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 [Dolland 00:00:25] to support course work in the PhD in Palliative Care offered by the University of Maryland Baltimore.

Hi this is Dr. Lynn McPherson, the program director of the online graduate certificate, Master of Science and PhD in Palliative Care, and we're recording this podcast series for use not only in our PhD program, but as part of our Palliative Care Chat podcast series. I'm here with Connie [Dolland 00:00:49], who is faculty in both a masters and a PhD, and we are so excited about our guest today. I am just over the moon excited. This is one of my moon shot interviews I would say. I thought what are the chances? But being just a lovely person, Professor Higginson agreed to do this. So we're very excited.

She is a physician. She is currently professor of palliative care and policy, and Vice Dean of research in the Florence Nightingale Faculty of Nursing, Midwifery, and Palliative Care, and, and this really gets me going here, Director of the Cicely Saunders Institute at King's College in London. She absolutely has had an international impact of the development of hospice and palliative care. I have heard her name my entire career and I am fan-girling on Dr. Higginson here. So Connie I'm going to turn it over to you.

Connie:

So very excited with this interview and I think of your... Dr. Higginson, I would love for you to talk about hospice development in England and your involvement and then it coming to America and your thoughts about that.

Speaker 3:

Okay, well first of all. Thank you so much for inviting me to be on this interview, and I'm just going to slightly adjust my camera because it's kind of wiggling around a little bit, so it doesn't fall over. But to say thank you very much to the interview and its a pleasure to be with you and your colleagues and your students and faculty and I hope its helpful.

So let's go back a little while. I trained in medicine. I always felt slightly dissatisfied with medicine. When I'd seen it handled, I wasn't that keen on it. I stumbled over palliative care by accident. I was interested in public health medicine. I was training in public health medicine and I saw a job advertised that was half palliative care, and half public health medicine. And the palliative care was working closely with radiotherapy and oncology at University College Hospital in London. I was a bit put off by palliative care, but I went and found a book in the library because I was a curious sort of soul and I read a book by one Cicely Saunders called Terminal Care in Cancer. I thought, "My goodness. This is what I've been missing in medicine." So I went along and I met the Bloomsbury Palliative Care team, which was in a little, very lowly office at the back of one of the slightly disused hospitals, you might say, which is where palliative care teams often are, were in those days especially.

When I met the team I thought, "Wow this is fantastic because first of all they're putting the person first and that's always what I was looking for in medicine. Secondly they're concerned about everything, the body and the mind together. And thirdly, it's more equal between nurses and physicians and others. And everybody has an important perspective in the team. And it's more holistic." And I just thought, "Gosh, okay I'll do this job. I think this is something I want to learn about." So I did the job and while I did that job I met a very influential person of mine called James Hanratty, who used to be the

medial director of St. Joseph's Hospital in London. He had worked very closely with Cecily Saunders and he had a brilliant knack of looking for people who might care about palliative care and attracting them to it.

He came up to me and he said, "Well, it's already [inaudible 00:04:43] you're doing what you're doing and it's very important and very interesting, but you better come and work in a hospice. So come and work for me in St. Joseph's Hospice and we'll really tell you what it's about. Why don't you? Just come and work for me for a bit." So I did. I went and worked for him and I was a little nervous. I was thinking I'd have to become very religious or all sorts of other things, and I didn't. I went in St. Joseph's Hospice in the inpatient unit and also working with the community unit and I learned such a lot and it was great fun.

So I just decided that this was something that I really cared about. Those days it wasn't easy to get a proper training in medicine because although palliative medicine had been recognized, it was recognized as a specialty within medicine in the UK in 1987 at the same time as the year the Journal in Palliative Medicine was launched. There weren't really training programs. So even though it was at that time officially a specialty, what was happening is that people who were already working in hospices were being recognized in that and you couldn't actually go and get a proper training. There wasn't a four year training program as there is now. So you had to make up your own training program.

