Lowenstein Sandler's Trusts & Estates Podcast: Splitting Heirs

Episode 9 -
As Long As I Have A Heartbeat

By Warren K. Racusin, Bridget Harris, and Cynthia X. Pan, MD FACP, AGSF
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Kevin Iredell: Welcome to the Lowenstein Sandler podcast series. I'm Kevin Iredell, Chief Marketing Officer at Lowenstein Sandler. Before we begin, please take a moment to subscribe to our podcast series at lowenstein.com/podcasts. Or find us on iTunes, Spotify, Pandora, Google podcast, and SoundCloud. Now let's take a listen.

Ken Slutsky: For men and women know not their time. As the fish that are taken in a net and as the birds that are caught in the snare, so are the children of men and women snared when it falls upon them.

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Warren Racusin: A homeless man staggers into the emergency room of the local hospital. He's an extremely serious condition, and when the doctors examine him, they see that he seems irreversibly sick with a variety of disorders and no reasonable prospects for recovery. The hospital's full, it doesn't have great resources in any event, and trying to keep him alive will be expensive, time consuming, and ultimately futile. There's no identification, and so no next of kin or acquaintances at all to reach out to. But as the doctors go through his pockets, they find a handwritten note seemingly written by him, and the note says, the Lord has been good to me, and I want to honor him. And so as long as my heart's beating, you must keep me alive from the law firm Lowenstein Sandler. This is splitting heirs. I'm Warren Racusin.

Our advice to its day planning clients always includes end of life planning. What do you want? If there's no meaningful hope that you're going to come out of whatever you're in, sickness, injury, trauma, their legal rules, and also profound moral, religious, ethical, and spiritual questions that circle around those rules. And the answers aren't always as simple as you might think to help sort it all out for us today. Or my colleagues, Bridget Harris, who counsels clients all the time on these decisions. And Dr. Cynthia Pan, the chief of geriatrics and palliative care at New York Presbyterian Hospital Queens who give us her thoughts from on the ground when patients are confronting the end of their lives.

Bridget, in one sense, this all began in 1976 in our beloved home, the great state of New Jersey, and with a woman named...

Bridget Harris: Karen Ann Quinlan. Karen actually grew up about one town over from where I live after she graduated high school, she went to work. She moved in with a couple of roommates and she started worrying about her weight. So she went on a crash diet, and one night after she didn't, very little, she and her friends went out to a bar. She'd been taking Valium to calm her nerves, and she had several gin and tonics that night. She started feeling faint, and so her roommates got her home, but when they checked her 15 minutes later, she wasn't breathing.

Warren Racusin: She lapsed into a coma from which she would never recover. She was moved into a hospital, kept alive through a feeding tube and breathing machine, but gradually deteriorated. Her parents wanted to take her off the machines because they believed she was in great pain, and there was no point. But the hospital refused, and the county prosecutor actually threatened them with murder charges if she did. So they went to court and the New Jersey Supreme Court ultimately said that the ventilator could be removed because her and her parents' right to privacy trump the state's right to keep her alive.

Bridget Harris: Largely from that case, the modern movement towards healthcare directives, which are also called living will sometimes developed. Pretty much all states now have statutes or rules that allow people to make decisions in advance about their wishes in end-of-life situations, and that's why they're called advanced healthcare directives.

Warren Racusin: Let's get some of the nitty gritty, Bridget, about how advanced healthcare directives work. They can actually have two parts, right?

Bridget Harris: Yes. So in some states, those two parts would be called the proxy directive part and the instruction directive part. So the proxy directive allows you to name someone who can make medical decisions on your behalf if you are incapable of communicating with health professionals. And so that part applies in any situation in which you can't communicate whether or not you're terminally ill or injured. It could be an accident situation where you're temporarily unconscious.

Warren Racusin: So that person acts as your eyes, ears, and voice communicating with the doctors to make decisions about treatment, right?

Bridget Harris: And you can be as detailed as you want in your instructions, so you can tell your proxy what kind of treatments you're interested in or not, or even the kind of medications you typically use so that there are no gaps in dosage.

