:13:53] in Washington, where literally there were screaming matches and throwing of chairs from the people who wanted Medicare to pay for hospice benefits and the people who said, "We will never agree to that. This is a volunteer movement. We will always be a volunteer movement, and we don't want Medicare to spoil it", so very, very interesting tension.

I remember myself going to meet with a group of hospice directors in Virginia. We are meeting in someone's home. Someone had put the soup on in their crock pot, that's the kind of place we were. You stayed with people, you didn't have hotel rooms, you didn't have the money for that, you did whatever you could do to make sure that you got the word out. To a person, all the people who were hospice directors at that meeting were like, "If we had rotten eggs and tomatoes, we would throw them at you because we don't believe that Medicare has any business paying for care at the end of life."

It was a rough time. If we put in context then, we're talking 1981, 1982 and then we have just an incredible political set of decisions that got made that were so successful. We had Bob Dole, very, very prominent on the Senate, and then we had John Kerry. One of the nights when we're trying to gather enough votes walked around the floor of the Senate with his clipboard looking for people to sign on and he got enough votes to get it passed in the Senate. On the House side, Leon Panetta and Bill [Gravison 00:15:48] from Ohio are the two big, big champions in the early, early days. We talked to Leon Panetta a couple months ago, he remembers fondly the times he spent trying to see if we could get the rest of the house of the House of Representatives to sign on to hospice as well.

Connie Dahlin:

Judi, what strikes me is, you've said a couple of things. One, this interesting point where you were saying that people were tired in trying to figure out a strategy. In the palliative care world, and I think the hospice world too, we wanted to be opening up and now we're overwhelmed and people were tired, so like, okay, cyclical. Then the other thing that you mentioned that was really interesting was this part about coming together when you have this split. I'm curious that, clearly, you remember that room in the Omni Hotel at Zindel, because probably there's a lot of pieces to that. I have to keep reminding people that hospice and palliative care folks reflect the population. I think because sometimes the sense that we're all Kumbaya.

Judi Lund Person:

Right, right, exactly.

Connie Dahlin:

But I think the part that, to me, is a big lesson for some of our students is you had this, I don't want to say fracture but this very divergent lot, but you came together and you had the benefit. How did you then go about healing and bringing people back together?

Judi Lund Person:

Well, so that, I actually have been thinking about this recently. It is so fascinating that the benefit was based on a study done by the administration. It's a demonstration project with 26 hospices. They were walking out cost-based reimbursement, that way I think in the past now. They were looking at cost-based reimbursement and they were looking at how can we provide care for the same patient population more efficiently and for less cost. The theory was hospice care would be 40% of what the last six months of a cancer patient's life would cost. A lot of that work was wrapped into the first design of the Medicare hospice benefit. But in 1982, the benefit was only designed for three years. A lot of the people who were in the, "We don't want Medicare, we want hospice the way we've always had hospice, we want to make sure that we are thinking about this as a volunteer movement," they were like, "Well, this is going to be over in three years, we won't have to worry about this anymore."

In the first two or three years, there were very few people who applied to become Medicare certified as hospices. Many, in fact, a lot of providers that I've worked with in the Carolinas, many of them said, "Well, we can't believe it's going to really go on. That would be too big a change for Medicare." They said, "We'll just wait and see what happens." Really, in 1986, that is the key, because in 1986 the benefit was made permanent.

Also, a lot of political back-and-forth, a lot of work behind-the-scenes tucked into, the language tucked into a bill, and once that happened then it was like, "Okay, you can either start thinking that Medicare will actually pay you services or you can continue to be a volunteer hospice," and we had, really, up until very recently, we had hospices who were only volunteer, and we still have a few around the country now.

Connie Dahlin:

That's just interesting to think about because when you think about how stretched healthcare is and then you think about, I'm just thinking about my being a provider, to have that energy to be able to do that, and also in realistic terms, financially for providers, if you're in rural areas there might be somebody who cannot afford to be a volunteer, right?

Judi Lund Person:

Right, right.

Connie Dahlin:

When you look at a health equity piece, it's an interesting dynamic.

Judi Lund Person:

You also have, I think, in rural areas, you have ... the numbers are not with you.

Connie Dahlin:

Right.

Judi Lund Person:

You might have a hospice where your average daily census is 10 or 15. A lot of the early work was what is the magic minimum number of patients you need to have in order to be solvent? I think, in the early days, I think our number was 20, so it's really just as nice.

