

Dr. Lynn M.:

Hello, this is Dr. Lynn McPherson and welcome to Palliative Care Chat, a podcast brought to you by the Online Master of Science and Graduate Certificate Program at the University of Maryland. Before I introduce our guest today, for which I am exquisitely excited, I'd like to share with you that when my father was alive, God rest his soul, he said that, "If I were invited to have dinner with the Pope at the Vatican, the only thing I would really be worried about is what's on the menu."

Dr. Lynn M.:

So my point here is it's not often that I am intimidated or a little concerned about speaking with anyone in the world, with the exception of our guest today. I am delighted to introduce our guest, Dr. Ira Byock, who's a physician, an author, patient advocate and founder of the Institute for Human Caring at Providence Saint Joseph Health Care. Welcome, Dr. Byock. How are you?

Dr. Ira Byock:

I'm very well, Lynn. Thank you. That was one of the nicest introductions I've ever had, and it's truly a pleasure to be with you.

Dr. Lynn M.:

Well, thank you. Thank you. And just of course, if there's anybody on the planet who does not know, Dr. Byock is exceptionally well published. His books *Dying Well*, *The Four Things That Matter Most* and *The Best Care Possible*. A little anecdote about his first book, *Dying Well*, it came out in spring of 1998 I believe and I read it over the Mother's Day weekend while I had the flu, which my husband found very intriguing.

Dr. Lynn M.:

He said, "I can't believe you're so sick and reading that book." I was like, "Well, what better time, right?" So an amazing, amazing author. So I have known Dr. Byock for a long time and I'm just so excited and that we have a chance to chat today. And what made me think of asking him to do this podcast is two essays that you've published recently. The one is *This Pandemic Is Personal* and the other is titled *A Crash Course In Being Mortal*. What prompted you to write those?

Dr. Ira Byock:

I have been living through this pandemic like everybody else, aware of so many implications. I've been part of the executive response within Providence Saint Joseph Health to the pandemic, and I think in the first essay I talked about literally every morning, we would spend a half hour as an emergency operations council pulled together by Amy Compton Phillips, the chief clinical officer, and across the enterprise probably 200, 250 people would discuss, "What are we going to do about this and how do we respond most thoroughly with all sorts of things that we do?"

Dr. Ira Byock:

The clinical enterprise, the supply chain, laboratory issues, regulatory issues, telehealth, probably 30 or 40 other things but those are big chunks. And I was busy and our team was busy, but I recognized that one of the messages that's coming through is, "This is personal," right?

Dr. Lynn M.:

Absolutely.

Dr. Ira Byock:

This is not H1N1 or even AIDS, which I lived and worked through, this one, at this time, the bell that's ringing tolls for me too. I'm in a high risk group. So is my wife. And so, we were kind of busily going on with our lives, sequestered, being safe at home, washing our hands, not touching our face, all of that, and I'm having meetings all day now by video with our team, but all the while aware that my life is threatened.

Dr. Ira Byock:

And I think about these things a lot and I'm somewhat introspective by nature, so after a while, the first few days I thought, "Well, maybe I'm just being overly melodramatic." And then each of my two daughters called. And they may have been talking, I have never asked them yet whether they were talking to one another, but each of them called and basically gave me the third degree: "Dad, where are you going today? Do you really need to go out? Can't you get groceries delivered? What about tomorrow?"

Dr. Ira Byock:

We were, Yvonne and I, were in Missoula where our real home is, but we've been spending 85% of our time in LA and we have a rental home there that we go to and blah, blah, blah. But we were having to be up here when the bottom dropped out of this and it became very clear that sheltering in place was the right thing to do. And both daughters said, "You're not coming back to LA, are you?" And I noticed they were asking questions in a way that weren't questions; they were clearly directives. And I immediately recognized that tone was a parental tone and that, uh-oh, our roles had just reversed. They were doing parents here, right?

Dr. Lynn M.:

Yeah. Shoe was on the other foot now, huh?

Dr. Ira Byock:

Right. And then I realized, no, I'm not being melodramatic. They get it too. This is real.