Warren Racusin: That's the part of the healthcare directive that doesn't get as much attention, but it's just as important because you need to have somebody who can speak for you in the event that you can't speak for yourself and talk to doctors and healthcare providers about what you need, what you want, and what's appropriate and necessary in your particular situation. So that's an important piece as well. And thinking about who should be your healthcare proxy, who should be your surrogate decision maker, is as important a decision in many ways as who you decide to have as your executor or your trustee or the

guardian for your kids. Let's go on and talk about instruction directives, Bridget.

Bridget Harris: So the instruction directive part sets out your wishes in the event that you're permanently sick, ill injured with no reasonable hope of recovery. So the first thing to know is that you can be very specific about what events trigger the instructions in the first place. Many people say that it should only take effect if you're in a terminal condition. Terminal condition may be defined in underlying state statutes, but it also can and maybe should be defined in the document itself. And so you would set out certain triggers.

Warren Racusin: So often people will say, only if I am permanently unconscious, or if I'm in a terminal condition, meaning there's really no chance that I am going to get out of this alive. Or sometimes people will say, if there's no meaningful chance that I'm going to be able to interact meaningfully with my environment to be able to communicate with my loved ones, to read a newspaper, to engage in activities of daily living. If that's not going to happen, if we're not going to be able to do that anymore, then I don't want any extraordinary life keeping measures. So let's say you hit the trigger, whatever it is, then what do you do?

Bridget Harris: So if you don't want any extraordinary life keeping measures, then you can be specific about the measures that you don't want. That might be things like artificial nutrition, hydration, it might be being on a ventilator, so on. And if you want, you can explain the reasons why. For example, you might not want your family to be burdened with the financial or the emotional cost of keeping you alive indefinitely if it won't serve any purpose.

Warren Racusin: Because the whole point of this is to make your wishes clear and to make sure that your wishes are carried out. And so the more that you can explain about what your wishes are and why you have those wishes, the more effective this instruction directive can be. So let's talk about what happens if you do want extraordinary life keeping measures. Our homeless patients may be an unusual case, which is why it's so interesting to talk about, but not unheard of. What happens if you have that situation where a person says, I want you to keep me hooked up.

Bridget Harris: You can say, I don't care how sick you think I am, like our homeless person. You can say, so long as I have a pulse, keep me hooked up because maybe what I have that's not curable today could be curable in the future. Or what's more common, not common, but more common than that is people who have space-based views about this. Often, it's a view that you cannot do anything to hasten death because life is sacred, what's created by God and so on.

As a counselor, my advice is if your instruction directive is faith-based, put in the name and the contact info of your priest, your rabbi, whoever it might be, maybe a successor too, if there's someone else, and put that you want them to be consulted to make these judgements because the situation that I worry about is that we write in at the client's instruction, keep me alive no matter what, because that's what my religion required. And they end up in a situation where the religion strictly would not require that they be kept alive in an agonizing situation, but then they have the directive that requires it. So I

advise building in just a little flexibility by bringing in the religious leader to help make some of those calls.

Warren Racusin: So can you go even beyond that and say, well, it doesn't look like there's any treatment that's going to cure whatever I have now, but I think there might be some time down the road. So in that circumstance, you call for, I guess what some people would call a Ted Williams and have yourself cryo. Is that something that you could say?

Bridget Harris: So yes, I'd like to say, "Haha, I haven't seen that yet, but I have." And so yes, if you're interested in cryo-preservation, you absolutely need to take that into account in your healthcare directive. If you're serious about cryo-preservation, you will have made arrangements ahead of time. And in that case, you might ask the company, or more likely they will bring it up about what should go in your advanced healthcare directive because this is important to them to put it unscientifically. And again, I don't know, but according to them, for a successful preservation, they really need you in good condition. So the advanced directive is important to them, so that that's more than you thought you'd get on that topic. But there you go.

Warren Racusin: Wait, so you've actually had clients who have directed that or called for that or wanted that?

