

Byock Podcast Transcript

Karen Wyatt: Today I'm very excited to welcome my return guest Dr. Ira Byock, who for most of the listeners of this podcast is probably someone very familiar, but I'll read a brief little bio for Dr. Byock. He is a leading palliative care physician, author and public advocate for improving care through the end of life. He is the founder and chief medical officer for the Institute for Human Caring of Providence, St. Joseph Health. And he's the author of *Dying Well*, *The Four Things that Matter Most*, and *The Best Care Possible*. All three excellent books and you can learn more about Dr. Byock at his website IraByock.org. And of course, Dr. Ira Byock is my most frequent guest on the podcast. You just won that category by being here today. This makes you the most frequent guest I've had, so welcome back!

Ira Byock: Quite a competition and I'm gonna keep showing up here.

Karen Wyatt: You might have to write some more books though.

Ira Byock: My super ego tells me that from time to time.

Karen Wyatt: Well, this conversation kind of came to mind for both of us because we had a conversation together a few weeks back where we talked about a whole category of issues that we each one of us has some concern about. And so I'm calling it: "What keeps me up at night" and I think it's good to explore. Sometimes we have to look at the dark side and the negative side of the work that we do. And so I figured you're the best person I could imagine to have that discussion with. So take it away if there's anything that you wanted to start with.

Ira Byock: Yes, so thanks for the invitation. I'm really delighted to be here. This conversation grew out of the conversation we had over dinner in southern California recently, and just so I can set the context for our listeners and viewers, there were martinis involved, and I was relaxed and I was I was giving voice to my cranky curmudgeonly self. And I'm well in touch with that part of myself as I thought about, you know, just in the last day or two, knowing that we were gonna have this conversation. What worries me is I don't have answers for a lot of this, and I try, when I do public speaking and teaching, to kind of be hopeful. I work at being hopeful, and, you know, my day job is all about creating a brighter future, and it's substantive and hopeful stuff, but there are stuff that keep me up at night that I don't have good answers for and that are just really worrisome. So that's what we've decided to talk about, and I will just prepare the listening and viewing audience too, that this is to put this in the context of everything good that's happening. But here, you know, here's my anxiety closet.

Karen Wyatt: And I think it's important to be able to have these discussions because if we can't look at what the problems are, we have no hope of finding solutions to them and we may not have solutions now, but we have to at least address the problems and be aware of them if we're going to get inspiration or find the wherewithal to address them.

Ira Byock: Yes. And any solution that might exist begins with honesty. And I find that that I frankly avoid some topics and some honesty at times. So, you know, I guess as a framing of this, I think in some ways our field and I mean, hospice and palliative care, we have become the problem in many ways for people. We have lived into our darkest and commercialized potential and I say this as somebody who was there, you know, started doing hospice palliative care work in 1978-79 it was pretty new in this country. The Medicare benefit was passed in 1982 and became a permanent benefit in 86. There were only demonstration projects and very early hospice programs when I was doing my residency in family practice, at the time. You know, we established the field or the field kind of evolved, but with a lot of intention to make it possible for dying people to see doctors because dying people were felt not to have needs to see doctors anymore. In the hospital they were quite literally often set down the hall ostensibly for their privacy and so you know, to not have noise and interruptions, but really it put them further from the center of interest and you know, frankly they got less attention. It was seen as a nursing discipline to care for dying people and thank God for our nursing colleagues because they really were the ones who led this movement very, very much. And we were supposed to be a corrective to that. We evolved to give people the best care, to make sure that dying people and their families receive the best of symptom management, medical attention and psychosocial and spiritual support—pretty simple basically. But it was stuff that the mainstream medical disciplines were not doing.

