Dr. Lynn McPherson:

This is Dr. Lynn McPherson, and 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 of our great podcasts for The University of Maryland PhD program, and I'm Connie Dahlin. And I'm one of the faculty for the PhD program. And I'm joined today by Lynn MacPherson, Dr. Lynn McPherson, who is the executive director of The University of Maryland Palliative Care Program, both the master's and for the PhD. And we are so thrilled this evening to be joined by Dr. Declan Walsh, and Lynn tonight is going to take over as the primary person to ask the questions.

Dr. Lynn McPherson:

Thank you, Connie, and welcome Dr. Walsh. I am very, very, very excited to have Dr. Walsh with us. He probably doesn't even remember when years and years ago, Cleveland Clinic had a program where practitioners could apply to come spend a week there. And I was fortunate enough to be selected for a week. Unfortunately, I had triple pneumonia while I was there. So I can tell you, they have a lovely emergency room ethically Mayo Clinic. And then, I saw Dr. Walsh about two years ago in Berlin at the European Palliative Care Conference. And I shared with him that I did not realize that the unit he had at the Cleveland Clinic for Palliative Care was really the first in the country. So I was very excited to call him and ask him to help us with this.

So, Dr. Walsh is an internationally renowned physician, researcher, educator, administrator, and, I would say, author. I wrote a chapter for his book on palliative care. He did develop the very first palliative care program in the United States. This was at the Cleveland Clinic, of course. In 2017, he assumed the position as Editor-in-Chief of the BMJ Supportive & Palliative Care. So he's very prolific in publishing many, many awards, and currently, he's with the Levine Cancer Institute. So welcome, Dr. Walsh.

Dr. Declan Walsh:

Thanks very much. It's so great to be here.

Dr. Lynn McPherson:

Thank you. So let's just go way back there. So clearly, you are a mover shaker, troublemaker of the highest order, which I applaud tremendously. So tell us a little bit about how you decided to do this. How did you get this bird off the ground? So go back to when you have this cool idea to open up a palliative care inpatient center at Cleveland Clinic.

Dr. Declan Walsh:

Sure. Well, I had done a medical oncology fellowship at Memorial Sloan Kettering and was actually intending to stay on there. And through certain Dippity happened to get a call from the Cleveland Clinic, and they were interested in starting a quote say palliative care service. And it was really exactly what I wanted to do at that particular time. So I decided that I would move to Cleveland from New York. I

actually wasn't quite clear where Cleveland was. I knew it was some are up on the great lakes, but the geography was a bit hazy, but I was very impressed by the clinic's culture.

And they had identified a need based on a particular bad patient experience that had come to the attention of both the medical and the nursing staff within the Cleveland Clinic. And the Cleveland Clinic is an internationally known hospital and is famous for innovation in healthcare. And so I decided to go there and although I had very little idea what a palliative care service consisted of. And when I arrived there, I found that nobody in Cleveland Clinic either had much of an idea. So it was a blank canvas to some extent.

Dr. Lynn McPherson:

So, where did you get the information or the wherewithal to do this? Did you know Dr. Balfour Mount? How did you get the skinny on this?

Dr. Declan Walsh:

Sure. Well, I had worked at St. Christopher's in London as a research fellow. And so, I had some knowledge of hospice from the UK perspective. I had visited Dr. Mount's unit in Montreal because we were doing a collaborative research project during my tenure at St Christopher's. And as a consequence of that visited the unit. And I remember walking around thinking this is more hospice in the hospital. What I think we need is a more acute care type of palliative care in the hospital setting and kind of parked the thought. But certainly, that unit was a clear inspiration for the inpatient unit we later developed in Cleveland.

Dr. Lynn McPherson:

Wow. So I know you said that it was one particular event that set this all in motion at the Cleveland Clinic, but do you recall anything about the whole healthcare political environment at the time that made this right for the development?