So I kind of made up my own training program then working back with the Bloomsbury Palliative Care Team and in the community and also working in public health medicine. So I got a jewel accreditation in both public health medicine and palliative medicine by doing a slightly extended training period, and also by doing a PhD. I decided then that I was very interested in trying to get more knowledge for palliative care, because I could see that we were struggling. So that's how I started. I worked later also St. Christopher's Hospice, so I worked there with Cicely for a period. Then working with Cicely actually, we had the idea to create an institute in Cicely's name. My vision for that is that palliative care needed to move beyond a single individual, being the important person and the founder, couldn't rely on one person anymore. What we needed to do was to create a whole caddock of people who would move in this and what better than to use Cicely's name for that and Cicely was all up for that. She thought it was a good idea.

She'd initially been a little cautious, but we persuaded her that that was a good thing to do. So it was her blessing that we started work and her engagement and enthusiasm and hard work. And I had the privilege of working alongside Cicely for many years and I learned a great deal from her. Then later on having spent early time in my career, spending many years working alongside James Hanratty, who incidentally told me and I believe him, that he was the one who introduced the battery operated syringe driver to community care at St Christopher's Hospice in Pain Management, and I believe him.

I also had the privilege in working alongside Victoria [Ventifrida 00:08:08] in Italy who was the founder of the EAPC really. He and I worked together on quite a lot of European guidance and so on. Again, it was a great privilege of working alongside these huge founders and laterally with Mary Banes who did so much on home care at St. Christopher's Hospice. She gave us a great deal of support as we first formed the Cicely Saunders Institute and came to all of our seminars and lectures and told me things that I should and shouldn't be doing, which was great because it was like having Cicely tell me what I should and shouldn't be doing, which was just fantastic.

So I think I've been very lucky to have worked with some amazing individuals and some amazing women who've had real leadership in this field and I've learned a lot from them.

Dr. Lynn McPherson:

Wow. Can I interject a question here? Was it your vision right from the start that the institute would be a degree granting institution?

Speaker 3:

So my view was yes, I think is the short answer. My view was that it was time for hospice to move back into university and hospital trust. If you look at the picture behind me, this is actually Kings College Hospital in London and immediately behind my head is the accident emergency department, and if I move around, you can probably see the ambulance is lined up outside the building.

Down in the bottom corner, just underneath where Kings College London is, is where the Cicely Saunders Institute is located. If you move across off the screen to your left, then what you can see there is where the university buildings would be. So the Cicely Saunders Institute actually on this campus is actually at the elbow point, if you know what I mean, of hospital and university and there we are. I think that's brilliant for us. So we have clinical and academic. We have research education and clinical services. So we have the clinical palliative care team there and one of the things when I moved into my role at Kings, which was a joint academic and clinical role, is that there was no clinical palliative care service either in the hospital. So one of the things I did was about not only building up an academic department, but building up a clinical service that we could establish, because I really didn't want to be heading a brilliant academic service with no clinical activity going on.

Working very closely with our local hospices including St. Christopher's and Trinity to the South, and St. Joseph's to the Northeast. The idea that it would be degree awarding then was part of that, because I felt that it was very difficult for independent hospices on their own to undertake research and to do degrees. And in a way, for palliative care to be considered properly, it needed to fit within that university structure. So my first target when I was appointed as professor at Kings, before we'd even planned the institute really, was to create a masters program.

Dr. Lynn McPherson:

Okay.

Speaker 3:

And we did that even before we built the institute. To be honest it was always my vision to create an institute. Although originally we didn't plan a physical building, but nobody would give us money for the original plan. So we honed them down to a physical building. We wanted a network initially, but nobody would give us money for a network, so we created a physical building in the end. We were helped actually by Help Hospices to pump prime a masters program in palliative care and it was really due to their generous support that we were able to create a masters program.

Dr. Lynn McPherson:

When did that start, your masters program?

Speaker 3:

That started in 1997.

Dr. Lynn McPherson:

Wow. That's amazing. That's freaking amazing. Wow.

