Dr. Lynn McPherson: Hello, this is Dr. Lynn McPherson and welcome to Palliative Care Chat, the podcast brought to you by the online Master of Science and Graduate Certificate program at the University of Maryland. I'm very excited to introduce my guest to you today. It's Dr. Dan Morhaim. Dr. Morhaim has a long and illustrious career. We could use up the whole 20, 30 minutes just talking about all his accolades. He's a physician who's boarded in internal medicine and emergency medicine. He was a politician, a state legislator for 24 years, an amazing career.

I think we met when we both served on the State of Maryland End of Life Council, and a couple of bills that you sponsored, that I had some interest in as well. But the reason we're talking with Dr. Morhaim today is, he's a prolific author, and we're going to be talking about his latest book titled, Preparing for a Better End: Expert Lessons on Death and Dying for You and Your Loved Ones authored by Dr. Morhaim and his wife. So Dr. Morhaim, welcome.

Dr. Dan Morhaim: Great to be with you. I'm a big fan of you and the University of Maryland School of Pharmacy. So thank you.

Dr. Lynn McPherson: Thank you very much. So tell me what prompted you to write this book, and tell us a little bit about what it's about.

Dr. Dan Morhaim: As an emergency medicine physician, just too often in my career, I found myself doing things to patients that didn't feel like care. And I used to say, "We would do this. We would intubate the patient, we'd put in a central line." Then I kind of realized there was no we, it was I, I was doing these things. And many of the times, of course, it was helpful, but too many of the times it felt like it wasn't appropriate. So I started thinking about advanced care illness and advanced care planning. There were a couple of personal experiences as well, because everybody is shaped by this. My stepfather, who was effectively my father, died peacefully at home, and that was the first time, and actually the only time in my life where I've been present in a non-professional way, where somebody died. And I thought, "From a public health perspective, this is the cohort 100% of us are in, and how can we approach this better?"

We're, in fact, the first generation in human history that likely has some say about how we die. A hundred years ago, or 50 years ago, you kind of got your diagnosis. You cut your foot, you got an infection, and you died. Now people, fortunately, thanks to all the science and great work that everybody's done. People are living longer, happier, more productive lives, and that's great, but the end does come, and we can shape that more to our own values and empowerment and respect for the kinds of things that we'd like.

Dr. Lynn McPherson: So I saw on the review on Amazon, which was amazing by the way, that one of the elements you touch on is, what doctors want for themselves in terms of end of life. So I assume that you and your wife had thought this through, and how does this drive how you talk to patients and families?

Dr. Dan Morhaim: It's a collective group. We clinicians have not done a good job about having these conversations. My training was, if the patient died, it was a failure. We would keep people going long past any hope of recovery. And I witnessed that, and it didn't feel right. I was too early in my training, or too young as a physician, to do much about it. But as I got a little more into my career, I started to think about how to approach this differently. And the answer to kept coming is, what did the patient want? It's not what I wanted, or what I'd like to impose, or the system, what did the patient want?

And in 1991, advanced directive laws became universal in the United States. But I asked this question, and I was also on the faculty at the Johns Hopkins Bloomberg School of Public Health, of one of my colleagues. How many people have completed advanced directives? We can look at how many people have sickle cell disease, or how many heart attacks, or cancer, whatever it is, you can look up psoriasis, whatever. And no one had ever done that study. So we got a grant, and did that study, and found that overall only about 40% of Americans had completed advanced directive. It was about half that in the minority population. And so we formally, in American Journal of Public Health, identified this as a minority health disparity.

Then we asked two other questions. If you don't have an advanced directive, and we explained what it was, would you like one? And these were peer reviewed published studies, by the way, with all the fancy stuff, but I'm summarizing. So, 60% didn't have... 90% of the 60% said they'd like to have one, that's over 50% of the adult population.

And then we asked them, where would you like to get the information? We gave them choices, faith-based, internet, attorneys, healthcare, all were there, but healthcare providers, what you and I do, ranked way above all the others. So people want to have that discussion with their physicians, and their pharmacists, and their nurse practitioners, and their physician's assistants, in fact, just about anybody that knows something.