Dr. Declan Walsh:

Well, I think there was a couple of important things as I look back on it. One was that the Cleveland Clinic, like the Mayo Clinic it's structured very similarly is physician-led. And I don't think that I could have done the things I did. And our group, later became a group, would have been able to do the things that we did in or in an organization that was not physician-led because we were able to talk to decision-makers who understood the clinical context of the problem. So that was one important aspect to helping us get it done.

A second thing that I found was that people had personal and family experiences and at that time, we were focused on cancer. All cancer diagnoses, cancer deaths in the family, and kind of intuitively knew that that had been a bad experience, but really weren't sure what to do about it. And the chief of staff at the Cleveland Clinic, unfortunately, his daughter, one of his children, his daughter had died six or seven years of age of leukemia. And it'd be a dreadful experience for the family. And he took me aside one day and said, "You're going to have a lot of opposition or words that effect, but I'll watch your back. So just go for it."

Dr. Lynn McPherson:

Wow. That's powerful. But I recall that when I was there, you had a fully developed multi-professional team. Absolutely. So were you able to do that right out of the gate? What obstacles did you face as you launched this despite physician support?

Dr. Declan Walsh:

Well, I did a lot of dumb things, so let's get that out of the way, first of all. But one of the smart things I did when I was negotiating for the job was to ask to have two specialists, nurses who would focus their cancer train cancer experience, who would focus on helping develop the program. And so the initial team was myself and two nurses. And that continued for probably two or three years before we started getting some other staff on board. And that was enormously important because of the nursing perspective that they brought because they had trained at the Cleveland Clinic. So they knew the culture. They knew the cast of characters. And so they were enormously helpful in both the clinical care, as well as some of the administrators and cultural and organizational issues that we had to face, which were considerable.

Dr. Lynn McPherson:

Mm-hmm (affirmative). Did you have any assistance from anyone aside from visiting Dr. Mount and your experience at St Christopher's? Did you have anyone to mentor you, or were you really kind of flying by the seat of your pants?

Dr. Declan Walsh:

There were individual people who were helpful in particular aspects of what I did. Some of the nursing leadership, there was a nursing leader called Meri Armour, who was at the Cleveland Clinic at the time. Mary is now in Vanderbilt. And has been for good number of years and people administration. There was nobody that I would call a mentor, but there were certainly people that were helpful in particular aspects of what we needed to do, whether it happened to be finance or data collection. But nobody that I could call it a mentor. No.

Dr. Lynn McPherson:

Now you didn't have that beautiful unit that I visited right out of the gate. Did you?

Dr. Declan Walsh:

No. That's opened in '98. The program started in August 1987, and our inpatient unit opened in 1994. So we were going quite a long time before that unit opened. That was as a result of a philanthropic grant that was matched by the administration at the time. And that was an interesting experience in itself.

Dr. Lynn McPherson:

I'll bet. I'll bet. So you function more as a consult service for the first eight to 10 years, is that correct?

Dr. Declan Walsh:

Yeah. When I was actually doing medical oncology, mostly for lung cancer, when I first went to the Cleveland Clinic. And the idea was that I would go and do the palliative care part-time. Now we got busier and busier, and I really lost interest in the chemotherapy side of things. There was some bit of friction about me getting out of the chemotherapy business, but we managed to work that out. And

then, probably about three or four years after I have been there, I managed to get out of that altogether and focused exclusively on palliative care activities at that point.

Dr. Lynn McPherson:

Good move. So did you ever despair getting sufficient referrals? Or what did you just hit the ground running and word spread? And that was that.

Dr. Declan Walsh:

It was a building process. There were many moments of despair over the years, but we focused very much on delivering an excellent clinical service number one. Number two, measuring what we did collecting data about what contributions we had made in terms of patient care. And so we did those two things right out of the gate, and between the three people in the team really kind of cranked it out over the first few years. And what happened essentially was that we started as an inpatient consultation service. Inpatient only.

