

Dr. Karen Wyatt:

I'm assuming that everyone knows Dr. Byock. But I want to just read part of his very impressive bio so you'll all be acquainted with the amazing work that he's done over his career. Dr. Ira Byock 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's Health – a 50 hospital health system serving communities across seven states. Dr. Byock advances efforts to measure, monitor and improve whole person healthcare system-wide. He is an active professor emeritus of medicine, and community and family medicine at the Geisel School of Medicine at Dartmouth, and he served as director of palliative medicine at Dartmouth Hitchcock in Lebanon, New Hampshire from 2003 through July 2013. Dr. Byock has been involved in hospice and palliative care since 1978 during his residency.

At that time, he helped found a hospice homecare program for the indigent population served by the University hospital and County Clinics of Fresno, California. *Dying Well* was Dr. Byock's first book, published 20 years ago as we're celebrating. And it has become a standard in the field of hospice and palliative care. But Dr. Byock has also written *The Four Things That Matter Most*, which is used as a counselling tool widely by palliative care and hospice programs as well as within pastoral care, and his most recent book – *The Best Care Possible* – tackles the crisis that surrounds serious illness and dying in America and his quest to transform care through the end of life. Dr. Byock has been the recipient of numerous awards and literally we'd take up the entire hour just naming all of his awards.

And he's also been a featured guest on many, many national television and radio programs. So, it is indeed a very great honor that we get to have Dr. Byock here with us tonight and if you want to learn more about all of his work you can go to his website which is IraByock.org. So, Ira – thank you so much for joining us tonight.

Dr. Ira Byock:

It is such a pleasure to be here. Thanks for having me. I look forward to talking with you and also to interacting with the people listening to us.

Dr. Karen Wyatt:

Well, yes, I've been very excited. I've interviewed you before but we never really provided the opportunity for other people to

interact and ask questions and I thought this is the perfect topic to talk about your book that's been out for 20 years now and give other people a chance to ask their questions too.

Dr. Ira Byock: I appreciate everybody taking time out of their evenings to do this. So, thanks, everybody.

Dr. Karen Wyatt: Yeah, absolutely. And we have people here from all over the country – Minnesota, Canada, Illinois, Tennessee, Georgia, California, Massachusetts, New York City, Virginia, Wisconsin, Texas, Oregon, Georgia, North Carolina, Minnesota – everywhere. So, thanks – yeah, thanks everyone for being here for this call. And because we're celebrating this 20th anniversary of *Dying Well* and it kind of amazes me, actually, Ira, that you had the presence of mind to write this amazing book 20 years ago. We're seeing lots of books right now coming out on the market about end of life issues.

But 20 years ago – there wasn't really anything that I know of that was being published at that time and so I'm really curious, take us back to 20 years ago and what inspired you to write *Dying Well*?

Dr. Ira Byock: Thanks again. Great question. And knowing that you would ask something like this has really caused me to reflect back at how things were at that time and what I was doing. I guess you can call it inspired, in retrospect, but at the time, it was like I had a fever that I couldn't shake. I was living in a world in which people were talking about *How We Die* – that was the best seller, right, Sherwin Nuland's really brilliant book about the physiology but also the process of dying in America. And what he described was really a lot of people dying badly, being victimized by their very biology; and a healthcare system that for all good intentions was striving to keep them alive at all costs. And most of those costs were not in money as much as people's own wellbeing and where they were spending their time—really remarkable amounts of suffering.

At the same time, in the part of my practice that was involved in hospice care and what we would now call palliative care, I was having the remarkable experiences of witnessing people experiencing yes, suffering and the symptoms of the pathophysiology of dying, but also expressing not that rarely, a sense of well-being to me. That if I asked people how are you doing, not uncommonly the answer would include some sense of a depth of their experience, an intensity of the quality of life or the preciousness of life or something that was happening within their personal lives – their families, their relationships; perhaps their

relationship in a spiritual sense to something larger than themselves.

That [message], I was challenged to share with others. People weren't open to hearing that there was more to knowing you were terminally ill than just suffering or its avoidance. And certainly, my colleagues in the mainstream of healthcare were [not open]. It seemed counter cultural to acknowledge that some of the people we were caring for were having not only difficult experiences but concomitant with the difficulty, they were experiencing some sense of wellbeing. So, I felt I had to tell that story – or had to contribute to this national conversation.

And it's not an exaggeration to say that it was literally keeping me up at night. I would sort of ruminate about what I had seen clinically – the people I had met, the conversations I had had with people. And I was trying to understand how that could be, that phenomenon that was other than suffering. Something sometimes significantly positive.

So, I decided I had to speak into this cultural conversation. And the best way to do that frankly, was to tell stories. I mean, I was trying to explain all this to myself. But the most powerful way to open the imagination of the culture if you will, the public consciousness, was to tell stories that stretched the realm of what we considered to be possible. So, that's really how it started. I thought long and hard about what I had to contribute and had this kind of fever inside that I had to get rid of and the best way to do that was to externalize it in the sense of expressing what I had to contribute, what I had to teach and the stories that I had to tell.

