

Episode 4 with Anna Rosenblatt

[00:00:00] Welcome to We Really Need to Talk a podcast about the conversations we could be having with our loved ones. These are conversations with the power to improve the way we live, the way we age, and the way we die. Talking about what we want for the end of our lives is not easy, but we've found it to be useful and powerful.

And suspect that others may as well. My name is Elizabeth Bergman, associate Professor of Gerontology at Ithaca College. And I'm Lisa Richards, the program coordinator for the Finger Lakes Geriatric Education Center. We are co-hosting this podcast from the studio at Ithaca College where we work. Together in the Gerontology Institute, we spend our days immersed in teaching, studying, and developing programs on topics many would prefer to avoid altogether or maybe just whisper about fearfully.

We have seen firsthand time and again the consequences of not talking about the end of life, but we've also witnessed the power of [00:01:00] talking about it, and that is our motivation for making this podcast.

Hello and welcome back to, we Really Need To Talk. We're so glad you joined us. Today we're gonna talk about an important healthcare document, A healthcare proxy, with our guest, Anna Rosenblatt. We'll discuss what a healthcare proxy is and why it's important. We'll also talk about what to consider when choosing a healthcare proxy and what happens if you don't have one.

But first, let's introduce our guest. Anna is a practice facilitator at Cayuga Health Partners in Ithaca, New York. She also teaches healthcare management at Syracuse University. In the past, she worked as a program coordinator with us here at the Ithaca College Gerontology Institute, and as a project manager at the Mount Sinai Health System in New York City.

She is an Ithaca College graduate who went on to earn her master's in public administration with [00:02:00] a focus on healthcare management at New York University's Robert F. Wagner School of Public Service in 2016, while in New York, she also earned a certificate in the Art of Dying from the Open Center in New York City.

City. Anna is just the person to talk with about healthcare prox. And her dog Lucille, but that's a different podcast. One of her professional interests is to help

people understand and navigate end of life care, she thinks, and we agree that patients should be empowered to ask for high quality person-centered approaches to the treatment of serious illness.

That same personalized patient driven care should also apply to end of life situations. It's so great to have you here, Anna. Really good to see you. We've been wanting to get you on the show, so can you tell us a little bit about what shaped your interest in these issues? Healthcare proxies, end of life stuff.

I think I've always been really interested in people and I think that's why even in undergrad, my undergraduate major was documentary film and [00:03:00] history, cuz I liked people's stories and people, and my own mom died when I was pretty young from early onset Alzheimer's disease, which she was sick with for about seven years.

So as a young adult, as a 15 year old and a 16 year old, I was already a care partner with my father and doing a lot of that work. And then additionally, when I was in college, one of my best friends dad died over a Christmas break and I ended up just kind of moving in with them almost for two weeks and trying to be helpful.

So I think I saw a lot of serious illness and end of life issues kind of come up in real life. And as a person who doesn't get easily emotionally overwhelmed. I was kind of able to be present and helpful in a way that I realized later was pretty unique to me. It was just who I was. And then, so I ended up being a hospice volunteer at the local hospice in Ithaca when I was in college, and really enjoyed that work and felt really useful and powerful.

And so all of these issues became things that [00:04:00] I felt really attached to and felt angry about some of how it was done, and wanted to learn more and figure out why stuff was the way that. . Yeah. That's such a young age to be exposed to all those things. You know, if you're lucky you don't have exposure to that stuff until you're a little bit old, you know, later in your life.

I would say those are really formative experiences. Okay, Anna, so let's start with the nuts and bolts. What is a healthcare proxy? So a healthcare proxy is an official document that would formulate designate someone in the case that you yourself became incapacitated to make decisions regarding your healthcare on your behalf.

Okay. So if I was in a car accident and was not conscious and able to speak for my own wishes, this is a situation in which a healthcare proxy would be relevant.

or if I had a progressive disease that at some point rendered me unable to advocate for myself or communicate my own wishes. [00:05:00] This is also a situation where that would be relevant.

Yes, exactly. Okay. All right. So it seems like it's something that would be applicable to a lot of people, regardless of how old they are or what situation they're in. Usually minors don't need them. So if you're under 18, it's pretty straightforward that your parents would make all of your medical decisions more or less for you.