Dr. Lynn M.:

It is real. I remember with H1N1, and AIDS was when I was in pharmacy school, and my prevailing thought for both of those was, "Gee, that's really too bad." But boy, this one has hit me right between the eyes, I think because I, probably, and my husband fall in that same category of being in high risk that you mentioned for you and your wife. It's very scary. It's hard contemplating the future.

Dr. Lynn M.:

And I mean, my immediate thought was all the meetings that would be canceled, but this has far greater implications I think. Let's talk about your essay on a Crash Course In Being Mortal. I found that very interesting. And you've already had alluded to, of the three assignments, assignment number one, which was to wash your hands, don't touch your face and so forth. I hope that everyone is doing that, certainly. I'm a little alarmed by the people who are protesting and want the country opened back up

again. I don't quite understand that. Do you think they just don't understand what's going on is really real? Or is this entirely driven by fear of unemployment? What are your thoughts on that?

Dr. Ira Byock:

Okay, well this is going to sound a bit extreme, but I think this is, they're not ... Everybody has a right to their opinion and they have a right to free speech; these people are actually endangering all of us.

Dr. Lynn M.:

Yes.

Dr. Ira Byock:

By coming together, they're not just being ill-informed, misinformed. I get it. And again, I think there is rights to assemble and rights to free speech with some limit being the balance of people's safety. Here, they're endangering all of our safety. This is not okay. So, you could call that politics but it's actually, no, if we had a functional central government, this would simply not be allowed.

Dr. Lynn M.:

It's a tough one.

Dr. Ira Byock:

This is the second wave, here. You are seeing the seeding of the second wave now. So, I feel very strongly. So assignment number one, and I was going to get there, let me just say that I wrote this, the first essay, This Pandemic Is Personal, was personal. What the implications are to each of us as individuals, and certainly to me, and having a different perspective, having sort of the veneer of simply getting through this epidemic as a professional, serving as a physician and other, whatever roles I have. That was that.

Dr. Ira Byock:

The second essay, A Crash Course In Being Mortal, was sort of, "Here's the cultural and social implications," right? That we are all being called to recognize that we're mortal. It's not like that nature is simply trying to get our attention; she's screaming at us and actually implementing it in a sense that not only is it now an existential become tangible threat, because it's still always existential until you're sick, I guess, but existential in the literal way where it could extinguish us. That's that.

Dr. Ira Byock:

But also, all the stuff that distracts us in our usual busy lives from recognizing that ultimately, we are just a human animal who's quite mortal and might die really at any moment from a lethal arrhythmia, from a car accident, from whatever. Because the stuff that keeps us busy and keeps us engaged, from our work to our busy family lives and travel and commerce and our fashion, our makeup, how we dress. For me, it's thinking about what I'm having for dinner that night two days before. All of that-

Dr. Lynn M.:

I'm with you on that.

Dr. Ira Byock:

Has fallen away. Isn't that interesting? I have to remember not to wear the same shirt I wore yesterday because I'm just going back down to my office. Right? I didn't get my hair cut for six weeks. I haven't used my car. All of that stuff has fallen away and things are getting pretty elemental.

Dr. Lynn M.:

Mm-hmm (affirmative). But you have ... I wonder though, how do you balance that with not going too far in the other direction and just becoming so paranoid about everything? I mean, we still are alive, so, do you know what I mean?

Dr. Ira Byock:

Well, so that's the point. You just skipped from assignment three, because assignment one was stay safe and don't die. [inaudible 00:10:53]. Assignment two is get your house in order, right? Make sure that on any given day, there's nothing left undone. All of your stuff. I mentioned that my wife and I are getting our In Case of Death box together for our documents and I've been reaching out to colleagues and old friends I haven't seen for years, just to let them know I care about them and leave nothing left unsaid. And all of that. Getting all our affairs in order.