But we collectively don't do that. But with physicians, at least I'll speak for the physician group, there were studies that said we don't really offer to our patients what we would want for ourselves. And that struck me as a disconnect. I know a lot of healthcare people say, "I wouldn't do this to... If it were me lying in the bed, I wouldn't get that." But then we do it to them anyways, and we need to make that synchronous. And it has to do with our own personal anxieties about end of life care, and death and dying. Which I think we have to overcome, and treat people that we'd like to be treated ourselves.

Dr. Lynn McPherson: Absolutely. So speaking of advanced directives, what do you recommend people do? I know that most states have a POLST, or a MOLST. My husband and I have used mydirectives.com. What do you recommend?

Dr. Dan Morhaim: I use mydirectives.com too, but advanced directives and MOLST/POLST are different things. So advanced directives are completed by an individual. You make it yourself, there's State of Maryland forms, AARP has a website. By the way, I always emphasize, it's not just for old people. You and I are probably over 40 by now, so we think about the future. But the three most famous cases in American legal history were women under 30, Cruzan, Quinlan, and Terry Schiavo, most people remember her name. And young people tend to get in trouble catastrophically, major trauma, subarachnoid hemorrhage, big bleeding inside the brain, or some terrible disease. And so it becomes relevant for them as well. In the Terry Schiavo case, she didn't have an advanced directive, her family blew up, it became a big national cause celebre.

You can change it... I like MyDirectives, maybe like you, it's online, it's free, it's easy. It has a lot of good information, but there are others. And whatever you do is fine. MOLST POLST... MOLST stands for Medical Orders for Life-Sustaining Treatment, and POLST is Physician Orders for Life-Sustaining Treatment. It's in many States, not all. MOLST is in Maryland, medical meaning physician, nurse practitioner, physician's assistant. And those are medical orders that are coordinated with the patient, because advanced directives are kind of general care terms, and also who generally are going to speak for you if you can't speak for yourself. More important now in the pandemic than ever, when families aren't at the bedside. Whereas MOLST POLST goes into much more detailed clinical decisions about antibiotics, transfusions, surgery, dialysis. So it's much, much more in depth, and that has to be signed by the provider. And usually we try to get the patient or their surrogate to sign too.

Dr. Lynn McPherson: Wow. When I look at the table of contents, it almost looks like your last to-do list in life, but don't wait till the last minute to accomplish these things. And you don't go really into specifics of like pain and symptom management. I do see you have some information on hospice and palliative care. As you know, that's what I do for a living. It still dismays me how often people don't get a palliative care consult, or patients are so late coming to hospice. What are your thoughts on that?

Dr. Dan Morhaim: Well, there's many different ways to look at it, but one of the way... If all else fails, think about it from a financial point of view, hospice care, you're entitled to six months of service. If you continue to live, it can continue. The average length of stay in hospice is about 14 to 20 days. So in effect, you paid for six months, and you're getting 20 days, that doesn't make any sense. If you paid for six months, get the six months of service. And hospice service is really wonderful, hats off to the people who do that work, and the people who support them. And I know you were really one of the leaders in this, so that goes to you too-

Dr. Lynn McPherson: Well, thank you.

Dr. Dan Morhaim: As well. Dr. McPherson. But too often, both for hospice and palliative care, the attitude has been in the past, and this is what we're trying to change. "Well, we

don't know what else to do. Let's throw in the towel and call those hospice and palliative care people."

Dr. Lynn McPherson: Yeah.

Dr. Dan Morhaim: There's a famous study... Palliative care is more about comfort, and function, and being able to live your life. Hospice care is end of life care, and they provide great support to families. But there was a great study in the New England Journal. Two groups, people with identical lung cancers, they divided them into two groups. They both got the same care, but one got palliative care early. And the palliative care group live longer, spent less money, and were more content with their lives. So it's a trifecta, you're happier, you live longer, and you spend less money. What's wrong with that?