If you're an emancipated minor, that might be different, but I would say anyone 18 years old or older should have a healthcare proxy. Okay, great. So Anna, there's. Planning documents like living wills and other forms. But it seems like the healthcare proxy is an important one. And can you talk a little bit about, you know, why it's important and why it might be more effective than some of these other advanced care planning documents you hear about?

Sure. I definitely think the healthcare proxy is the most important form. That's a hot take though. I would say. I don't even think a d DNR is as important as a healthcare proxy. I. The biggest difference is that you're designating [00:06:00] a person to speak on your behalf, who can make didactic and fluid decisions based on new and incoming information because they truly should understand your values and what's important to you and what you might be willing to try for a little bit.

But there would be some. Line in the sand. That's hard to tell, especially when you don't know if this person would be making decisions for you based on a traumatic event like a car accident, or it might be different if you kind of know that you have a degenerative illness that over time, Will look different and you'll no longer be able to make those decisions for yourself.

So I just tend to think that a person is a better decision maker than a piece of paper because they can take in new information and change their mind. The other thing is, in especially acute healthcare situations, papers are hard to find. So I think having a human who can be present and advocate on your behalf and ask questions and be a physical presence sometimes in the room and make sure things are [00:07:00] happening the way that you'd want them to happen is a more powerful.

Tool to have on your side, right? So somebody who really knows you because you might think you never wanna be intubated or you never want this or that, but there may be some situation that comes up where if they did something like

that, it could change things a lot for you. So you want someone who really knows and kind of can assess the situation and make a reasonable determination based on what they know about you.

Yeah, and I think there's a lot of situations where if you say, I never wanna be intubated, the problem with some of those is like, you can't have surgery. Like they won't do certain surgeries on individuals if you have a D N R because they literally have to revive you during a surgery. And that happens commonly for a lot of people.

They'd say, well, that would be fine if I was in surgery and you had to do that, that's fine. But I mean like, I don't want to, if I was at home or at these situations, and it's. A DNR form or these other forms isn't gonna yield that level of specificity and detail. Right. Versus a person who's making those decisions would understand the differences in those situations and how you [00:08:00] might want them handled.

Yes, absolutely. So, Anna, you, you used the term d n r. Can you tell us what D NR stands for and what, what a Dean R is? Yes, it is. Do not resuscitate order. You see it all the time on Grey's Anatomy when people are revived and C P R, and it works a lot more effectively on Grey's Anatomy than it does in real life, and it is pretty traumatic to watch.

So you have stories sometimes of families who are seeing a loved one have C P R, and it doesn't help the way that they may be envisioned. And it's an incredibly traumatic thing to witness and have done to a body, I mean, to do. C p r effectively, you're breaking their ribs. Might be too dark for this podcast

So Anna, when should somebody really think about getting a healthcare proxy? I mean, I know you said earlier about minors, um, their parents, but you know, so I think that younger people just don't wanna think about this kind of stuff. So I'm [00:09:00] curious, what would you recommend, or when did you get one or tell us about.

I would respectfully disagree. I think the ages of like 18 to 25 people love to talk about death and love to talk about what would happen if something happened to me and what would that look like. And maybe there's part of it that it feels so unlikely to happen that it feels really safe to talk about.

I think maybe there's something at play there. . I think that when, for example, college students and college student age are often more interested in engaging with these big concepts and questions and what do I really want and what would

constitute a meaningful life? And then I think there's this entire period of life where that's really scary and I just can't think about that.

It's too overwhelming and I, it's almost more difficult when it's almost more relevant. I stand corrected. I, I mean, I don't know that for a fact. I'm, you're having me as a guest. Here's my hot take. But I think there's kind of a sweet spot [00:10:00] when people are young if they're introduced to it and know what it is and kind of what it's for.

And then I think there might be a sweet spot later too. But I think it's a lot of the in between, especially like people with young kids and kind of. That just feels impossible to talk about. So how do you, how do you people get introduced to it? I mean, I'm thinking about, I go to a doctor's office and somebody asks me, do I have a healthcare proxy on file?

And I say no, and they just kind of move on to the next thing, . So how would a 22 year old even know to, to do this or think about this? Where would they learn? They take Dr. Bergman's aging studies class at Ithaca College . I think that is the problem. I think that it's not, I, there are some legal cases that are really interesting, albeit depressing, about young adults who were in car accidents and stuff, where their best friend from college and their college roommate says, this isn't what she'd want.

