

Living Beyond Cancer Podcast Transcript

Advanced Directives

Guest: Valarie Blake

Lauren Hixenbaugh (00:01):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh, the Coalition Manager for Mountains of Hope. Living Beyond Cancer is a series of podcasts created for cancer patients, survivors, and their caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and produced by the WVU Cancer Institute's Cancer Prevention and Control. Today is slightly different as we are recording in multiple locations, so please forgive any of our tonal differences or background noises you may hear. We have a great episode planned today. Our topic is advance directives and our guest is Valarie Blake. Valarie has worked in clinical ethics at the Cleveland Clinic and helped develop the American Medical Association Code of Ethics. She is currently an Associate Professor at the WVU School of Law and a steering committee member for the Mountaineer Health Initiative; we are happy to have her expertise today as we dive into this exciting topic of advance directives.

Valarie Blake (01:02):

Thanks for having me, Lauren.

Lauren Hixenbaugh (01:04):

We are so thrilled to have you, and this is a topic that we've gotten lots of questions on, so I'm excited to dive in and kind of get a feel for things. First off, if you just want to tell me a little bit about your background, comment on some of the things I just talked about in your intro, if there's anything there you want to talk about.

Valarie Blake (01:22):

Sure. So like you said, I'm currently a law professor, and my specialty is healthcare law, so I mainly look at how it is that we finance healthcare, and what the most equitable system is. A lot of focus on Medicare For All and things like that. But prior to coming to the law school, most of my work was in medical ethics and specifically working directly with patients. So when I graduated from law school I went right to the Cleveland Clinic and I worked in their Ethics Department where it was a group of about 15 people who wore a white coat and carried pagers, and went along with the medical team, to help deal with all of the different ethical questions that might arise in people's healthcare. In that experience, I got really comfortable with working with advance directives, with end of life planning, and a lot of the issues that we're going to talk about today.

Lauren Hixenbaugh (02:32):

That sounds like a really interesting job. A very cool way to get your career started.

Valarie Blake ([02:42](#)):

Cleveland is a big competitor with Pittsburgh and with West Virginia, so that was a little tough, but the Cleveland Clinic was an amazing place to work.

Lauren Hixenbaugh ([02:51](#)):

Yeah. So the question today is going to be, what are advance directives?

Valarie Blake ([02:56](#)):

So advance directives are a couple of documents that patients can prepare ahead of time for the event where they may not be able to make medical decisions for themselves. Advance directives arise from the general idea that patients have autonomy, patients have the right to make their own medical decisions. So even if a patient temporarily or permanently has lost the ability to make those medical decisions, the advance directive is a way in which they can continue to have some say in their medical care.

Lauren Hixenbaugh ([03:44](#)):

So it's really important for them to let their families know, and kind of give us a background of why. Why is it important for them to know that?

Valarie Blake ([03:54](#)):

Well, it's important for family members to have a sense of what the values and preferences of their loved ones are in the event that they find that they are not able to make their own medical decisions. So when it comes particularly to end of life care, often, not always, but often, there are a set of questions that your healthcare providers need to know about you to make sure that the medical care that you receive is in line with your values and is in line with the kinds of things that you prefer, the kind of life that you want to live. So many people at some point at the end of their life will find that they might need to be on a breathing machine for some period of time. They might find that they need artificial nutrition for some period of time and some people don't want to live with that kind of circumstance. They do not want to live dependent on a machine. Other people are perfectly fine with that for some temporary period of time, or perhaps longer than that. It really just depends on what individuals think about their lifestyle, their preferences, their values, their wishes, their religious beliefs, all sorts of different things. And so advance directives are a way to document what you think you would want or not want at the end of your life when it comes to medical care.

Lauren Hixenbaugh ([05:33](#)):

And so these advance directives, there are specific documents in place. What are those documents? We will get kind of into that.

