

Jeffrey Kahn Interview

Karen Wyatt: [00:00:00] Welcome to End of Life University on YouTube. Today, I'm sharing with you a conversation I had with Professor Jeffrey Kahn of the John Hopkins Berman Institute of Bioethics about medical aid in dying, and this was covered in a podcast episode the institute produced recently titled "I Need You to Help Me Die."

And, you'll find this very interesting, thought-provoking conversation about the ethics of medical aid in dying. So stay tuned for that. Make sure you subscribe to this channel down below, and also subscribe and leave a rating and review for the podcast wherever you happen to listen. And go to eoluniversity.com/support if you're willing and able to make a small financial contribution that will help keep this channel and the podcast on the air.

So we'll move on now with my conversation with Professor Jeffrey Kahn[00:01:00]

Today I'm very happy to welcome my special guest, Professor Jeffrey Kahn who is a bioethicist, researcher, and author. He is a professor of bioethics and public policy at the Johns Hopkins Berman Institute of Bioethics and professor in the Department of Health Policy Management at the Johns Hopkins Bloomberg School of Public Health.

Professor Kahn has published several books and more than 150 research articles in bioethics and over 100 commentaries in popular media with a focus on the intersection of ethics and health science policy, including human and animal research ethics, public health, and ethical issues in emerging biomedical technologies.

And today we're gonna be talking about a recent podcast episode that the Berman Institute of Bioethics released on their award-winning podcast, Playing God, and the title of the episode is [00:02:00] "I Need You to Help Me Die," and it's about medical aid in dying. And so Professor Kahn, Jeff, welcome and thank you so much for talking with me today.

Jeffrey Kahn: It's great to be with you and thank you for having me. Looking forward to our conversation.

Karen Wyatt: I had the chance to listen to the podcast episode which was really wonderful. your production is very beautiful and very professional. but I

wanted to ask first of all about the decision to focus on medical aid in dying and what prompted that.

Jeffrey Kahn: It's a good question. so I should say maybe to just a little bit about the podcast. This is our second season. we had a little hiatus between seasons one and two, but we're now back in full production, and i- the idea of the podcast, in addition to bringing bioethics topics to a broader audience through the medium of podcasting, we really like to focus on first-person stories that raise bioethics [00:03:00] issues, and, and show some tension in the personal story and kind of leave listeners thinking about, what would they do if they were in a situation like the one that we're, we're covering in a particular episode.

And as you said, the first episode of this new season is about, a first-person story, related to medical aid in dying. it's a topic that y- I guess I would say is evergreen, but that doesn't-- that's not a compliment, right? it's been a, an issue for a very long time in bioethics, one that I think has, people have very strong feelings about on both sort of sides of the issue.

It's a really important issue for everybody to think about because we all die. We all have family members who, face end of life decisions and it's a very relevant issue for, professionals and for the public. And so we thought it was a really good topic to launch this new season with.

Karen Wyatt: And, it's very effective that you begin with a personal story, and I [00:04:00] believe it's journalist, Esme Depez. She's talking about her own father with a diagnosis of ALS, who made the decision to use medical aid in dying, and her family's experience with that, which is so well told, and also it's very compelling to understand the reasons why he made the choice and why his family ended up supporting him in that.

Jeffrey Kahn: Yeah, absolutely. And as you say, it's very compelling to hear a person who is going... went through this. we obviously don't hear f- we... I shouldn't say obviously. We don't hear from her father. His name is Ron, or his name was Ron Depez. he's already, he- his life has already ended by the time we, hear, Esme talk about it.

But she's an investigative journalist. That's her professional, her role then and now. And so she's a very good storyteller as a result, right? She knows how to, to tell stories. she's, I think, a very wonderful, representative of, what they [00:05:00] went through.

but you get a sense of how challenging and difficult it was for her and her father, of course, and the family, at a time when in Maine, which is where, her father lived, he was the, among the very first people to take advantage of the law that had been passed in that state.