I know this isn't what she'd want. Yet the parents are kind of doing quote unquote everything, and there was an entire legal case about who gets to make the decision for this young adult. [00:11:00] Is it the person who really knows them well and says, I can remember a conversation on this date where they said this to me and I think this goes against what they'd want.

Or is it still the parents? I don't think many 22 year olds have healthcare proxies. I think the ones who do had it introduced to them by a professor or a teacher, or I guess perhaps lived experie. I didn't have a signed one for a long time. My healthcare proxy is my best friend from college, Kristen Levit, who's now a physician, which I also think helps.

Um, and we're gonna talk about that a little more later on in the show. Yeah. But yeah, anyone 18 or older should have one. It's a great idea and should have hard conversations. Hmm. I really what you said about sort of young people being really open to having these conversations resonates with my experience.

I'm teaching a course this semester called that Centers End of. Issues and discussions, and I find that to be really the case. Students are really eager to

[00:12:00] unpack and ask questions and dig into some things that, you know, my peers, my friends who are my own age are a little less likely to relish digging into.

Why do you think that is? Well, I agree with your observation that maybe things are just a little too real. The notion of confronting our own mortality gets harder as we get closer to it, right? And also for a lot of people, having parents who are getting older and maybe beginning to experience some health related challenges might also make it more complicated or difficult to.

and I think there's like a curiosity about the world that sometimes diminishes as people get older, and I think what's not more interesting to discuss. So talk a little bit more about who is a good choice for healthcare proxy and why I would say, A type of person who would make a really good healthcare proxy is someone [00:13:00] who's able to remain relatively steady during really turbulent or emotional times, and who respects you as a person enough to listen and carry out your wishes, even if they are not what, as a friend, that person might want for you, because it's really not about your healthcare proxy.

Making the calls for, for you, it's about them being your voice when you cannot be. So it's about them doing a good enough job of, let's say if Lisa was standing here, this is what I think Lisa would say, even if that's different than what I, Anna, as Lisa's friend would want. Yes. And I think that's a really hard role.

And I think there are certain people who. Can do that a little more easily than others. It's a bonus if it's someone who does have some level of understanding about any health conditions you yourself have, just because they would understand how you deal with them and kind of a little more of the intricacies.

So if it's not someone who'd be okay with. I, they don't even know everything. But like knowing some of that stuff, it's probably not someone who knows you well enough to serve in [00:14:00] this role. Often the people closest to you are not the ones who would be absolutely the best because if something, like, if you're in this situation, something has gone wrong and something is will never be the same.

And if it's someone who you love most in this whole world, that just might be setting that person up to fail and to. Like they're failing in a, like, so if it's, I don't know if that's making a ton of sense and I can try that again, but you want someone who can remain steady, who loves you and respects you and can stand their ground and separate what they want from you, from what you would want from you.

Absolutely. Cuz I think that in the moment when things get really crazy and emotional, I think it's natural for people to wanna do everything. Save this person, do everything you can to every measure. And because that's your feeling is I wanna keep them alive. Right? And it may not be what they want. And somebody who's a little bit more removed from that situation, like you said, could be a much better choice to make those decisions that are more reasonable.

And also what [00:15:00] constitutes alive to that person. Like, okay, there's a heart. , but is that alive as that individual would constitute it, and understanding kind of what that would look. I think is important. Yeah. Quality of the life. Right. And some people are okay with different levels and that's fine. It's about understanding that.

Yeah. I think my father one time said, he is like, as long as I can still play golf, I'm good. And I was like, okay, well 18 holes or nine. And he said nine. And I said, are you walking? Are you taking a cart? And he said, I can take a cart. So like that. That's very different though. Yeah. Absolut. That's a really helpful sort of conversation to restate for us.

It's, it's interesting and thought provoking to think about, okay, what questions, questions do I need to ask, right? If I am the person who's in this role, and also based on what I'm hearing you say and, and, and based on conversations I've had with some other people, you may be closest to your spouse [00:16:00] or your partner.

but that person may not be the right person to act in this role. Right? It might be your best friend or a neighbor who's a physician and knows you very, very well, and, and would be available or something like that, and those are, those can be tough conversations to have, but that's, that's why we're here, right?

To encourage people to have those conversations and pick the right person. . And I will say in that regard, that's why I think it's really important that your healthcare proxy themselves have a copy of the healthcare proxy. Cuz if you don't feel super co, you should tell some people who your healthcare proxy is.