Bridget Harris: Yes.

Warren Racusin: Well, your practice is even in more interesting than mine, I guess.

Bridget Harris: Yeah, I'll say it's kind of an unfathomable decision, but if you have a disease that they're studying now and you're dying of it, but in 20 years you might not die of it, who knows what they would decide? You can't say what you would decide, I guess.

Warren Racusin: We've both also seen situations where clients will say, "Well, before you pull the plug, make sure you've exhausted all possible avenues of treatment that might lead to recovery or a cure, including methods that are sometimes called alternative medicine." And another wrinkle can arise if you're a woman of childbearing age, right?

Bridget Harris: So they will occasionally say that they don't want extraordinary measures except if they're pregnant or perhaps if there's so many weeks or so many months pregnant. And in that contingency, that's an exception. Then do everything to keep them alive long enough to bring the child to terms, and I guess a little less dramatically. I've seen instruction directives that say, keep me hooked up for 30 days and see what the situation is. Give me 30 days, however long. Give me a chance to come back. I guess in that situation, I would just encourage them to think a little bit about what that 30 days might look like for their family and whether costs would be a concern for them or whether their insurance is such that it would not be a concern, but I have seen that.

Warren Racusin: Cynthia, that's how lawyers think about and advise clients on healthcare directives in sort of a large nutshell. I know that you deal with this all the time

in your medical practice, but when we talked, I was first struck that you dealt with this in your own family, and the way that that went down was very instructive in terms of how these issues play out in a real family in the real world. And love for you to talk about that a little bit.

Cynthia Pan: Yeah, thank you. And when you talk about the 30 days, I actually had a patient who exactly had 30 days in his living will, and we can talk about what happened to him. It was very difficult. But back to my family, the reason why I started discussing advance directives with my family is because I discussed advance directives all the time with my patients' day in and day out. And one day I realized I never really talked to my family, and God forbid something should happen. And the national motto for advanced care planning is it always seems too early until it's too late. And I don't know how many thousands of situations I've seen about that. And I'm Chinese American, so my parents are Chinese, et cetera. Chinese people generally don't really like to talk about that. So I decided that I wanted to really get to know my parents and my brothers advance directives.

And so I went to visit them at home. My brother lives with them. He has intellectual development disabilities, so he's in a separate category. But anyway, I went there to visit, and I started this discussion with my mom to say, "Hey, I talk about this all the time in the hospital. We've never really, really talked about it. So what's important to you? This is an insurance policy for end-of-life wishes." And she was very cooperative. We had tea and we talked about it, and it was pretty easy. And she basically told me that if something would happen to her, she would want a trial period with any kind of invasive intensive care unit, trials, that kind of thing. But if she couldn't be brought back to a good state of life, she would be able to go out with her friends and enjoy her family then that was it.

So that was pretty good, pretty standard. So then I had the same discussion with my dad, or I attempted to, my dad is a little bit more difficult. He's very hardheaded. So I started the same conversation with him, and a few seconds in, he looked at me and he goes, "You're one of my three children, and after I die, one third of everything will go to you so you don't have to rush it." And I was like, "Oh, okay." So that was the end of that conversation. And then I said, well, all right, I'm not going to give up. I got to think of some way, and a couple days later, fortunately, I also do a lot of academic writing, and a journal asked me to review a manuscript that had come in, and it was all about a survey of Chinese American patients and how they would like to have advance directives.

And the big lesson for that is that don't ask directly because that's off-putting is disrespectful, and it may be a taboo issue. You're cursing me by discussing end of life wishes, that's going to bring it on, that kind of thing. So it's all about coming from the side, which is very different from New York State law, which says clear and convincing evidence, applying to yourself. So for Chinese patients, and maybe some other patient populations come from the side. So I would just continue to visit. My parents would go out and walk on the streets of flushing, and my father would say, "Oh, how's your work going?" And I would say, "Oh my God, you wouldn't believe the cases that I'm seeing." And he goes, "Oh, what happened?" And I say, "Oh, this patient

in the ICU and he has heart failure and kidney failure and diabetes and stroke and whatever else."