So in addition to being a challenging issue and a challenging topic, they con- they were confronted with all of the obstacles of being first, how hard that was for them to navigate. And you get a sense in the context of the story that you have to work really hard to take advantage of what for many of us feels like a right that people should, not only have, but be able to act on.

and you get a sense of the difficulty of acting on it in this particular story.

Karen Wyatt: Yes, that comes through loud and clear, that they're, the way the law is set up, it has really built-in obstacles in a way that the patient and the [00:06:00] family have to get through before they can even utilize the law, not to mention other problems with access where people live because they may not be able to find physicians who will support it.

They may, there may not be a pharmacy that carries the medications that they need. A- and so it actually takes quite a bit of persistence on the part of the patient and family.

Jeffrey Kahn: Exactly. and you get a very strong sense of that in the way that Esme tells, their story. and I don't remember the exact distance, but I, there's one pharmacy in the state, and it's b- quite a, hundreds of miles away.

m- so it's as you say, it takes persistence, it takes, a fair amount of wherewithal, and it takes some, practical effort in order to act on, a- as I said before, what feels like when we argue about it or talk about it, debate it, from a philosophical, perspective, feels like a right that individuals ought to have.

But you fine, sure, b- let's have, pass a law, but then all the challenges of actually, making it, uh, a, a [00:07:00] real possibility for people, become clear. And I think that's a, that's a big what we should be paying attention to as more states enact, medical aid in dying legislation.

Karen Wyatt: in the podcast, point out that some of parameters laws which end up feeling like obstacles are ac- are actually put in to protect healthcare providers in a way from any type of liability. Could you mention that again?

Jeffrey Kahn: yeah. For, yeah, for sure. It's interesting, and Esme I think herself says they're not flaws, they're features of the, the way the law is, um, is set up in Maine, and I think, uh, Maine is not unique this way.

and individuals need to be able to, to take the, uh, the medication themselves, and by that, it, it means they have to be able to, you know, put- pick it up in their, with their hands, put it in their mouth, and swallow it. So no one can help them do that. That would cross a line between aid in dying and, and you could be prosecuted for homicide [00:08:00] in, in many states if you, you know, d- did something to actually put a drug in the mouth of a patient.

Um, there needs to be, um, more than one physician. I think in Maine it is at, at least two who independently certify that the individual is within six months of dying, so they're at the, you know, the end of their life, um, that they're of sound mind and body and can make this decision themselves, and that they are making that decision willfully.

So m- many steps, um, which, as you say, are, are meant to be b- I think, but protective certainly of the healthcare, um, professionals involved, but also of the, the p- the individual from being, you know, taken advantage of or exploited. Um, and so A- as you say, um, they're all steps that are part of the law, which means it takes, again, a fair amount of wherewithal, it takes, uh, persistence, and it takes time, um, to move from y- a decision to actually acting [00:09:00] upon it.

And in the case of someone like Ron DePrez in the, in, in the story, he's suffering from, late stages of, of ALS, as you said in the introduction, and, you know, the longer you wait with a neurodegenerative disease like that, the, the harder it will be for the individual to be able to take the medication him or herself.

And so as we hear in the episode, towards the end of his life, he couldn't walk anymore, so somebody had to carry him upstairs to his bedroom where he slept. And so you realize as you start to lose function, you also start to lose the ability to act upon this right to you end your life on your own terms.

Karen Wyatt: And that is such a dilemma because there are certain diagnoses, Alzheimer's for one, that e- end up precluding people who may, who may be some of the people who need a, a law like this in a sense the most at the end of life, but they're not able to use it because the [00:10:00] trajectory is, is so long between the time that they, their health declines before death and, uh, they simply can't meet the parameters of the law.

