Katie Johnson: Good morning, and welcome to Apple a Day, Lake Region Healthcare's health and wellness podcast where we feature news and information to help you live a healthier life. I am Katie Johnson, your host, and my guest today is Deb Forstner. She is a chaplain here at Lake Region Healthcare and she's one of our resident experts on healthcare directives. Good morning Deb.

Deb Forstner: Good morning Katie.

Katie Johnson: Thank you so much for joining me. We have talked about the importance and benefits of having a current health care directive on this show before, but I wanted to invite you back for a conversation on the topic again in light of our current COVID-19 crisis. Obviously now more than ever, people are reflecting, they have time to do that and their life values, what kind of treatment they would want in the advent of a medical crisis, who they would want to speak for them if a time came where they could not speak for themselves, are all top of mind when we have this kind of medical situation going on. But it's also just this really crazy time of rapid change and fear, uncertainty around this illness and roller coasters of emotions.

Katie Johnson: So sometimes that makes us kind of push things, conversations like that to the back too. We maybe want to be in denial or don't want to face them. So we just wanted to bring this topic to the forefront, offer some help in getting those conversations started and getting more people to consider this as a good time to complete their healthcare directive. So I know you're going to have some great information for us on that. So let's just start really with the basics and framework about what is a healthcare directive and maybe how it's different from living wills, poles to advanced directives and some of the different terminology we hear around that term.

Deb Forstner: Yeah, that does get confusing because of the different terminology, but living will, advanced directive, healthcare directive, are really all terms for the same thing. It's just that in the state of Minnesota at this time, the preferred term is healthcare directive. POLST on the other hand is different, and let me explain. POLST stands for Provider Orders for Life-Sustaining Treatment. So it's an acronym, POLST, Provider Orders for Life-Sustaining Treatment. And whereas our particular healthcare directive is the eight page document, the POLST is just one page, front and back, and it's asking for a decision regarding CPR, yes or no. And then whether a person would want full care, just selective care at the hospital or perhaps would prefer not to be hospitalized and receive comfort cares. And a POLST is signed by your provider. So it becomes a medical order, and usually it is something that does not go into effect until what's projected should be the final year of life.

Katie Johnson: Okay. But all those other terms, advanced directive healthcare directive are kind of what we are talking about-

Deb Forstner: Exactly.

Katie Johnson: Right?

Deb Forstner: Mm-hmm (affirmative).

Katie Johnson: So I read a statistic that 92% of Americans say it's important to discuss their wishes for end of life care. So that's a great majority, but only 32% of people have actually had that conversation. And again, great majority, 95% say they'd be willing to talk about their wishes and 53% say they would actually even be relieved to do that, but yet only 32% are doing it. What makes this so difficult for people? And maybe how can you overcome some of those difficulties or barriers?

Deb Forstner: Yeah. Well, I think like a lot of things, a big barrier is simply getting the conversation started. So there seems to be a stigma around the topic of death, even though eventual death is a reality for all of us. And sometimes bringing it up as a topic may seem like a person is being morbid or pessimistic, rather than realistically viewing death as just part of life. However, as the survey said, there can be relief in having a genuine conversation about end of life. People may then be able to look back with comfort later knowing end of life wishes had been discussed and you don't need to guess what another person would want. I've heard people tell me when we're doing their own healthcare directive things like, I'm really glad my dad and I had talked about this, so I knew what he would want when the time came.

Katie Johnson: It really is like a gift that you can give yourself and those who love you. I don't think we can overemphasize that enough that, that it is a gift and a relief like you said. And I like what you said about death being a part of life, that's a really much more positive way to talk about it. So since these conversations seem to be so difficult for people to start, what do you have for advice for maybe overcoming that?

Deb Forstner: Well, I think I'd suggest clearing time without distractions and that could be set aside for the conversation. It really can be a very beautiful time talking about your values and what makes life most worth living for you. But on the flip side, it also can be a time to discuss those circumstances when quality of life would be so poor that a person would prefer that a natural death be allowed.

Katie Johnson: When we think about completing a healthcare directive, what kinds of questions should you be prepared to answer? Or maybe what kind of homework do you need to do before you're ready to sit down and tackle that eight page document?

Deb Forstner: Well, it's always important at the beginning to really consider why you're completing the document in the first place, and like we talked about it, as a gift for your family. Generally it's to ensure that you receive the treatment you would desire if it's available and not receive treatment you would not wish to have. So it gives you that opportunity to think through questions before you're

in that situation. So you have time to carefully think about them, and sometimes it's frustrating because you're thinking, well, I'm being asked about dialysis, well, I'd never had kidney problems, but you're projecting ahead what could happen. And so by becoming more aware, you're communicating these ideas to your loved ones and decision makers because as much as possible, when you're feeling it out, you're hoping that that person then that you've designated as your healthcare agent will be the one to communicate and act to help the medical team properly act.