"Oh, how old is this patient?" And I would say, "This patient is around his age." So he became more interested and what's happening? And I said, well, this patient is very confused and he's trying to pull the tubes out and the nurses have his hands tied down and he can't do anything, and he's getting worse. So he goes, "Oh, that's horrible. I mean, if I had something like that, I would never want that." So I have an inkling of what he maybe wouldn't have wanted. And I said, "Well, I mean, what would you want then?" He goes, "Well, if I can't go out shopping like this or travel and get on the airplane and plan things in my garden, then forget about it." So that was great. So I knew his wishes. So I kind of got it from the side kind of surreptitiously. And then I realized that neither really had that discussion with their doctor.

So I called up their doctor and I said, "Hey, aren't you supposed to discuss healthcare proxies and advance directives with your patients?" And she goes, "Oh, yeah, I didn't get to that yet." And I said, "Well, maybe this is a time." So all of a sudden my parents called me up and said, "Oh, my doctor wants us to complete the healthcare proxies. We don't know how to do it, but we know you know how to do it." So they actually brought their own proxies from their doctor to have me complete it for them. So we got it done.

Warren Racusin: And Chinese culture is very different than other types of cultures, and you are able to navigate that successfully knowing your own background and family and culture. But it goes down differently in different kinds of groups. You wrote an article about an elderly Orthodox Jewish man who approached this, and for how this shook out in a very different way. I'd love for you to chat about that just a little bit.

Cynthia Pan: In our hospital, because the population is so diverse, we encounter all kinds of situations. It's really kind of the theater of life where you see the drama being played out. But for the Orthodox Jewish populations, and we've had discussions with our rabbis and community rabbis as well, there's a very different approach in terms of the bioethics. So in regular medical bioethics, the withholding and withdrawing of a life sustaining treatment. So if you never started at all versus you tried it and now it's not working, you want to stop it, there is no difference as long as a decision is aligned with the patient's goals of care.

But in Orthodox or Jewish ethics, there is a difference between withholding meaning never starting at all, versus withdrawing meaning you started and now you want to stop it. And you can't really do that because if you stop a life sustaining treatment, whether it's a ventilator or a dialysis or IV or whatever, and the patient dies, that is implied that you killed the patient, and that would never be allowed. Some Jewish patients, Orthodox patients are okay with that, and some really don't want their life extended artificially like that. So that was the patient case that I wrote about.

Warren Racusin: You had a client who's had goals that bumped up against each other. On the one hand, the patient said that he didn't want to suffer needlessly. On the other hand, he said he wanted his end of life to be treated in a way that was

consistent with Jewish law, with the Jewish way. So you sat down with his rabbi who turned out to be a pretty flexible and subtle thinker about this. And how did that rabbi help you work your way from here to there and accomplish both of those goals?

Cynthia Pan: Yeah, so fortunately, we have very strong relationships with our chaplains, who include rabbis and Buddhist faith and many others. And fortunately, also that patient had some sort of advanced directives. He had told his family at the end of life, he didn't want to have be in pain. He didn't want to be a vegetable, he wanted to die the Jewish way. So we had those directives. And because his condition was so severe, he had brain damage and we didn't really think he was in pain. He had no expressions of that. And of course, we could always put him on some pain medication to prevent him from having pain. So that was the first thing. And then the second thing is vegetative state, he was going to be in a coma, and he wasn't going to come out of it. And the third thing was the Jewish way, because he was already on the ventilator being artificially sustained.

So the way we worked it out, and this is a community discussion in involving not only our hospital rabbi, his rabbi, his family, our intensive care unit, our palliative care team, and together we said, "Well, we could offer maybe a middle ground." Let's say if we tested him and he is able to breathe on his own for a certain period of time, a reasonable period of time, which then a rabbi said, "Yeah, a reasonable period of time, like a few hours, we're not talking about months." That would be unreasonable. So if you could take him off the ventilator and he could breathe for a few hours and then die, it's not cause and effect take off the ventilator patient dies that will be cause and effect. But if there was a reasonable time in the middle and then he died, then we would be able to consider that a natural death and that would be okay with him.