Jeffrey Kahn: That's right. A- and there, a- and that's a point that we make in the episode, as you are rightly pointing out, th- that it is a, I don't wanna say narrow, but a limited category of people who can qualify. And so as you say, people who suffer from Alzheimer's, and I went through this with a member of my own family, and you realize that i- whether the individual would have wanted it or not, it's too late by the time, you're in a position because they're not eligible any longer.

so th- it's tragic and it's, it's one of the challenges I think as, as- We understand more about cognitive decline and dementia, m- trying to figure out ways that individuals might be able to execute advanced directives about the end of their lives in a way that will maybe help people like those you're describing also act upon what we think of as a right to, [00:11:00] to end their own lives.

Karen Wyatt: And, I will admit the very first time I heard about medical aid in dying as a physician, it-- my own father died by suicide when I was quite a bit younger, and I instantly had a negative reaction to medical aid in dying because of that experience with suicide and thinking I could never help someone cause pain like that to their families, like what I went through.

But I had to be educated that it is actually not considered suicide because it's a rational choice that in- often involves the family and everyone participates in. and, at the same time, it's also not euthanasia, which is legal in some countries. So could you talk about this unique place where medical aid in dying resides?

Jeffrey Kahn: Yes, and a- as you say, it's different than either suicide or, euthanasia. one important feature of medical aid in dying is that the individual has been, certified [00:12:00] as being at the end of their life, and so th- that's a feature, right? it's a way of allowing people to control what, amount of suffering they're willing to endure.

it's a way for people to control whatever the indignities of the end of life they feel might be coming. and it's a way to avoid what some people feel like is a, maybe an over-medicalized, death. as you say, it almost always, I would say, involves, loved ones in the decision-making, and, it's not the same as somebody saying, "I'm gonna take my own life and leave behind people who will suffer as a result."

It's quite different than that. I think it's also important to say, in a large proportion of case- of individuals who are actually prescribed the medication for medical aid in dying, they don't end up using it. it... the experience is a little

bit limited because there hasn't been, there hasn't been that many years of that many states with laws that permit it.

But in Washington and Oregon, which have the longest standing laws, [00:13:00] there are substantial proportions of people who, end up being prescribed, medical aid in dying medications who don't use them. it's a way of their being able to control the end of their life on their terms, but they don't end up feeling like they need to do that.

so I think that's an important aspect of MAID, and laws. It gives people control and that's a really important thing. euthanasia is a different thing altogether in that it's, people actively, being killed, by usually somebody who's a medical professional, but they're not, necessarily at the end of their life.

someone else is actually doing the act that ends up ending the life, which is different than medical aid in dying. And as you say, it's, available in a few countries in the world, not in any states in the US, however.

Karen Wyatt: And I think it's in- interesting the fact that many people who receive the prescription don't end up using it 'cause it tells us it, it isn't so much about people wanting to die sooner.

It's [00:14:00] mainly that people want some control over how much suffering they might experience, and there's a lot of fear around that. And perhaps they can approach their end of life, um, more comfortably in greater peace when they know, "I have this alternative, I have this backup plan just in case I need it," and that makes so much sense to me.

Jeffrey Kahn: Yeah. I think that's exactly right. It's... And you said it very well. and I think people, y- um, there are all sorts of reasons why people, fear the ends of their ends of life, and a lot of it has to do with the way either we've experienced other of our family members going through end of life experience, sometimes the way it's portrayed in, television or film.

but I think that people sometimes say, "I don't want that," and they point to a, an experience or something that is portrayed, in terms of a h- a heavily medicalized, end of life experience with tubes and ventilators and things that people say, "I just don't, I don't want that, and I want to be able to control the way I leave this world."

And so the, the [00:15:00] prescription of the medication offers them that, that tool. and as you say, not everybody needs to use it, and oftentimes people don't

need to use it. I think there's also a sense that people are afraid of suffering, as you said, and, I think the better the medical profession is at, palliative care and hospice care, the more those concerns can be alleviated.

I don't think it goes away altogether, but, I think they, obviously they go hand-in-hand when we're talking about pain and suffering and end of life.

Karen Wyatt: Yeah, so very true. And on the healthcare side of things, as a... I'm a primary care physician and also who's done hospice medicine, but I have many colleagues who have a lot of negative feelings about medical aid in dying themselves.