Dr. Ira Byock:

Assignment three is face your fears and actually acknowledge it and go into it. So what would happen, were I to die? How do I affect all of that? And the point is that, and we know this, those of us who do this work in palliative care and hospice care, when you sit with people who are forced to face the fact that time is short, life doesn't become less rich, it becomes more rich. So often, people talk about the enhanced intensity of living. It seems paradoxical, but I get it because you get this tangible [inaudible 00:12:13] that life is a precious gift. It's always been a finite gift and it's a fragile gift, but it's so precious, so sweet. You know? So ironically, in facing death, we begin to live fully.

Dr. Lynn M.:

Boy, but it brings with it a sense of almost being frantic sometimes, or I don't know. It just seems to me it's tough to balance not going overboard and not being completely fatalistic. Do you know what I mean?

Dr. Ira Byock:

Yeah. For me, I think, and I think for many people, when you actually acknowledge it and can incorporate it rather than react merely with fear, if you are able to breathe through that, that sense of panic, that flight or fight, mostly flight. "I don't want to think about it. I don't know. Am I going to get distracted? What's on Netflix? Dammit, what are we having for dinner?" You know?

Dr. Ira Byock:

But if you're just able to sort of, in a kind of centered way, breathe through that and stay with it, what ends up happening is not a pall on life, but a sense of ... How can I say it? The freedom to live fully and to celebrate life and simple pleasures become precious. Our relationships, which may have, even if we like somebody, may have been kind of more transactional because we're all busy, right? It somehow becomes, it's more easy to be aware of how precious every phone call is.

Dr. Lynn M.:

Absolutely.

Dr. Ira Byock:

And time together. So that's been my experience. I think in those of us who have some sort of Buddhist leanings, I call myself a Jew-Bu.

Dr. Lynn M.:

I love it.

Dr. Ira Byock:

Jewish by upbringing and Buddhist by orientation, there is this sense that when you're actually able to face that and go through the fear of death, where you arrive is right here and, "Oh, isn't this great?" Right? Well, you know, that's fantastic.

Dr. Lynn M.:

Yeah. WTF, right?

Dr. Ira Byock:

Yeah. Right. Well, that's [inaudible 00:14:47].

Dr. Lynn M.:

Goodness. I was very struck by your line in your essay that, with your assignment three, facing your fears, you wrote, "It is the loss of having been that evokes death anxiety and the prospect of endless separation from the people we love that occupies the core of what we dread about being dead." And boy that nails it. That nails it. I'm really going to miss me.

Dr. Ira Byock:

Yeah. Yeah, me too. I'll probably precede you, but yeah.

Dr. Lynn M.:

I don't know. I hope you live to be 105 and the last voice you hear is mine. How about that?

Dr. Ira Byock:

Thank you very much.

Dr. Lynn M.:

Goodness.

Dr. Ira Byock:

So yeah, this is a cultural moment. It's the WTF moment, right? To not notice that in the face of a pandemic, and it's not just old people, because a lot of the people who are dying are in their thirties, forties, fifties, in the face of that happening, being on the news, happening in our communities, still not being reminded because we have to wear masks now and stay six feet apart and all that. Those are constant reminders. This is the alarm that won't stop ringing. So, I think the psychologically, emotionally

honest and robust way to respond is by facing the fact that we're mortal. Let's finally acknowledge it and live fully as mortal human beings. That's the sort of macro lesson that we're being offered here.

Dr. Lynn M.:

I think watching the news every day almost makes things worse, especially when you watch the heart-rending stories of nurses for example, on the front line who are crying hysterically about recounting how they've held a phone up while they FaceTime their family to say goodbye. That just rips my heart out. The statistics and the political pundit shows, which my husband watches 24/7 and I may kill him yet, so I think that sometimes it's too much. What do you think?

Dr. Ira Byock:

Yeah, you have to, I think you definitely have to titrate it, right? You have to titrate your dose of all that. It's good to be reminded of it, to know it. For me and our team at the Institute for Human Caring in this quality improvement engine within Providence, we've been very active in trying to bridge those physical gaps and think creatively about how clinicians, frontline nurses and doctors, the palliative care consultants who are now often either at the bedside or working through video, how can we use the technology, and sometimes it's low tech things, to maintain or even create new connections between people in these extraordinarily unusual and difficult times. I'm not willing to accept that disconnection is necessary despite the physical distancing that is necessary.

