



The Victory Summit® Virtual Event: Care Partners
Getting Your Ducks In A Row
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Davis Phinney Foundation

Judy Kinney (Executive Director, End of Life Washington):

Hi, my name is Judy Kinney, and I'm the Executive Director of End of Life Washington. I was really looking forward to being with you today in a big zoom room and talking about being end of life ready. But I'm also very thankful to be partnering with the Davis Phinney Foundation folks, to record this video and get it to you. And I will work with them to also identify how we can make arrangements so that any questions that you have can be answered. So thanks for your flexibility. And again, I wish, I was so looking forward to being with you this afternoon, but this afternoon, or right now, whenever you're looking at this recording, I want to talk with you about being end of life ready and what that can mean, why that's important and what are your choices when it comes to being end of life ready.

As I mentioned, I come to you from the End of Life, Washington, where we provide free services, education, and awareness, resources like this presentation today, as well as resources that we have on our website, support for individuals and clients. We have over 70 client advisors across the state of Washington that are providing one-to-one support for individuals who accessing medical aid in dying and VSED, which I'll discuss later today as well as very active in the arena of advocacy. So we played a leading role in passing the Death with Dignity Act in 2008, and we continue to work on multiple levels to increase access to end of life choices. Last year, and this upcoming legislative sessions we're looking to really make improvements to the Death with Dignity act as well.

In today's session, there are two parts. The first part is really thinking about or talking about planning ahead, being aware of end-of-life choices, what's important to you. And then the second part really talk through in more detail, what are our end-of-life options within the state of Washington? So I grew up in a family where we talked about things we weren't supposed to talk about. And definitely we talked about end-of-life choices, my mom lived to be 97 and a half. And for the last 27 and a half years of her life, we talked about death and dying and choices. And I kind of grew up thinking that everyone talked about end-of-life choices. And yet that isn't true. And so one of the most important things that we can do to really access the kind of death that we would like if that's available to us is by beginning to talk about and exploring what's important to us.

So you'll hear me talk about in multiple ways, multiple times the importance of having a support team. So it could be a care team, could be a care pod, you could call it different things, but it's both professionals and personal people in our life that support us in making our end-of-life choices. A first good place to begin is to explore what's important to you. We have a values worksheet that allows you to rate what's important to you. There are other value resources, value worksheets that are out there. The idea here is to take time. These are really personal questions that we may, there may be, you'll have people that you care a lot about and you're going to have different values. You're going to want different things at the end of life, and this really, worksheets, whether it's ours or others really allows you to think through what does living well mean to me?

Do I want to be at home? Do I want to be in a hospital setting? Do I want to pursue all choices, all options available to me, do I really want to reduce my suffering? What is quality of life? And again, these are really, really very individual decisions and taking the time to go through a values worksheet is really one of the most important things that you can do. It is, only you can do, and it really provides the foundation for all the other things that I'm recommending or exploring today.

And we raise this because what we have found is that individuals who take the time and who can take the time to think through what's important to me, to talk through that with people that they, that are potentially in their care circle, circle of care, and also document for medical and legal reasons, what's important to them. Individuals, when we do this, we are way more likely to reduce our own and our loved ones' stress and also have autonomy throughout our you know, living and dying process. So after you've completed a values worksheet, again, whether it's ours or someone else's you know, obviously we've put a lot of thought into ours. You can find ours on our website but there are others. It's the process for you that matters most. And once you do that values process, a next step is twofold is to create a set of advanced directives.

And one is a healthcare directive and this, or some people call a living will. And the next is identifying a healthcare agent completing a durable power of attorney for healthcare. So it's a set of advanced directives. It has these two parts to it that are really important. And the healthcare directive really gives both of these combined, gives directions on what kind of treatment you may want or not want if you're not in a position for speaking for yourself, if you're unable to speak for yourself. And there's a combination of your healthcare directive and your durable power of attorney for healthcare it's that healthcare agent that makes decisions for you. What we're hearing from medical providers is that in an acute situation, doctors are going to turn to your healthcare agent and say, what do you want me to do? And so who you identify as your healthcare agent is needs to be able to make recommendations that are important to you, that you've articulated in your values and in your healthcare directive that

may not be what they want, right? It's may not be what they would want for themselves. And so you need someone who can stand up really in tense situations and say that this is what you want for your quality of life and quality of end of life.

You know, it's important to keep these, your, both your DPOA and your healthcare directive close by. You can share it with your care team. You can have it posted electronically so people can access it. Again, in an acute situation, when decisions need to be made right away, people aren't going to pull out your health guard directive. It really is a legal backup document that supports your healthcare agent and your healthcare provider to make decisions based on what you want. I'm going to keep saying that. You know, when I think about who I've chosen as my healthcare agent, it's not my best friend, it really is someone for a variety of reasons. It really is someone who I know can, they live close, they're not afraid to speak up on my behalf and they are comfortable doing so. A third part is to consider and evaluate a need for POLST.

