

IDEAS & VOICES

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- To present balanced views.
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THE TOUGHEST TALK

People don't want to talk about death and dying, and that makes sense. As many as one in five Americans fear dying, so why bring it up? There's a good reason. Advanced care planning means you have discussions about the type of health care you want to receive and you put that in writing so your health-care team understands your wishes. This planning takes the guesswork out of the decision-making process and relieves your family from making potentially uncomfortable end-of-life decisions on your behalf. This week, three local experts talk about why people avoid advanced care planning, why planning is a gift to family and friends, and how a local program provides free help to those who need it. The conversation has been edited for brevity.

What's the most challenging aspect of advanced care planning?

Kay Wyse, a medical social worker with Fidelity Home Health, a division of Premier Health: The most challenging part, for me, is convincing my patients and their families that it is important and that they shouldn't wait, that it can be beneficial to everyone themselves, their families, the doctors, their entire health-care team.

Why is it so hard to convince people that they should engage in advanced care planning?

Dr. Richard Gregg, an intensive care physician and a member of the Leadership Council of Decide to be Heard: Because none of us are going to die. That's our default view. You have to rub our noses in it to make us even think about it.

In many cases in our society, we fear death or fear talking about death, correct?

Kay Wyse: The fear, the process of dying. I hear people say, I don't want to talk about it. I'm going to let my kids make any decisions. Well, have you told your kids that you're defaulting to their wishes? Have you put that in writing?

Richard Gregg: It's especially a problem in groups, right? 'Well, my oldest daughter will decide.' What if the other kids don't agree with the oldest daughter? The most challenging part of end-of-life decision-making is that it's not done.

Lisa Henderson, vice president of health initiatives at the Greater Dayton Area Hospital Association: You want to be sure that the person who does speak for you knows what your wishes would be. This is not just for you. This is really for all adults over the age of 18. It's really important to have these conversations and these plans in place for a whole host of reasons.

Kay Wyse: For example, I'll say to people, you know your 21-year-old kid is away at college. If something happens to him, who will they call? Who will make the decisions, that doctor in Florida or Michigan or wherever your child is at college?

What are some of the reasons people haven't done advanced care planning?

Lisa Henderson: The No. 1 thing is 'Oh, I don't want to talk about that.' It's an uncomfortable topic.

Kay Wyse: I often say to people that this is a gift you can give your family, to put your wishes in writing, and to help them navigate those challenging decisions when you come to it. It takes a lot of the burden off that family.

Richard Gregg: It's a hard gift to give. But it's absolutely essential.

Did COVID make advance care discussions more difficult?

Kay Wyse: It made it more emergent for younger people.

Lisa Henderson: It certainly created an awareness. You know people at a younger age started to see they could get this. It could turn unexpectedly. It's kind of that's the reality in the times we're living in. The other piece brought to light or changed because of COVID was, folks couldn't in a lot of cases have all of their family with them when they were in the hospital. So important that they had those plans laid out and those conversations with her family.

Richard Gregg: Post COVID, we hope that it will act as a wake-up call so that more people have these kinds of important conversations. This is our community's opportunity to say, hey, have these conversations. What happened in 2020 could happen again.

Kay Wyse: I had a young man, a diabetic, who had some increasing heart failure issues. I did his advance care planning, and less than two weeks later he was in ICU with COVID. And when I saw his name show up that he was hospitalized, I thought, 'Oh my gosh, they're looking at my documents right now.' He pulled through, and he's become a champion. He's now 53 years old,



Kay Wyse, medical social worker with Fidelity Home Health, a division of Premier Health



Richard Gregg, intensive care physician and a member of the Leadership Council of Decide to be Heard



Lisa Henderson, vice president of health initiatives with the Greater Dayton Area Hospital Association

End of life deserves more time and planning

Medical social worker **Kay Wyse** is passionate about making advanced care planning as important as the beginning of life celebrations. Here are her thoughts:

In today's age, especially, so much energy and time go into planning for a birth. You know, we pick out the nursery color. We buy furniture. We have gender reveal parties. We pick a name, and we want that name to have substance and meaning. And we talk and talk and talk. We pack a bag for the hospital. All

this work to prepare for what is a very significant event. I see that it makes sense. But at the other end of life, whether it happens when we're 18 or 98, there is such little, comparatively at least, effort and time that goes into planning, discussing, sharing our values, talking about that substance.

So my passion is to change that and the little time I have left as a social worker. And to encourage people that the end of life is as important, maybe more important, or more

deserving of time and planning. You know, we do life reviews with our patients. We listen to them talk about their time in Vietnam. Or you know, their time in World War II or what it was like living in the Dust Bowl or whatever because significant things have happened all along those years. And families deserve to hear that and to know what is important and what I value and how I want to live. Because then they are empowered to make the decisions guilt-free that I want them to make for me.