And so I feel like that's something we really have to work on education on the one hand, but also understanding these deeper ethical issues around what is the role of a physician-

Jeffrey Kahn: I think you're right. I'm not a physician. [00:16:00] I'm-- my-- I have a PhD in philosophy and, I did, science in an-- as an undergrad, and I have a public health degree, but I'm not a healthcare professional.

that said, I'm the director of a bioethics institute, a large one, at Johns Hopkins, and I have many colleagues who are physicians. And I will say, we, we-- some of our most heated discussions in faculty meetings are around when the state of Maryland, where I live and most of us live, is considering, the passage of medical aid in dying legislation in our state.

And we have, colleagues who go and testify on both sides, right? Who are close colleagues and good friends, and they don't see this in the same way. and I think there's a concern on the part of those who, object to it, for medical professionals like themselves being involved in, people's deaths in any way, shape, or form.

They're-- they see their-- the role of healthcare professionals as preventing death, right? Of helping people get through an, a illness and disease and not helping them to [00:17:00] die. on the other hand, we have colleagues who say, listen, I'm doing the m- the best that I can, of course, to help people get better, but sometimes the best thing we can do is help people, suffer less and experience an experience that is, the best for them at the end of their life."

both those things can be true. I guess for me, I'm happy for my colleagues who object to say, "I just don't think I can participate in this." It's a kind of conscientious objection, but that's different than saying it shouldn't be

permitted. and that's the position I've long held since I was a graduate student, in fact, and I still feel that way.

and it's interesting that we have colleagues, who feel so strongly that they think that just n- there's just no role for medical professionals in what we call MAID and what we used to call, physician-assisted suicide, to harken back-

Karen Wyatt: ... to the

Jeffrey Kahn: terminology you were mentioning earlier.

Death with Dignity. There have been numerous, terms for this concept. but I think there's [00:18:00] been a consistent, group, I don't wanna say majority or minority, I don't know, of physicians who just think it's inappropriate for them to be involved.

Karen Wyatt: Yeah, and I agree with what you were saying, that certainly every physician has the right to decide what they could be involved with or not.

Excuse me. but many of my colleagues cite our Hippocratic Oath, "Do no harm," but then my question always is, but who decides what harm is? And, because can we look at harm from the eyes of the patient? And is it not harmful for someone to have to live with severe suffering in order to die a natural death a month or so later, but to spend that entire time in intractable pain or suffering?

Jeffrey Kahn: Yeah. I think you're right. And, and- the Hippocratic Oath is a, is, a kind of touchstone for many who i- in this debate, but of course many of the things that happen in medicine cause harm, but there's a, an offsetting benefit [00:19:00] to the harm that's caused, right? And so if you amputate a patient's limb with somebody who's got gangrene, you're causing them harm of course, but you're saving their life in the process.

And so it's never as simple as, don't cause harm. and the argument in the case of MAID is that it's, it may be harmful, but it is providing the benefit, as you said, of relieving suffering, at the end of an individual's life, and again, on their terms. we haven't used the term autonomy yet or autonomous decision making, but that's really, I think a big focus here.

That individuals get to decide many things in the context of their own medical care. You can refuse life-sustaining, life-saving treatment. You're permitted to do that, right? And then the argument from an ethics perspective is individuals get to decide for themselves. So it seems a natural extension of that to say if

people get to refuse care that will save their life, shouldn't they also be able to, choose the way that their life will [00:20:00] end when they're at the end of their life.

Karen Wyatt: It's interesting. This is really a, it's a growing edge, I think, in, in healthcare in general, but also for end of life workers as we grapple with this and figure out what side of the argument to be on. And I'm hoping there'll be a day when we can all agree for autonomy, but also agree that it's very difficult, and even the patients and families who are making the decision, that there's no easy answer.

I do not for one moment think that it's easy to decide that you're gonna take the medication. And even, when Esme described her father had planned to take it on a Monday, but then wanted to eat the dinner that was prepared for him- ... and postponed it for a day because he didn't wanna miss the dinner that night.