And then as patients got discharged from the hospital, people would say, "Well, why aren't you following them after they go home?" So we started outpatient clinics, and then those patients would come back in the hospital, and people would say, "Well, I don't know what to do with these people. Why don't you guys follow them?" So then we started having our own if you like, dedicated inpatient service. It was all over the hospital. We put a pedometer on our first fellow. He did 10 miles a day around the hospital, and I did five.

Dr. Lynn McPherson:

Wow. I'm glad I don't work at Cleveland Clinic. So how long did it take for you to reach a tipping point where the clinical, economic, humanistic outcomes made it a moral imperative that this had to be a mainstream thing?

Dr. Declan Walsh:

Well, I think we certainly hit that when the inpatient unit opened because that gave us credibility, it gave us operational flexibility, and it gave us very importantly significant revenue streams generated by the inpatient work that was being done. We subsequently wait a minute, not subsequently. Prior to that, we had opened a hospice home care service, which was owned and managed by the Cleveland Clinic. And so, we ended up with a continuum of care for cancer patients that was able to deliver very effective services. So it was a respected program. And the clinic is one of those places where clinical practices that is the absolute priority, research and education very important. But if you didn't deliver on excellent clinical care, you were not going to prosper in that setting. And I think that that was a good commitment we made right out of the box. But it was extremely challenging in terms of the patient population and the if you like, unlimited demands on our time.

Dr. Lynn McPherson:

Mm-hmm (affirmative). So as you look back 33, 34 years, if you had to do over what would you do differently if anything?

Dr. Declan Walsh:

I would have asked for more resources out of the gate, that was a big mistake, but I was naive. I think that I would have been wiser to perhaps go more slowly and some of the program development. It

certainly had a fairly high cost personally, we basically introduced a new service or program about every 18 months. So it was pretty frenetic over a period of about 5, 6, 7 years. But it was kind of one of those situations where I wasn't. As the movie says, failure is not an option, and we certainly could have failed.

And there were many moments when we told we were going to because there was some hostility to the idea amongst some physicians and others. Administrators worried about where are all these various sick cancer patients coming from? Seem to be unable to understand that we already had the very sick cancer patients. They were worried about was you're going to bring in a lot of very sick cancer patients.That we were inventing a new patient population and didn't understand that these people were already there, we just needed to improve the care of the patients that we already had.

Dr. Lynn McPherson:

If we went back 33, 34 years and said, what do you think palliative care will look like in 2021? Would what we have today have been what you would have predicted? How is it different from what you would have said at that point?

Dr. Declan Walsh:

Well, our focus at that time was on the cancer population and that was my own particular interest. In fact, of course, still is that we did, we did broaden our remit in later years to include intensive care unit consultations, cardiology, and so on. And that has continued at the Cleveland Clinic to this day. And so I think I would not have perhaps anticipated the wider commitment to the other patient populations outside of cancer that, that has developed so effectively and so rapidly. And also probably the growth and the number of programs has been just extraordinary looking back on it now.

But we were in the moment it was so all-consuming to do what we were doing that for example, I didn't travel very much or go to meetings and stuff like that because we were so busy simply trying to keep our nose above water and to demonstrate that the program and the services we provided were meaningful and that this was something that was worth supporting. And we were very fortunate, as I mentioned, there were several senior physician leaders who really got behind us and I'm sure they took quite a lot of heat about it, rather from some of their colleagues at the time who must have thought that they had lost their minds supporting this crazy guy Walsh.

Dr. Lynn McPherson:

Well, I don't think that was the case. I mean, clearly, you've shown indisputably, just the idea of the continuum of care that you developed back then, and we still can't pull it off in a lot of places today. It's just amazing, I think. You must've served as a model of excellence for many other institutions, but a lot of people come and visit you and ask how you did this and how can we do it?