Connie:

I think also, just thinking the evolution of where you all went pretty quickly to education and recognizing how it needed to be part of the university. I think one of the things we heard from Professor Clark was, this interesting dilemma of where hospices are now because they were charity driven and so what some of that is. So you're speaking to the need to have this palliative care institute to help keep the practice going. But I think the other part of that in my mind is, when we still think forward about the specialty, how do we keep moving forward in understanding that it is a specialty practice? Because I think there's this part of trying to integrate it as all care, but then knowing it's a specialty care and that we're wanting to have people with masters and PhD's, so just that sense of moving forward to that duality. Any thoughts about that?

Speaker 3:

First of all I should correct myself, I think it was actually 1998 when we started it. We started planning in 1997, but we didn't get it approved. So I think it was 1998 when we first had it. And it's great that we're in touch with many alumni who came off the masters program.

So I think your question is a really interesting one about the balance. I think that in a way, for me, it's the needs of patients and families that always come first. The boundaries of specialty versus non-specialty is a little bit drawn by the way in which we organize how we organize health care and our folk in health care. What my view is though, unless you have expertise, and you have people who dedicate time and energy to it, it doesn't move forward. We need to move forward because there's so many things that we don't do well enough for our patients and families.

We have symptoms that we don't manage that well and could do more for. We have, even in pain, which is our most researched symptom and our most able managed symptom, I would say. Even in that, we have the challenge of people with neuropathic pain, people who don't respond very well to opioids, the challenge of opioid switching, et cetera. Even in that we have challenges. Then if you move into symptoms that I'm interested in like breathlessness, there's even less research. But we've got huge opportunities in breathlessness because we've got a wonderful [inaudible 00:15:35] of non-pharmacological treatments.

Then you think of the mind, body interface and you think of, how do complicated things like advanced care planning work on an individual basis across different cultures and different ways of being. You can't get them to a very simplified system of just applying things without expertise. If you think of an outcome measurements. So how do we know we're doing a good job? The standard outcome measures never worked for us, and unless we had a field of people who were working on this and who were thinking about it and who understood palliative care, one of my passions, we'd still be in the dark ages of trying to measure everything with mortality, which is a very crude indicator for palliative care and doesn't really help us out that much because it's the universal thing and we're interested much more in quality of life. But the standard quality of life developed for the chemotherapy trials and studies, doesn't necessarily apply to our field because many of those measures are very focused on the side effects of chemotherapy drugs and on functional status.

So unless you have a specialism and an interest in that, and people who develop specialist knowledge because they see these problems all the time, you will not be able to deal with the complex cases. Now where the boundaries lie between generalism and specialism I think is a moot point. And in some ways what I'd say is, "Well what do the patients feel that they want? What do they want in terms of how expert a person is? Why can't we have more patient determination over what they see?"

Because in many ways palliatives are actually often very good generalists, in general nursing, general

medicine, general care, as well as their specialists knowledge of advanced illness and complex symptom management.

In some ways, they can work in partnership. So you wouldn't in maternal care start having these arguments, so why are we doing it in palliative care?

Connie:

That's a really interesting thought. I wonder if it's a little bit of, does it have to do with our payment system? Because as you know in the United States we, for better or for worse, we've sort of heard it was a compact with the devil, of the hospice Medicare benefit and that has really been a focus about why we do things. If this distinction between hospice and palliative care, of this whole payment. Even to your point about outcomes of what are the appropriate outcomes for patients with serious illness knowing that everybody will probably have one, because that's how they'll die. But also the intensity that's needed for it. If thinking about how do we accomplish that. So I wonder if there's certain areas that you feel like we do need to focus more specifically in outcomes or in understanding what it is we do or the work that we do.

Speaker 3:

Oh, well I do feel we need to look at that. The problem with palliative care and hospice care... I have to apologize to you, because I'm British, so in the British context and I think in many other countries, there is not the distinction that you would see in America between hospice and palliative care. So I have learned over the years to speak your language, so I'll try to put my comments into your language in a way.

What I would say is that, in the US you have this separation, which is written by the funding mechanisms, there's no doubt about that, and the structures of health care that you have. All health care systems are written by the funding mechanisms, its not a judgment, it's just a fact. Which means that what hospice is in the US and what hospice is in the UK is not exactly the same thing. I think what palliative care is in the US though, is more similar to what palliative care and what hospice is in the UK. But the difference in the UK is that hospice often refers to voluntary managed units, although we do have NHS managed units that operate with a specific philosophy, which is very similar to the US philosophy.