It's not easy.

Jeffrey Kahn: He wanted his favorite food.

Karen Wyatt: Yeah.

Jeffrey Kahn: And I think that's, that's real. That's human. and it's, part of why stories are compelling because we all can relate to, living an experience like that. but, you're [00:21:00] totally right. it's a challenge.

We don't die well as humans, I think, and many c- certainly not in our culture in the United States. We haven't really figured this out yet. and maybe we won't. We're complicated, organisms. it's not easy for us. It, and lots of things are not easy for us, so I don't know that why we should, categorize a death as being somehow special that way.

but we've spent a lot of time focusing on the ethics of a lot of other aspects of healthcare, and so it feels appropriate, that we are spending this kind of energy and focus on the end of life, too.

Karen Wyatt: Yeah. And I noticed that your podcast is titled Playing God, and so I think that's a good, that's a good, last topic to consider here.

And I believe the physician, Dr. Jennifer I- Iding- I'm not sure how to pronounce her last name. Eidington?

Jeffrey Kahn: Edington.

Karen Wyatt: Yeah. Edington discussed, is it playing God to write the prescription for a patient to use medical aid in dying, but is it not playing God to put a patient on a ventilator who might [00:22:00] have died without that?

Jeffrey Kahn: Yeah. I think your question's a rhetorical one 'cause I think, of course, the answer to that's the notion of playing God in both examples. And modern medicine's amazing in its ability to, bring people back from what clearly would have caused them to die in a different, century, if not a different decade.

and so the title of the podcast is playing god, all lowercase with a question mark at the end. Which is part of the point here. is it playing God? And i- if it is, then, as y- as you're rightly pointing out, when is it appropriate and when is it not? When have we crossed that line?

And that's really the point of these stories, to help people think that through. and people can, we hope, will have different opinions about the answer to that question and talk about it. So if anything, we hope that people will listen and think about the story of Esme and Ron DePrez, and maybe at the dinner table the night that they heard it, raise this conversation with their friends or their family or both.

'Cause it's important to talk this through so people [00:23:00] know what you want.

Karen Wyatt: And that's the point of our conversation, to direct people toward your podcast and the episode, Season 2, Episode 1, I Need You to Help Me Die, because we all do need to give this some thought. We never know when the issue might arise in our own lives, um, personally, professionally, and w- we need to start considering it and be prepared for these difficult discussions.

The more we can come together and really work through it, I think the better off we'll be as a whole society.

Jeffrey Kahn: Absolutely. A- and I think, Part of what we have to hope is it doesn't take the kind of wherewithal and effort and, insight and in, and, ability to navigate a system that we hear about in the episode, because many people just couldn't do that, right?

So there's a maybe a last thing to say is if this is important, and we think people should have the opportunity, then we need to make it available in a way that people can [00:24:00] access it, right? And not make it so hard. Obviously, there need to be, guide rails and, rules and ways to go about what is a very difficult and life-ending decision, right?

That's done in an ethically appropriate way. But if we think it is ethically appropriate, then we need to make it available to people who choose to seek it.

Karen Wyatt: And that's such a good point. And I do want to direct listeners, I'll leave a link in the show notes where you can find the full podcast episode, and I really encourage you to listen to it.

you come away with a, with such a positive feeling about first, that Esme was willing to share her family's experience and talk all the way through the process, and including, the beautiful last moments with her father. And, it's really worth listening to, so I hope everyone will check out this episode.

And, Jeff, I just wanna thank you so much for j- joining me here to talk about it. And I, for one, I'm gonna check out the Playing God podcast 'cause it sounds like I'd enjoy all of your [00:25:00] episodes.

Jeffrey Kahn: I hope so. nice to talk with you too, Karen, and really pleased to have had a chance to talk with you.

Karen Wyatt: Yes. thank you once again for giving me your time today.

Jeffrey Kahn: My pleasure.