Dr. Karen Wyatt:

Well the book, I believe, was truly groundbreaking at the time. I just remember being a young hospice physician myself back then, and I came to the academy meeting in 1997 – I saw you speaking there, I bought the book. And I just remember being astounded that there was actually a book titled *Dying Well* that was out on the market, that had been published, that was available for people to buy. I just remember thinking, this is incredible, what a huge breakthrough this is.

And so, anyway, I want to thank you for doing that – thank you for listening to that urge, that fever to write those stories. I would imagine this book has inspired a lot of people. I'm seeing here, someone just typed in here on the chat, that *Dying Well* was the first book she read when she started her end of life doula training and other people saying they read your book long ago and have

been enjoying it over the years – re-reading it. and I just want to thank you from all of us here listening to you, for writing the book and how important it has been for so many of us.

Dr. Ira Byock:

Can I share that for a long time-and I probably still have it somewhere in my files-I was keeping a paper file. This was before computers – you could scan things easily – of notes and letters that I received, some from physicians that said that the book changed their practice or helped them to understand what these hospice people have been nagging them about and coming to their office, sort of detailing hospice. But then I had a collection of notes from the spouses of hospice physicians who wrote to say I finally got what my wife has been doing. Or I finally understand what my husband does with his hospice work. I could never quite understand what he or she was talking about, and now I get it. So, thank you very much, your stories and this book have helped me finally understand what my loved one has been doing all this time.

Dr. Karen Wyatt:

Isn't that interesting – those of us who are called to work with the dying, we have a very hard time explaining it to other people who are not in this field – why we feel the calling so much. And we can't really tell our own stories very well to our loved ones because of confidentiality, we can't really share those stories. So, your book and sharing the stories of the patients you worked with, it's a perfect illustration of it's the potential for transformation for all of our patients, but also for us as end of life workers. I think that shows up in this – in the stories you tell. It's a great lesson – letting the rest of the world know why we do this work feel about it and why we like it so much.

Dr. Ira Byock:

It is something else. People often say, “How did you choose this work?” The truth is this work chose me. I wasn't looking for another branch of my career, as you and I have talked – I thought I was gonna be a rural family doc just like you've become. So I went to residency thinking I was going to be a rural family physician and drinking deep of general medicine, learning everything from obstetrics to fracture management to neonatal care to intensive care, all of it. But this kind of got under my skin.

And frankly, what got under my skin, what really attracted me to this field was not just the potential we have to alleviate suffering but this remarkable sense that humans thriving – human wellbeing, human flourishing was possible through the very end of life. That I was not prepared for. That I did not come to medical school thinking was a significant potential. But the universe was trying to

teach me something and in retrospect, I had the good sense to listen.

Dr. Karen Wyatt: I know that in the beginning of *Dying Well* you talk about the death of your own father and it sounds like that was significant for you as well. I loved this quote – “telling the story of a loved one’s dying and receiving the story of another can be healing acts.” So, I was wondering if for you writing *Dying Well* was a healing act for you?

Dr. Ira Byock: You know, it really was. I wrote that first chapter in fact, last. I knew the book needed to open with my dad’s story. That was pretty clear as I started to put the book together and sort of the structure of it. If I’m going to tell these poignant quite intimate stories of other people, I needed to tell my father’s story. As I did that, I had been collecting memorabilia from the time that he was ill and dying.

But it was 15 years before I wrote the book. So, a lot had happened and I had a very early VHS videotape, which actually is part of that first chapter. I talk about a conversation we had had and I put on that videotape. What I say in the book is quite literally verbatim what was on that tape. I had that, I had some notes that I had made and just some of the family stuff – the pictures and the like from that time in our lives which as you can imagine was not an easy time.

I was in my third year of my family practice residency in Fresno California. My dad had come out to visit. My wife and I and our – at that time – eight month old daughter, mom and dad had come out from New Jersey and he got off the plane and was a little sallow but the next morning I realized he was jaundiced and his pancreatic cancer had obstructed things.

Anyway, when I was writing that 15 years later, I was alone, quite intentionally, I was going through this. And I had to get back into that mindset and basically relive that time in a pretty tangible emotional way. There were times when I was writing that first chapter, when I was literally in tears, missing my dad, feeling again how hard this was for all of us. And writing from the heart, certainly. Often, I would be sitting there in a little cabin deep in the mountains of Montana at that time, and kind of writing with my eyes closed – just typing, trying to remember the conversations we had.

And spill my guts on the page so to speak. It was very cathartic, frankly. Once that was out it felt like – not that I was free of it, but that something – I had expressed something in a way that acknowledged or bore witness to its meaning, its importance. While it was my own story, it felt like a story that deserved to be shared in that public square, in the Zócalo of our culture. So, it did feel good. It was very healing.

