

Doctor Lynn McPherson:

This is Doctor 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:

Hello, everyone! Welcome to another one of our University of Maryland PhD podcasts. My name is Connie Dahlin, as you know, and I'm one of your faculty for the PhD program. I'm joined today by Doctor Lynn McPherson, who is the Executive Director of the University of Maryland Graduate Program and the Master's in Palliative Care Program.

And we are really honored today to be joined by Doctor Ira Byock. And many of you will be reading things, and you will see Doctor Byock's name. He has been in palliative care and hospice for many years. He really was able to get us in a very good spot, because he was able to work with the Robert Wood Johnson Foundation and run the... promoting excellence in palliative care and end-of-life care. And from that, created a lot of really good resources and a lot of collaboration between a lot of people.

He has also written several books on Dying Well, The Four Things That Matter Most, and The Best Care Possible. He has been all over the country, starting from Montana to New Hampshire. And now he's at California, because he is the founder and the Chief Medical Officer of the Institute for Human Caring of Providence Saint Joseph health system. So we are very thrilled to have you, Doctor Byock.

Doctor Lynn McPherson:

Very much.

Doctor Ira Byock:

Hi, Connie. Hi, Lynn. Thanks for having me!

Doctor Lynn McPherson:

Absolutely!

Connie Dahlin:

So we are so excited for our students to be able to hear you, and really hear your voice and your passion. Because I think you can read about things, but then you don't really know where people are coming from.

So I gave a very small snapshot about you and what you've done. And I would love to have you be able to sort of say, "Okay. This is who I am. This is what palliative care has meant to me, and what my role has been." Because I think people's own narrative is always more interesting than what we offer.

Doctor Ira Byock:

Thank you for asking. So let's see... I grew up on the Jersey Shore, so I tend to talk fast. And Lynn and I get along very well together, because we can complete each other's sentences.

I went to medical school in 1974 at the University of Colorado thinking I was going to be a rural family doc. I was sure of it. I picked a residency program that trained for rural family medicine: Cradle to grave, everything. Right?

And I did that, too. I went to a residency in Fresno, California, part of the UCSF system. But I was very dedicated to small town, rural practitioners.

I started residency in 1978, and I quickly realized that I was deeply proud of the hospital I trained in. We gave great care. It was a safety net, busy county hospital. I was quickly aware that there was a lacuna of excellence around people who were acknowledged to be dying. Somehow, they quite literally were down the hall in the hospital. And somehow, there was this sense that we didn't have much to do for them. And they got less attention.

And that seemed, to me, to be both an odd lapse in our commitment to excellence, and sort of a social justice issue. You know? Like, "When did they stop mattering?" And I helped found a little fledgling hospice program in this county medical center with liaison with county health nurses and a nurse from med-surg. And I was the medical director, but I was an intern and early resident. And I had a faculty oncologist who was nice enough to back me up. And there was a social work student that was my collaborator, Kim Dougherty.

And we developed this little hospice program. And I got really, deeply involved. Not by intention, because this was really not my main focus at all. But in addition to preventing people from waiting six or more hours in the emergency department to get their Ty-3s refilled... their Tylenol with Codeines refilled... or meeting people in the ED who were being admitted for rule-out bowel obstruction, when if you took a careful enough history... usually in Spanish... found out that they were just constipated for the last two weeks and literally hadn't had a BM. And now, I'm sure they looked like they had a bowel obstruction! But... You know?

That's what we sort of developed this to do, or make sure that the county health nurses could find them in the vast central valley of California. Because they might move from one family member's home to another, and there was no way of cluing in the public health nurses. All of that, we did all that.

What seduced me to what has become this field is that every once in a while, I'd meet somebody who knew they were dying, because I'd had the conversation with them myself. But if I asked them, "How are you doing today, Mister Rodriguez?" Looked me straight in the face, and then say, "I'm well, Doctor. How are you?"

"Well!" How are you well if you know you're dying and your liver is full of colon cancer? You know? And I usually quip... because it's true... when I first heard something like that, I thought, "Well, it's the morphine." You know? Or, "It's the prednisone I have them on." Right?

But I heard it... not often, but just occasionally, and enough that I had to realize that I had no idea what that meant. Or a family would come back after the death of their mom, the matriarch of the family, and just thank us and bring us cookies or something, and say, "You know, when you told us that Mom was dying, it was the worst thing we could imagine. But you know, this last month has been remarkable. It's been some of the best time we've ever had."