Dr. Declan Walsh:

Sure. We had visitors from all over and we were designated by the WHO as a demonstration project and some other things like that. So yeah, we had people from all over the country and all over the world. In fact, that program that you participated in, I think we had people from every state in the union come to visit us. And that was fantastic. I personally really enjoyed meeting people from multiple disciplines, as well as from so many different geographical areas across the US so that was a fantastic experience.

Dr. Lynn McPherson:

It was lovely. I know we were also impressed with the unit. We were all picking out our individual rooms because it was so beautiful. Where do you think this train is headed? What do you see when your crystal ball for the future of hospice and palliative care?

Dr. Declan Walsh:

Well, I personally feel that the way the hospice was introduced to the United States was unfortunate. And I wrote an article about it some years ago, it was sort of critiquing it. I think it is. If you compare that experience to the European experience, it's a very different concept in the United States and people in the US and people in Europe often don't understand how different posthumous is operationally and clinically between the two parts of the world. So I don't have much contact now with hospice. I was the hospice medical director and was very involved with that. But I really wished that hospice was an additive benefit to traditional clinical care. I really don't like the idea of people being forced to make that choice between hospice. It just seems it various from being cruel to being unnecessary. So I can't think of a good thing just to say about actually. So I would like to see that change, and I know many people in the field would share that sentiment.

Dr. Lynn McPherson:

We had a discussion last night with Steve Connor who was part of creating the benefit and his sentiment was somewhat similar of saying that they had to make a deal with the devil. That if they didn't do something, the outcome would have been worse. And so sort of the whole part about making a compromise, and yet here we are and people have been so terrified of touching it, given the political realm. And I think in my mind even like around the end of 2008, 2009, when people were wanting to do that, once the whole advanced care planning became death panels, people sort of were like, "Okay, we're not going to go into this because this is not that." Although I would say, I worry we could be going into a conservative wave again, that has implications.

But I think that's one of the things that I'm really intrigued about because I think when your comment about what hospice looks like in Europe versus what it looks like here. Here it is, we make people make the difficult choice and there's still inequities about it because you have this federal benefit. If you're not old enough, you don't get it, or maybe if you have certain conditions. If you have Medicaid, it's so variable from state to state. And we know in the South it's pretty non-existent.

And then if you don't have insurance, for all the right reasons, you have some hospices that can do, whatever they call it, subsidized care, charity care, whatever. And then you have others that can't. And so then you kind of have a lot of people who are left with nothing. But then they get upset with palliative care. It's a very interesting part because I think it's also, that's part of the reason of this I'm going to say nicely friction between hospice and palliative care. Is that kind of your thoughts as well? Kind of that?

Dr. Declan Walsh:

I think so. I think that it was just unfortunate. And I totally understand that people at the time who were involved with setting it up, wanted to get something done, but the trouble is this got set in stone, it's in the permafrost. And I think that the experience since suggest that it's time for a change. And in fact, we're well beyond the time for a change in my view, and I don't underestimate the difficulties of that. And the complexities of dealing with the federal bureaucracy and so on, or just extraordinary political ramifications that you've mentioned. But I think it's time for a change that will be my feeling.

Dr. Lynn McPherson:

So that didn't work. What would you have liked to have seen? Or where would you like us to go if you had a complete blank slate?

Dr. Declan Walsh:

I think it should be as you said, as a benefit that irrespective in the sense of your prognosis or your particular illness. That if you are frail, you need help, you have a life-threatening illness that type of backup and support should be available to you and your family. The hospice is trying to sort of deliver care and their budget for I'm sure this figures out a date, but their budget for medications is $10 a day for patients. It's nuts and that the constant patients getting referred three days before they die. It's not the intent of what, excuse me, of what Cicely Saunders originally envisaged. It just is not. And it's a different society and different cultures. And the US is a much more complicated society than many European countries are.