Deb Forstner: So we encourage people to really talk through their answers, think about these things. It removes the burden and stress for the person that's going to be the decision maker. And as we talked about, the very first thing that you do on the first page of the form is identifying your healthcare agent. So when you talked about what kind of questions there are on page one besides your own identifying information, you name a primary and secondary healthcare agent, that's the person that will speak for you if you couldn't speak for yourself. And then in subsequent pages there's health care instructions. So things like the decision about cardiopulmonary resuscitation or CPR, whether or not you'd want to be on a ventilator respirator, and if so for how long, dialysis and other life sustaining procedures.

Deb Forstner: As I said, usually the question does have a trial period where you could say that I would like it tried but while you may not designate the exact number of days, it would be a trial period to see if it is giving you benefit or not. Otherwise, if you know you want it, you have the option of yes, or if you know you do not want it, you have the option of no. And there are also questions related to pain management through medication. And for after death, there's also questions about organ donation and autopsy.

Katie Johnson: I really I'm proud to say that I completed my healthcare directive-

Deb Forstner: Yes, good for you.

Katie Johnson: This year, just maybe a month ago, and I really liked that option for an answer that kind of allows you to not have to say all or nothing, so I really appreciated that about the healthcare directive form that we're using. You mentioned the designation of healthcare agents, that person who will make decisions about your medical care if you're unable to make them or express them for yourself. Do you have some advice about what we should think about when either choosing our own agent or being asked to be an agent for someone else?

Deb Forstner: Yes, those are good points. Number one, it needs to be an adult, it does not have to be a family member. So you could choose anyone you trust that's over 18. It cannot be your healthcare provider. I know a lot of people put a lot of trust in their healthcare provider and might want to say, I'd like my agent to be my doctor because they could help me decide the best, but the doctors are looking for somebody else they can consult with. They certainly will be involved

with your care and have the knowledge, but they want somebody they can communicate with that you have designated. You want to make sure the person you choose is somebody that will follow your healthcare instructions. You've laid them out in writing. So that takes some of the emotional stress out of it and they don't have to remember everything about the conversation because they have it in writing.

Deb Forstner: But you want somebody that says, yes, I can honor your wishes. Sometimes you might choose a loved one that truly would feel like, no, I could not do that, if put in that situation, that would be too difficult for me to say. I'd rather just be allowed to be a family member and not your healthcare agent. And that's important that you have agreement that both sides are saying, yes, this is something I can do because it is a big responsibility and there can be an emotional toll in it.

Katie Johnson: For sure.

Deb Forstner: So you want somebody that you can trust, that you've had that conversation with and that you've come to an agreement both ways.

Katie Johnson: Yeah, really good advice. Let's talk a little bit more about this time we're experiencing right now with the spread of COVID-19. We know that most people who get the virus get a mild or a moderate illness and don't need to go to the hospital, but we also know that those who do get a severe case are mostly people who are older or have other medical problems. So I think one of the things that's important to emphasize is that completing a healthcare directive is not or shouldn't be tied to your level of risk if you're thinking about COVID-19. It's smart for everyone to have one. So why is that?

Deb Forstner: Well, yes it is for anyone over 18 and the circumstances can be wide. I mean they could be because of a motor vehicle accident, boating accident, a heart failure, a serious stroke. I do think COVID-19 has raised people's awareness about end of life choices, but it certainly is not the only reason to prepare a health care directive.

Katie Johnson: Right. I think that's important that we remember that, that if you just think well, I'm not at high risk for having a serious complication from COVID so I don't really need to listen to this. Then you're missing the point of what a health healthcare directive is about. When we see on TV and read about COVID-19 patients, especially those who are older or sicker and not likely to survive even on a ventilator. Those are heartbreaking stories, they really can get us thinking about what it might look like or feel like for ourselves or our loved ones if we were in those situations. So I'd like to get your advice on language to use in your advanced directive, if you are thinking about this and don't want to find yourself in a place, whether it's from COVID or another serious illness that yes you survive but your lungs are damaged. You're rehabilitating and nursing facility

without strength or unable to return home. How do you advise people to express those wishes?

Deb Forstner: One thing on our form is there a lot of places with blanks where you can write more. So doctors have encouraged it, has meet a facilitator to tell people write down and express your wishes. What's most important for you? Like for example, is it important that you want to live as long as possible, even if it means you might go through considerable pain and suffering and have a permanent disability going forward? Or is it more important for you that when you are alive, you have the best quality of life possible? Even if it means your life is shorter. You want to consider whether you'd want to receive your care in the hospital or at home with the possibility of skilled home care. Even though without hospitalization you may not have the same outcome. And if you are in need of the hospital and you choose to be treated there, would you want intensive care? Which is and it may be called for because lung failure is the main cause of death from COVID-19 and so as the patient becomes more ill from the infection, he or she may be first offered oxygen support.

Deb Forstner: But if that isn't enough, then a ventilator is a machine that may be necessary to move air in and out of your lungs to breathe for you. Inserting a ventilator through down your windpipe is called intubation. And when the tube is in place, one talk or swallow, they received medicine to stay calm while the tube is in place. Being on a ventilator requires care for sure in the intensive care unit or in one of the beds designated as ICU at the hospital. And early studies show that people placed on a ventilator for COVID-19 will likely require lengthy mechanical ventilation and the risk of death then increases the longer somebody is on a ventilator.