I couldn't explain that to myself, and I was honest enough to know I couldn't. So I went along... And I'm coming to the point, I promise. But I went along and did my family practice for a while. Ended up leaving it, and doing emergency medicine, and getting bored in emergency medicine. But along the way, I was always doing a little hospice work. I changed communities a couple of times, but I was always volunteering to stand up a little hospice program. And then I started sitting on committees and going to conferences. And NHO, the National Hospital Organization, was just forming. You know?

Anyway, I have an unwholesome predilection for committee work, apparently, and did that. And this field, from my perspective, stuttered as it formed. There were at least three attempts to get doctors to form a standing committee or organization. But we met together occasionally at national meetings, or we ultimately came together-together at Lake Granby in the mountains, or in Rocky Mountain Park a few years.

And we were like a support group, because in our own communities, we were oddities. You know? In 1980, I was at a... It might have been 1981. In 1981, I think, I was at an emergency medicine conference, and standing up around a table top having drinks with people after the meeting. All docs, ER docs. And somebody asked, "Well, what are you doing?"

And I said, "Well, I'm doing... half the time... emergency medicine. And half of the time, I'm trying to develop this board of directors for this fledgling hospice program I helped start in Fresno, California. You know? Just trying to get it on its feet." And one of the docs literally took a step back and said, "Hospice! Why would a doctor do that?"

That's where this started. It started as a support group trying to talk with one another as docs. A lot of old farts, many of whom have retired, had the good sense to retire. But around a literal campfire in the Rockies, I can remember... with wine and beer... having conversations about what the future might look like. "Well, wouldn't it be cool if one day there was actually a textbook about hospice-like care? Wouldn't it be cool if they actually taught some of this stuff?" You know? I mean, "Wouldn't it be cool if there were departments, or professorships, or something?"

And then, we would laugh. And we'd say, "Well, but really, what we're trying to do here, it's really just good care! I mean, I don't know if there's a specialty here!" You know? "Talk to people? Find out what matters to them? Make sure they're not in pain, and they're not constipated, that's a specialty?" Right?

Scroll forward: We talked about... The first time I heard the phrase "wagging the dog" was around that campfire. Wouldn't it be cool if, in caring well for people at the end of life, we actually wagged the dog of the healthcare system? Explaining that: You could actually take care of whole persons.

When I'm scrolling forward now, what, 40-some years? I'm actually wagging that dog within my health system, the Institute for Human Caring that maybe we'll get to. But we're kind of wagging the dog.

Doctor Lynn McPherson:

Mm-hmm (affirmative). That's quite a story. So I first encountered Doctor Ira Byock when everybody was talking about this book called *Dying Well*. So I ordered a copy, and I got it. And I remember reading it over Mother's Day weekend in bed while I had the flu. And my husband said, "You are one sick puppy!" I said, "Probably so!" But I sure enjoyed it very much! So tell us about your other books you've written, Doctor Byock.

Doctor Ira Byock:

Oh, boy. So I wrote *Dying Well*. It's a story-driven book. It begins with my Dad's story, Seymour Byock. And if you read it today, I hope you see that the stories are built around a kind of conceptual framework of human development that... *Dying well*: How can you be well within yourself as you're dying? It's not just dying "well" as an adverb, like dying "right," or dying in a skillful way. But it's, "Can a person be well as they're dying?" Can you die "well?"

So there's that. Every talk I gave for many, many, many years, I had talked about saying five things before... as... you're dying: "Please forgive me." "I forgive you." "Thank you." "I love you." "Goodbye."

I lost count of the number of times people came to me after and said, "Oh, I loved your lecture! Loved those five things. But you know, you don't have to be dying to say those things." And I'd very politely say, "You're right."

And then after a while... and it took several years... I realized I say that a lot to people. I mean, I had that same conversation innumerable times. And I said, "So, you don't have to be dying!" So maybe there's a book here for the general public called something like Saying Four Things Before Goodbye. Because even if you don't get to goodbye, if you just said those four things, then if you die suddenly, you know there's nothing critically important left unsaid. Your relationship is kind of complete in the sense of... A circle is complete if it's unbroken. Right?

So about five or six years after Dying Well came out, I decided I'm going to write a book for the general public. Drop a grade level, or reading level, or two, and just tell real stories about people who somehow used one or more of these kind of expressions of asking for forgiveness, offering forgiveness, gratitude, and love. Whether or not they had a chance to say goodbye, okay?

And then... But there was good... Anyhow, it was called The Four Things Before Goodbye. And then as it was going to press, quite literally, I got this frantic call from my editor who said, "We have to get 'Goodbye' out of the title!" I said, "Why?" He said, "Well, the marketing people said that if 'Goodbye' is in the title, it's going to end up in the Death and Dying ghettos of the book stores. Way down. You know? And nobody is going to..." You know?