Scroll forward now 40 some years. And it turns out that in many hospice programs you can't see a doctor, they don't do visits. Inpatient hospice is rare and very difficult to build and finance these days. So it's a home care exercise, which is fine mostly. But we're not staffed to really support families in caregiving and they have the biggest burden. We are particularly terrible at emergencies and I hope we come back to that one. I'm just laying it out there. And you know, let the buyer beware because some hospice programs give really awful care. Quite a few of them, I would say when they're stressed. For-profit hospices now outnumber non-profit hospices by at least 2-1 or getting close to 3-1. We know that for-profit hospices are less well staffed. If you're in a for-profit hospice you're less well staffed, you're likely to get 10% or less nursing visits than the non-profits, you're much less likely to see a social worker, you're very unlikely to see a doctor. The for-profits are extracting up to 20% margin from hospice care under Medicare. And that shows they they're doing that in ways that cherry pick patients, that pick longer term patients that are less likely to need intensive care. They make it harder for the nonprofits to even stay in business because of their kind of predatory nature. It's an absolute mess.

Karen Wyatt: And I can attest to that because in my career I worked for a small community based nonprofit hospice that was bought out by a for-profit hospice and it took about two years before the for-profit mentality gradually took over. We continued to operate as we had as a nonprofit for a while. But we saw everything change and eventually I was told I wasn't allowed to go visit patients, just as you described, when I had seen every patient on our service before but I was told “we don't need you to do that. We're not paying you to do that. The nurse will tell you if the patient is qualified to be admitted or not and you just are here to sign papers.” So I saw that happen within my own experience.

Ira Byock: Tragic. We have the privilege of taking care of the sickest patients in the health care system. And they are often prevented from seeing doctors. We accept care for these people and they're usually cared for at home. But if they have a symptomatic emergency we tell them to call us rather than 911. But when you do that these days you usually fall down a rabbit hole of insufficient response. So if somebody is in their home and they have internal bleeding, or infarct their bowel, or have any number of emergencies, they're basically left. They need to call 911 frankly because there you're going to call a nurse, a nurse is going to take time to get back to you and the nurse may need to come out and evaluate you. He or she may need to call a doctor to call in a prescription. If it's an opioid or Benzo or something, you're going to need to find a pharmacist who can fill that prescription. Somebody needs to go and get it and then come to your home. Really, you know, crescendo pain, dyspnea, agitated delirium seizures—it used to be when I was a medical director, Karen we had contingency plans. I've published a little bit about what goes into a real symptom emergency kit at home. What we did when I was the palliative care medical director at Dartmouth, we created a Symptom Severity Order Set - S. O. S. Kit - and in it were very small vials of injectable haloperidol, midazolam and hydromorphone. They cost a few dollars really because injectable meds tend to be cheaper and they were only intended to be the first dose of whatever somebody would get in an ambulance or in an emergency department for, you know, recurrent seizures, status epilepticus, severe dyspnea, agitated delirium or crescendo pain. It worked by the way! We knew that at least occasionally it stopped an ambulance transport but mostly it avoided really severe symptoms because you know when a family called with real emergency, the nurse only had to get to the house. The medications were already pre-prescribed by a physician. It was already prescribed to be given as needed for PRN nursing discretion. The first dose was there and then the nurse would only have to call for continuation or make plans that bought time to then decide what needed to be done. When the patient was discharged or died we simply threw them all away - lost about \$60 or \$65. It worked. But of course it has gone away because of the opioid crisis and because of the lack of leadership among our professional associations and those of us in authority.

Karen Wyatt: And also I think that's a great example of patient-centric care that is thinking about what might we need in the moment to give the best care to this patient and to help with their suffering, not what is the least bothersome thing for our staff to take care of, or what do we not have policies to cover? So we're just not going to do it

Ira Byock: Right. You needed to get policies. You needed to go through the PMT committees or you know we can to give asylum. We had to talk to the nursing board and the pharmacy board of the state to do that. But we did and they signed off on it and we did it responsibly. You know I've long thought that in hospice and palliative care, one of the component services we provide is crisis prevention and early crisis management plans. Again, these are the sickest patients in the health care system. If we're not thinking what can go bump in the night and don't have contingency plans, well we're abandoning them when it does happen for them to figure it out. It makes no sense. And by the way, in a value based environment it's way too costly not to be thorough in these regards.