But there's definitely situations that arise, that someone thinks that they should make the decision because they're your best friend. and you wanna equip the person that is your healthcare proxy with the paperwork they need that that's not a fight because any unnecessary disagreements during a time, that's that critical you wanna avoid.

So you wanna equip your healthcare proxy with all the documentations that they might need [00:17:00] and all that work so that someone can't say, no, it should be me. Well, I have these things. No. Right. . Right. So, so that brings up an interesting question, right? So you've had the conversation with your best friend.

Your best friend has said, yes, I will serve in this role as your healthcare proxy. Like, what do you need to do then? Like, how do you, how do you go about making it official? So, . What I will say is healthcare proxies, as most healthcare documents, uh, vary state by state in the us. So we're talking about New York state right now, but there are different terminologies and different paperwork that needs to be completed depending on what state you live in.

And sometimes that also matters of what state you're living in. So if you're someone who spends your summers in New York state and your winters in Florida, it's probably a good idea to have paperwork for both of those states in those. What was the other part of your question? How do you make it official?

Like, Anna, you and I have had a conversation. You've decided to, you've said, [00:18:00] yes, you'll be my healthcare proxy. Like, where do I get the form? Do I need to go to an attorney? How do I, what do I do? So you go online. To be honest, I wish we had, we should have printed one to have I I do. I did upstairs. I don't have it with me for the most part.

You can go to the.gov website. State and your state health department even, and find the form and print it out. And sometimes they come in little packets. They give you a little more information about what this means and some suggestions on things to talk about. They often need to be witnessed by people who are not.

So if you were going to be my healthcare proxy, we would sign that paperwork and maybe also Lisa would sign it as a witness. That again, varies depending on the thing. What I will say is there's a spot on most healthcare proxies to name. If you can't get ahold of my first person, then this person can be my healthcare proxy.

So that might come into play if they, if you were traveling, you were out of the country and no one could reach you or say we weren't a car accident together, and so it's not, you can't be my [00:19:00] healthcare proxy, then it kind of makes that next person the proxy. . What it does not do is make both of those people the proxy.

So two people cannot beat your healthcare proxy. You can name successors, but it would never be both. And where you see issues around that is adult children. So that's where it's really tricky and you wanna kind of make sure that all of your adult children are on the same page about who it is. And.

Because that's where, I mean, that's one of the stories actually I could talk about later, but that can get really messy quickly if people don't understand that you're not naming both. You're naming this person and in case that person cannot do it. This person. That's helpful. Thank you. So just to clarify, Is it fair to say that a healthcare proxy is both a document and a person?

I think so, yeah. So if you haven't named one or you've never done the paperwork or you just can't deal with it, what, what, what happens to you? Like, who gets to make decisions through if you do become incapacitated and you [00:20:00] do not have a healthcare proxy designated? So in New York State, the first person they would look to is your spouse or domestic partner.

Really what they want that to be is. Lawfully married partner. There is a little bit of wiggle room if you can kind of prove that you are in a partnership that's official with this person. If you are engaged, for example, mind you, it's harder when there are couples who are engaged, quote unquote, for. 20 years are you really ever intending on, they'll push back on that and that wouldn't be uncommon.

If you are in a domestic partnership or you own your house together and have kids together, it's pretty easy to argue that you are that person's spouse and have been. But it definitely is trickier when it's not that marriage certificate. After that, they would look at your adult children. So if you had children over the age of 18, maybe children over the age of 16, , it's an adult child and that's who they'd assume that would you wanna make decisions for you?

And that's where it [00:21:00] gets messy. If you have multiple adult children, no healthcare provider wants to sort out who's the right one to talk to, and sometimes it's the loudest one who ends up being listened to, whether or not that's the right child, then it would go to your parent. So if like I, for example, I'm not married, I don't have adult children, they would call my.

and see if what they thought, and they would make the decisions on my behalf if they couldn't get in contact or if I didn't have parents, they would contact my sibling. Then you have your adult child issue again, where you might have multiple siblings, all of whom think that they should be the ones making these decisions.

After that is when you can kind of get into the close friend area, and I would say that's the greatest. You would have to prove that you're in regular contact. You'd have to prove that you are really that person's best friend. This likely wouldn't happen, but this is what can happen in any legal issues down the road once we're getting to this.