And I said, "But 'Goodbye' is a chapter! There's a whole section on goodbye. And saying, 'Four things before goodbye,' that phrase is woven around through the book!" She said, "Yeah. Yeah. It can stay in the book. It just has to come out of the title. So it became The Four Things That Matter Most."

And then a lot of things happened. As Connie, you mentioned, I was asked by the Robert Wood Johnson Foundation to lead this remarkable grant and technical assistance program called Promoting Excellence in End-of-Life Care. They knocked on my door in '96. We stood it up in late '97. It ran through about 2006. We gave away... I don't know... 25 million dollars or so.

And most of it, in model-building, in standing up prototypical models of what an... early on, we were calling "hospice-like care..." integrated within mainstream healthcare. And what we did was basically stand up mostly hospital-based palliative care programs. Now, we could call those "palliative care programs." Those were the prototypes.

With taking away the terrible choice, it was like the avocado with no pit. You know? You can get your cancer treatment, or your heart failure treatment, or your specialty pediatric care. And you get an interdisciplinary team to listen, to align goals, to attend to your emotional, social, spiritual wellbeing, your physical wellbeing as well, and your family's wellbeing.

And we found that people felt better. Sometimes it seemed like they were living longer. And costs went down rather than up with all this lavish care. Why? Because people spent more time at home and less time in the hospital.

So that was pretty brilliant. And we did some other stuff with Promoting Excellence. And then I went to Dartmouth, and I was running the palliative care program there. And along the way... Healthcare transformation is in the water at Dartmouth. I mean, it's everywhere. Jack Winberg was there. Elliott Fisher was there. And so many. And now, Amber Barnato is there. You know?

And I wrote *The Best Care Possible*... which, again, is a story-driven book... about how what we do in palliative care is really a template for value-based care, writ large. That you can actually attend to giving the very best care to people, aligning what we do with what matters to them... their priorities... and do so in a way... and really meet their needs. And do so in a way that meets their needs, but doesn't always require them being in a hospital or getting the most tests and treatments. You know? That phrase, "The Best Care Possible," is really what everybody wants.

But what it means is very different from one person to another, because quality care, ultimately, isn't medical. It's personal. Illness isn't medical! Illness is personal. So you can give people the very best care.

How can I say this? I don't know what it is from one person to another, but I know how to determine what it is for every person. And that's what I wrote about, again, mostly through stories. So that's the last book, was *The Best Care Possible*.

Connie Dahlin:

Well, and I think what's been interesting for me, Ira, is that I've been trying to help people frame where we are, and think about the future, and looking at some of the things. And so one of the things that was a little bit interesting for me is we had the 1997 IOM Report. Right? And then you have the 2014 IOM Report. And really, it's-

Doctor Ira Byock:

They look a lot alike. Right?

Connie Dahlin:

... pretty much the same. Right? Maybe advanced care planning, maybe not. And I was sort of chuckling, because I'm like, "Why is everybody so excited? Because we still have a lot to do."

And I also think about the Commonwealth Report from 2018, which really spoke to how much of a financial burden getting sick was. You know? This whole health disparities, health inequities part. And it-

Doctor Ira Byock:

Family caregiving as its own diagnosis, because if you're a family caregiver, you're at high risk-

Connie Dahlin:

Right. And then you know-

Doctor Ira Byock:

... for serious-

Connie Dahlin:

... we still haven't kind of looked at this whole part about healthcare. Because we have illness care. We don't have healthcare.

And I think also, just about... We keep saying, "Okay. Healthcare reform." But we've been saying that for 10 years. And so what are we? I guess we're sort of in the middle. We keep thinking we're moving towards something, but I'm not... You know? I think that we get stalled.

And then the last part about that is that my own thought is for 10 years... We were so hopeful in 2010. I think it was our moment. You know? The ACA had been passed, and we were all, "Ah!" And it's 10 years. And PCHETA still hasn't gone there. And people are still focused.

And I'm like, "Okay. Maybe we need to think about new strategies." And, "What do we need to think about moving forward?" And yes, there's more to this palliative care part than just the clinical any more, because we've got to be more innovative. And we've got to think more about what's going on in the world. So big question of: How do you take all of that piece and kind of think forward?

Doctor Ira Byock:

Huge void of leadership, clinically and culturally. I really appreciated your framing.

Congress isn't leading. It's in the way of leadership. It is reinforcing the status quo. And I could get party political here, but I'll try to avoid it. But nothing is happening.