Dr. Karen Wyatt: Well I'm so glad that you included it in the book because it gave us so much insight into your own process and as you were working with these patients in hospice what you had learned from experiencing the death of your father and how you were able to bring that into the work with your patients, and it's such a good teaching example for all of us as well.

Dr. Ira Byock: What I learned was that as hard as these times are. They're not only hard. There was a preciousness to that time that I couldn't deny. You know? Within his illness there were gifts to our family. Dad was during that time, the mindset certainly at the time, and I think still today, is people want to die quickly – hit by a truck, struck by lightning. Woody Allen famously said, "I'm not afraid of dying, I just don't want to be there when it happens."

But my dad was able to meet his first grandchild – my eldest daughter Lela. We had the time and his condition encouraged us, sort of pushed us, to talk about the times in our lives. To share our past experiences. To share hopes and sadness that we knew he wouldn't get to see Lela grow up, wouldn't get to meet other grandchildren. All of that. We got to apologize for the hard times.

And my dad and I talk about this openly in the book too: we had gone through some serious hard times. We went through that whole Vietnam war thing with me dodging the draft – we had a big falling out; didn't talk for a couple of years. And that was huge, because my dad was a huge person in my life. We got to put all that back together. We made ourselves whole, you know? The relationship was complete. Not like it was already over, but there was nothing left undone or unsaid. And then we got to celebrate our family and our lives. That it was a remarkable time of life. That I hope is what that book in general conveys – that – I titled it *Dying Well* – not just the process of dying, doing it right, or doing it better than doing it badly. But thinking of the word well as an adjective – that someone can be well even as they're dying. I think my dad, as much as he hated being ill, as much as he didn't like being cared for. He was a fiercely independent person. But there

was this sense of wellbeing that was kind of admixed within the sadness, and the arduous nature, the real tragedy of his illness.

Dr. Karen Wyatt: That's really beautiful. I'm so glad that you said that, because one thing that I was going to ask you is what did you mean by dying well as the title – but you explained it perfectly.

Dr. Ira Byock: It sort of has a double entendre. People were talking about and still are of course, the good death. There was a book called *The Good Death*, that's a phrase – that's in the vernacular. But I was always bothered by that phrase, because really death is more something that's beyond life. Death is a lifeless state. So to talk about a good death seemed to me to be a contradiction in terms. I don't know anything about death, never been there. But I know something about dying, because it's a part of living.

And there are ways to do it better or less well than others certainly. And that's fine. But then that notion that you can be well – that's all that this book is about. The conceptual framework of this book was really about human development. Within the book and the different stories I choose to tell, really illuminate particular task work or landmarks of human development – completing the business aspects of life, completing relationships, aspects of forgiveness, thinking about our relationship to something larger than ourselves that will endure – all of that stuff of human development that we usually associate with pediatrics in our family medicine training, Karen. It's all about the developmental milestones – Piaget's developmental milestones, and Maslow's work and all of – Eric Ericson's work. It turns out that stuff applies to those waiting phases or stages of life as well.

I've been really seething from the pediatric developmentalist, the childhood developmentalist for years in my academic work, trying to illuminate a path work of late life development.

Dr. Karen Wyatt: And so in many ways dying well is a bit of a guidebook in a sense of some of the steps that we need to masters as we move into the last season of life.

Dr. Ira Byock: Yes. At least the last steps that are available to be mastered to continue to experience a sense of wellbeing. At every developmental cusp of life, our strategies for living fully need to shift. You know, for the toddler to become a preschooler, things have to shift. The usual strategies no longer work. When you leave home and go to college or get married and start a family of one's own, strategies need to shift. You can't rely on your parents or

things that used to work, now you have different strategies. And those developmental challenges can cause suffering. But we grow through them.

Achieve a new sense of stability or at least a sense of some confidence that comes along with that wellbeing. And I think I'm quite certain those opportunities present for many, many people during serious illness. If you're fortunate enough to have some time to know that your life is coming to an end – which is kind of antithetical to the usual hit by a truck or die in my sleep or get struck by lightning wish that most Americans have.

Dr. Karen Wyatt: So true. Well that brings to mind, Ira, one of the big things I wanted us to discuss tonight is given the length of your career in hospice and palliative medicine just to talk about from your perspective some of the changes that you've seen taking place. And initially I was thinking over the 20 years since you wrote the book, but your career actually started long before the book was written so in all these years, could you sort of share with us your thoughts on how has our end of life care really evolved and changed over that time?

Dr. Ira Byock: Well –

Dr. Karen Wyatt: That's a big question I realize [*laughs*].

Dr. Ira Byock: I think it's the good the bad and the ugly. I'll start just so I don't bum everybody out who's spending their evening with us, I'll start at the ugly. The fact is that despite all the advances we've made, people who are seriously ill are still at high risk of dying badly. What I mean by that is people are at high risk of suffering needlessly during the last months, weeks and days of life. That's just a fact.