Valarie Blake ([05:44](#)):

So there's two types of advance directive documents. There's a living will and there's a healthcare power of attorney. A living will, and let me first say that you can have both, and

they're different, and you probably should have both, because they apply at different times and they can complement each other. So a living will is a document that sets forth what types of medical care you would or would not want at the end of your life. The living will only applies, first of all, when you lack decision making capacity. So it only applies, it only triggers when you yourself can no longer make decisions for yourself.

Valarie Blake ([06:35](#)):

Second, the living will only applies in one of two instances. You either have to have a terminal illness or you have to be in a persistent vegetative state. In the state of West Virginia, a physician has to sign off on that and say that you currently qualify as either a terminal illness or a persistent vegetative state, which basically means for a persistent vegetative state that you are unconscious and you cannot respond to or interact with anyone.

Lauren Hixenbaugh ([07:05](#)):

So that to me, that's also going back to why it's important to talk to your family member. So if you have this in place, they know you have it and they know your wishes on top of that.

Valarie Blake ([07:18](#)):

Exactly. Certainly there are people who you go through life and never encounter a scenario like this, but there are many people who do, and when the time comes, it's too late. So it's always good to plan ahead and make sure that if you have wishes, that the people who love you and are going to be around at that time know what those wishes are. So the living will then applies at that point when you're either, A) in a persistent vegetative state, or B) a terminal illness, and you no longer can make decisions for yourself. So note that it only applies once you can't make decisions. So let's say that you leave the hospital and your physician has just diagnosed you with a terminal cancer. The living will doesn't apply right then, because you still have your ability to make your own decisions and state your own preferences. So let's say you have to be in the hospital on a ventilator and you're not able to communicate your preferences or wishes then. At that time you would have the terminal cancer and not be able to make your own decisions. That's when your living will would kick in, and it would help the providers be able to know, "Does this patient want or not want a respirator? Does this patient not want or want life sustaining therapies of any type?" So the living will lets you set forth specific types of treatments that you may or may not want.

Lauren Hixenbaugh ([08:53](#)):

So the living will has nothing to do with finances?

Valarie Blake ([08:56](#)):

The living will has nothing to do with finances. It is only dealing with medical decision making at the end of life. It's a good question that you raise about finances. A lot of people, if there's going to come a time where they can't control their own finances, they will sign what's called a financial power of attorney, which gives someone, typically a family member, the right to manage their checking account, manage their rent, their other bills, and basically stand in their

shoes for their finances. But these types of advance directives are completely separate from the financial issues.

Lauren Hixenbaugh (09:40):

Well, I'm glad you differentiated between the two, because often I think people get confused when they hear the word "will" and what each thing covers. So that's great. So let's kind of go back to the medical power of attorney and how that's different.

Valarie Blake (09:54):

So a medical power of attorney, or sometimes it's called a healthcare power of attorney, they're interchangeable, this is that second type of advance directive. In this form, what you do is you pick an individual, can be a friend or a family member, someone who knows you well, who would be your decision maker if you can't make decisions for yourself. So it's different than the living will in a couple of ways. One, it doesn't have to only apply when you're talking about persistent vegetative state or terminal illness. The healthcare power of attorney can apply at any point where you're not able to make your own medical decisions. The other difference is that instead of saying what types of medical care you would want or not want, what the healthcare power of attorney says is, "Here's who I want to make decisions in my shoes when I can't make them for myself."

Lauren Hixenbaugh (10:55):

So it seems like we've talked a good bit about talking to a family member. So what exactly should we be talking to them about?