Karen Wyatt: Yeah. And I recently talked with Dr. Jessica Zitter whom you probably know who is an ICU doctor. And she was saying how often they send people home from the ICU to receive hospice care at home. But the caregiver gets no training whatsoever. They're sending a very sick patient home - bringing in a hospice team, yes - but the caregiver is the person doing the burden of the care and deciding when their loved one might need more help or when they need to call someone and they've had no training. They have no they have no idea how to manage what they're being asked to do at home.

Ira Byock: And this has become routine now, this is the new normal. So it's really distressing and this keeps this keeps me up at night. I get emails from people who's you mother develops agitated delirium and calls the nurse and doesn't get a response and asked to see a doctor and there's no doctor available and you know, things of that nature happen. It's awful. I have an email from a hospice nurse who's really pleading, you know, what should she do? Because she's at an agency and I think it's a nonprofit actually, but under new management has been told that doctors no longer visit and she has complex patients where she really feels like she needs to have a physician visit to evaluate - not available.

Karen Wyatt: It's interesting because I read statistics that sound good, like, well around 50% of patients die at home now, which sounds like a good thing until I talked to Jessica and she was saying how she became aware of the fact that these caregivers are burning out, completely stressed, and not knowing how to take care of their loved one. And so we're sending people home, but is that a good thing? And are we making the best decisions there?

Ira Byock: Well, I think it's a good thing to send people home assuming that you can wrap care around them to support them. And again, I come back to, I think the profit motivation drives a lot of these problems when you have 70% of hospice programs trading on Wall Street, there is a stakeholder involved who has a legitimate stake in extracting money from this. I mean that's impacting staffing levels right now. You know, it's not uncommon for hospice nursing case managers to be carrying 14, 15 patients. These are the sickest patients in the health care system there at home. You often have to drive between their visits unless you're clustering them in a long term care or assisted living facility. It just, it doesn't pass the sniff test, you know. How are they going to get good care? You know, I would estimate and from having been a clinician for 40 some years, having eight patients would be reasonable, right? 10 is pushing it, 12 starts to get untenable, 15 is ridiculous.

Karen Wyatt: Yeah. Yeah. So no wonder we're burning the staff out at the same time. People are leaving jobs that they have loved that they feel called to do because they can't handle the caseload.

Ira Byock: Yeah. So there's that and I think we're burning them out and not just because of the hours of the day, but because of moral distress, which I think is directly related to

the discrepancy between your own expectations, your own quality standards and your experience.

Karen Wyatt: Yeah, so true. Well, I've heard hospice team members tell me that now the interdisciplinary team meetings that we used to have every week, got moved to once every other week, and then they became shorter and shorter - the time that the staff got to come together to actually plan for patients care and talk about how things are going but also support one another. And then they she said all kinds of things started being removed, like we no longer start with five minutes to remember our patients who died in this last month, we no longer have that. There is no longer time to sit and discuss anything. There's no longer time for the staff to share how they're feeling. It's just a cursory glance at patients' charts just to say that they had a meeting.

Ira Byock: It's all become quite transactional, hasn't it? Used to be, you know, hospice and palliative care were relational. It's a relation of people in the community: experts doing the best they can to serve people who are going through the most difficult times in their lives, their individual and family lives. Now it's become transactional, what can you build for, what's medically necessary. I was like, I won't give too many details, but I was kind of a fly on the wall in a planning call with an evolving new inpatient palliative care team. And they were talking about how you know, one of the best hours they have all month is their interdisciplinary team meeting because everybody can come together and huddle and discuss cases and share and introduce one another. And, I was quiet but my jaw was dropping because in the inpatient palliative care teams I've directed and been part of we huddled every morning. That's the secret sauce. That's when the magic happened. It was quick. Yeah. We opened with a poem right, just to center people. But then we ran the list: which patients are in the hospital? Who's seeing them? Right. What are the anticipated problems? What are the goals of the day? Who are the outpatients that we've been following that are in the hospital since yesterday? You know, who's going to see them? What's happening? That sort of stuff. It doesn't take long. But without that it doesn't feel like team based care, right? That was the secret sauce. So, you know, I mean there's so much peril and we've developed something over the years that is so valuable - better quality, less use of resources that people actually don't want, less time in the I. C. U., less time in the hospital, more time at home. All of that stuff is good for people's health and well being. But it also frankly costs less money. We've already developed that and now we're kind of dumbing it down to see more patients, to do more productivity. It's immoral.