And for those of us who are still working, still seeing patients, still working in healthcare, I can tell you that healthcare which is populated by loving, smart, earnest people, often inadvertently and unintentionally makes things worse rather than better for seriously ill and dying people.

In our quest to fight disease and save lives, unintentionally we often contribute to the burden of illness and the burdens of treatment and we conscript people time and energy for treatment and diagnostic tests that have diminishing returns. What I often ask people to consider is that despite all of the advances of science and medical technology we have yet to make even one person

immortal. So if we haven't even made one person immortal at some point in time, just increasing the intensity of medical treatments, at some point is not likely to be better care for the human beings that are living with those diseases.

I continue to see. I now live in Los Angeles which is a hot bed of high risk dying. Here within a few miles of me, you can get state of the art, best treatment on the planet, for your heart disease or your cancer or your liver failure and not uncommonly your life can be saved and you can live longer with that treatment than without it, but ultimately as your life is coming to a conclusion, as that liver failure, your cancer progresses, your heart disease just gets ever more problematic, in this city you are at high risk of getting treatment that is burdensome, non-beneficial, and spending your days in hospitals and even in ICUs when you'd really like to be at home surrounded by people you know and love and who love you. In this town, the chance of getting a peg tube – you know, feeding tube – if you've got advanced dementia is 12 times what it is in Salt Lake City or Portland, Oregon.

The chance of getting excessive amounts of radiation treatment for your bone metastases, the chance of getting 12 or 15 treatments when one has been shown for the last 30 years to be as good as many, is really high. Well over 50% of people with bone mets get excessive radiation treatments.

It's not necessary. So you know, things are still pretty darn tough. Nursing homes in this town, there are a few very, very exceptional ones. But they are the exceptions. Our nursing homes are understaffed. People – the turnover rate of aides and nurses in nursing homes is often 100% per year, because they're not paid a living wage and they're understaffed and nurse's aids are at risk of suffering themselves. I could go on and on, but I won't. The good news is that while those of us in hospice and palliative care, and I should include geriatrics, the people who work in PACE programs, we haven't yet changed American Healthcare systems or our social services entirely.

But we have proven without a shadow of a doubt that much better care is both possible and readily affordable. The best programs in America have shown that it is possible for people to be cared for in ways that allows them to be confident of being reasonably comfortable. Surrounded by people they know and love. Not too heavy a burden to their families and when it's their time to die they can be assured of leaving this life in a gentle manner, honored and celebrated, their inherent dignity intact. We have shown that.

So, the fact is, what's needed and I think that's next – probably talked about – we just need to bring these models that we have shown worked to scale. We know that PACE programs work. We know that Greenhouse models of nursing – long term care in nursing homes – and the beatitude models and the Planetree models, we know that they give dramatically better care than most nursing homes, certainly the chain operated for profit nursing homes. We know that the retention of nurse's aides is far higher. Heck, in the Greenhouse models, none of those nurses and nurse's aides leave. You know?

It's a rare event. They have to retire or move away to leave, they want to work there. And we've shown that it costs less money rather than more money to take really good care of people through the end of life. So, we simply have to bring these models to scale. Frankly, I think what I'm missing – what we're missing here in America, is consumer demand, frankly. We're all too polite – and I include those of us in hospice and palliative care, we are so nice. Which is a good thing and that's authentic. But you know, to use that famous term disruption – right now creative disruption is called for.

You and I, Karen – those of us who work in hospice and palliative care, we've really been standing on a two-legged tool. We've demonstrated beyond a shadow of a doubt that much better care is possible. Our data has shown again and again that we can deliver much better care at significantly lower cost, not with more cost. I mean, people say, "Who is gonna pay for it?" It actually costs less to do the right thing. So, with the two legged stools, we know that much better care is possible, we know it's completely affordable. But the third leg of citizen consumer demand has been missing. People remain fearful of those terms hospice and palliative care, rather than realizing that they represent much better care for them and their families during these difficult times.

Dr. Karen Wyatt:

So we really need to be working on empowering consumers, empowering lay people all around us to speak up and have a voice, because I'm seeing more and more people who are becoming aware of end of life issues, who are talking, they come to death cafes, they come to various meetings and workshops and saying I want to have a natural dying process. But they need to be empowered so that they can stand up against this machine of the healthcare system in a way and not get sucked into it, in order to have what they want.

Dr. Ira Byock:

So yes, I think we both – we all have to be both advocates for ourselves and for those we love. We have to come with our questions for the doctor's office. We have to have our advanced directives filled out so we've clearly appointed someone to speak for us if we're unable to speak for ourselves. Someone we know and trust, who knows us well. We have to embrace second opinions, and third opinions if you've got something serious like a cancer or bad heart failure.

You deserve a second opinion and sometimes a third or fourth opinion. I'm all about that. But these days I suggest that one of those opinions be with a palliative care specialist and team so that you're not only getting the best disease treatment but you're getting the best care for your wellbeing, your symptoms but also your emotional, social and spiritual concerns and that of your family.