And then if none of [00:22:00] these people show up and really wanna make decisions or contactable or reachable, or if you're a Jane Doe, that's when the hospital or the health system might start to look for guardianship so that the providers themselves can make decision. And that's an entire other realm of legal questions.

So how important is it, Anna, that you'll have a conversation with your primary healthcare provider about your healthcare proxy or the fact that you have one? I think having a primary care doctor who you really feel a relationship with is a privilege that not many people have. Yeah. I think part of that is the transient of people in today's age.

I mean, I've lived in multiple states. I haven't always had good health coverage. I now, with the Affordable Care Act, there's really less of an excuse to not go and have an annual wellness visit every year, but I still think it's not common. On that note, find a primary. Position and go see them. I think it's a good idea and I think the more you get comfortable with someone, the more you can have conversations and really ask [00:23:00] vulnerable questions that relate to these.

With your provider who is an ex, the medical expert in this stuff. Some primary care doctors will ask, do you have a healthcare proxy? Do you have any other documents that you want me to have on file? And some of them, Explain what that means to you, and some won't, and you'll just say no. And they'll say, okay, moving on

And not explain what that was or why it matters. And part of that is just they only have so much time and some providers understand it more or less than others and feel more or less comfortable having these conversations with people. But I think if you have a healthcare proxy, you should definitely say, yes, I have one.

It is this person. This is their phone number. I can get you a copy of that. I think the most important place to have the actual paperwork of the healthcare proxy is in your healthcare proxy's hands at the site when you need it. So [00:24:00] I would advocate for you having your own copy of your healthcare proxy.

and your healthcare proxy themselves having a hard copy that they can really show up with. I think it's great if it's in your primary care provider's electronic medical record, and maybe if needed, you could go know that people could find it there, but realistically, that's not your site of care. At a time that you're being deemed incapacitated, you're in an acute hospital setting.

Right. So I could imagine a scenario happens pretty frequently that like someone is in the i c u in an emergency situation or you know, in a, in a real health crisis and there's a healthcare proxy file, but. it might not be seen or, and therefore not respected, not out of negligence, but just because everybody's really busy really quickly trying to do the next right thing.

Yeah, so I've been really fortunate, I think. over the last several years to have a, [00:25:00] a primary care provider who is willing to have those conversations with me. But it's only been because I've brought it up, right? Mm-hmm. , I've not been asked, do you have one? What, what would they, you know, what would you want?

What? So you're starting that conversation? Yes. Yes. And as soon as I start the conversation, she, like, she kind of perks up and is like, oh. So let's talk about this. You know, and she gives me the time and we have the conversation about it. I feel like we should name draft here, and advertise this Doctor . Um, it also, I think, helps that she is also my healthcare proxies primary care provider.

And so she knows him as well and has a, a relationship with both. But if I were in the I C U, she's not the person who would be around. So it, you remind me that he needs to. Where those documents are as the person in the family who keeps the files, who keeps things organized, who uses my own system, he might not necessarily know where [00:26:00] to look or where to get it or that sort of thing.

And so it is important. I have never been asked if I have a healthcare proxy. Have you, Lisa? There's one place in town where I go each year to get my mammogram, and they ask me if I had a healthcare proxy and true confession, I don't have one. And I say, no. And this time, this was only about a week ago, I said, so how, how do I get one of those?

And the person at the front desk kind of rustled around in these papers and handed me, um, a healthcare proxy. So I need to get that done. But I have to say, it kind of seems like we're on our own here. I mean, nobody's pushing this, nobody's, that's the only place I get asked. You know, even your experience, Elizabeth, with you bring it up at the doctor.

Right. And we come from this place of privilege really. You know, we have these primary care doctors we visit regularly. We have health insurance, right? Mm-hmm. and, and we're fairly educated about this kind of stuff, and yet we're still like, I don't even have one yet. So I just, I feel like how do we get this out in the open more and have people really take ownership and do it, you know, because they're not gonna get it foisted on them by any doctor's office or state regulation or [00:27:00] anything.

Right, right. Literally, the only place I've ever been. , if I have a healthcare proxy is when I go for my mammogram. And I'm not gonna, you know, my answer to that question is yes, but I'm not gonna go in and talk to the person who's doing my mammogram about what I would want or who my healthcare proxy is.

Like those are details that are not relevant to that clinical interaction. Well, to be honest, they don't care either. Right? They wanna know if you have one and that that paperwork is somewhere, but the person doing your mammogram does not care who your healthcare proxy is or what your thoughts are. Yeah, frankly.