Connie Dahlin:

I was going to say that, Judi. I remember those days, where as long as your average daily census was 20, you were okay and you could survive. Survive, I don't mean do beyond that. What is the average daily census now that you need to survive?

Judi Lund Person:

I don't think I have heard in a long time what the average, what the survival number is, but I think our average daily census among all hospices is in the 80s now.

Connie Dahlin:

Okay. It's like four times as much.

Judi Lund Person:

It's still small but some small providers, certainly.

Connie Dahlin:

When you think about, so that was pivotal and so coalescing and then from '86 to 90s, I definitely remember this whole movement or people getting certified and then the different states deciding whether they are going to do CMS survey or they're going to create their own, always this interesting part rather than making it simple. We tried to have many different ways but that's how we are as humans. Then when you think about that what was another pivotal moment? Because I know that, so in the 90s, early 90s is when we're starting to see this movement of people moving out of hospice to develop palliative care. There starts to be this conversation about the two roads, but was there something else that you would think that was important that played into that? Or was that just a natural evolution?

Judi Lund Person:

Well, I think before we even get to palliative care, I really want to talk just for a minute about the state level work. Most states now have some hospice licensure, but in the days we were really very concerned about protecting the name hospice. Do we need to have a licensure? Do we need to be licensed as a healthcare entity in order to provide care in the home? How do we think about that? I think that's where a lot of that 90s work was is, what's the definition of a hospice, who can provide hospice, can we protect the name and what are the licensure requirements, never mind Medicare for a minute. What are the licensure requirements>?

If you're a volunteer hospice, or if you're a Medicare-certified hospice, you still have to meet these bottom, first rung, absolute requirements in order to use the name hospice in your state. We had, I think, a lot of conversation among various states just say, "Can we all use a standard definition?", and a lot of states did. Now, I think, and I'll just do a slight side road into palliative care for a minute, but if you had a very limiting definition of who can be a hospice patient, let's say, which many states have had and you said a patient who is terminally-ill with a life expectancy of six months or less, typical MEdicare definition of hospice patient, then the chances of your being able to broaden your services to palliative care very tricky.

Many states said, "You can't provide palliative care under your hospice license." There's a lot of work that went into and probably a lot of that work didn't happen until the early 2000, if you really know. I think that's another piece of the work, is to say where do hospice a palliative care did together? I think a lot of our conversation has been here for seriously ill individuals is palliative care. Hospice is a subset of palliative care for patients nearing the end of life. I use the word "nearing the end of life" very purposely, because if you say at the end of life, then the perception is that you are only taking care of that last week of life or the last few days of life and we don't like that perception. Just another wrinkle to some of the early work on this.

Connie Dahlin:

But I think you make this, that's a really interesting point and I'm really glad you brought it up, because I think, again, what you're speaking to and we're trying to have students think as leaders is there is this national part, because when you were talking I was thinking, "Well, of course it would be easy because it's the Medicare definition." But right, we have 50 states and territories and they're going to interpret that and they do that with licensure of everything else. Of course, with hospice and then you bring up a really important thing because I know when we think about Hospice of Connecticut, how they had to get, how Connecticut would recognize them because in some states it's a skilled nursing facility. Other case it's like-

Judi Lund Person:

Specialty hospital is another one.

Connie Dahlin:

[crosstalk 00:26:19] or someplace a group home, and that does vary state to state, and that can be really tricky. I know in my own state of Massachusetts, we have one in-patient hospice but it was so hard for them to get that. I don't know the facts and I should probably ask that, if the state said this might be a one time deal because everybody else who's open has been a hospice house. I'm like, "Hmm, that's an interesting trend. Was it because of the licensing and it's too expensive? Or you have to be too big or whatever?" But I also think then that is an important part of, "Okay, if we have limited at that and healthcare is changing and we're moving beyond cancer care and so the hospice definition doesn't fit, then it's not only a philosophical reason that palliative care comes in, it's actually a policy issue of how-

Judi Lund Person:

It is. Absolutely, it is.

Connie Dahlin:

You know better. I've lived through some of this about who we would admit to hospice. We were a little bit allowed to be more generous certainly in the beginning. Then when we had HIV-AIDS patients, that blew everybody away because the exact type of population, you never want an HMO, you take a risk and you think you're going to do it on a young population and you pick this young population and they are sicker than your older population. That happened and then I think when OIG got involved and then everybody went from, "Oh, we're going to do this too. We're really interpreting [tiebreak 00:27:57] because we're terrified." It is interesting.