There's been a flurry of articles in the literature about taking a little MP3 recorder to the doctor's office and recording what the conversation is with the doctor so you can play it back later and your family can hear it. I think that's a great idea frankly. So we have to advocate for ourselves, knowing what we can expect, raising our own expectations and then knowing what we have to demand and be insistent upon when we're not getting our expectations met.

On the other hand, at the same time, collectively all of us who go to those death cafes, who have had death over dinners, who are part of the conversation project and who are really using this particular moment to advance these conversations culturally about how we can take good care of one another and live as fully as possible, all of us together also have to realize that there are policy ramifications.

That this notion of a social movement – that has some tangible impact on access to good services, quality of good services, voting not only at the ballot box but with our healthcare and social service dollars, being able to discriminate the best from the merely mediocre. All of that also needs to take place.

We need to demand transparency and quality measures from our healthcare providers, our – you know – hospitals, long term care, certainly, but also hospice and palliative care programs. We have to demand quality metrics that allows us to separate again, not merely the good from the bad, but the excellent from the mediocre, so that our loved ones get the best care we can possibly provide.

That's part of change – right? An engaged consumer base if you will, is really part of how things change. And that's been missing.

Dr. Karen Wyatt:

That's such a good point and that's a good kind of clarion call for what we all need to be working on. Right now because we're more than halfway through I want to start to open up to questions. If you're on the telephone you can press star two on the keypad that will indicate you want to ask a question. Meanwhile, a couple of questions have been typed in Ira and one person wanted to know, I did an interview with Dr. Fred Mirarchi – who has done the Triad Study – studying the interpretation of advanced directives. And he found that in about 50% of cases, in the emergency room, advanced directives are misinterpreted by hospital staff.

Because they're in too big of a hurry, they don't read all of the document because maybe the document has confusing or conflicting instructions. So in his studies all around the country, he found out that our advanced directives are failing us in some ways right now. And a few people typed in and wanted to know what you think about that?

Dr. Ira Byock:

I know Fred and I've read his papers. I understand and share many of his concerns. It's so funny, because I spend a lot of time and energy – even now and have for years – promoting advanced directives. And at least getting people to appoint a healthcare proxy. I still think it's essential.

I am less committed to having people complete the living will portion of an advanced directive – what for you and I – we know what I mean by when I say that, that part of the advanced directive that talks about whether you would or would not want mechanical ventilation or renal dialysis or all of those things. Medically administered nutrition and hydration. While I think it may have value as a guide to the person that you appoint as your healthcare proxy or power of attorney – it's really that – the appointing of someone you trust to speak for you that I think is the importance of an advanced directive. And even if that's not perfect, I understand. I know the studies that show that the people who are appointed as proxies often misunderstand the individual appointing them – their perspective or their priorities.

But I don't know what a better alternative is at the moment and I know that in the absence of appointing somebody, those same people in the emergency department or the hospital medicine team or the intensive care team will be on the side of doing everything

possible, which because of as we just discussed we've yet to make even one person immortal.

Doing everything possible ends up being burdensome and frankly harmful. Now, what I'd like to see happen and I think that I may live to see this, is us moving towards some other form of an advanced directive. At the moment, I'm quite enamored with the idea of video advanced directives, where somebody – we turn on your smart phone or a small MP4 video recorder and ask someone to appoint someone to speak for them and address some key questions.

What are your priorities? If you had something that was serious and there was diminishing benefits for intensive care like ventilation or being in an ICU – where would your priorities be? Something of that nature. And structuring the sorts of questions that we ask in the document like the honoring my choices or prepared document or Five Wishes document and doing that on video I think is a very powerful way of conveying to later clinical teams what this person had in mind, what their priorities were and who they were as a person. I think the electronic medical record is starting to have the capacity to do those sorts of things for us routinely.

Dr. Karen Wyatt: Okay, thanks Ira. And we do have a caller on the phone – B.J. Ellis from Dallas. So B.J. – I'm going to unmute your line so you can talk to Ira.

B.J. Ellis: Hi, thank you Dr. Karen and thank you Dr. Ira. I've read all of ya'all's books and I want to thank you, and I've been a hospice volunteer, and also most importantly in the last three years, helped my mother and I was with her until her last breath and was an advocate for her of course. And again, what I see here in my local area, there's still a state of going to battle – that we're not gonna die if we just fight enough and gain, it's like there's one advertising campaign from what I call the medical industrial complex about fighters wanted.

And of course, we do want to stay alive. But again, I think it's that going to do battle with this thing and hopefully we'll beat this. But I do believe that we're at some sort of tipping point by virtue of having this conversation tonight. There will be ultimately consumer demand. But just seeing what we went through the last, say, six to eight months on this just about healthcare, just trying to get respectable amounts of healthcare and what I see in the assisted livings and the independent livings – that what they call continuum

of care, that they promote – it's called a cruise ship lifestyle. I myself have also – I teach yoga.