Katie Johnson: That's good to know.

Deb Forstner: Yeah. So if the vent does not improve the condition or if your condition actually worsens, a person would be assessed to see if it's still providing a meaningful chance for survival. And your healthcare agent, the whole, this is another reason that it's good to have one designated person or a secondary person if the first one isn't available. They would be kept informed to see if you're showing any sign of improvement and if you're starting to breathe on your own while on the vent and they would be told also on the flip side, if there was no measurable sign of improvement or your symptoms were getting worse.

Deb Forstner: The longer a person is in ICU, the more weak or frail they do become. And so then the greater the need for subsequent therapies and the potential of an ongoing disability. It also does tend to be a traumatic event to some degree. People, who have received this level of care do go on to have some emotional trauma after the event and it's uncomfortable, it can be quite uncomfortable. And so, especially for those with underlying dementia or a major memory concern, it can cause or worsen the confusion to a significant degree.

Deb Forstner: So while the decision regarding whether or not you want to be intubated, that's always been on our healthcare directive form and also the consideration as for how long you'd want that to be intubated. It seems especially important to discuss this in anticipation of a hospital stay for COVID-19. In general, the more you have a rising intensity of treatment, there's a increasing likelihood of discomfort and a risk of chronic impairment. So generally for people, if you have a good baseline of health the risks of hospitalization, ICU care, ventilator use and CPR are less than they are for people who have more burden of chronic disease or impairment coming into the hospitalization.

Katie Johnson: Which is why we talk so much about those protective measures, the wearing of the face covering, the social distancing, and so-

Deb Forstner: Hand washing.

Katie Johnson: Exactly. It's so important to protect those vulnerable people.

Deb Forstner: Exactly.

Katie Johnson: Because they do face much more difficult potential outcomes if they do catch the virus compared to the healthy population. Those are all really, really good points to consider and I appreciate those thoughtful comments and insights for our listeners to take.

Deb Forstner: And that is an all my thoughts either because I did want to consult with our doctors before answering about the COVID-19 in particular because it's new to everyone, but they are the ones most abreast of research and the best ways for treatment.

Katie Johnson: That's great to have their input on that as well. So if you could summarize the main benefits to a person for completing an advanced directive, what would that be? How would you summarize it?

Deb Forstner: I would say that I'd want people to know that patient rights are very important to everyone here and in the medical profession in general. You would typically be the one who would be consulted about decisions about your own health. But in an emergency you may be unable to speak due to loss of consciousness of serious injury and so on. So that's why having someone you trust know about your values and preferences is so important. And it will be an emotionally charged moment for that person who is the healthcare agent. I mentioned that before, but that's again why having a directive that's in writing becomes so important because they takes out the guesswork and the need to remember as much as possible.

Katie Johnson: Excellent. So if we've convinced any of our listeners, that today that-

Deb Forstner: We tried.

Katie Johnson: We tried. If we've been successful and they're thinking now is the time I want to do this, what kind of resources do you recommend for people as a starting point?

Deb Forstner: Well, I would recommend going to the Lake Region website, which is www.lrhc.org and click on patient and visitors tab, and then from there, there's a healthcare directive link. And when you get there that's where you can find our fill-able healthcare director form. It can't be saved online but it could be filled and printed or just print a hard copy and write. There are also at that link reading materials on some of the choices that you'll be asked to make and that includes breathing support. And that's all those materials are from a wonderful organization called Honoring Choices, Minnesota. So I highly recommend doing that reading before you start tackling the directive.

Katie Johnson: Great idea. Any other information you'd like our listeners to know before we wrap up today, Deb?

Deb Forstner: Yeah, I would want our listeners to know that completing your healthcare directive is not a one and done kind of proposition-

Katie Johnson: Yeah good point.

Deb Forstner: So if any time in your future, your circumstances change in such a way that you would prefer that your healthcare director reads differently, a new one can be submitted. And I think that helps with people not procrastinating as well. Because if you know that this is how I feel now but I can change it later it helps you not maybe think it has to be the perfect directive forever. And they're good situations to consider doing a revision might be any time you receive a new diagnosis or enter a new decade of life.

Katie Johnson: That was good timing for me then, as I approach a new decade.

Deb Forstner: All right good job Katie.

Katie Johnson: Well Deb Forstner chaplain at Lake Region Healthcare, thank you so much for taking some time to talk about healthcare directives with us this morning and particularly in light of COVID-19 and with that kind of as our framework, it's been a helpful conversation. And really hope that our listeners find some good knowledge and inspiration for completing their own healthcare directives as well. Thank you again for your time.

Deb Forstner: Yes. Well I appreciate the opportunity and if anybody wanted to call Lake Region and ask for me, I would be glad to do a consultation about your healthcare directive over the phone as well.

Katie Johnson: Oh, that's wonderful. Deb Forstner chaplain at Lake Region Healthcare my guest today on Apple a Day. And Deb and Katie remind you, there is so much to do here. Stay healthy for it. Have a great day.