We have to be sensitive to those issues, but I think it needs some adjustment, and the friction between the palliatives the hospice folks is a continuing feature of that, which has been very unfortunate. And so the question then arises to, what's going to happen with palliative medicine, palliative care as a philosophy and as a discipline. And I like to refer to palliative care as a philosophy and palliative medicine as the discipline. That's how I like to sort of construct it. But for example, suggestions have been made that palliative medicine takes on everybody with Alzheimer's well okay, that's fine, but where is the workforce? Where are the trainees? Is this really practical?

So I think we need to revisit in a very clear-eyed way, the business models around how palliative medicine services are constructed of what they can realistically accomplish. And I think there's been a lot of loose thinking about that, put it that way. And it's a young discipline and it's still in evolution. And it's one thing that's key in any kind of program development is to never promise anything that you can't deliver on. And that was one of the absolute principles on which we worked, that we would not do anything unless we knew we were going to be successful. So I think there've been some loose talk, put it that way about what palliative care can realistically deliver given his current stage of development and given the workforce that's available. Can I just interject for a moment? My battery's just running a little bit low. I just noticed, so I'm just going to take a moment to plugin. So we don't want to run out of juice here.

Dr. Lynn McPherson:

So for all of our students in our listeners, just in case, you're wondering where Dr. Walsh got his adorable accent, it's because he's from Ireland. Beautiful green, green grass of Ireland. So why don't we wrap things up with a couple of things? Number one, Dr. Walsh, what is your very best advice for the graduates of this PhD program? What do you got for them?

Dr. Declan Walsh:

Well, I think the field is a challenging and stressful endeavor. And it's very important to have a plan of work and of life that will allow you to continue to be successful in the long term. And I think that my experience has been that there are many people who are motivated to go into this area, but they sometimes have not thought through the realities of, and I'm talking about patient care not talking about research or education. The realities of confronting the multi-system disease, the complexity, and acuity of these illnesses in confronting those every day. If you're in an active clinical practice in this setting, there's no light relief. If you're doing pulmonary medicine you can have your patients who have chronic asthma and they're on maintenance therapy and you check in on them every six months and make sure that they're doing okay.

But if you're an active palliative medicine practice, you're confronting a rapid turnover of patients, multi-system disease, their families are often distraught. They've got socioeconomic problems that are coming to bear their communication challenges, et cetera, et cetera. It's an enormous clinical challenge. And I salute anybody who's going to go in into the field. But it is important that people are clear-eyed about what they're getting into. And I do worry a bit if you think about people that influenced people like myself, and you mentioned Balfour Mount or [inaudible 00:29:53] and Cicely, Saunders, or other people like that. They all had a life, both personal and professional before they got into this.

We're now taking on just talking from the physician perspective, physicians straight out of their residency, putting them into a palliative medicine fellowship, and then saying, "You're now going to spend the next whatever 45 or 50 years of your life doing this." And I wonder sometimes whether that's wise and the risk of burnout and disillusionment and so on are significant. And again, speaking, just from the physician perspective, many of the stresses and strains that have come to bear on physicians, particularly in recent years, with the advent of the electronic medical record and other major irritants life that has increased stress and burnout on the physician population in general.

And I do worry about our graduates and how their best looked after. Should they be doing palliative medicine 80% of the time and the other 20% they do something else that is going to refresh them can still make them productive physicians and so on. And of course, the same issues apply to nurses and others who are in the front line in that regard. Whether they're working in a hospice unit or a palliative medicine unit or their clinical nurse specialist in the area you've got these great people. How do we keep them? And how do we nurture them? I think is something that is very important. I congratulate you on the PhD. I think people who are well-educated and well-prepared and are much more likely to be successful and strong support systems and strong educational programs build that kind of professional confidence that will reduce. It won't eliminate, but it will reduce or minimize some of the stress and strain that people experience. But it's inherent to the field and it will never go away.

Dr. Lynn McPherson:

Yeah. To have you left, would you do it again? Or would you have stayed on the chemo wagon?