Independent in assisted living just enough to keep a little bit of movement, and I try to promote what I call conscious living, conscious aging and conscious dying. Some of the powers that be, they would just say, "We don't want to talk about dying, it's too depressing."

And to me, I think it's so important. And again, it's just mainly to help people reflect and I think we are at a tipping point. But I just want to thank ya'all for providing a venue for me to feel like I'm not alone in this. So thank you very much.

Dr. Ira Byock:

Thank you, B.J. Thanks for the work you do and the model you set – you're really modelling what healthy human life is like, the commitment to caring for our parents and loved ones in your personal life is also really remarkable. And really – I talk about people living fully. And not all of life is happy. Not all of life is easy. But we can embrace the fullness of human life. And I think you're modeling that. Thanks for your call and for the work you're doing.

Dr. Karen Wyatt:

Yeah, thank you B.J. And Ira – I'll share with you – Karen typed in a comment and said, "Ira, how about writing a book about guidelines for consumer demands." Huh – excellent idea. There's your next assignment.

Dr. Ira Byock:

I like it. you know, I write a number of articles. I'm just completing an article that I hope will come out in a journal this November, we'll see. But I talk about some of the things that could comprise a policy agenda that was pretty bold but would substantially change the landscape of dying in America.

It involves things like really finally by statute requiring medical schools and residency programs to teach a sufficient amount of curriculum around caring for people who are seriously ill, people with dementia, people going through difficult decisions and need the guidance of a physician as the member of an interdisciplinary or multi-disciplinary team that physicians should be able to communicate with people who are seriously ill, should be able to listen to them and allow them to feel heard.

And should be able to go through shared decision making where we as doctors come with the expertise to diagnose and treat people's medical or physical conditions but acknowledge that

patients and their families are already experts in their personhood and in a true partnership help them to determine what the best care is for them at this point in time. We could you know, by statute, require that nursing homes have sufficient staff so that there's someone to answer the bell when a frail elder needs help getting to the bathroom, or when somebody is soiled and needs help in getting clean.

These days, our nursing homes – so many of them, and I know that there are exceptionally good ones. I'm not trying to cast too broad a brush. But many, many nursing homes are staffed and constructed in ways that people are destined to feel undignified – the people who live there. That's unnecessary. We know that nursing homes can be much better. But at this point, as consumers, as citizenry, we really have to pass regulations to require that sort of stuff. I could go on and on. I don't want to spend the rest of our time talking about policy unless people want me to. But there is – we're at a point in time where yes, culturally that tipping point is within reach.

But we have to translate that into robust policy that expresses our needs and demands that the healthcare system – public and private healthcare system responds to our needs in ways that alleviates our suffering, avoids unnecessary suffering and unduly burdensome treatments, but also preserves the opportunity we have within our families and communities to achieve or retain a sense of wellbeing, despite the arduous nature of illness and dying.

I don't want to put rose colored glasses on this, but in fact the human condition is remarkable, and people deserve the opportunity to do what matters most to them and through this difficult time, again, thinking developmentally, to grow individually and together as families and communities. That much we can do in our lifetime. That much we can deliver. We may never make people immortal. But we can reclaim the rich, fullness of human life.

Dr. Karen Wyatt: That's beautiful, Ira. Kind of along these lines in talking about the care we're providing and the system, Jan asked what do you feel about the hospitalist movement in hospitals which removes one's primary care physician from the hospital room?

Dr. Ira Byock: I think it was inevitable. The hospitalist movement has much that is good about it, but I do think that it has been disruptive to people's relationship with their primary care doc. Some health systems and hospitals have really invited the primary care doc back

into the hospital at least to be a part of these decision making conversations.

Really good hospital medicine teams also make it a point of staying in close contact with the primary care doctors and also encouraging them to drop by before or after their clinic days so they maintain a relationship with patients. But also after a hospitalization, a good hospital medicine doc reaches out and makes sure that the handoffs are smooth, that the doctor who is going to be seeing the patient as an outpatient, knows that the patient is being discharged.

They plan or discuss what the discharged medications would be, what the frequency and how soon the person needs to be followed up after discharge, who's gonna make that post hospital call to the patient and all those sorts of pretty simple aspects can smooth the transition. I think that the hospital medicine docs need to reclaim the fullness of their practice as well. I do think that hospital medicine is at risk of being overly transactional and just seeing themselves as just kind of there to fix problems rather than take care of whole persons.

That's not inevitable. As an emergency room physician for many years, I found a way – and I'm not the only one – to maintain real relationship based care. Yes, we're only seeing one another perhaps this one time, so if you're practicing emergency medicine in a community hospital and I would assert that this is the same for a hospital medicine docs, you end up seeing their families and their neighbors and sometimes the patients again and again and again.