We can look at this from any number of different ways. The book does go into pain management discussions, by the way, and I talk about medical cannabis, and the opioid issue, and things like that. It is in there, because one of the things people fear at the end of life, it's typically, I'm going to be in pain, I'm going to be isolated. And both of those fears can be managed.

Dr. Lynn McPherson: Yeah, that's right. Talking about palliative care, I'm reminded of the expression I've heard Dr. Steve Pantilat from California say many times, "That if palliative care were a medication, every prescriber would want to prescribe it, and every patient would want it." Because it's just an added extra layer of support for the patient and the family. So that's why I would encourage practitioners to consider a palliative care consult when someone's in the hospital or the nursing home. Don't wait so long. As you said, that big study with the non-small cell lung cancer patients, very, very impressive. So-

Dr. Dan Morhaim: That quote is in my book too, by the way.

Dr. Lynn McPherson: Oh, is it? Awesome.

Dr. Dan Morhaim: I actually got that from you, and I got permission from him to use it. So thank you-

Dr. Lynn McPherson: That's wonderful. That's great. So what about the fears with cannabis, or opioids, that people have at the end of life? How would you explain that to a patient? So many times we will have a patient in hospice, and it's the adult son or daughter who says, "Oh, no, no, no, I don't want my mom to be addicted." How would you handle that?

Dr. Dan Morhaim: Well, obviously, if someone's really in hospice care and it's predicted they're going to have less than six months to live, I don't think addiction is really an issue. Constipation may be an issue, but not addiction. In terms of medical cannabis, in the election that just happened, five or six states added medical or personal use cannabis to their regimen, and these were conservative states as

well as non. So I think medical cannabis is becoming more and more accepted, I certainly support it, I know you did too. We'd love to see more science, but in the meantime... I think the deeper question, and I throw this out to this audience and any audience is, think of it this way, we're all going to die, let's accept that as a given here.

So where do you imagine yourself, that you'd like to be, in the last day, hours, minutes of your life? Where are you? Who's around you, what's going on? And that's a five-second thought exercise.

Dr. Lynn McPherson: Mm-hmm (affirmative). There you go.

Dr. Dan Morhaim: Now I've done that to many audiences. And nobody says killed in a fiery car crash. Nobody says shot in a drive by. Nobody says dying in an ICU, in an intensive care unit, long past any hope of recovery, hooked to machines and monitors with all my bodily functions being serviced, my family a hundred yards down the hall in some room.

Now, I want the best of modern medicine, when it's appropriate. I want the best of both worlds, I want the best of modern medicine. But when the end of life care comes, I want to be what everybody else is, at home, with my family and friends around me, pain-free. And that's the better end that we can be aiming for. And so pain management, cannabis, hospice care, palliative care, pharmacy consult, all those things, can play a role. So can music therapy, acupuncture, recreation activities. My advanced directives says, "Take me outside as much as possible, and if I can't go outside, at least put me near a window so I can look outside." I also have to say, "I want control of the remote."

Dr. Lynn McPherson: You deserve it at that point.

Dr. Dan Morhaim: So, all these things are part of it. Medical cannabis is fine in that situation, and I think all the other drugs can be managed perfectly appropriately, whether they're pain medicines, or sedatives, or whatever [inaudible] for comfort.

Dr. Lynn McPherson: I see that you have a chapter on how to deal with dementia. That is such a challenging disease for the family and the informal caregivers. What are your thoughts and what do you discuss in that chapter?

Dr. Dan Morhaim: Well, you could do all the things right, but there are no easy answers to some situations. And dementia is clearly one of them. Maybe we can manage it a little bit better, but it's really a tough one. And there is the dementia avalanche that's coming. More Americans, we're all going to be dealing with this. And we don't know what seriously demented people are experiencing, and how they feel, and how they value their lives. But the important thing is, they should do it before they get demented, or very early dementia, when those first signs come up. If you haven't completed an advanced directive, that's the time to do it, and have the conversation with the people that you've designated so they know what you

want. There's no way to understand that. There is no easy solution to this problem. It's one of those very difficult things.