Warren Racusin: So through some creative and subtle thinking and some discussion with the community, you found a way, a path through the maze to accomplish all of the client's goals, but it took some work, but you got there.

Cynthia Pan: Some rabbis may not be okay with that.

Warren Racusin: But you work with one who was able to think in a way that ultimately got to the bottom line of what the patient really wanted, and which is the goal of all this. When you're sitting with a patient who's confronting this situation, what do you talk about? What do you ask the patient? What do you try to find out so that you can do what you all need to do?

Cynthia Pan: Yeah, so I think the most important thing is that every patient, every person is unique. We may have the same medical condition and we may want different things. We may value different things in life. And back to my brother, he has developmental disabilities. He doesn't have the ability to make these complex medical decisions, but I know what he likes. I know that he loves the color orange, and he likes clothes that are orange and color. I know that he likes to go out and get dimsum and donuts. He'll fight my kids for donuts. I know that he likes to walk around. He doesn't like to be confined in one place.

So we just try to find out as much as possible about a person and what makes their life tick, and what are their hobbies and what are their preferences, any inkling. And then to be able to use that to guide if they were so medically sick and all the treatments that we're giving them cannot get them back to a state where they can do the things that they enjoy, whether it's donuts or McDonald's or whatever. Then is that really the life that they want?

Warren Racusin: What might complicate that a little bit? The question comes up based upon some new research that we've seen is end of life, really end of life. There's some research that shows that brain activity may continue even if there's no outward evidence that this person is continuing to function. What are your thoughts about that?

Cynthia Pan: Yeah, so there are a lot of different neurological states that people may get confused about. So let's talk about brain death. That's one extreme situation where also the Orthodox Jewish community don't consider brain death. Death. They only believe in cardiac death. But in New York state law, brain death is actual death. So brain death is one condition where there is no brain function and there's testing for that. Then there's coma where your eyes are closed. There's no day night change differences. The brainwaves are slowed down. You may or may not wake up, who knows? One day you may, and different people may want different kind of timeframes of trial. Then there's persistent vegetative state, which is what Terri Schiavo had the case in Florida, and probably Ann Quinlan too. And then there's this thing called Locked-in syndrome where it appears that you're not interacting because you have a deep neurological injury, but in fact you are able to make sense of things, but it's just very, very hard to communicate with you. And that's a very, very difficult situation.

Warren Racusin: And so I guess if somebody's really fine-tuning their healthcare directive, they could address those different situations if they wanted to dive that deeply into what their wishes are and what those healthcare directives are going to look like five or 10 years from now is research develops might be different than what they look like now. We always tell clients it doesn't matter to us what your healthcare directive says. What matters to us very much is that you put your wishes in writing and sign them so that you and not a hospital administrator, or even worse a judge, you aren't making the call. And as Cynthia says, it always seems like it's too early until it's too late. And so we urge people, we urge you to think about these issues, make some decisions, write it down and sign it so that you've made this final call.

And that's what our homeless person did, artfully lawyered. He wrote what he wanted, and he didn't want, and it stood up. The hospital went to court to ask for instructions to remove life support, just the opposite of Karen Ann Quinlan. And the judge said, no, this person's made his wishes clear. You have to keep him alive. And he lived for another three months, and then his heart gave out just as he wanted it. Oh, and Karen Ann Quinlan, to everyone's surprise, they removed the ventilator, and she didn't die. She actually stayed alive for almost a decade with the help of a feeding tube. Her family said they didn't want her to die. They just wanted her to live or die in God's time. God works in mysterious ways to, my mother always used to say.

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Thanks to Cynthia Pan and Bridget Harris for a wonderful and meaningful discussion. As always, thanks to all of you for listening. We'll see you next time. Until then, hug someone you love and have a good one.

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