Valarie Blake (11:04):

So I think it's always good, if you're on the caretaking side and you find out that you're somebody's healthcare power of attorney, it's always good before that happens, before you're at the hospital and something serious has happened, and the doctors say that you're the one who has to make the decisions, it's always good that you know ahead of time that you are the one who's been appointed that person. That's because you suddenly have to make decisions for this person, and in ethics we talk about it through a special framework. So you're applying as a healthcare power of attorney, what's called the substituted judgment framework, and it sounds exactly like it sounds. You are not making the decisions that you would want. You're making the decisions that that person would want. So hopefully you know them well and hopefully you know a little bit about what it is that they think about their life, what do they think about the end of life, what kinds of life do they want to live? So let's say you have someone, let's say you're the healthcare power of attorney for your spouse. That person has to go through a surgery, and at the end of the surgery, the surgeon says, "This really didn't play out the way that we expect, and this person is now going to have to be on a ventilator for probably six, eight weeks before they recover." You, as the healthcare power of attorney, get to decide whether or not that person is going to be on that ventilator and you're not going to say, "Gee, do I want my husband Frank to be on the ventilator? What do I think?" You're going to say, "What would Frank want? What would Frank want in this position if he were able to speak for himself?" And

so it's really important for family members to understand what it is that is important to their loved ones before these events play out so that they feel comfortable speaking on behalf of that person.

Lauren Hixenbaugh (13:20):

Because you're really putting that decision maker in a tough spot.

Valarie Blake (13:25):

Yes, you are and I have seen a lot of family feuds. Family tensions play out because one person and another family member don't agree with what the decision. So making sure everybody understands who the health care power of attorney is, and making sure that there's been a conversation about what that family member would have wanted can alleviate these concerns before you get into these high stake, really stressful situations that are playing out in the hospital when somebody is really sick.

Lauren Hixenbaugh (14:06):

So how do folks get started? How did they create their living will, their medical power of attorney? What are those steps?

Valarie Blake (14:13):

You can get the documents online, and there's a few different websites that you could go to to get them. I'll just share a few. There's a lot of different places that you can get some form of an advance directive, but there are ones that are specific to West Virginia, so it can be good to make sure that you have the right, updated West Virginia form. So one place you can go is the West Virginia Center for End of Life Care, and that website is wvendofoflife.org or evendofoflife.org. A second place you can go is The Caring Connection. This is a website that's for hospice and palliative care, and their website is caregiver.org. Either place you're going to be able to find both of these documents, and then there's actually a third document that combines them, sort of a hybrid form, so you can go there and get the documents. You also can feel free, if you're in the hospital for lab work, for a particular procedure, to ask your medical providers then and they should be able to get you the documents when you're in the hospital as well.

Lauren Hixenbaugh (15:34):

So this is something folks can go ahead and do on their own?

Valarie Blake (15:40):

Yes. So they can get the documents on their own, but to actually finalize the documents, they need a little bit more help. Once you've got the document and you're looking at it, what you'll see at the end is that you have to have two things. One, you have to have a witness, so somebody who's going to watch you sign the document, and basically attest to the idea that you're of sound mind when you do it, and that you're the one who is signing on and agreeing to this. That person cannot be a family member or somebody who is likely going to inherit from

your estate. You can kind of imagine why that would be, right? You can think of the kind of dark scenario where the evil stepmother stands over you when you're on your death bed and forces you to sign something allowing her to make medical decisions, and when she is the person who's going to inherit from your estate. So basically there has to be a witness who's not going to be related to you and isn't going to ever inherit from you, and then there also has to be a notary public. So a notary public is a person who specializes in officializing legal documents, and a notary public also has to be there to sign and approve the document. So this is a bit of a formal procedure. To make sure that this document really sticks and that your health care providers are going to honor it, you can't just write a note and stick it in your TV Guide and say, "Look, this is what I prefer if something happens to me," and hope that somebody finds it. You would definitely want to fill out the formal paperwork and go through these formalities to make sure that it's an official document. Probably one of the best ways to do this, given that you have to have a witness and you have to have a notary, again, is to fill out the paperwork next time that you're in the hospital, because hospitals often have a notary and they will have witnesses around, like a social worker or somebody else will be there by that can sign on. You also can typically do these forms at the bank, as well as other places where you might find a notary. So some businesses and things like that.

Lauren Hixenbaugh (18:16):

So they're pretty accessible documents.