There is some leadership, but you kind of have to look for it. But whenever I recognize a serious void in leadership, I think, "Well, there's an opportunity to fill it!" Right?

I see some voids in leadership right now that our field could be filling, clinically and culturally. And we're not yet, or we're not enough. But I think we still think, "Oh, well, we need a law! We need this to go to Congress!" How many years do you have to live through this to realize that's not going to happen?

Leadership... If you're waiting for Congress for change, you should be depressed. It ain't happening! But you can move things forward in other ways. I could... I should probably shut up there. But I-

Connie Dahlin:

Well, but I think for students who are listening to this, it would be helpful for you to kind of say... So, where are the areas of a void that we should be having them think, as leaders of palliative care, of stepping in? What are some of the things that they need to do?

Because I think we need to... You know? I think so much of how we used to focus on what was good care, and pain management, and figuring that out. And we have. I think we have a better place of it. Now, yes, I know we have an opioid crisis. Yes, I know we have some whole other issues. But I think the science of pain management, we have much better. Right? We have the whole sense of this interdisciplinary team.

So I think sometimes why I'm asking this question is we default to the clinical. And it's like, "Okay. We got to..." We have that. Let's, now, move the whole piece up and say, "Okay. What's the new technologies we need to think about? Because we focused a lot of things on cancer, and we had to quickly pivot because of the HIV crisis. And now COVID has pushed us now." What's another thing for reimbursement that people really need to understand?

You can't be naïve any more. The heart and the dollars have to go together any more. You know? What's the whole part about helping people understand, "Okay. So if we can't get Congress, what are the policy things?" That's what I think students need to hear, because they don't know enough to even know where to step in.

Doctor Ira Byock:

Okay. Here we go. So things that keep me up at night include... Well, let me step back before I launch into the particulars and say... Another thing that's happened since those IOM Reports is that the profit motive has once again shown itself to be utterly pernicious and toxic in healthcare.

I worry about hospice care. I used to be able to say to a friend or relative who called from middle America, "My aunt's sick and she's having a lot of pain. What should I do?" "Get her to a hospice program!" Now, I have to say... You know? I'll look online and find out what hospice programs you have to choose from. And, "Tell me your aunt's health plan, and I'll try to help you find a hospice program." And dah, dah, dah, dah, dah.

But the profit motive has eroded... We politely say, "The quality of hospice care is variable." Yes, but mostly it's problematic, because the majority of hospice programs are deficient now. And it's not just the for-profit programs. That's simplistic.

I think it is the investor-owned for-profit programs. Right? Those that are traded: That's a problem. Some of the best hospice programs I know of are wholly-owned, family-owned programs, or individually-held programs. And they're superb!

But in general, I would... If I have to choose, one of the quality criteria that I look at is... that I ask people about their hospice programs are... "Who owns it?" Because if it's traded on Wall Street, I know that they're sucking margin out of quality. And it's reflected in case loads, in staffing, in whether you can see a hospice physician, in... and I'll come to this... what the emergency plans are. So that's a framing.

One of the things that keeps me up at night is the quality of response to critical situations among hospice programs, and even palliative care patients, particularly if they're not in the hospital. The crescendo symptoms: Somebody infarcts their bowel, or starts seizing, or having severe dyspnea. What are we doing? What do you do then? Right?

And I've seen that erode. And again, I am now... I was trained as a family doctor, but I was an ER doc for a very long time. And as an ER doc who does palliative care, I want to know if I can give the first dose in the home of what I would give in an ambulance or in the ED if somebody is seizing, or having crescendo pain, or agitated delirium.

And if the answer is, "Well, you know... You call the hospice nurse. She calls back. If it's really bad, she goes out and makes an evaluation. Then she finds a doctor who would prescribe something. You find a pharmacy that's open. You get somebody to go get it. Come back..." Sorry. If that's the case, put somebody in an ambulance and get them to the ED! Right?

We could... And I've developed them. I've even published about this. But I've developed these crisis packs and protocols in the home that have tiny vials. They're very cheap. IV meds are very cheap... or injectable meds... Of the first dose of the exact medications you'd get in the ambulance or ED that you can give sub-Q in the home for these problems.

The opioid crisis has made that... We were getting traction about disseminating some of that with disposal being a challenge. But there's technology for disposal now that makes that easier. But the opioid crisis made that go away.

And now, where is the leadership? Who is speaking for the patients and the families in their homes for these crises? Because I have a website, and people write me directly. And I can tell you that things do go bump in the night. And this is as an industry: The Academy, HPNA, NHPCO, we should be asserting leadership to fix this problem. It's a solvable problem.