So it's not that farfetched to think about relationship based emergency medicine or hospital medicine. But I also know and I used to say this to myself in the ED [Emergency Department], I teach the medical trainees – that when you're in front of a patient, particularly somebody who is ill or scared, time is not simply measured in length, it's also measured in depth. And if you can center down and take a deep cleansing breath and be fully present, even a short period of time with a patient can feel much longer and much more substantive than one might imagine. So I encourage my hospital medicine colleagues to reclaim the fullness of that part of doctoring and to be able to bring their whole self to their role as a hospital medicine physician.

Dr. Karen Wyatt:

I like that. And Ira another question came in from Mary Kay who is wondering if you'd comment on the trend of shorter lengths of stay in hospice care and why we are seeing this recently?

Dr. Ira Byock: It's been happening for a long time, Mary Kay. We've watched hospice lengths of stay get ever shorter. It's actually bimodal, there are some people in long term care who are on hospice for a very long period of time, but up to a third of people admitted to hospice die within the first two weeks after their admission to hospice. So it really is getting very short. I think it's a real problem. I think it is an artifact of the legislation that created the hospice Medicare benefit. The requirement to have to give up treatments for your cancer or your heart failure to receive hospice care has really been devastating, and it causes people to come to hospice care very, very late.

Because it feels like if you accept hospice care you're acknowledging that you're dying and it still feels to too many people like giving up.

One way to change that is to make concurrent care possible within hospice. And again, that's gonna take legislation. But I don't think congress is a barrier. I think if the industry of hospice care – NHPCO and all of our groups – the American Academy of Hospice and Palliative Medicine, the Hospice Nurses Association, the National Association of Hospice Social Workers – all of us – the National Association of Hospice Chaplains; if we all demanded that congress finally revise the Medicare benefits allowing concurrent care, meaning you can have your disease treatment, your cancer care, your late stage cancer care, your late stage heart failure treatments, you can be on a transplant list and receive hospice care concurrently, I think we start to see lengths of stay increase.

And people would be getting better care, frankly.

Dr. Karen Wyatt: That's excellent. Ira – I know we're almost out of time. But there's another caller on the line. Do you have a few more minutes to answer another call?

Dr. Ira Byock: Of course, I'd be pleased to.

Dr. Karen Wyatt: All right. This is Lucy – at least it's my caller ID says it's Lucy from Bailey's Harbor Wisconsin. To Lucy, I'm gonna unmute your line.

Lucy: Thank you for the opportunity to hear this question. When you write your book on policy or a consumer guide or however it comes out, I want to put a pitch in there for you to consider having

non-facility based end of life care centered in the home. I just fear that we are not having enough room in institutions, long term care particularly, because I'm in a rural area that I have this sense.

But we have to take care of our elders – our baby boomer bulge in the home, or there's gonna be nowhere for them to go. And part of that is if we can center the caregivers – if we can center that on family members, and give them the training and the education that they need to attend to their loved one in the home, I think it would satisfy many needs and not make it impossible for those who have that calling to attend a loved one.

Many would have to quit work. So perhaps, maybe there would be a compensation available to pay the family member, do it in the home, have under the hospice umbrella or maybe this is the avenue for doula giving. Anyways, I think that's part and parcel of it and I just want to ask you to further that idea if you do support it. Thank you. I'll just listen now.

Dr. Ira Byock:

Thank you, Lucy. I strongly support what you've said. It makes every bit of sense. Part of what I have in mind with the changing of the hospice Medicare benefit is allowing people to be in their home, or in the home of a family member being cared for. But that also does require as you very perceptively pointed out, that the family care givers have some support. Extended leave from work, and/or some compensation for doing what is really the most important job that any of us can do – taking good care of our loved ones. As B.J. Ellis mentioned, when she called in.

So I agree there are European, Scandinavian countries that do provide some significant support for caregivers to be able to do just that. Some of the more innovative programs that are out there across the country, we started to talk about pace without pace, using the medical support, the transportation, the nutritional support, to help people stay at home that PACE represents. So I don't think the solutions are all in facilities—quite the contrary – I think the best place to be is at home.

Dr. Karen Wyatt:

I so agree with that, Ira. And thanks for making that comment, Lucy.

Dr. Ira Byock:

Yeah, you're right on point Lucy.

Dr. Karen Wyatt:

Ira, I know – we're running out of time. A number of people have typed in and asked about how you feel about physician assisted dying. I know – that's way too big a topic for us to address. We'd

need an entirely different phone call to discuss that topic. I know you've written about your feelings – can you direct us towards something and I could send out a link to some of the articles you've written that everyone could read about your opinion.

Dr. Ira Byock:

So at the top of the hour you gave the website where I post many of the things I've written – IraByock.org – just my first and last name strung together .org. Anyone who is interested can read the things that I've written about physician assisted suicide or aid in dying if you will. I've been very, very out there – outspoken. I happen to be in opposition to legalizing physician assisted suicide. But I would point out several things. One is that we all have to be patient with one another about this issue.