And we can all talk the same language to each other, because we all are driven by the same sorts of principals, but we do have slightly different nuances in ways in which we organize things. There is a slightly different emphasis. So UK hospice has more medical input, I would say in general, than US hospice, and we do treatments different some of which is driven by our funding mechanisms. So it may have changed now, but I've been shocked at in the US if I see people with bone metastases, and in the UK you would give them a single shot of radiotherapy, because we know that that's an effective as multiple shots and nobody would bat an eyelid and they'd go from an inpatient hospice to go and get it and come back and they wouldn't need to go again. Whereas in the US I think they still quite often have to have multiple shots. We would use bisphosphonates as routine for the prevention of bone metastases, there's very good evidence for that, there's [inaudible 00:21:19] and review level evidence.

We wouldn't be saying, "Well it's not within our hospice budget to do that because we have the GP budgets to do that." You wouldn't do that. But if you go to on call out of hours care, I've been so impressed in the US, that you have a single call system and there isn't a business that a patient can not have a home care nurse, or a home help person, it comes from one agency. Whereas in the UK, when you're out of hours, you're scrabbling around a whole bunch of different persons and peoples to try and

get somebody to sit with the patient because the fragmentation of these different systems working together, that you have in a way better in the US with the single payment system, than you have in the UK with multiple different agencies looking after people in the home.

We're trying to get around that locally with a pal at home service, in South London, run by a hospital just up the road from us guys in St. Thomas'. Where they have a pal at home service, and home care services like St. Christopher's also try and get round that with their more comprehensive offerings. But it's where I might admire the US system because you have it all in one lump. So I've seen the pros and cons across it in all ways. I might have drifted slightly off- [crosstalk 00:22:49]

Connie:

No, I think you answered exactly. I think that's the interesting part because I do feel like, knowing that... I was one of the early people who did Michael Glasgow's course on visiting England, so really got a big vision of that, and I know you were good friends with him. I think that's the other piece too, that when in England you have hospice in palliative care and its seen as a specialty and you need to know a lot. And I think what's happened here is palliative care is academic, hospice is not. We have people going into hospice with no background, who get very little training to do the hospice part. So then you also see a disparity of some of the decision making. It becomes this one stop, here's what you do because people are dying, rather than thinking about what their diagnosis is and what some of their family is.

So it's an interesting place about thinking about what your even expectations are for decision making that goes on in between the two. So I think that's important. I think for our students to be thinking in the future of elevating and keeping it across, and I think the other part of these international expectations, if you will, of palliative care being both specialist and generalizable to our colleagues.

Speaker 3:

I don't see why we have such difficult discussions about it in a way. I can understand in one way why they're difficult, but you don't say, "Well we don't need clinicians who are expert in diabetes," just because it's actually a core part of a lot of doctors and nurses do. We still say, "Well we need people who have expertise in it." We don't say, "Oh well we don't need people who have expertise in birth, just because we have a lot of people and we have a basic knowledge in quite a lot of it." The idea of maternal care, which is shared, is not an inappropriate idea. I think we in a way, in palliative care, we should stop apologizing for it.

I personally think, and I've come to this view over the years, that it was very helpful in the UK for my predecessors, and I'd lay a great tribute to experts like Baroness and Laura Finlay, and if you could get her to talk to you, and you should try because I think she would, then that would be fantastic. But pioneers like her creating a medical specialty, because she was one of the pioneers that made it happen. She came in to palliative care from a general practice background, which I do feel was very important thing, because the community angle is important. There was a period in the UK where it did drift a little bit too hospital-y in my view, but its coming back to the community and anyone training now in palliative medicine and medical training, has to do a period of time in the community as well as in the hospitals.