But even though my, my question, I mean, my answer to the question is yes, but then there's no follow up, like mm-hmm. . . Okay, there is one, but what does it matter? If the answer is yes or no, if yes, my healthcare proxy is my pet alligator is at home , it has, it has a copy of it, , so it doesn't matter if the answer is yes or no, there isn't really any follow up or it doesn't seem, it seems like a box they're checking.

Yes, it is. I think, and you know what? The fact that it's a box that they're checking is [00:28:00] a step better than it used to be. Yes. Okay. The fact that they're asking means also that the individual. In that practice, probably know what it is, which probably they didn't until they had to ask again and again. The fact that they found a copy, a hard copy to give you, I'm actually really impressed.

Okay. So I think the first step is just awareness. That's something I should have. I don't. Think that that's good enough, but I also don't know that the imaging clinic is the right place to have those conversations or even the right electronic medical record to house a healthcare plan. Cause the other complication of healthcare is all of these electronic medical records that your primary care doctor has, your hospital has, the imaging center has.

It's very rare that they're all the same one and that they all talk to each other. So just because you think that you gave your specialist this document, your other

specialist or your primary care doctor, May not have access or even note that that exists. So who, do you have a healthcare proxy, and if so, who is it and why did you choose this person?

I do have [00:29:00] one. Kristen Lavin is a EMT physician in Louisville, Kentucky. So the problem is a lot of people say it's bad to have a healthcare proxy who doesn't live in the same state as you, or it doesn't live in the same town. Because if something happened, they'd have to call her, find her. Maybe she'd have to come here, which she may or may not be able to do.

So, especially some people who live far away from their families will have a healthcare proxy who lives closer to them just so that they can kind of be easier to reach and get a hold of and be present. Kristen is mine, but it really wasn't made official. Official, and probably we should sign more papers until we did a presentation together.

The New York State Society on Aging. Yes. That place, , and we were just talking about it. . I mean, she's been my friend for a very long time. I mean like 10 plus years. And we talk very openly about these topics. It's actually her dad who died when we were in college, and I think we like to have difficult conversa.

I like them more than she does, but she comes right along. . [00:30:00] This does not surprise us. , you should have her on and she'll probably say the same thing. But it's been, I've kind of taken this ride along with her when she went to medical school too. She would send me the stuff that they were reading. And Cooper Medical School in New Jersey does have a more woke just curriculum that touches on a lot of these issues, un unlike some historically medical school, historic medical schools and stuff.

So at some point, I just realized that she really understood me as a human and she. She does have the knowledge that I don't necessarily have of like, you know what? Intubation is worth a try right now, and then maybe it's not. And we, especially when she was first a physician, would have conversations about like when people died under her care and when she saw family situations that were really horrible and even our own family situations, what they were then and what.

Know now and if they would look similar or different. So she just seems like I also, I have a [00:31:00] wonderful father and a wonderful twin brother who are very emotional , and I just don't think it's setting either of them up for success,

and I wouldn't wanna burden them with that. So Kristen just makes sense for me.

She sounds like a great choice for you and, and also the, the things you said about the conversations you had. I think that's so important, right? To be having these conversations with people and that's how you figure out who is the right person, right? Who is gonna act in my best interests. Yeah, absolutely.

I also think what we don't, a really, a healthcare proxy form is a pretty simple form to fill out. Anyone can do it. That's why I made like the alligator joke. Like it really is simple. However, I don't. Just having a healthcare proxy doesn't mean that's the right person. It means that it should just be kind of a signature at the end of an ongoing and long conversation as you get older and as situations change and.

As you're a witness to more situations too, I think people can change their mind and I think as long as it's someone [00:32:00] here having these ongoing dialogue with who really feels like they know you and can represent you in that way, that's a good healthcare proxy. So it is a box that they're checking when they're saying, do you have one or not?

I think that is better than them never saying anything about it. But I don't know that having one i e having a document really means that you have an effective healthcare. Right. Right. I've heard there are some, some organizations and some providers who suggest that you, like every year at Thanksgiving at at Thanksgiving dinner, you have a conversation with your whole family.

Right? If that's what your family does at Thanksgiving, , I don't know about like having a conversation about. What my values are about the end of my life over Turkey and dressing is like my idea of a good time . But it, I mean, it is interesting to think about having that conversation with several people who are likely to be around or part of the [00:33:00] conversation.