We're not. So that keeps me up at night.

Doctor Lynn McPherson:

Well, it's comforting to know-

Connie Dahlin:

You know, I think, Ira, one of the things that is my thought... And I'm going to throw this out to you... When I do... Okay. Hospital crisis: You get, and stuff changes. Right? That's the nature of a hospital. Right?

You're in a clinic. When I would have my patients, I knew I would see those patients. In what order? Who knows. But I was one of those practitioners that said, "Okay. I'm going to figure out where people are. If they're in a private room, I have a little leeway. My ALS patients, they're not going to have to come over. I'm going to go find them." Whatever. Right? So I knew that if it was hard for me, it was actually better patient care.

We are still on this nine-to-five healthcare, and we wonder why the urgent clinics, the minute clinics, whatever, are popular. But to your point: Families can't afford to take the time off. Right? Things do happen after hours. And we've set up a system that is like, "Well, 9:00 to 5:00, you're fine. After that, it's all up in the air."

But more than that, I've been working with my state. And we did a survey. And we were trying to look at community-based palliative care, not hospice. And what the responses were is, "We don't want to have responsibility for these patients 24/7." And it was like, "But if you're trying to keep them home, then you have to. That's part of the care!" And so there was a real disconnect about almost putting in the time and effort to be patient and family-centered. Thoughts?

Doctor Ira Byock:

Well, I'm... This is part of my day job. A big part of my day job is to meet people's needs, including people with complex needs, without forcing them to come to the ED or be admitted.

The cost of the shift from volume to value, which we thought was going to happen quickly after the ACA was passed... But it's still happening. Because of that shift, there's actually a business case... a value proposition... for doing what you, and I, and all three of us have been trying to do for years. Finally, there's a business case!

And so within the health system that I work in now, Providence Health System... And it's not just Providence. It's any progressive, forward-thinking health system. We're trying to move from volume to value. And to a certain extent, I'm swimming downstream, finally, in trying to say, "How can we build new models? How can we design our delivery models so that we genuinely meet people's needs? They're getting better care. We're just not forcing them."

Not to be oversimplified, but it's mostly... The area under the curve of acute care has to drop. You don't have to say no to somebody going to the ED or the hospital. You just have to keep that to as low as possible. If they're in the hospital and you already have a relationship with them, you can get them out of the hospital faster. Do it at home! Finish the antibiotics at home! Do the physical therapy at home! Right?

And that's all good. You know? A lot of what I do, I point out... We're showing that there is... even under DRGs... there is a business case for getting people out of the hospital sooner, a big business case.

But also, I point out: The other metrics that our health system cares about is falls in the hospital, catheter-related infections, central line-related infections. These are the metrics the quality people look at every month. Right?

Well, if you can get somebody home three or four days earlier, it's harder to fall in the hospital if you've been home for two days. Right? It's hard to get a CAUTI or a CLABSI if your lines are out and you're getting sub-Q medicines at home, or taking it orally. You know?

So there's actually a business case for all this. And people sleep better at home, and they eat better at home, and they eliminate better at home, and they walk around more, and... You have to monitor it, but-

Connie Dahlin:

So the flip side of that, though: What I would say that I see is... and you must see this or have seen this... because of DRGs, the person gets admitted. The discharge planner is already starting. But they haven't thought about, "What are going to be the needs that meet the patient?" It's going to be, "What gets the patient out of the hospital?" Two different things. Right?

Doctor Ira Byock:

Very.

Connie Dahlin:

And I think, for my years of palliative care, for some of the floors, they did not like me. Because I would say, "I see you have a discharge plan. But let's talk about if this discharge plan is going to be successful." Because my goal is to do the right discharge the first time. Right?

And what would play into that? You know? You have somebody who may not live the way you and I choose to, but they're doing quite fine. And they've told us they don't really want to interact with the healthcare system. Right? But they're doing quite fine.

And then we deem them unsafe, which just is so mean. Right? And then when they disagree, they get a psych consult. But if they agree, they don't get the psych consult.

I mean, this whole construct of how we honor patients and families based on what they want versus what we want, it's really been... as you can imagine... sometimes, it's just really so frustrating to watch. And it's like, "This is not healthcare! This is..." I don't know what it is.

Doctor Ira Byock:

And in a value-based system where the deliverers of care... the delivery organizations... also own financial risk for the total costs of care, the discharge planners will eventually get the message that having the person bounce back in a week or two wasn't successful. That's not actually... That doesn't look like success any more from our... You know?

The metrics have to change to align with what you're trying to do, which is... Again, part of my day job these days is at the Institute for Human Caring. We're helping our health system measure things that actually matter in a value-based way. And it's all aligned with better care for the patient and the family.