Karen Wyatt: Yeah it's so sad. I wanted to say one more thing about those team meetings. That is where synergy happens when we bring our ideas together and our perspectives together. And then also creativity. Because always for us it was in the team meetings that somebody would get the idea for how we can solve a particular problem for a patient. But it's because we came together and we at least spent some time talking about it together and that's completely missing now, that idea of creative problem solving in the moment.

Ira Byock: You put your finger on it for me, the word synergy does it. And you know, the synergy for me means the whole is more than the sum of its parts. Something has happened there, right? I can't tell you how often at Dartmouth, you know, we have this still happening: No One Alone volunteer program - not No One Dies Alone. This is just "no one alone" volunteers. We created about 30 volunteers for the palliative care program that would sit with people in the hospital, just go buy them a newspaper if they could read their newspaper, do an errand for them, or just sit with them and visit, sometimes pray with them. Sometimes get them a book or music. We had a whole little, at the time it was a walkman or ipod. And one of the volunteers acted as a liaison and was at that morning huddle every morning. Well, sometimes the volunteers had information that kind of unlocked the case. Right? That made it clear what was really happening here? What mattered most? Why waste that sort of magic - that clinical magic?

Karen Wyatt: Yeah. And as you were saying before, we've turned over this sacred precious care. It's as if we've opened the doors to shareholders who we can't expect them to even understand what hospice is about or what our teamwork is about or how we give care. That's not their area of expertise. They're involved in how to make profits and how to do an I. P. O. on Wall Street and make money for shareholders. That's what they're good at. We've given them so much power and control over this very precious work that we do. And it's a tragedy.

Ira Byock: And we haven't even pushed back. I mean, I don't want to start ranting against our national organizations, but they have not pushed back nearly hard enough. If you're going to have for profit hospice care, okay, let's set quality standards. But let's have the field set quality standards so that we can really distinguish the good, the bad from the nearly mediocre. Right? You know, we have to do that and it hasn't been done. Instead our organizations have been whining that oh, the Medicare stars don't work well, or oh, Medicare is so late and we only get surveyed every three years. Okay. So why aren't we doing it? I'm sorry, but you know, this is our responsibility first and foremost, we should be in tension with the government to help us to enforce things, but it's our responsibility to set performance standards and to at least help the public distinguish the good, the bad and the merely mediocre.

Karen Wyatt: Yes, exactly. I mean, we need to have much louder voices and as you said, we need to push back in areas where it's important and it feels like so far, everyone has just acquiesced and said, Okay, this is just the way it's going to be.

Ira Byock: Right. And now, of course, with 70% of the field being owned by for-profit, it's basically impossible to change because your board of directors, your dues paying members on your associations are representing a majority from the for profit world. They're not going to put stringent measures in place that they're not gonna be able to meet. The question I've been asking for decades now is, who speaks for the dying people and their family? Where's their voice? I thought we were supposed to be giving them a voice. So there's that. Let me see, I've talked about the for profit versus non profit. I should have mentioned nowadays, not only are there for-profits being traded on Wall Street, there are now private equity firms buying up the hospices, both for profit and

nonprofit. And as our friend, Dr John Tino, has mentioned, that's like introducing a predator into your environment. I mean, they exist to turn over companies and extract profit in the short term. It's wacko. So there's that. I worry about staffing levels. I mentioned that access to doctors, responsiveness in symptom urgencies in the home, all of that.