This is a very heated topic for many of us and people who are well intentioned, loving people, can feel vehemently on both sides of this issue. So while I happen to be strongly opposed to legalization of physician assisted suicide, I think it's out of scope of physician practice. It's not what I was taught, what I understand, it's not part of medical practice. I do understand that it's now legal in multiple states and that being against it I'm in the minority of the general public.

Setting that aside, understanding that we really have to agree to disagree, hopefully civilly, and in a friendly way, I would say that the policy agenda that I would like to see roll out, would substantially improve care for seriously ill and dying people. And I think that people on both sides of the issue of physician assisted suicide could come together, agreeing to vehemently disagreeing about legalizing physician assisted suicide but agreeing that by statute, we have to dramatically improve staffing in nursing homes and long term care.

We have to get rid of the ridiculous requirement that you have to give up treatment for your disease to get hospice care for your comfort and your quality of life and your family support. We could agree that medical schools and residency programs have to by law do a much better job of preparing young physicians to care for seriously ill and dying people.

Unfortunately, my take – and I would strongly defend this – the laws that have legalized physician assisted suicide in multiple states have not done one thing to change staffing in nursing homes, to improve medical education and post graduate medical training, they haven't really improved palliative care capacity in our hospitals. They haven't gotten rid of the barriers to hospice care.

All of those things persist in Oregon and Colorado, Montana, Washington, now California. And we need to change that. So I'll leave it there and allow people to read more about what I've written about this issue.

Dr. Karen Wyatt: Thanks Ira – you've done a great job of summing up your feelings about it so everyone knows where you stand and it's IraByock.org – go to the website to get more information. Before we close, I wanted to mention that you are doing some teaching at a symposium that is coming up next month. It is the symposium on palliative care, pain management and whole person care. And so I just wanted to make sure we mention that in case anyone listening might be interested in that symposium.

Dr. Ira Byock: Yeah, this is gonna be a remarkable symposium. I'll be there, my colleague Matt Gonzales will be there presenting. Glen Komatsu—one of the country's best pediatric palliative care and hospice physicians will be there. Steve Pantilat— who runs the PCQN program – the Palliative Care Quality Network—will be speaking as well. And Steve – for those of you who don't know him – is a hospital medicine doctor. He's a leader in hospital medicine, who is also a leader in palliative medicine and well worth hearing.

This is happening in Anaheim California, the 21st and 22nd of September and you can get there by going to the St. Jude Medical Center website – at StJudeMedicalCenter.org. and then look for the palliative care and pain management whole person care symposium. Please, join us if you can. It promises to be a very, very good couple of days.

Dr. Karen Wyatt: Yes, and there are continuing education credits available too, for people that attend that symposium. It sounds fantastic. And I am really excited that you are addressing pain management – that's so important right now when we're in the midst of an opioid crisis in our country and looking at all of those questions. So that will be a wonderful symposium and then I want to mention, if anyone listening has yet not read *Dying Well*.

I know people can buy it at Amazon and Barnes and Noble Ira and I encourage you to get the book. I sent everyone a link to download the reader's discussion guide for *Dying Well*, so if anyone wants to, you can use that discussion guide while you're reading the book. It actually leads you to a lot of questions that are really helpful to kind of explore your own feelings. And that's something people can use in a book group or a workshop or community

education. You could use the discussion guide with the book *Dying Well*. It's really excellent. So Ira, any closing thoughts that you have for us before you go?

Dr. Ira Byock: Only that all of us should claim all of life. That you know – life is a precious gift. But it's a finite gift. The Declaration of Independence says that we have a right to life, liberty and pursuit of happiness. That right persists through the very end of life. While life is not always easy and certainly illness and dying are inherently hard, we can live fully, we can love one another and celebrate this remarkable precious gift of life. I hope that *Dying Well* and the stories comprising it, allow people to think more broadly about the fullness of living. That for me would be the deepest satisfaction I could derive from having done this work and put this book out into the world. I'll just end where we started by thanking everybody for spending the time with us tonight.

And thank you, Karen, for taking the time and devoting so much time to this topic. I hope that people have found it worthwhile. Thank you so much.

Dr. Karen Wyatt: Well I am certain that people have found it worthwhile. So I want to – congratulations, Ira, on the 20th anniversary of your book. Thank you once again for all of your work, all of your wisdom and your generosity in sharing this with us. And it's such an honor to be part of this community with you as one of the leaders of this community. Thanks again. And as Ira said, and as Ira said, thank you to everyone who tuned in. We had a lot of people listening in tonight. Sorry if I didn't get all of your questions answered. I tried to get as many of them answered as I could. To everyone – I'll say goodbye now. Thanks again. And Ira – take care.

Dr. Ira Byock: I look forward to our next conversation. Thanks Karen – you are a gift in this field and a gift in my life.

Dr. Karen Wyatt: Oh, thank you so much, very kind. Take care everyone. Glad we all made it through the eclipse today. Good bye.

Dr. Ira Byock: Good bye everybody. Thanks again.

[End of Audio]