Valarie Blake (18:19):

They're pretty accessible documents, absolutely. Certainly short of this, short of these two official advance directives, providers always want to know what a patient wants, what their preferences are when the patient can no longer speak for themselves. So if you had something less formal than this and there was evidence of it, then the provider might keep that in mind, certainly. But it is always best to have these official documents, because then we know that the person who filled them out was able to and had the sound mind to do it, that they voluntarily did it, and that that really is their wishes, because these are really important things at the end of the day.

Lauren Hixenbaugh (19:09):

Yeah. Is there any point where folks should seek professional advice or help with the advance directives?

Valarie Blake (19:18):

That's a really good question, Lauren. So I would say that for advance directives, you really don't need any special help. You don't need help from a lawyer or an accountant or any sort of professional. If, though, you're dealing with other types of end of life decisions related to finances, then it's good to get a lawyer involved. So like you mentioned earlier about the will or a financial power of attorney, so if you're talking about who's going to inherit your property or who can pay your bills or manage your finances if and when you lose capacity, or at the end of your life, then it becomes an important thing to involve an attorney.

Lauren Hixenbaugh ([20:04](#)):

Okay. So I want to go back to one thing that you said just a minute ago about your healthcare provider. So if we have a scenario where I've already created my advance directives, and later on I find myself in a situation where those documents need to be utilized, how would my healthcare provider know about these documents?

Valarie Blake ([20:28](#)):

West Virginia has an e-Directive registry, and at the top of the West Virginia forms, you can find more information on that registry, but basically on the form, you check a box that says that you want it to be posted on the registry, and then you fax the form to the registry. So that's one way, and every healthcare provider in the state should have access to that registry and should be able to pull it up and see whether or not Mrs. Smith has a living will or healthcare power of attorney, or both. The other option, and a really important one too, even if you put the documents on the registry, is to have copies of the form and bring it with you anytime you have an important healthcare encounter. So you can always go to the hospital that you regularly get your medical care from and bring it with you to your regular cancer appointment, and say, "I really want to make sure that you have access to these documents, that they're on file in case we need them." If you have a preplanned surgery or some event that's bringing you to the hospital and you anticipate that they might need something like this, you can bring it ahead and make sure that the providers know that these documents exist. Certainly make sure your family members know that these documents exist and know where to access them.

Lauren Hixenbaugh ([22:04](#)):

So one of my favorite questions is always, what are some questions that you get from people that you work with?

Valarie Blake ([22:10](#)):

When it comes to advance directives?

Lauren Hixenbaugh ([22:12](#)):

Yeah.

Valarie Blake ([22:13](#)):

I would say one of the biggest questions that I get is, "How do you have this conversation?" So especially if you're the person who is a caretaker, or maybe not even a caretaker yet, but maybe you have parents who are starting to age. How do you say to them that you think is smart for them to fill out these forms, and how do you have that conversation about what their wishes are when this is such a sensitive area, and a lot of people don't want to think about this?

Lauren Hixenbaugh ([22:56](#)):

Right.

Valarie Blake ([22:58](#)):

I always say that it is a really hard conversation to have. I haven't successfully had that conversation with my parents. I mean, I've had a little bit of that conversation with my family, but even though I work in this area, it's still something that I struggle with and that my family struggles with. So I think making sure people understand the stakes, I think making people understand that this can lead to a lot less family stress and family fighting later is helpful for people, and I think it's good to remember that just because you signed these documents doesn't make your bad outcome real. This is something that's hypothetical in the future that's careful planning and it's always smart to plan, but just because you planned for an outcome that you wouldn't want doesn't mean that that outcome is going to happen.

Lauren Hixenbaugh ([24:05](#)):

Absolutely and it is a tough conversation. We all get that, but certainly makes it a lot easier for the person who might have to make a decision if they know your wishes, and hopefully easier for you in the end.