Karen Wyatt: But the one thing I do want to say from my experience working with hospice is right now still the staff members who are drawn to work in hospice are some of the best people I know. The nurses, the aides, the volunteers, the chaplains, the social workers, everyone on the team. These are incredible people with huge hearts who really care. And so patients still may get very good care from the staff. The staff themselves might be feeling beaten up and depleted, but they still, I believe, give the best care they're able to to the patients, but the stressors on them are enormous.

Ira Byock: Thank you for that. You're absolutely right. They are our peeps. I mean, and if you're getting good care, it's because of the commitment, the professionalism, the skills of the staff. No question. I guess from somebody who's been there at the inception and has been medical director of a number of programs and run programs, I feel like the leadership class has let down that staff - that we haven't resourced them, that there's not enough doctors to support them if there's all of that, but you're absolutely right.

On another shelf in my anxiety closet is the lack of cultural leadership and the real misconceptions that are being perpetrated by the leadership, the intellectual leadership of the field of hospice and palliative care. It comes out in terms of the language that we use and our "brand" and the like. You know, we now have presentations, there was one just last week by our colleagues - my valued colleagues and friends by the way at Ariadne Labs - talking about messaging in hospice and palliative care, the public messages that we give and it's built on work that CAPC did - Tony Bock and Diane and others at CAPC. And it purports to show that we should not be in any way conflating or really associating palliative care with hospice because hospice is associated with death and hospice made the mistake of associating itself with death and comfort care. And palliative care providers should not repeat those errors, should not talk about end of life care, I could go on and on. And now, you know, I've attended two CAPC webinars on this.

There are articles, you know, articles that have been published that I have method and logic qualms with, but they're out there in the literature now and this Ariadne webinar is like a secondary webinar of that, so this is out there. It also dovetails with of course, the deliberate decision to avoid the term "palliative care" in a number of academic and community based programs, even though what they're doing is palliative care, but they're not going to use that term because - they quickly explain - people respond badly to it, they're worried about it. They associate it with hospice and they associate it with end of life care and death. Now I get much of where these folks are coming from and I say again, many of them are my respected colleagues and quite a few of them are genuine friends, but I respectfully and strongly disagree. I think that we play into a fear based environment when we start avoiding calling ourselves by our proper names and again, much like the other shelf in my anxiety closet, it's really ironic because from my

perspective, so much of this field evolved from Ernest Becker's Pulitzer prize winning book, *Denial of Death* and now, you know, we see some of our leadership actually deliberately saying we should basically be denying death, right? Use the term "serious illness," don't use the term advanced illness, right? Don't talk about dying. Get rid of those pictures in your website that have people holding hands for heaven's sakes, right? And so my response is what happened to our cultural leadership? Like, you know me, I'm an old family doc, right? I thought one of the things that we were doing in this nascent field was reintegrating illness and caregiving and dying and grieving within a cultural mindset of full and healthy living, this sort of frame of this too is part of full and healthy human life. Yes, it's hard, it sucks, but it's part of living fully. And I think and you know, I and quite a few of us have tried to do that quite deliberately - your books and I think this podcast do that. I think a number of us have tried to do that, but the field doesn't quite get that we have at least a potential role to play in cultural maturation, and instead they're actually quite deliberately fostering this notion of denial.

Karen Wyatt: It's so distressing to hear that, and amazing to me to think we're at this point, but again, I've seen that myself, because I had a person in marketing talking to me about why do you call your podcast *End of Life University*? That's really off-putting, nobody wants to hear about the end of life. Why don't you do something like "you can live forever" or "we don't die?" Why don't you call it something like that? Because people are really comfortable with that idea and I said but that's not what people need to learn. They don't need to learn what they're comfortable with. We have to be brave and we have to be willing to take these risks in terms of talking about what people are afraid of. That's the only way we make progress.