I think it was a very good move for the UK that there was a specialism created. I think the important thing was to offer a number of routes through it, because it's only by having that can you get physicians wanting to work in the area and to develop in it and so on. I think that the specialism for nursing and for allied health professionals has come behind a little more slowly. You'd have to talk to your nurses and allied health professionals about how clear that training is but we certainly have

leadership within those fields of people who are trying to create and insure that there is an appropriate training and development and so on in those areas, which I think is also good.

Then you have the health service of researchers and the applied health researchers who have also now developed an expertise in this and goodness, thank goodness we have also some health economists who have an interest and an expertise in this field and that's so helpful for us because the standard health economic measures like Qualies and the Standard Health Status Measures like EQ5D are very problematic in our field. If you just applied them un-robustly to what we do, it would just look like what we do is a waste of economy for health care, at least in the British system. I know in the American system you don't use Qualies, [inaudible 00:27:39].

We have economists and we have people who handle big data and trialist's even now. So at Kings now, I'm very proud that I have created a new clinical trials unit called the Nightingale Saunders Unit, honoring Florence Nightingale who after all was both a mathematician and a nurse and Cicely Saunders who was a nurse, a physician, and a social worker in one. So these multi-professional people. And it's the Nightingale Saunders Complex Clinical Trials with trialist's and statisticians interested in how you do the trials that relate to our sorts of populations across palliative care and also over complex illnesses and nursing and midwifery.

Connie:

[inaudible 00:28:34] You've been so involved in all of that and the European part, what do you think are some of the challenges both internationally for palliative care as we move to a lot of developing countries? What are some of the areas we just haven't focused on yet and probably need to start focusing on a bit? You've mentioned a little bit with the economics and some of the clinical trials, but in terms of thinking of this, what are some of your thoughts on that?

Speaker 3:

Yeah. Well I think one of the important things that palliative care has done is its embraced the world beyond cancer. And the next step in that is to embrace the multi morbidity, be that in children or adults and we should remember that health in children is very important. So my view is always that we should respond to what people need in society and also what health care systems and practitioners need. Where are we going with health care? We've seen a pandemic, just recently with a need for people who have been very ill and dying in a very different way in people dying with COVID. We may see issues of long COVID and multi morbidity, which may come into the fall in the future.

So we really do need to be able to respond and use our expertise in complex serious and progressive illnesses and holistic care for people and their families for these other conditions. We're a bit thin on the ground to be able to do that well, but we have to try and we have to look to the resources to do that.

When you look globally if you look at the projections of the global need and there's a good paper published by Katherine Sleeman on this in the [inaudible 00:30:38] Global Health. You can see a massive increase in the need for palliative care if you look at the population projections, and we are woefully short. So a big challenge for us is to respond to the great need, which we're not even meeting now and which is going to increase in the future. I do think that that's where institutes such as our own have a role in highlighting that this gap exists, because without our work nobody would know that the gap was there. Also, highlighting and finding effective and cost effective solutions. Ways in which you can do things effectively, taking advantage of technology, remote support, consultation, ways to help people develop their own ability to self manage symptoms.

In some ways the boundaries, in my view, between the treatments that we used to consider as curaty, but are probably not and are potentially life extending or possibly life enhancing in palliative, those boundaries in the new or multi morbid populations that is what most people are, is an important thing to think about how we adjust our services and our interventions to help there. I do see a big role for greater integration of rehabilitation within palliative care. Not rehabilitation in the old definition of the word, IE rehabilitation to restore function back to normal, because in this context that's not practical. But rehabilitation to prevent or to slow deterioration in functioning for people. So the people are able to do as much as possible.

So there's some lovely simple research, for example, that shows that in people with breathlessness and chronic obstructive pulmonary disease and heart disease, if you teach people to pace themselves so they don't rush and they go more slowly, they actually start to walk farther and get fitter. It's such a simple intervention isn't it? It's like the work that Eduardo Barrera did, that actually if you just sit down with a patient, even if you spend exactly the same amount of time with them, they're more satisfied with what you do. I think that these, what I would call frugal innovations and appropriate interventions, is where palliative care is always been and it's why we need the leadership in the field.