And there's so many tough decisions. A person's somewhat demented, they fall and break their hip. Do you do treat that, or not treat that? Do you treat it aggressively knowing they may not be able to do the physical therapy required? What if they then get pneumonia? Do you treat that? Well, if it's mild, maybe yes. Or maybe not, if it's real serious.

These are very difficult questions. And they're not hypotheticals. These are going on in every hospital in the United States, every hour of every day, people are trying to make these decisions. And so the element that can be operative, and that is often missing is, what would the patient have wanted?

Dr. Lynn McPherson: Mm-hmm (affirmative).

Dr. Dan Morhaim: And what you have wanted, what I have wanted, what our spouses may have wanted, may be entirely different. And I also tell stories in the book of two people who... One who pulled the plug early, a little bit, you might say, the other who wanted a full court press. In both their situations, I would not have done... If I had their situation, I would not have done that. But it was what they wanted, and that's what I respected.

Dr. Lynn McPherson: That conversation [inaudible] very interesting.

Dr. Dan Morhaim: Yeah.

Dr. Lynn McPherson: Yeah. One of the students in our master's program sent me a link to a video of an elderly woman in Spain, quite elderly, who was a prima ballerina in her prime. And someone in her family, a young man, put headphones on her and played Tchaikovsky's Swan Lake. And she immediately snapped to and did all of the dance movements sitting in her wheelchair. And I sent it out to everyone and said, "If you don't cry over this, you have a heart of stone." But that is a heartbreaking disease.

Dr. Dan Morhaim: One other thing I [inaudible] to mention though, is that not all dementia is Alzheimer's, and people should have a proper workup.

Dr. Lynn McPherson: Absolutely.

Dr. Dan Morhaim: Because there's vitamin deficiencies, a condition called hydrocephalus, there are a whole bunch of things. They don't come up too often, but you shouldn't get the workup because some of them are treatable, or at least the damage could be minimized before we end up with that term at the end-

Dr. Lynn McPherson: And some of the medications we use for Alzheimer's can be harmful in other dementias, like Lewy body, for example. So it's very important.

What else do you think is a gem in your book? There are so many, what else should we talk about? Would you like to mention?

Dr. Dan Morhaim: I think the key thing is the empowerment issue. And a lot of people... The healthcare system has a tendency, despite all the caring and compassion that's out there, kind of pushing people one way or another. You may have to be your own advocate for this, or the advocate for the person... If you're their surrogate, they've designated you. By the way, on the surrogate thing, you can also say in your advanced directive, I choose this person and that person. But you may have in your family an annoying relative who takes over conversations. You can say, "Please, don't let cousin Fred in the room when you're discussing my end of life care." You can anticipate some of these things. There's a lot of stuff you can do within the advanced directive. But I think it's taking advantage of the tools that are before us, that we collectively don't.

Our culture values... We say we value individual autonomy, individual respect, and respect for values. But in this one arena, which all of us are in, only 40% have completed advanced directives. In our study, and by the way, in more recent studies, that number hasn't budged. So this is something where you can actually shift the likelihood about what happens to you according to your values. And you may have to be a pretty strong advocate. Look, I get it's a hard topic. I get it makes people uncomfortable. It makes me uncomfortable. I got elected six times to the Maryland General Assembly, won six elections, and people would say to me, "Delegate Morhaim, what are you working on?" I'd run down all the issues, and then I'd say, "Have you completed your advanced directive? I want to talk about your death, the death of everybody you know, also please vote for me in the next election."

And people would say, "what do you... You're talking about all this stuff. Do you want to win the election? Are you Dr. Doom and Gloom?" And actually the opposite happened. I got reelected every time I ran, and people really appreciated it. They wanted someone to break the ice. Because we're living through this, we're living through it because we're all human. We know that life is finite. We're not immortal. And that's, in fact, what makes life beautiful and precious. And so we have an opportunity here that nobody's had before. It may be difficult to think through, but once you do you, the burdens really come off. It's amazing. And I'd love to share an anecdote about that, if I may?