Ira Byock: And giving them a healthy alternative to the fear, right? You know, if we love, if we act out of love, our arms go out in an embrace, you're doing this right. Um, you know, one of the things that I find we do is talk about end of life care, I do think is a problem saying your end of life care or we do care at the end of life, right? I think that's really a problem. I think our brand is "providing the best care possible." As you know, I love that phrase because it comes from the vernacular, I didn't make it up. I just listened and it's their people, all people want the best care possible. We deliver the best care possible, not just *at* the end of life. We deliver the best care possible *through* the end of life. And if you move from *at* to *through* yes, the whole world changes. If I come to you and you're a patient with advanced heart failure or cancer and you're worried about palliative care, if I say well we give the best care possible at the end of life, good chance you're gonna say, "well, nice to know, nice to meet you, I'll call you when we get there but we're not there now." If I come to you and say we you know, we give the very best care possible through the end of life. Well man, nice to meet you. You could start today, right. It's a big difference,

Karen Wyatt: It's huge.

Ira Byock: I think that is a an approach and language that does not deny our mortality, does not deny the illnesses that we address. The people we serve are seriously ill and are mortal and may die during our care and will definitely die at some point. But it positions

us in the service of their lives. I'm afraid that the = model that CAPC now is promoting sees us in service in a more transactional way in service where we are another member of the treatment team that are treating this person's illness, but in that personal realm where somebody is faced with mortality, we are at least in our public facing aspects, not going to go there, they're going to be left to wonder, well, what do we do if you have the thought? What do you what do we do when we're facing the end of life?

Karen Wyatt: And as you said, if you describe it as care *through* the end of life, you're creating a time frame, it's like a container for everything that the future might hold. We can and will address whenever it's necessary and you're making it a huge container and the end of life part is way off in the future somewhere. So we're not looking at that right now, but we're able to if we need to.

Ira Byock: Yeah, it's a continuum. That's what we want to do. We want to create a continuum. We want to create a team of team of teams for the patient and family and we're part of that team of teams that goes *through* the end of life. And we have a continuum with our colleagues in hospice, we share a discipline, we share a specialty there, right? And we're gonna at some point involve hospice when you're at home and we're gonna work closely with them through the end of your life. We may not be there yet, but just know that we got you covered, right?

Karen Wyatt: And to make just to make people aware of the continuum that is actually a huge step forward. So that patients with serious illness are thinking of the fact that they are on a continuum. We're all on some sort of a continuum. And for them to think in those bigger terms that is progress at least over just being afraid of ever imagining that one day they'll die.

Ira Byock: Right. So I again, as somebody who you know, have tried to contribute leadership to the evolution of hospice and palliative care, it just seems strange to me that we're at a time here in the year 2022 when a number of my colleagues are kind of embarrassed about our name, we don't want to say our name and that can't be good. You know, if our name is associated with a lack of hope or with people dying, like let's change the meaning. I have two quick anecdotes, I spent a decade at Dartmouth leading the palliative care program at the Dartmouth Hitchcock Medical Center and for the Dartmouth Hitchcock Health System. And there was a time about three years after I got there - I came in basically in early 2004 and about 2006 or 2007, early one morning, it was about 6:30 in the morning or 6:15. And I was descending a staircase down to the radiation oncology suite where in a conference room there the G. I. Tumor Board was held every Tuesday morning and I happened to be walking down with a colleague, a medical oncology colleague of mine who had become a friend by then. And we're coming down the steps and he stops and he was in front of me and he stops and looks back and says, you know, this is remarkable. I said "what?" he said, "well you know, you came, it hasn't even been three years and when you came and they made a big to-do about expanding the palliative care program. And I thought to myself in all honesty, Ira the last thing we need is another specialty team touching our patients there. They've got enough going on." And my goodness, I rolled my eyes. "But I gotta tell you at this point, I don't

know how we used to take care of these people without you guys.” And then he went another few steps and coming back and said, “but you know, I gotta talk to you. I mean you gotta change the name because the phrase, you know the term palliative care scares the daylights out of people.” And I laughed and I said, “oh man, Mark, I gotta tell you first, thank you very much, I want to get this on tape, you know your first statement because that's just music to my ears. That's exactly what we hoped to do, thank you. About the name, I gotta tell you, it's odd that we're having this conversation in the cancer center, because you know what word scares the daylights out of people? I mean, you guys gotta start talking about this place as the slightly unusual cell center, right? Because cancer scares the heck out of people.” And he laughed and we, you know, moved along and went to GI Tumor Board.