Judi Lund Person:

It is interesting. I think that's calm approach to it, if you will, is a lot of early hospice work and a lot of work even into the 90s was, part of my Master's work was on what characteristics are there about the volume of patients? I was at a regression analysis on, is a tertiary care hospital that's close by? Is it the number of oncologists? What's the patient mix look like? Here is where we went. In the 90s, this was a 90% cancer, 10% all other diagnoses. Today, we are 25% to 30% cancer and 70% all other diagnoses, with the highest utilization of Medicare side for neurologicals, so Alzheimer's, dementia, Parkinson's is our number one diagnoses today.

Then we have the, guess what, what everyone now calls the organ diseases. We have the heart and the COPD diseases also being very high. Imagine that as a part of our story as we're thinking about, we have a group of staff who know how to care for cancer patients. Now, all of a sudden we have AIDS patients, we have COPD patients, we have patients with a much more jaggedy, if you will, process for dying than the cancer patient with a very typical trajectory. Another part of the challenge I think.

Connie Dahlin:

Well, I think also in the sense that, for what you were saying before, the Medicare benefit was based on this cancer population-

Judi Lund Person:

Correct, absolutely correct.

Connie Dahlin:

... and adjustments made. I think, and you can speak more to it, while people wanted to make those adjustments depending on what administration was there, being terrified of opening it up because, I think, for our students to understand that in the late 2000s when we're trying to talk about advanced directives and it got very effectively tagged as death panels, it took us years to recover.

Judi Lund Person:

Absolutely, years.

Connie Dahlin:

I think everybody was going, "Wow, that's how they did that." God only knows. I remember, actually myself at one point, practicing in Boston and starting an urban hospice, we would have really complex patients. There was one day where I said to myself, "The right to life people could interpret this in a different way. We have to be really careful about our message." I wonder if you can talk about some of that messaging and outward focus that we could have what we would talk together, but then how we were sort of trying to deal with this public imaging.

Judi Lund Person:

Right, sure. Let's go just for a minute to the Terri Schiavo case, Florida case, young woman in a persistent vegetative state did not have a advanced directive. Perfect story for some of this. Her husband and her parents disagreed about what should happen to her. She ended up being cared for in a residential hospice in Tampa. Now, as Terri Schiavo, as the case got bigger and bigger and bigger and bigger, right to life was very involved. I was at NHPC at that time and our 800-number was plastered on a banner that was featured on national television. We ended up having to have all our mail sent to a mail facility to check for bombs and powders and all that thing. We had armed guard at the front door of our office.

Connie Dahlin:

Wow!

Judi Lund Person:

It was very, very, very serious and very scary even though we are hundreds of miles away from Florida, because it was such a national event. I think, the challenge, I think, and the challenge is always going to be with care at the end of life is, are you limiting care? Are you rationing care? Are you sending these patients to hospice, so that they get something but you're not giving them the full range of care that some part of the patient population would get if they didn't have hospice or if they were in a certain economic group or something.

I think it is probably the trickiest place we are, always. Even though we have not had mentions of death panels in years now, it is still right on the edge of ... there is a case that we got notified about at NHPCO recently where it's like, "Okay, is this the next Terry Schiavo case? Is this the next case where we're going to be accused of not providing all the cure that a person should have." It's so dynamic, I think, that it is very connected to our American culture, where we say that death doesn't happen to us, it happens to someone else. I will always remember the director of St. Christopher's, we came to the United States, he would say in his I won't be able to do the English accent justice but he said, "Ugh, you Americans! You think somehow that dying is optional." That's a lot of where we are. That is a lot of where we are even today. We are a very interesting thing.

Connie Dahlin:

But I think also, if we were questioning our roles, COVID exploded anything that we're doing. I think hospice and palliative care has stepped up to the plate quite well. I think hospice has done a great job for the patients that it was like, "Okay, they don't want aggressive care, they don't want to be in a hospital, this is what they should get." Although, the one thing that I did not like was that instead of focusing on the philosophy, some of the care was like, "If you want to see your family then for hospice." Yes, that's part of it, but just didn't quite feel right.

Judi Lund Person:

I know. I don't like that.