Dr. Lynn McPherson: Yes.

Dr. Dan Morhaim: This is when it really got driven home to me, many years ago when I was a young doc. And the call came in, an elderly lady was brought in, and it was clear, right from the beginning, she'd had a major neurological catastrophe, an intracranial hemorrhage, as it turned out. We did the whole workup and stuff, and it took hours to go through this. The calls went out to the family. They started coming in

in small groups and we put them in the quiet room where we could have this discussion.

And I observed the family, and they were really getting in arguments with each other, as sometimes happens when families get together, whether it's holiday time or a stressful situation like this. And the ones who knew her best said, "Let grandma die in peace." And the ones who knew her less, or came from farther away, looked at me [inaudible] and said "You do everything for her." Well, it turns out she had an advanced directive. It was obtained for me, I read it and it said, "If I'm in extremis, and there's no hope of recovery..." And we had the neurosurgeons and the neurologists, and we went through the whole thing, and there was just terrible intracranial hemorrhage, bleeding inside the brain.

And I went back to the family room, and I said... And all hell was breaking loose. And finally they quieted down, all the screaming, and yelling, and tears, and accusations, and guilt was all coming out. And I said, "Okay, listen, let's all take a deep breath. This says, If I'm in this state, no heroic efforts. So I'm going to go in the room and I'm going to disconnect the medicines, I'm going to take the tube out of the wind pipe, I'm going to do all these things, and you can come in there with me." And you might think at that moment, it would get more explosive. Actually it quieted down completely. The burden was lifted.

We all went in the room together. I did the little medical procedures that I had to do, and then I stood in the back of the room and watched this family, that only a few minutes ago was that at each other's throats, family friction. They gathered at the head of the bed, they stroked her brow, they held her hand, they whispered in her ear, they said things. They may have sang songs, and said some prayers, whatever they did. And I was looking at this woman, I thought, "I'll never get to talk to her. I don't know her, but she has enlightened me and giving me a gift. And she's given a gift to her family." If you're awake and alert and competent, you make your own medical decisions. Advanced directives and all these things come up when you can't.

And so she took this burden off her family. Her family came together in closure, and I thought, she's really given me a lesson here. We say we love the people we love, but we don't act like it, we don't take care of this paperwork. We don't do this little bit of work that would take care of them. We don't want to leave them in that situation. Like this family could have been, like the Terry Schiavo family was, or like other families are, that I see all the time in my clinic work, and maybe you do too.

The next day, I sat down with my wife. We had just had one little baby at the time. I said, "We're going to complete our advance directives right now. I'm not going to leave you in this lurch. And I don't want you to leave me in that lurch either, that situation." So that drove it home for me personally. And that also launched me on this trajectory.

Dr. Lynn McPherson: Wow. That's a lovely story. I know when my mom was ill, she did not have an advanced directive, and didn't want to talk about it. My mother hated what I did, for a living, her entire life. She hated that I did hospice, she'd say, "They all die." I said, "I know mom," but then we did have a conversation. And sadly, three months later, I had to recall that conversation to help direct her care. But you're right, it did take a big burden. It's so much anguish involved in those kinds of decisions.

Dr. Dan Morhaim: There's already anguish, but by doing some paperwork, you relieve a lot of that anguish. Nobody gets out of here alive, as I like to say sometimes, "Despite all the great advances in medical care, the death rate in this country is the same as every other country in the world. One per person." I try some levity in there too, because I get this is tough, and bring it up as hard. But I think everybody who's listening to this, I hope they will take this to heart.

In the book, Preparing for a Better End, and the website I'll plug, thebetterend.com, I try to walk through, in a very practical way, here's the kinds of things that can happen. Here's some of the choices, here's what you might have to do, or not do. But it's up to you. It's not preachy. I'm not telling people what to do. I'm suggesting how they can approach this, because it's going to come for all of us. And you can put your head in the sand, or you can deal with it with enlightenment and empowerment. I'd like the latter.

Dr. Lynn McPherson: Absolutely. So who do you think should buy this book? Everybody in North America, or the whole world?