At the same time, right? So if for no other reason, then it could be stated with the group of people who are likely to be involved, like who your healthcare proxy is, who is the one that has the, the authority to speak for what you, what your wishes are. Please pass the mashed potatoes. What is an acceptable quality of life?

That's like my idea of forced fun after I find out if you want to be intubated, I'd like some gravy, please. . No, no. But seriously, like it's useful to have a conversation with, with people about what your values are, and also for people

to know who your healthcare proxy is so that there's some legitimacy in that situ.

I do think it's important for those close to to know who it is and that you have one. That might be it. I think it's very lucky if you spend Thanksgiving with a family. Who you feel safe really having those conversations with, and I don't think a lot of people do. Yeah. [00:34:00] I would say even the people who particularly have kind of fraught relationships with their families.

That's almost the person who's the most important for you to have a healthcare proxy. Yeah. Because when you've defined your family as this group of friends, you live and you breathe with who support you, they have no legal. Standing or a foot to stand on if anything happened. So I think those are almost the pop, that's the population that I hope hears this and takes that to heart and really thinks about who is the right person, because it's when, it's to me, like people ask me all the time and have healthcare practices where they're naming their husband.

So what, like, okay, cool, good, but like obvi, like if it's gonna be your husband, that's the default anyway. So it's probably good, and I think especially if you have a relationship where maybe you and your partner don't talk about that often having a document to sign can start a conversation and that might be really helpful, even if it is your legally married partner.

Mm-hmm. . But what I will say, so, so what I'm hearing you say is sometimes in some [00:35:00] situations it's more important to have a healthcare proxy because of who you wouldn't. to speak for you, who that might be somebody who, in the eyes of the law or in the eyes of a healthcare institution, might be the defacto person that they would look to.

If you don't want them to speak to your treatment, then you would want to have someone else designated. And I will say, I think it's helpful for the person who's your healthcare proxy. I've known you for a very long time. Mm-hmm. , even if you. The best friends because we all evolve as people. We evolve as people and we say, this is what I believe.

Absolutely this nothing else. And then five years later, you know what? The world gets grayer and you change your mind and that's fine, but it probably would be difficult if someone was, even if they're your best friend, the whole wide world, but you've really only known them for two years. I just. It's not official.

You're not gonna find this in a textbook anywhere, but I do think someone who's known you and seen you evolve and seen how your mind works and how you, you can [00:36:00] change your mind or have changed your mind in the past is probably a helpful person to have in this role. When I first started working at Mount Sinai, I was a graduate intern, and I think really the reason I was hired is there was someone in one of my classes who.

Working already at Mount Sinai and was hiring an intern because they were doing a project on palliative care referrals in the inpatient unit, and she knew me from class as kind of being, I was very well known for often writing papers and being concerned on issues around serious illness, death, and dying, and in part, something that I used to write about a lot then and I still am interested in is Upstreaming palliative care, upstreaming referrals to hospice, and so.

I think a large reason why I got that internship was because that was a big project that was on the horizon, and that was an area that I was really interested in. And then luckily they liked me and I kept doing work and it turned into kind of [00:37:00] my career in New York City was at Mount Sinai. But Mount Sinai is also renowned as one of the, if not the best, one of the best palliative inpatient units in the us.

So, What I did, and it still isn't perfect. And it's really frustrating. It's frustrating for people who work in that unit. Sometimes it's frustrating for palliative care doctors to hear, we're gonna withdraw care and bring in palliative. Well, what is palliative care if it's not medical care? And then there's, there are people who are well-intentioned and want to help support, and so then they come up with things like, we're going to stop futile.

but like half the people don't know what the word futile means or futile. I don't even know what it, how to say it. So, and I have gone to school for a really long time, so I think it's complicated and those issues are still at play there. And they were trying to come up with ways to kind of automatically trigger in the medical record to make sure that palliative [00:38:00] care was being consulted on cases earlier.

but even on that palliative care unit, part of why I think healthcare proxies are so important, you would see these really challenging situations where someone was dying and had multiple adult children and one, I mean, this is a real example that I don't wanna go into too much detail, but one of the adult.

Children was a daughter who was pretty estranged from the family and had stayed in touch with her mom for a long time and felt very connected to her

mother, but really had not been even in a room with her siblings and her mother together in years. And she had very different feelings on what was an appropriate care situation than her siblings did.