Dr. Lynn M.:

I agree. From what I've observed over the past month or so, I think when we come out of this, hopefully we will come out of it eventually, there will be a new recognition of an appreciation for palliative care. I think palliative care has risen to this occasion magnificently. What are your thoughts on that?

Dr. Ira Byock:

I completely agree. I think we've proven ourselves indispensable and there's no going back. I mentioned I'm on these calls and I'm very much involved in our health system's response, and interacting regularly with utterly brilliant committed clinicians, particularly those in critical care and infectious disease and all across our system, and let me tell you, there is a ever-deepening appreciation for the specialty of palliative care.

Dr. Lynn M.:

In what way? What has palliative care brought to the table that you think is most appreciated?

Dr. Ira Byock:

We don't freak out when people are dying and families are struggling, mostly emotionally, when decisions have to be made that nobody wants to make. Well, our core skillsets match this situation so well. And I say that knowing how damn hard it is for us, too, to be doing this. It's really extraordinarily difficult, but who better, right?

Dr. Lynn M.:

Absolutely.

Dr. Ira Byock:

Who better?

Dr. Lynn M.:

Talk about trauma informed care, right?

Dr. Ira Byock:

Right. Right. And I have long thought, for years I've been aware of and trying to, in every way I can, foster the integration of critical care and palliative. We ought to be joined at the hip. I thought it was, way back when I was directing the Promoting Excellence in End of Life Care project for the Robert Wood Johnson foundation, we recognized early on, "This is a match made in heaven." Right?

Dr. Ira Byock:

And I can tell you, I then for 10 years ran the palliative care program at Dartmouth Hitchcock in New Hampshire and one of the reasonably early things we did was just start rounding everything in the ICU. And man, the familiarity, the presence bred warm collegiality and here was another mature set of clinicians who weren't freaked out by critically ill people and had stuff to offer. And it just grew. So that, I think now this crisis and this tragedy of COVID has kind of forced that familiarity. And with it comes this, sense of, "Oh, we are so much better together than separate."

Dr. Lynn M.:

Absolutely. I know that MedStar Health is a big healthcare system here on the East coast in Baltimore and Washington, and they have a very robust palliative care service throughout all of their eight to 10 hospitals. And they have gone to offering palliative care 24/7. A lot of tele-health, much of it in person as well, but huge uptake. And I know, I mostly work in hospice; I get calls like, "Well, if we can't use meperidine, how can we treat the Rieger associated with COVID? What do we do? We just found out we're out of IB morphine and hydromorphone or fentanyl. What do we do now?" So, very real questions. A lot of interesting challenges.

Dr. Ira Byock:

Yes. Yes. Well, so I don't think there's any going back. I think our health systems are likely to see the specialty and service lines in a new and different, better way, frankly.

Dr. Lynn M.:

I do too. I do too. Lots of resources available. I know that CAPSI has provided quite a bit on their webpage gratis, which is very helpful. Any other resources you'd like to point out to our listeners?

Dr. Ira Byock:

Well, there's been many. VitalTalk certainly has done great work. We work from VitalTalk's talking points and remap to tailor it to our system, tweaking a number of things, but using their very strong framework. Ariadne Labs in Boston, the Serious Illness Conversation Guide. They've tailored some very good communication tools. So many things. One of the things that our team has done ... Well, I'll highlight two things. No, three.

Dr. Ira Byock:

One is tele-health and tele-palliation is going to be a thing going forward. In our system, we have made more progress and we've been working on this for four years, we've made more progress in the last four weeks than we have in the previous four years and there's no going to that either. That that capacity will now create a new platform on which we build going forward.

Dr. Ira Byock:

Second is just we've had this thing called the Get to Know Me poster for years and have been using it across our system locally, with great regional variation and local variation in how often it's used, but these wonderful posters, they're 11 by 17, they have a little outline of a person's head and then balloons coming out of bed. "This is what I like to be called, these are the things I need to hear and see, these are the people most important to me, this is the kind of TV I like and movies I like or those verses I don't like, this is what I look like when I'm well."