Dr. Declan Walsh:

The chemo wagon lost its charm for me pretty quickly. I was never really that interested in it. I just did it because at the time there was no palliative medicine. When I was working at St. Christopher's, I became more and more interested in the problems of patients with advanced cancer, but there was nowhere that you could specialize in that. So I thought the best thing to do is to train as an oncologist so I at least be able to make a living and I would have some professional specialist qualifications, but my intent was always to focus on the needs of patients with advanced cancer.

Dr. Lynn McPherson:

Well, it's certainly been a boon to our whole field to have you on this side of the fence, Connie, anything else you want to ask Dr. Walsh?

Connie Dahlin:

I guess there's just in the sense of kind of just touched on it and I feel like we have to ask you. You've seen a lot over your career and just moving into the oncology part, certainly the AIDS crisis and then COVID, I'm just sort of curious if that also has changed your perspective of palliative care at all? Or just reinforced your thoughts or?

Dr. Declan Walsh:

I think it's interesting, you say that. Managing this BMJ journal now we've had a lot of contributions about the interface between the pandemic and various palliative medicine in the hospice services and programs around the world. And I think it's just broad integrator clarity, two things. One is that it's important that there are these structured palliatives of medicine services that can come into the ICU or whatever or the emergency room, wherever the patient might be, and bring that expertise to bear. And so that's one thing. It's quite clear that every hospital, every major cancer center should, and I don't mean like we have access to palliative care services, that's like in U.S. News & World Report. It's a wishy-washy thing that we may have, maybe we don't have it, but at least we can say that we kind of have it, but I'm talking about you really go to something that's a substantive program.

And then the second thing is that it's not sufficient to have that because of the enormous number of patients who need these services programs and help. And so educating our colleagues in nursing and rehabilitation and in various medical specialties and particularly in some obvious specialties like cancer care and cardiology, and so on. Educating them about the principles and practice of palliative care as part of their education as specialists is absolutely critical. And we have to get these ideas into specialty training. And just to give you one example in medical oncology training, as far as I'm aware, there is next to zero education for physicians about malnutrition in cancer care. But despite the fact that nearly every cancer patient suffers from malnutrition, at some point during their illness. And why is that? It doesn't make any sense.

Dr. Lynn McPherson:

And you can make the same comment about the inclusion of palliative care education and every professional curriculum, especially primary palliative care skills, every doctor, nurse pharmacist, social work, chaplain, all should have some exposure.

Dr. Declan Walsh:

Yeah. Absolutely. Right on the money. Because there will never be enough quote specialist to deal with all of the issues. In the United States, it's just unfortunate that that primary care has not been developed as well as it has in some other countries. When I grew up in Ireland, the understanding was your local general practitioner would take care of many of these issues and they did and did a very good job about it.

Connie Dahlin:

After you left Ireland.

Dr. Declan Walsh:

Well, that's a longer story.

Dr. Lynn McPherson:

[inaudible 00:36:54]. Any last thoughts, Dr. Walsh, as we wrap up?

Dr. Declan Walsh:

The only other thing I would say is that as we developed this, we tried to, and in Cleveland, we tried to take a businesslike approach to it. For your students, I mean, let's not be starry-eyed about this. At the end of the day, we have to deliver high-quality clinical services. They have to be at least economically

self-sustaining. And so a businesslike approach to develop into these programs and services is very important. I mean, just because we think something is great doesn't mean that everybody else has to think it's great. And sometimes there's a naivety there around the realities of medical practice and hospital administration. And I think that has contributed somewhat to the lack of integration of some of the services and the lack of continuity of services and programs that you referenced earlier on.

Dr. Lynn McPherson:

All excellent points. Dr. Walsh, thank you so much. Thank you for your career-long contributions to our field. We wouldn't be where we are today if it weren't for people like you. And thank you so much.

Dr. Declan Walsh:

My pleasure. Thanks for having me on.

Connie Dahlin:

Thank 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 chat presentation is 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.