What we're doing is taking the knowledge, attitudes, and skills of palliative care and driving change through the health system. We're wagging the dog.

Connie Dahlin:

Right. But I think about, though, what also has to happen is... as you and I both know... the whole way the system has been done... even the way that we have shifts. Right? Who made up those times? We

picked those off of factories! Right? And we have sort of figured this part out, but it's not about what happens in people's real lives and the timing. Right?

So I mean, if you think about what people really need, is we actually need to overstaff in the evenings and on the weekends, because that's when things happen. But that's when we don't. And so it's just really interesting when you start looking at that, because then... when I talk to some of my colleagues who are in the workforce... it's a real mix of saying, "We're going to have to even change how we think we work."

Doctor Ira Byock:

So interesting. You know, that's so interesting. Yes! Yes, with exclamation points! Including our palliative care programs!

Connie Dahlin:

Yeah, absolutely! I think they are primary.

Doctor Ira Byock:

Right. You know? Within my health system... Well, my stock, I think, is high again. But there was a while there where the palliative care teams were not happy with Doctor Byock, because we were showing them metrics... their own data... about their performance, including what days of the week they see patients. And where some of the metrics are on seeing palliative care consults within the first two days of hospitalization... basically, within the first Medicare day, before the second midnight. Right? And if you see patients before the second midnight as opposed to patients you see any time thereafter, their lengths of stay in the hospital are somewhere between four and six days shorter.

Doctor Lynn McPherson:

Wow!

Doctor Ira Byock:

I mean, when you see patients during the plan of care being developed, they spend less time in the hospital. We've done this four years in a row. It is remarkable what a difference that is.

Okay. But it's harder to see people in that first Medicare day if two-sevenths of the week you're not seeing them at all. Right? And so we were showing this to our palliative care teams. And man, there were a lot of people: "Who elected you God?" And, "What do you... We've been doing this just fine!" And, "Our patients are doing..." Blah, blah, blah, blah, blah, blah, blah, blah, blah, blah. You know?

And I would have to gently say, "You know, I get it, man. I've done it too." You know? But it's not about us! It's never been about us. It's always been about them.

So one way or the other, we have to staff up. I'm not saying you have to do this with your current staffing. We're going to go to battle with the CFOs to show them that there's a business case for staffing up, but this has to be on your strategic plan. You've got to see patients seven days a week. Somebody has to answer the phone at night. Sorry, it's got to happen.

We're now beyond that. And we've done battle with the CFOs. And so everybody is staffing up across Providence. And if anybody listening here wants to look for a... work for... a system that really gets it, think about us. But we are staffing up, and we're all going to seven days a week, because it's so obviously what we need to do!

Connie Dahlin:

Well, and I would even say... I mean, I do think hospices had it right when they were saying... The ones who are more progressive have that liaison team from four to 10. Right? And getting people home, and getting their questions.

Same thing for palliative care. And I'm one of the ones who I would say my colleagues, my APRN colleagues, were not happy with me, because I sort of felt like I needed to step in and create a role for the APPs to take weekend call as much as the physicians. And knew it was the right thing. Tried to say to the hospital, "You're not even capturing my costs. So by doing this, I'm going to show you how many people I'm seeing you're losing revenue on." Right?

But that was new, and I was told academic hospitals sometimes are like the Titanic. It's really hard to change them. You can do smaller ones. But I just think that we have this whole part of... We have a whole bunch of Millennials, and we're going to have Gen Z-ers. I mean, this whole thing about work and where... I kind of wonder if that will be one of the biggest things that changes about healthcare, because this nine-to-five just feels so constrictive.

And then we get upset when the minute clinics or whatever... And it's like, "They're there!" Right? You know? The CVS down the street here is 24/7, and they have a weekend clinic that... So if I can't see them for palliative care, they're going to go there. And we get upset about that, but it's like, "What have we done to facilitate that?"

So it's just interesting, I think, when you think about that. And then sort of thinking about some of the... Again, when you're talking about the value part, the whole part about if you... We're going to have to turn everything on its head. Because again, for the hospitals, and I think for some of my physician colleagues, the incentive has been, "If you do a procedure, that's how you bring in money." And that is so pervasive. Right?

Doctor Ira Byock:

Yeah. It's changing quickly, but it's still there. And the CFOs: I mean, there are CFOs who get it and understand value-based care. And there are CFOs who still think, "It's heads in beds. I want to have my hospital full. I want to have my procedure rooms full." You know? And if you're not contributing to that and you're not booking RVUs, you're a part of the problem. You know?