Dr. Ira Byock:

All of that, and it's just to deliver people from anonymity. And it's good in the ICU because so many of the people are not able to respond or insensate because of their illness or because we've sedated them so they won't buck the vent and all of that. Or in the rooms of dementia, people with dementia or delirium and all of that. They also work in longterm care nicely with people with dementia for instance. All well and good.

Dr. Ira Byock:

We realize this is one of our many strategies to kind of counter this physical distancing in the sense of people being abandoned, or that's the wrong word. Isolated is the better word. Being socially isolated. So we started printing these things and we're sending them out to our 51 hospitals and we're also working now to digitize this so that families can, with the help of nursing staff or social work staff, help populate these things. Now, these posters belong to the patient and family so HIPAA doesn't apply, right?

Dr. Ira Byock:

They're a way for everybody who walks in a room or outside the room to know that, "This is a whole person. This is not just a patient with respiratory failure or congestive heart failure or hypertension and diabetes. No, this is a whole person." So, that's something that, in the midst of this ... It's something that's always had value; in the midst of this, it's getting it adopted at accelerated pace.

Dr. Lynn M.:

It sounds like the dignity therapy question: "What do I need to know about you so I can best take care of you?"

Dr. Ira Byock:

Sure. We are trying to move healthcare from a problem-based only kind of transactional, "I'm going to assess and treat your problems," to relational, "I relate to you as a whole person." In Providence, we like to say, "We are whole persons caring for whole persons."

Dr. Lynn M.:

That's great.

Dr. Ira Byock:

That's the quadruple aim, right?

Dr. Lynn M.:

I like that.

Dr. Ira Byock:

We are whole persons caring for whole persons.

Dr. Lynn M.:

Definitely.

Dr. Ira Byock:

And then another one that I would call attention to is we developed something called the trusted decision maker designation, and this is not an advanced directive but it looks like an advanced directive. It is entered into the patient's electronic health record when signed by a physician, a nurse practitioner or a PA. Those are the three categories of clinicians who can sign it, and that, because it attests to the patient in front of me today has capacity to make decisions.

Dr. Ira Byock:

And then, the designation is, "This is who I trust to speak for me if I'm unable to speak for myself. And here are four boxes of: I checked one of these boxes, these are my general preferences for care if I were to become seriously ill." Not a menu of, "I want CPR, I want mechanical ventilation, I don't want dialysis or medically administered nutrition, hydration." Nope. Different form. It's, "My general preferences to inform the person that I just named as my trusted decision maker and my future clinicians." Okay?

Dr. Ira Byock:

And basically, the three preferences are, "I want everything. I don't care if you think my quality of life is worth sustaining or not; I want to be kept alive." Two is, "Life is precious, but I realize we're all mortal. Please balance my quality of life, particularly my ability to recognize and interact, with keeping me alive." And the third is, "If I'm seriously ill or injured, I simply want to be kept comfortable and allowed to die naturally."

Dr. Ira Byock:

But I said four boxes. The first box is, "I don't know today what I really want, how I feel about this. I trust the person I just named to make suggestions on my behalf." Right? So, we designed this couple of years ago, recognizing that there are two basic things that keep people, adults, from completing an advanced directive. One is, on any given day, there may not be two witnesses or a notary available to sign it and make it legal in statute. But the second is, when you ask people if they would want mechanical ventilation or to be hospitalized or to have dialysis, it's a hypothetical and conditioned on a number of circumstances that are hard to kind of envision.

Dr. Ira Byock:

"Well, tell me more. Have I just had a head injury and I might recover, but we don't know yet? Or am I at the far end of far advanced cancer and there's not a Tinker's chance I'm ever going to get back to functional status. Tell me more." Right? "I don't know." It would be hard for me to fill out that menu right now, but I can tell you what my general preferences are and even if I can't do that on any given day, and I'm not sure, I can tell you for sure who I would trust to speak for me and I can give them formal recognition in my health record.

Dr. Ira Byock:

The vast majority of adults on any given day can answer that question. So we built a form to do just that. And we actually included places for a witness, witnesses or a notary, we've called it our easy advanced directive form, our easy form. Okay? It's one page, right? Really simple. And that has gotten a lot of traction in our health system.