Connie Dahlin:

I think the palliative care part, we need to step in and help people with the conversations and learn that.

Judi Lund Person:

Absolutely.

Connie Dahlin:

I think the peril for palliative care is that great things done, but it may have pushed back again against thinking, "Okay, well, palliative cares is only for these really sick people who are dying." Having to help, as the pandemic eases up, we're not through it but eases up, to say, "Yeah, we need to keep going back because there are still seriously old people not just COVID patients." I wonder, in a certain sense, what are some of the things that you think are important for hospice and palliative care to think forward about learning from our past and in terms of how we move forward?

Judi Lund Person:

I think, actually, one of the things that COVID has taught us is that very large group of seriously-ill individuals, not terminally-ill, seriously-ill individuals, who do not have the care they need. It's stunning, I think, for us to think about that group of patients and how fragmented their care is or how little care they get. For the last year or year and a half or so, NHPCO has been working with the National Coalition for Hospice and Palliative Care on a community-based palliative care benefit and proposing it as a demonstration project through the centers for Medicare and Medicaid innovation or CMMI. It is continuing to get a lot of very favorable response.

I think what we should all be thinking about is what kind of support, what kind of wraparound support, do we need for patients, so that they are connected, so think loneliness in terms of the COVID pandemic, especially. If we're thinking about supportive services for socialization, supportive services for check-ins, in-between doctor, telehealth visits, that thing. But I think there is a lot of interest now in developing a palliative care benefit. That would be a very nice complement to hospice, but also thinking about how can hospice change. What are the things that we need to really be thinking about now that a 40-years old hospice benefit is not the same group of patients that we saw 40 years ago, so another piece of the puzzle.

Connie Dahlin:

Judi, explain a little bit as I'm just trying to think through that. We have hospice benefit and we're thinking about a community-based palliative care benefit. Yeah, I could see that that would complement because it speaks to I think one of the things that I think about that I had to learn in my nursing history was this movement from the community to the hospital to make it easier. But that's not where people want to be and in fact with health equity and all that, it's really hard doing that of keeping people in their community.

I think it's been interesting though, because when I think about my own work, one of the things that I made a personal commitment to to say, I've done national stuff, I need to come back and do some work in my state, so I've been working on our palliative care council for our state and our network. We did a survey, and I would love to see what it was now because it's about four years old. We're trying to get a sense of what people even understood about community-based hospice and palliative care. The hospice part, they got. The palliative care part still, particularly even by hospices, was hard for them to understand, didn't understand that you still need to have 24 hour access if you're going to keep people out of the hospital, that the care was going to be a little bit different because people were still having their diabetes treated or their heart failure.

It's been interesting because I think, in my mind, what it showed me is that we make a lot of assumptions for the public about what they understand, but I still think that there's been a lot of, I guess, non-consensus opinion about what that is and what it takes and understanding, and you have done so much of this work that it's not going to be about one entity, it's got to be a collaborative effort, right?

Judi Lund Person:

Right, and it could be different entities providing the group of services. It could be, in one community, it's the hospice in collaboration with the home health agency and the assisted-living down the street. In another community, it could be somebody else leading the charge. I think it's both the challenge and the beauty of community-based palliative care program is it's bigger than hospice for sure. It may be some version of the same set of philosophically set of services, but definitely not the intensity. You're looking at the patient's primary care physician or primary care provider being absolutely the driver of a lot of the care and the supportive services being your wraparound to whatever care that patient is getting.

I think in a lot of ways it is the exciting new frontier, and hard to know what we'll see when we get to the end of it. I think, in some of the ways that the hospice benefit was tested in the demonstration project back in the 70s, this will be the same. It's like we'll have a group of hospices and a group of other types of providers who test this out and say, "How does this work? What are the things that patients really wanted?" We know from our experience with Medicare care choices model that what patients wanted the most was aid services, somebody to help them with personal care. This is not rocket science here. Occasional check-in from somebody who gives them a phone call or just checks in once a week or whatever, but support in the home, that's what everybody is wanting. As all of us get older, we also think about that for ourselves, and for our families. It's like, "Okay, how can I make sure that we keep mom at home as long as we possibly can?" That's, I think, for all of us that's, at the end, that's our goal.

Connie Dahlin:

It's an interesting part there too, right? Because what we have structured in our current healthcare system is we call that custodial care as if to devalue it, right?

Judi Lund Person:

Right, correct.