'Decide to be Heard' starts the conversation

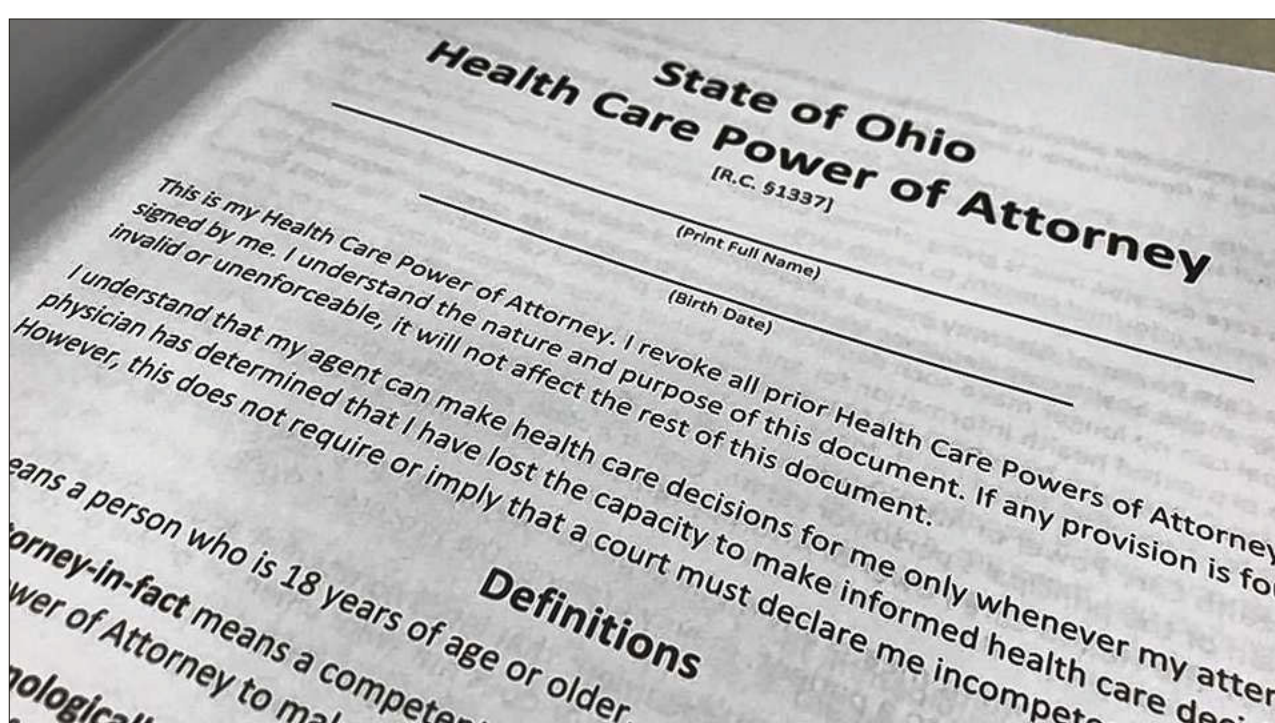
Lisa Henderson of the Greater Dayton Area Hospital Association explains the program Decide to be Heard:

We have trained facilitators who have this robust conversation about wishes and values and then ensure that the documentation is available for anyone who wants it. Ohio's Hos-

pice launched Decide to be Heard as an initiative in 2015 to start a conversation in the community about plans for care at the end of life. Decide to be Heard joined forces with a hospital-funded advanced care planning initiative and now operates through a partnership involving Kettering Health Network, Premier Health,

Ohio's Hospice, and GDAHA. These four entities, along with the University of Dayton and Wright State University, make up a community-based steering committee providing support and guidance for the initiative.

For more information, go to Decidetobeheard.org or contact Henderson at lhenderson@gdaha.org.



Local experts say advanced care planning is a conversation for everyone and anyone. "Pick a time and have the conversation. If you need help, call a specialist," says Dr. Richard Gregg, an intensive care physician and a member of the Leadership Council of Decide to be Heard.

which is young, you know, to face death in an instant ...

Are there enough of those conversations going on in the community?

Richard Gregg: No, not hardly.

Lisa Henderson: It takes more than one effort or one conversation to change the narrative around this type of planning. The conversations that we facilitate are not just checking boxes and filling out legal forms. It is a focus on your wishes. We ask about your spiritual or cultural beliefs that might be a part of how you would want these decisions made. So it's a really powerful and sometimes emotional but a really powerful conversation, even just be able to listen in on.

Richard Gregg: The typical family member, whether there is or isn't advanced care planning, will look over at me and say, 'What would you do?' But I don't know your rela-

tionship right? I can't speak for your mom, and, you know, that's why we're in a dilemma. But at the end of the day, faced with that problem, they will turn to the local authority figure in that room. That's an awesome responsibility that I don't really want because I'll end up making generic, instead of personalized, decisions and offer generic advice. It's whatever conference room you end up in, and whoever happens to walk in the door. Is that really the person that you want deciding whether your mom wants church music or not?

Lisa Henderson: We are facilitating a really important conversation. It is not just documents at the end, but we will do that. We can inform them of you know what's required in the state of Ohio. We will help them to what extent we can to complete that paperwork. We emphasize the need to get that document to their primary care provider or

medical team. Certainly their health care agent.

What message do you want people to receive about advanced care planning?

Richard Gregg: Pick a time and have the conversation. If you need help, call a specialist.

Lisa Henderson: Don't let it drag out forever. I know some people are exhausted at the notion of this. Well, start the conversation. Hey Mom, I want to be able to talk with you about this. Let's start thinking about it and then really do set a time to actually have the conversation.

Kay Wyse: It's a conversation for everyone and anyone. It doesn't matter how old you are, it doesn't matter how sick you are. This is about how you live your life, how you want to live your life, and who knows you the best and can help honor those wishes.