Valarie Blake ([24:19](#)):

Right. Yeah, absolutely. That's exactly what it comes down to. It's easier for the family, easier for the person who has to make the decision, and for the person who ends up suffering this medical issue, it's best if they are treated in the way that they want to be treated. The other thing that comes to mind with your question is that a lot of people confuse the living will and healthcare power of attorney with the idea that you then won't get any medical care at all. So you hold up the living will or you hold up the healthcare power of attorney and the providers will say, "Oh, this patient doesn't want any medical care. We're packing our bags. We're going, and we're going to leave her on her own." And in reality, what the living will at least tends to say is, what you want is comfort care. So what that means basically is that you want them to do anything and everything to make you as comfortable as possible, to alleviate your pain, your nausea, any sort of suffering that they can do, but you're not going to have these procedures that extend your life because you're in a terminal condition or because you're in a persistent vegetative state. So these documents don't say that the doctors stop giving you medical care. In fact, I think most providers would really like to highlight that at that point, there's still so much they can do to help patients to make them feel comfortable, and they don't want people to think that these documents mean that you're left alone and uncared for.

Lauren Hixenbaugh ([26:09](#)):

Good. Great information. Very important for patients and their caregivers to understand. So Valarie, I think one of my last questions is, what happens if these documents aren't in place for folks?

Valarie Blake (26:24):

That's a good question. So you won't be completely left without as a decision maker, hopefully. Most states, including West Virginia, have a state law that basically puts forth a hierarchy of who would be your decision maker if you haven't chosen one. So if you haven't put forth the healthcare power of attorney and said, "I want my cousin, and then my boyfriend to be the decision maker," what the state law says is, "The most important person is ..." And I believe it's first your spouse, and then parents, and then adult children, and it goes down the list all the way out to grandparents and siblings and people like that. So the law defines this hierarchy of people who will be your decision makers if you don't have a healthcare power of attorney. But here's why you still want advance directives, even though that's in place. One, you might not like who the state has chosen to be your decision maker. So maybe it's your spouse, and you think that would be wonderful, but there's nothing in the state law that says about spousal estrangement. So perhaps you're not with your spouse anymore, and you don't want them to make decisions. Perhaps whoever else is first or second on the list isn't somebody that you particularly feel would make a good decision in your stead, or would understand your values and preferences. So it's good to pick that healthcare power of attorney just because you might not like who the state would pick instead. The other important point is that even if you have the state pick your decision maker for you, they still should have a living will to be able to be informed about what your preferences are in the event that you're terminal or in a vegetative state, and you don't have capacity. So even if say you didn't have a healthcare power of attorney, and they go to your husband, and you feel perfectly comfortable with your husband deciding, it would be nice for your husband to have a document that tells him what type of care you do or don't want, because you don't want him to be put in a position of having to make these big decisions without ever having talked to you or having some sort of proof or information from you as to what it is that you want. So he may well feel much better having that document that says, "This is what I want." That can cut down on family turbulence and make that person feel more comfortable if and when they're in that position.

Lauren Hixenbaugh (29:25):

Yeah. We certainly don't want to be putting family members in the positions they don't want to be in, so I can understand that importance there for sure. Well, as we begin to wrap up today, I'm going to take a moment and kind of revisit with our listeners some important points. So if they remember one tip out of today's podcast, what would you hope it would be?

Valarie Blake (29:48):

I would say that advance directives shouldn't be scary. That they're an important part of planning for your healthcare future, and that it's not too cumbersome to fill the forms out and to importantly have the conversation with your loved ones about what it is that you would want at the end of your life, and who you would want to be deciding for you.

Lauren Hixenbaugh (30:15):

Okay, great. Valarie gave us lots of different resources. I just wanted to add you can find out more information about Living Beyond Cancer if you visit moh.wv.gov, or you can visit the WVU

Cancer Institute at wvucancer.org. There's also a Facebook support group called Living Beyond Cancer and you can just go to Facebook, search for it. We have a really supportive community of folks can join that and feel supported and ask questions, and be exposed to folks like Valarie who are giving great expertise on different podcasts that we've recorded. But Living Beyond Cancer would like to thank Valarie for joining us today, as well as our listeners. We hope that you'll continue to join us.

Valarie Blake ([30:59](#)):

Thanks, Lauren.