Connie Dahlin:

Yet, that is the very foundation of which we could be doing more appropriate services or preventing things because of that.

Judi Lund Person:

Right, right. I think it is your right, it's that combo. It's that providing services and preventing. If we're thinking about preventing, our goal is keeping that patient out of the hospital, keeping that patient out of the ER. How do we do that? We provide whatever care is needed, so that they can continue to manage at home.

Connie Dahlin:

Are there other things that you think about for our students? Because we think of them as being leaders and they're going to step into a new area, are there other things that you think that they should be thinking forward about what they need to step into?

Judi Lund Person:

For me, I think my biggest single worry on the palliative care front is overmedicalizing it. Really thinking as broadly as we can about what things ... If we keep the patient and their family at the core, at our center, I think for me that's always my driver. I have a mother and several friends who have had a hospice, and so I go there in my own mind to say, "Okay, what would mom want? What would be good for Bill, who for whom I was his neighbor and a hospice caregiver for a year?"

I think that's the biggest, I think, our challenge is, what is it? What services are offered? Are they the same no matter where you are in the country? Or is there some version of the same no matter where you are in the country? Then, how can we keep the patient and their family at the core, at the center of how we provide care? Those are my inflections, and certainly much broader than nurses and physicians and even social workers. Chaplains music therapy, art therapy, massage therapy, all the other things that a patient could possibly need.

Connie Dahlin:

Which I think, for me, broadens it from medical care to health care.

Judi Lund Person:

Absolutely.

Connie Dahlin:

Really thinking about that. Do you have any other advice for our students in terms of leadership or anything else?

Judi Lund Person:

I think find your own true north. Find the place where you go in your head to say what would this person I loved, what would they want? What is my belief system, so that I can always go there and say, "This will help me guide decisions I make for how this will work tomorrow, next year, whatever. I think that's the bottom line. For me, it's always how do we make sure that we're being true to the patients who need us?

Dr. Lynn McPherson:

The same thing with drugs.

Judi Lund Person:

Yeah, right.

Dr. Lynn McPherson:

Medication, will this help the patient or not? Get rid of it.

Judi Lund Person:

Exactly, exactly.

Connie Dahlin:

That has been wonderful. Lynn, do you have any other final questions or comments to make?

Dr. Lynn McPherson:

No, Judi is the queen as far as I'm concerned.

Connie Dahlin:

I think, Judi, what I can just say for our students is this is why it's really important to understand the history, because so much of it has guided and, whether you agreed with it or not or however you interpret it, we're still working within that confine, and so how do we change sometimes the framework, but also helping people sometimes look at different perspectives because we all are not going to agree all the time and what is grounding us. I think you remind us of the patient and the family and I would even add to that the community because the patient and family are a part of the community.

Judi Lund Person:

Of course.

Connie Dahlin:

Those are just really important because I think then when you wrap it around to that, it's not just about the clinical care, it's about understanding the community. It might be community development, it might be technology to help with that, it might be policies as you're saying that this demonstration project financing to think, "Okay, do we need to rethink about this?" Maybe another social context to help people remember that the one thing we have all in common is that we all are going to die. Whether we try to pretend not, it is one of those sobering moments that bringing us together.

Judi Lund Person:

Right, absolutely.

Connie Dahlin:

Judi, thank you so much for sharing this time with us and your insights. It's wonderful to walk through that timing with you, because I'm sure in some ways it feels like no time has passed and then you look and think, "wow! Here's where we've gone to."

Judi Lund Person:

Right, exactly.

Connie Dahlin:

Right.

Dr. Lynn McPherson:

Thank you so much.

Judi Lund Person:

It was my pleasure to be with you, and always it's my pleasure to talk about the past because I think it does inform our present and future.

Dr. Lynn McPherson:

Absolutely.

Judi Lund Person:

Delighted to be with you.

Dr. Lynn McPherson:

I'd like to thank our guest today and Connie Dahlin, for the continuing journey in our podcast series titled Founders, Leaders and Futurists in Palliative Care. I'd also like to thank you for listening to the Palliative Care Chat podcast. This is Dr. Lynn McPherson and this presentation, this copyright 2021 University of Maryland. For more information on our completely online Master of Science, PhD, and graduate certificate program in Palliative Care or for permission requests regarding this podcast, please visit graduate.uMaryland.edu/palliative. Thank you.