I just got to say, you know, if we've got to change the meaning, which is what we went on to do at Dartmouth, we had to change the meaning of the term palliative care within that health system. It didn't mean you were dying, it meant and still means today that you have a serious illness with needs that deserve the very best care we can possibly give you. And that involves this team adding to our team to care for you and your family. We, you know, and I used to get challenged like that GI Tumor Board, you know, “so we've got this guy's 63 years old and he's got cancer of the head of the pancreas and we're gonna try to downstage him with chemotherapy and hopefully we can get him to Whipple, right, you're gonna see this patient, Ira?” “Absolutely, we want to see this patient.” Or being in the ICU saying, “well, this guy has severe pneumonia on top of his idiopathic pulmonary fibrosis, but he's you know, not about to accept dying. And you know, we think he's got a small but viable possible chance. And do you want to see him?” Absolutely. We want to see his family - they need all the help they can get and we're gonna help them pull through this, right? And the CHF patients in clinic, right? The cystic fibrosis patients, the end stage liver disease patients who may or may not get to transplant. All those people deserve palliative care. And as you build that so that we aren't an alternative to curative or life prolonging treatment, but an adjunct, a compliment with them through the end of life. Change the meaning of the term palliative care. It lost its sting. I just suggest that as a field, we should look at that alternative.

Karen Wyatt: I like that. Not necessarily get rid of the word palliative. I mean, what's really behind that is let's just not talk about anything related to the end of life. It's not just get rid of that word, but doctors don't want to talk about it either. Doctors are just as afraid of the word as patients are.

Ira Byock: We've become embarrassed by our own discipline. This is not a good thing. This is not a healthy thing, right? I said to my friend the oncologist that day, I said, you know, we could call this program the Rainbow Program, right. We want to refer you to Rainbow Care. But if all we accepted were people who were dying or were soon to be dying, within two years, you'd come to me and say I really would love you to see this patient, but please don't mention rainbows in the room. Right? Because it would be associated with giving up, right, with pushing death in their face. I agree with my colleagues about that, right? No, death remains a hard sell. But we want to integrate what

we do within the concept of full and healthy living, which, you know, does include living fully as mortal beings.

Karen Wyatt: Exactly. And it includes more than focusing just on the physical body and treatment of what's happening with the physical body, which is why the palliative care and hospice teams are so valuable because of that multidisciplinary team approach that can look at all aspects of wholeness and wellness for the patient.

Ira Byock: I would even say, interdisciplinary team approach. And that gets back to our previous comment because I think the difference when I'm asked to distinguish the difference between multidisciplinary and interdisciplinary, I think the difference is that in multidisciplinary, there's multiple disciplines involved in the patient care and contributing ideas and services, interdisciplinary means that at some point in time they're actually in the same room, even if it's just a zoom room because that's when the synergy happens.

Karen Wyatt: Excellent point. You're so right about that and it's the interconnection and the communication that happens between those teams because a lot of patients now do get multidisciplinary care, but it's completely fragmented and there's no communication or connection between any of the providers.

Ira Byock: That's right. It's a collection of transactional interactions. It's just different.

Karen Wyatt: Yeah. And that word, transactional keeps coming up in all of these situations and in a way, I feel like that is a problem in our entire society for other institutions as well. We've become very transactional about everything that we do and we lose a lot, we lose a lot by moving in that direction.

Ira Byock: We do and I know counterpoints to that. You know, veterinarians tend to be more relational than medical doctors in so many regards, and maybe except for concierge medicine and the stuff that we used to do. It's not like it's all over - there are certainly incredibly good hospice programs and palliative care programs that are more comprehensive and reflect very much the whole person caring model, the flame of which I try to keep alive. But veterinarians tend to do it better than we do. You know I live in Missoula Montana most of the time and you get your tires changed a few times a year around here because of snow and I have this tire company in town that I have a relationship with - they actually know my name. I walk in and they know they ask which of the cars, are you doing the Honda or the Rogue this time, Ira, you know, they call me, it's remarkable. What's up with that? You know, it's just a small business, actually a franchise, but it's owned by a family and a small team locally and there are others of course - there are places we shop and restaurants where we're known by our names. I don't know why we can't do that in health care.