We're showing them with their own data that there is an alternative, and that, frankly, if you continue on the path that you're at, you're going to go out of business. Or somebody else is going to buy this organization, because you're going to be losing money.

I want to... before we close, I want to turn attention to something: I'm still about wellbeing through the end of life. Another thing that keeps me up at night... well, several things... is that palliative care in the hospital is being sold, and palliative care is being monetized through some organizations that have gone for-profit, as ways of getting people out of the hospital.

And it both is, but it shouldn't be, a way of skimping. Right? It's not the end-all. It just happens to get people out of the hospital quicker, because that's where they want to be. They want to be at home. And you avoid some of the complications of being in a hospital, the iatrogenic complications, by getting them home.

But in its fullness as it was developed by Dame Cicely and all of us in the earlier days, it was about alleviating symptoms and suffering and promoting wellbeing, promoting quality of life. I think the cultural leadership that we have as a health... as a specialty, as a discipline... to bring to the larger culture is that human wellbeing is possible through the very end of life.

That doesn't mean that dying doesn't suck. Dying sucks. Right? Yes.

But concomitant with all of the arduous nature of illness, and caregiving, and dying, wellbeing is concomitantly possible for many, many people. More so than I ever thought possible. And even in their caregiving and in their concomitant grieving, there is the ability for people to feel that they... a sense of wellbeing. That, "This is hard. This is awful. And yet, it's also wonderful to be strengthening the sense of family, to be caring for Mom or Dad." You know? We can become closer together.

I'm not in any sense diminishing or romanticizing this at all. Believe me! I'm an old ER doc. Right? I get it. It sucks! But it's possible for people to grow through this.

And I know it's possible not only because of what I've seen, and the stories I've written about and told. Occasionally, I'll get a call from a widowed man or woman who says, "You know, Ira, I think... I don't know if I'm in denial or something. But you know, it's only been four weeks since my spouse died, and I'm feeling pretty good. I miss her... or him... but I'm feeling okay!"

And when either I know that person and I know what happened, or I ask some clarifying questions... And it was like, "Yeah, because there was nothing left undone! You know? You honored and celebrated your wife as she was leaving this life." "Wow!"

So yeah, it doesn't surprise me. You know? Complicated grief is all about would-haves, could-haves, what-ifs, should-haves. You know? All of that. If you've really done it, it didn't have to be easy. But if you've done it and there's nothing left undone, there is a sense of wellbeing. You know?

Doctor Lynn McPherson:

Because it's dying well. Right?

Doctor Ira Byock:

You can die well!

Connie Dahlin:

And what's your other worry? What's your other worry? You said you had a couple more.

Doctor Ira Byock:

Well, I worry about emergencies. I worry about the profit motive. I worry about CAPC recently. And I love CAPC. We're a member. Ardently support them, and I love Diane. She's been a friend forever. But I have a different opinion, a different take, on CAPC's market research and their strong emphasis on not saying the word "dying," not connecting us with hospice. You know?

I'm just about exactly opposite. If we're not going to provide cultural leadership around integrating illness, and dying, and caregiving, and grieving within a frame of full and healthy human life, who possibly else could do that? This is part of why we exist!

So I respectfully disagree. I don't think their research, that market research, is very strong. And I disagree with the conclusions they've drawn.

I think it is us! Part of the work that we do has to be fostering cultural maturation. It's time for us to grow the rest of the way up as an American culture and integrate these difficult times, these unwanted times, these inherently sad times within our notion of full and healthy human life.

Doctor Lynn McPherson:

So it must make you crazy, the places that have even moved further away from... not only "hospice," but the word "palliative care" and gone into "supportive care" for fear of what the meaning of "hospice" and "palliative care" represents.

Doctor Ira Byock:

Yeah. I think it's a little bit foolish. It has stopped bothering me as much. It depends on what you have to do to get into that program. If you have to be dying to get into the Supportive Care Program, in two years, the oncologists will say, "Don't mention 'supportive care' when you're in the room!" Right?

It depends on what it is. You could call it the "Rainbow Program." But if it was wink-wink, "Send me the patients who are dying," they'll say in two years, "Don't say 'rainbow' when you're in the room!"

When I was at Dartmouth, we took the other stance. We said, "We're going to change the meaning of what palliative care means at Dartmouth. It doesn't mean you're dying. It means that you need and deserve an extra layer of support and another team involved to meet your and your family's needs."