Dr. Dan Morhaim: Yes, absolutely. That was the easiest question you've asked. I do believe that everybody over the age of 18 should complete advanced directives. So when I brought it up to my, now adult, children, one of them said, "Gee, dad, when I was 16, I checked organ donation." People... Teenagers are aware that at the end of life, care comes. And when they're 18, they're age of majority, and they're adults. And I think we should treat them as adults. And what you choose at 18, obviously, is going to be different than when you're 28, 38, 58, 88 or 98. And your life situation may change, relationships may change, your values may change, your spiritual orientation may change. You can update an advanced directive anytime you want. Mydirectives.com you can sit down this afternoon and change it and do it [inaudible]

Dr. Lynn McPherson: They even send you a reminder once a year saying, "Do you want to revisit your advanced directive? Do you want to make any updates? You want to review it?" So they do a nice job with that.

Okay. So I'm going to brag on you for a minute now. So you'll just have to sit there and listen to it. So when I went on Amazon, I see that your book is number one in the field of geriatrics, number eight in public health, and number 17 in ethics. And when you consider that Amazon carries 32 million books, that's pretty awesome, that's pretty sweet. And your book has earned many

endorsements from diverse groups and very distinguished people, including Dr. Leana Wen, Dr. Leon McDougle, who's the President of the National Medical Association, which is the oldest and largest organization of black physicians in the U.S., two U.S. senators, faith leaders, and many, many more. And you just mentioned the website, www.thebetterend.com. Can they go there to order the book? Or do you recommend Amazon? What or do you think?

Dr. Dan Morhaim: Whatever works. If they go to the website, and they go to the ordering tab, they can see Johns Hopkins Press, which gives them a 30% discount [crosstalk] for those who want to do that. But Amazon is fine. It makes a great holiday gift. In fact, it's a good gift anytime, for anybody.

Actually I do have one friend who's in his fifties, and his siblings, three or four siblings I think, were all in that same age range, their parents were in their eighties. He had a heck of a time having this conversation get started, so he bought everybody a copy of the book, gave it to them, and then they all read it. This was the first book back in 2010, called The Better End, which was endorsed by Maya Angelou on the front cover.

Dr. Lynn McPherson: That's awesome.

Dr. Dan Morhaim: But he gave it to all of them. They read it. And then they had a conversation because the book brought them all up to the same starting point. It was an easier way to break the ice with their parents, than sort of a confrontational intervention, so to speak. And so a lot of people have found it useful that way. I know there're some attorneys who do estate planning.

It's like when I was a young person, we dealt with the will part, our shaky finances at the time, and who would take care of the baby if we weren't around. We left the advanced directive to the side, that happens a lot. So this helped her clients complete the advanced directive. She bought the book in bulk, and gave it away to her clients with a sticker with her name on it. And they were thrilled. Not only were they thrilled because it helped them deal with this issue, but a lawyer gave them something for free.

Dr. Lynn McPherson: There you go.

Dr. Dan Morhaim: They were very happy. It got her referrals and built her business.

Dr. Lynn McPherson: Absolutely.

Dr. Dan Morhaim: It applies to everybody, whether you read the book, or get the book, or not, I think the book's the best thing out there to get you through this stuff. But take care of the paperwork, do the right thing for yourself and your family.

Dr. Lynn McPherson: Well, I'd like to thank you, Dr. Morhaim, not only for our time together today, but for your work throughout your entire career in this very sensitive field.

You've done so much to advance healthcare. And I know I'm personally appreciative, and I know the citizens of Maryland are, and now with your book, and your wife's collaboration on the book, people worldwide can read it. So thank you so much. I appreciate your time.

Dr. Dan Morhaim: Always good to be with you. Thank you.

Dr. Lynn McPherson: Absolutely. So I'd like to thank Dr. Morhaim again, and thank you for listening to Palliative Care Chat Podcast. This is Dr. Lynn McPherson, and this presentation is copyright 2020 University of Maryland. For more information on our completely online Master of Science and Graduate Certificate Program in Palliative Care, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.