Karen Wyatt: Exactly. Exactly. And well, we're at a place where I think our healthcare system is in a lot of trouble right now and some things seem to be falling apart and we're just going to have to find a way to change. We're pushed there.

Ira Byock: Yes. So I know we're getting late in the hour, but I wish I had, you know, tangible next steps and here's what we all need to do. I really do like to assert some cultural and systemic leadership in the work that I do. The best I can say at the moment is we need to be honest with one another and not assume that just because something is coming from the mouths of hospice and palliative care leaders or is coming from a hospice or palliative care program that we already agree with it and it's the best there is because that's - from my perspective - not the case anymore. With regard to some of the deficiencies in our systems are our own palliative care programs which are also not well staffed in many if not most places with the hospice programs. We certainly covered that in this conversation. I think first and foremost I would ask people not to lose your outrage. Some things are just wrong. And if a hospice patient has barriers to seeing their physician or there's not a good crisis plan and or the nursing that's seeing your mom or your spouse. If you're one of 14 or 15 patients that that nurses caring for, that's wrong. And let's just be honest about that. And then I think we all have to be strong advocates for ourselves and for each other. You know, we need to use our ability to make choices among hospice and palliative care programs which are these days often determined by your payer or your health system, but we need to complain loudly at times when our loved ones or we ourselves aren't getting the care that we need. We need to fire and choose other programs when necessary. And we need to ask who owns this program? And I would just, I would assert that as a generality, community based nonprofit programs tend to provide better care. Not always and they're not perfect. I'm not trying to in any way assert that, but be an advocate and think about one of the criteria. And one of the questions to ask is who owns it.

Karen Wyatt: That's a good point. And I would say if you happen to be fortunate enough to have a community based nonprofit hospice and or palliative care organization in your community help support them. Like go to fundraisers, like ask what they need, be a volunteer, step up because it is fortunate if you have an organization like that available to you and don't take it for granted.

Ira Byock: I so strongly agree. Put them on your annual giving list. The local nonprofit hospice program deserves your support if you've got time on your hands. Think about supporting them in other ways, volunteering either in office work or seeing patients. If that if that draws you or supporting them with pet therapy. My dear sister Molly has long been a pet volunteer. I mean not herself but her dogs to visit patients, you know, spread some joy.

Karen Wyatt: Exactly, exactly. So let's take what's working well or wherever we find something that's good in this, in our field. Let's amplify that. And let's see if we can't get creative. And so this is our little way of creating some synergy between us and maybe who knows? Maybe we'll have some ideas down the road and maybe we'll sleep better after talking about it.

Ira Byock: Well, this has been very therapeutic for me. Dr. Wyatt, thank you for listening to me and I feel like my anxiety closet has, you know, just the airing of it has helped me a lot.

Karen Wyatt: Well, I could have charged you for it if I had known I was going to be so helpful. But you know ...

Ira Byock: I'll get the martinis next time.

Karen Wyatt: All right, That sounds good. Well, thank you for joining me. And it's been a great conversation and it does feel good. It feels good that we air these issues and be able to just talk about it freely and openly.

Ira Byock: I agree. You know, that's where solutions start: by being honest, being connected over these issues, expressing oneself, feeling heard and understood. I feel heard and understood. Thank you for that.

Karen Wyatt: You're welcome. Well, I hope we empower other people to speak up when they see injustices and when they see things that are wrong in their community or their field. So thanks. Ira.

Ira Byock: I look forward to talking with you again. I'm committed to staying, you know, at the top of this podcast.

Karen Wyatt: Alright. I'll keep you informed when you're slipping from the rankings, and we'll get you back here again.

Ira Byock: Take care.

Karen Wyatt: You too. Bye.