One of the pieces of work that we've done that will be coming out in press, I think it might even be out, it's about some of the frugal innovations that were generated during the COVID pandemic where services were very stretched. Actually many more resource poor countries actually have an extremely good ability at seeking frugal innovations. My colleague for example, Richard Harding, whose leading a lot of the global work, is very interested and he's kind of South North learning, so we learn from places that are doing this. We have a massive, massive challenge ahead. We have to work together. We have to support each other and we have to grow capacity to be able to respond to it. But I think the more that we can work together, and I think that's one of the things I love about the people who work in palliative and hospice care is that they do work together. The more that we can work together to drive this and accept that there are a number of arms of work that need to be done, the better it will be.

Dr. Lynn McPherson:

So you have a 25th anniversary coming up for your institute. Yes?

Speaker 3:

We do actually. Yeah. Well we were going to have a 10th anniversary coming up for the institute itself, because the institute formally opened in 2010. Her Royal Highness Princess Anne opened the physical building. So the year 2020 was going to be a big year of celebrations as it was going to be the year of the nurse as well, and both of those completely got destroyed by COVID. But actually your point about 25 years is a nice one, so I'm going to borrow that, because I hadn't really thought about that. So thank you very much.

Dr. Lynn McPherson:

Absolutely. I was doing the math. I was thinking, "Well maybe by the 25th anniversary COVID will be gone and I can go to London and visit Dr. Higginson." That would be amazing wouldn't it?

Speaker 3:

Well that would be very nice. I'd like that.

Dr. Lynn McPherson:

Tell me about your PhD program. Obviously we're very interested in the amazing success you've had. Our programs 20 minutes old, so we're like The Little Engine That Could, compared to you. So please tell me a little bit about that.

Speaker 3:

So it came out of the MSC program. So it was always the plan that the MSC program would lead to enabling people to go on and do PhD's and we have had a few people, including Richard Harding, who was one of our first PhD students, who actually didn't do the MSC because he already had one, but went straight into a PhD program. But we've got it more clearly aligned now. So it works within Kings College London. It's a specific program where we take people with interests in palliative care. We have a number of topics that we're particularly interested in recruiting people on the website. We're also very interested in working with people to get fellowships. Individuals who come on the program have the opportunity to attend a couple of the modules on the MSC program if they haven't done the program already. And we're very interested in also people who've done our MSC program going on to new PhD's.

We take people full time and part time. And we take people from across the world. And we've now developed, and they have, the PhD students have their own middle peer review group, where they meet together and discuss things and agree things and obviously since COVID, and even before that, because some of them go back to their own countries, they've been doing it in country.

We take advantage of and use the structures of Kings College London, which means that there's a lot of transferrable skills training that people can get access to. How to do presentations. How to do [inaudible 00:37:27] searches. How to do all those sorts of things. Then we take people on a wide range of subjects that we can take. So people from health professionals are doing it more in the rehabilitation palliative care space. People who are working on specific symptom managements, so pain or breathlessness or whatever. People who are interested in the economics, have done PhD's in the economics and have found co supervisors who are health economists. People who are working on large data set. But most of them are working on the clinical or applied health research areas of palliative care.

Often we link these to projects that we've already got funding for. We're part of the university. We rely on two sources of funding primarily, philanthropy. And philanthropy has made the big difference to us. Without philanthropy, we wouldn't have had the institute or the building and we're very, very grateful to the donors who helped that and who supported that vision. And also specific research grants from research funding bodies like the National Institute of Health Research or from charities. Those are our two main funding and survival sources. So we try to make the PhD programs align with something that we're already doing, so it has a bit of momentum and has energy. [crosstalk 00:38:57]

We had lots of money for fellowships. We occasionally get donors who give us money for fellowships, but otherwise we don't.

Dr. Lynn McPherson:

Yeah. Both your masters and PhD are face to face education, or is it distance?

Speaker 3:

We're moving to distance. At the moment the PhD requirement is that the person has to spend six months with us in country out of the period of the PhD and we're working with the university to change that so it could be more completely online because we're very keen to go there. The masters is becoming a blended hybrid program, partly because of COVID, but we were also moving in that

direction and we've actually got a project running at the moment to take views from individuals to try and understand the best way to do that. There's pros and cons and there are some things that are easier to teach that way and some things that are particularly more skills orientated that are a little bit easier to do in the face to face way.