I mean, I had this same thing said to me: "We can't say the word! Please, don't say 'palliative!'" You know? I was in clinic with an oncologist who is a friend. And I said, "Mark, you're telling me not to say 'palliative care,' but we're meeting here in the Cancer Center. You want to scare the shit out of somebody, just say, 'You have cancer,' to them. Why don't we rename the Cancer center the, 'Odd Little Bump Center?' Because we could scare the daylight out of people!"

Why don't we just say, "You need the best care possible, and Doctor Byock and his team will provide you a layer of service that you really need and deserve right along with you. Whatever you decide, whatever happens." And that's what we did. And it really lost its sting!

Doctor Lynn McPherson:

Good! Good. So let me... Any last advice for our graduates as they go forward? Psilocybin for everybody? What's your best shot?

Doctor Ira Byock:

Ah! You'd have to have me back for the psilocybin discussion!

Doctor Lynn McPherson:

Totally!

Doctor Ira Byock:

By the way, I worry about... I think psilocybin has the potential of being transformative and remarkable in alleviating people's suffering, fostering wellbeing. But I worry about the profit motive.

Doctor Lynn McPherson:

Mm-hmm (affirmative).

Doctor Ira Byock:

We will find a way to screw this up if we're not really careful.

Doctor Lynn McPherson:

Mm-hmm (affirmative)-

Doctor Ira Byock:

It has to be done carefully.

Doctor Lynn McPherson:

... Definitely.

Connie Dahlin:

And other things for people who are entering into the field, or that you want our students to be thinking of? Because this is... They're going to be the leaders, and we hope the next generation. You know? What are your thoughts for them, going forward?

Doctor Ira Byock:

Have a centering practice. Meditate, or pray, or do silent distance running... don't listen to the podcasts while you're running... or something, throw clay pots, whatever. But you need a centering practice.

The best way to protect against burnout is to bring your whole self to the clinical encounter and allow yourself... You'll feel drained at times, but allow yourself at other times to be filled up by the incredible privilege and opportunity to come into intimate relationships with people you know as patients or families and allow yourself to be gratified and filled up by that. I think burnout happens not because of the sadness or stress of the work, but mostly from being under-supported or under-resourced in doing this work.

If you're working within a team, and you've got sufficient staffing, and you feel supported, and you can consistently provide the best care possible from your own internal sense of what that means... You know? You'll still weekends not on-call and vacations, but you can go the duration. You can do this for a very long period of time, because you can allow yourself to be resourced and filled up.

And so if you're feeling burned out, consider that you may be working for the wrong organization or not getting the support you need. Or you're not able to bring your whole self to the clinical encounter, so you're not available to be filled up as well as serving.

Doctor Lynn McPherson:

You know how people who work in this field look around, and they look at nurses and doctors and say, "Would I like that nurse to take care of me, or that doctor to take care of me, or someone I care about?" Doctor Byock, you check all the boxes for me, booboo! You're the best! Ah! Thank you so much.

Doctor Ira Byock:

Thank you. Thank you, Lynn. Thank you.

Connie Dahlin:

Yeah, no, this has been really helpful, because I think you've done a really lovely balance of kind of thinking about where we've come from, and how it really directs to the future. And whether people don't like to have the historical context or not, we have to have it, because that's what's going to help us think about, "What are some of the rabbit holes we want to avoid, or some of the lessons that we have learned?" That it was like, "Okay. Let's think differently this time."

So I mean, I think that there is just so much. There is still so much more! And I think with this next evolution, to watch it is really great. And I think that you have... in your different iterations, and when you think about some of your different books... you've really helped people kind of think about some of the different areas. And that, really, in the end, it is all about the human connection, and each of us as an individual.

So thank you for that. And thank you for all your work in the field. And thank you for sharing this time with Lynn and I. We feel that-

Doctor Ira Byock:

Such a pleasure!

Connie Dahlin:

... Yeah-

Doctor Ira Byock:

And-

Doctor Lynn McPherson:

Now, go write your fourth book on self-care!

Doctor Ira Byock:

Well, I was just going to say that I think your students are lucky to have you. We're all lucky to have you. Thank you for involving me. I hope I get to meet some of your students in the years ahead as colleagues. Thank you.

Those who are watching, thanks for doing this work and choosing this field. It's deeply rewarding. Tough. You know? And poignant. Wrenching at times. And so deeply rewarding. So thank you all.

Doctor Lynn McPherson:

Thank you, Doctor Byock!

Connie Dahlin:

Thank you!

Doctor Ira Byock:

Ira, please.

Doctor 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 Doctor Lynn McPherson, and this presentation is Copyright 2021 University of Maryland.

This transcript was exported on Aug 17, 2021 - view latest version [here](#).

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!