And I think you hope that everyone's well intentioned. , but when emotions are running that high, it's just really hard and everyone is hurt. Like people in that situation were hurting. This woman was dying. There was no question that she [00:39:00] was dying. And unfortunately a lot of what was being done was physicians trying to calm down a turbulent room and social workers working their tails off to try and make sure everyone's heard.

But that's shouldn't be where the focus is. And I can remember. . I ended up bringing in a nurse who you all know to, and kind of said like, Hey, a friend of a friend knows his family. They're on our inpatient unit. Can you just go in? I think there's a lot of pain going on in that family right now, and she did, and I think she luckily really could reach a lot of them and help and bring people together, and it was as good of an ending situation as I think it could have been given the circumstances, and I definitely know.

That daughter came up to me and thanked me for bringing in someone who she felt could hear her and listened to her and make her feel valued. But I remember thinking for a long time if I did the right thing and if it was [00:40:00] right, and I, there's no right and wrong and it's all confusing. But six months later, I was at the gym in New York City and this guy came up to me.

and said, I just have been staring at you, and I realize you are that person who brought in the nurse who helped our family so much, and I really just wanna thank you. Wow. And it was really touching and moving because they didn't get along. But I do think at the end of the day, he felt better knowing that everyone had felt heard and listened to, and that they could all calmly be in the room with their mother when she.

And that's really powerful and meaningful. However, a lot of that pain, I think could have been removed if one of those adult children had that piece of paper and said like, listen, I talked to mom. This is the piece of paper. Even better if mom had said, Five years ago. Listen, I really think I want you guys to, maybe it's not one of the kids, like, I mean, maybe at the end of the day, especially if you have a [00:41:00] situation with adult children who, you know, don't all get along, it's not one of your children.

But that was definitely impactful for me to hear. And you know, it's always nice when a guy coming up to you at the gym isn't just hitting audio. So

Yeah. And I think it drives home the point that, that these end of, that end of life situations can, especially fraught and can be especially difficult, and it's having these conversations in advance, exploring the issues and taking the steps of appointing a healthcare proxy and making sure that healthcare proxy is empowered to act on that role when the time comes is really important.

And you don't have to have those conversations with everyone. Like maybe the only conversation with your adult kids is like, fyi, Sally has my paperwork. If something was to ever. Period. And you don't have to have like, right. No one wants to torture their children with a conversation that they aren't ready to have or don't feel safe having.

Right. But just having it kind of known as fact in advance so that [00:42:00] later, that's not one of the many things that feels impossible to accomplish. I think. is really important. Yeah. We also didn't talk about, but we could talk about power of attorney cuz I think people get confused and think that that is a healthcare proxy.

Yeah. So how is power of attorney different than a healthcare proxy? So a durable power of attorney. If I sign that right now, it would say that this other person is designated and can make financial and legal decisions on my, but there is something called a future power of attorney, which is to say that if something happened to me and I was incapacitated, this person can do my legal financial handle.

That in some states there is a power of attorney for medical care and that is a lot like it, like it is a healthcare proxy in those states. Right? And that's where I think maybe why some of that gets used anonymously. That does mean that, but in most cases a power of attorney is referring more to like finances and bank accounts and stuff like that.

And [00:43:00] I think that gets confusing as well. Yeah, and I think it's important to remember that the laws vary state by state. And another thing that I wanted to say was that you've heard Anna talk some about palliative care today. If that's a topic that you, if you, if you're not sure what palliative care is or if it's a topic that you have some interest in, hang in there cuz we're gonna get to the topic of palliative care and hospice and how they're different and the same.

In future episodes. So thank you so much for being with us today, Anna. It's been really great to talk to you about all of these important things. Thank you for having me. Thanks Anna. I'm happy to come into the Ithaca College

basement and talk healthcare anytime. Thank you so much for listening to, we really need to talk.

You'll find more information and links in the show notes. We hope you'll continue to tune in as we talk with end of life experts and champions of tough conversations, who will teach us more about the important questions and how to ask them of our loved ones and healthcare providers. We hope you'll subscribe on Google, apple, Spotify, or wherever you get your [00:44:00] podcasts.

Our contact info is also in the show. Drop us a line and let us know your thoughts, your questions, or ideas you have for future episodes. Or just say hello and remember starting is the hardest part, but we really do need to talk.