Connie:

It also speaks to if somebody wants clinical and they haven't had it. You do want to be able to offer them some sort of clinical experience, because I think one of the challenges is when you do a distance and you have people try to find their own clinical placement where they are, they may not be exposed to somebody whose expert enough to teach them anything. So that's been something I just notice in terms of what you can do as skill and role playing via Zoom is very different than being in person. Yet the flip side of that, which you mentioned, is because of COVID all of us had to pivot and had to use Telehealth, and so where is that going to be with palliative care because we love that in person connection and yet when you think about health equity and all that, it has a huge role.

Speaker 3:

Yeah. My view is that it needs evaluation to understand what is good and what isn't good, and it may need supporting mechanisms to put things in place. As you say, there are pros both in terms of the interface directly with patients and also in terms of the interface between clinicians and then in terms of the interface in teaching. Those different angles all need an assessment and appraisal of the best way of doing things.

In the patient clinician business we're actually turning one of our interventions of the breathlessness support service into a patient self help pack. I've got a colleague that I'm working with, Charlie Riley, whose leading on that work supported by a fellowship from the National Students of Health Research. And there's all sorts of interesting things to think about there like acceptability of the kit for patients and families, what they're willing to have in the home, how they feel about it, how they feel about using it. All of which has changed during COVID.

Then you've got other people doing work like Project Echo, that is being led from Hospice UK, where you've got support going into care homes, where you've got discussions and remote [inaudible 00:42:29] about patients. Then you've got direct face to face education which is not in person education but is kind of like the conversation that we're having now. Your interview two years ago would not have been so easy would it?

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No.

Dr. Lynn McPherson:

No. You're right.

Connie:

Well even just the acceptability. I've been a face to face person and I was trying to get people to do video calls instead of phone calls, because you just couldn't [inaudible 00:42:59] to your team, and there was such resistance and now the other day I had somebody wanted to be in contact with me and I'm like, "Do you want to use a phone or video?" And they're like, "Why would I want to call you? I want to

see you." And I'm like, "That is so funny," because she was one of the people who was the most resistant. So it was just kind of funny.

Speaker 3:

Now, I'm a bit conscious of time, so I'm going to have to leave you a moment I'm afraid.

Dr. Lynn McPherson:

One last question. Any advice for our students coming into the PhD program to best take advantage of this educational opportunity with an eye toward the future?

Speaker 3:

Oh wow. Do something that you enjoy, that you're interested in, because a PhD is a long-ish relationship to get it. Get it finished. So have an eye to finishing the thing. It'll never be the most perfect piece of work on earth. I think the advice I give my students most is try and take it in a staged way. Do remember that, and certainly that has happened to me, you get interested in what you're working on sometimes. Don't do something that really doesn't interest you at all. But sometimes you can find interesting things in something that didn't completely interest you at the first, and I do think it's important to have supervisors who are interested and enthusiastic about the subject. Supervisors, choose a good place. I'm sure your place is a wonderful place, so that's good.

Then it's about I think taking it in stages and trying not to be too ambitious. The biggest mistake, in my experience people make on a PhD, is that they want to solve the whole world and they think, "Oh I've got three years I can solve every problem that's needed." And actually why you probably need to do is choose a specific focused issue and try and make progress with that, and not try and do everything, but try and make a significant contribution in a specific area. And enjoy the journey, because I think it's the one time in your life when you really are allowed to work primarily on one thing and all the rest of your life you have to be working on multiple things. So enjoy the journey.

Dr. Lynn McPherson:

That's wonderful advice. Thank you so much.

Speaker 3:

Thank you. Good luck with your program.

Dr. Lynn McPherson:

Alrighty. Thank you so much.

Speaker 3:

All right. Take care.

Dr. Lynn McPherson:

I'd like to thank our guest today and Connie [inaudible 00:45:35], 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 is copyright 2021 University of Maryland. For more information on our completely online Master of

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