Dr. Lynn M.:

That's great.

Dr. Ira Byock:

The trusted decision maker designation stops just short of witnesses or notaries. And yet by policy, we took this through governance of our massive health system and it's a completely legitimate way of documenting in the health record who a person would trust to speak for them and their general preferences. And we're very clear, it is subordinate to any advanced directive and it's subordinate to a surrogate decision maker named in a state hierarchy law if the state has one. But absent an advanced directive, it's important information that clinicians can use as evidence of a patient's wishes. Okay?

Dr. Ira Byock:

That was a very long explanation. With COVID, this thing has gotten traction and in fact, it's gotten attention nationally. The company called Cake just picked it up and is socializing it because it can be done in a virtual visit simply charted in the patient's records. Right? And it turns out in some states, I would call out Alaska and New Mexico, which is in our catchment area, it actually becomes legal in absence of an advanced directive because it precludes any state hierarchy. There's a line in their statute that says, "If there is documentation of a patient's wishes, that can be used as a surrogate decision maker." So, it is superseded by a formal durable power of attorney, but absent a power of attorney, it's real.

Dr. Lynn M.:

Awesome.

Dr. Ira Byock:

So, that's something we've been working on for a long time. We think it has value and would have value nationally, but all of a sudden, this is one that in our health system, there no turning back. This will gain traction and we will finally, I believe, begin to move the needle of how many people have documented their preferences in an electronic health record.

Dr. Lynn M.:

And is this resource available to other people if they'd like to investigate further or adopt it?

Dr. Ira Byock:

Absolutely. You can go to the instituteforhumancaring.org website and read it there. Angelo Volandes, Aretha Delight Davis and I published an article in Stat, the healthcare website, in which I talk about the trusted decision maker and give a link to that form on our website, on the Institute's website. And Cake, C-A-K-E, I think the website may be choosecake.org. Something like that. It's partnering with us and having this form available for download that you can take into your physician.

Dr. Lynn M.:

That's wonderful. Let me take you off topic just for a second. I did a podcast recently with Dr. Arif Kamal. I don't know if you know Dr. Kamal, but he has been part of developing an app and a website, which is the3goodthings.org, with three being the number, where every day, and you can do this in groups like friends and family, you just journalize three things you were grateful for that day and they link to literature suggesting that if you do this for a week, it actually can make you happier. Have you ever heard of this or do you have any thoughts on this? What are your thoughts on gratitude and happiness?

Dr. Ira Byock:

I'm totally with it. I completely agree. It's remarkable. Practicing gratitude is something that actually changes your mood and kind of your physiology. That's a different way of looking at life. And, oh, by the way, it's bending all the way back to where I started with assignment three. When you actually go through this and realize how precious life is, and how fragile, really, life is, the natural tendency is not to flee. It's to celebrate.

Dr. Lynn M.:

Wow. I think we've come full circle with that.

Dr. Ira Byock:

It really is, yes. So yes, I like it. I hadn't heard about this project of Arif's, but- [crosstalk 00:35:47]

Dr. Lynn M.:

Yeah, it just came out today. Well, Dr. Byock, you are awesome sauce. What can I say? You are the berries. I could listen to you read the phone book for three days straight. You're a fabulous orator and your thoughts are ahead of your time and we're so grateful that you've spent this time with us. Any last concluding thoughts you want to share with our listeners?

Dr. Ira Byock:

I think the most healthy, most authentic response to being mortals is to live lovingly and joyfully. And so, I will leave you with the traditional Jewish toast, L'Chaim, "To life."

Dr. Lynn M.:

Indeed. Well, again, this is Dr. Lynn McPherson and this presentation is copyright 2020 University of Maryland. For more information on our completely online Master of Science and Graduate Certificate Program in Palliative Care or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Again, thank you Dr. Byock, and everyone have a good day.

Dr. Ira Byock:

This transcript was exported on Apr 27, 2020 - view latest version [here](#).

Thanks Lynn.