So POLST are not, at this point are not recommended or needed for everyone. It is a medical order needs to be signed by your physician, POLST stands for either portable or physician order for life-sustaining treatment. If you have a serious diagnosis serious illness diagnosis, and end stage of your life, you want, this is a medical order that documents your choice around life-sustaining treatment. Again, this is a core choice. You know, am I, are you a do not resuscitate? Do you want to be resuscitated? This is directives. And again, this is your POLST form needs to be available and visible. It's in your home. People put it on their refrigerator. Your doctor, physician's gonna sign this. They're going to keep a copy as well. This isn't for everyone, but you want to evaluate a need for it.

So all of this can get complicated and this slide, I liked. It really like lays out what this process looks like. So if end of life, Washington, if we had our way, all adults 18 and over would complete an advanced directive and identify a health care agent. Obviously, these need to be periodically updated, you know, like our choices, where we are in our life stage, things change, and they are to be periodically updated. When you have a serious diagnosis or serious illness. They need to evaluate a POLST. And again, updating as anything change when they document, these, you want to share these with people in your care team and your physician and your wishes are well-documented.

So in this first part planning ahead, really, again, it starts with what's important to you. What matters to you? Going through a process, a values process to think about what's important to you, what matters. As you're doing this, it's really natural to talk with others about that. It's great to hear what others want to do, what they, how they would do differently. For me, this is really best when it's a conversation. It is hard to do this alone, even though so many of these decisions are very personal decisions. You want, these are things we want to talk about. The more we talk about in the process of talking about values, what's important to you in that



process. You're just naturally putting your care team together. You want to talk with your physician about this is what's important to me, and we'll talk later in this presentation, can you support me in what's important to me, right?

Not all physicians can or won't, right? You want to complete set of directives, a legal binding document, advanced directives for health care directive and choosing a healthcare agent. I want to emphasize again, the importance of identifying and choosing a healthcare agent, because that individual likely is in the position when you can't communicate your preferences yourself, it's that person who's going to be ensuring that your needs and wishes are met and then also evaluating a need for a POLST. So that's planning one, putting those pieces together. And to support you in this section around what's important to me, important to you. This next part is really I want to walk through end of life choices, what's available to you.

Let me get my notes organized here, hang with me for a moment. Great. And when we think about end-of-life options, I want to emphasize that you always have a choice. You and we always have choices at a foundational level. You can accept and refuse treatment at any point in time. You can change your mind, right? There's really important decisions. And our culture, our medical culture really knows how to pursue treatment by any means and as much as possible. We're not as familiar or comfortable or aware or value around refusing treatment or not pursuing all options. Again, you can choose and accept any and all treatment at any point in time.

And that's always true. A next level of choice is called comfort care. Palliative and hospice care are focused on symptom relief, which is often referred to as comfort care. Examples of comfort care could be pain reducing medication, symptom relief, a massage, breathing, could be emotional, psychological support. It's really any and all measures to provide comfort, whether it's physical or emotional, that's associated with an illness that is either being cured or one that is terminal. You can see on that palliative care side that palliative care can be offered at any stage of a disease, even as you are receiving curative treatment. Palliative care really is considered about reducing anxiety you know, and can include reducing depression, anxiety, you know, fear of death, as well as physical pain. Palliative care is often paid by insurance or by individual paying. Hospice care on the other end is provided at the very end stage of life when someone has stopped or is unable to receive treatment and has a prognosis of six months or less to live. Hospice is covered by Medicaid, Medicare and insurance. It can happen in your home, in a facility or hospital, it includes resources for family and the support team, and often comfort care is provided along with medical aid and dying and voluntary stopping of eating and drinking, which are two choices I'm going to talk about next. And so you can see these are comfort care is, can be treatment, but is often, can be provided in conjunction with other choices.

So I want to transition to talking about hastening death, ending suffering, so along with the choice to stop or refuse treatment, you have the choice to hasten your death, to end suffering, enabling you to die on your own terms with autonomy. And if or when you find quality of life so diminished that you may choose these options. These options, I'm going to talk about medical aid, dying and voluntary stopping eating and drinking, also known as VSED, are not for everyone. Obviously, we all have different cultural, spiritual, and philosophical beliefs about death and dying, but these options are available to people within the state of Washington. And we really believe strongly that we want to introduce these options to everyone so that everyone within the state of Washington can make informed, value-based decisions for their own end of life choices. Right? So we're not twisting any arms, or we're not saying what's best for anyone.

We want you to be aware of, know how to access these choices. You know, again, as I said earlier, like we talk about end-of-life choices because our system is so focused on sustaining life and treatments. It's challenging for medical providers to talk with patients about their end-of-life choices because they don't want to be in a position of conveying that they've given up on them. You know, and so it's hard for providers. So oftentimes it is really up to individuals to initiate this conversation with their provider. It's really important way before you need to access any end-of-life choices, to talk with your providers about what's important to you and to identify if they will and can support you because not, not all providers will or can. And so way in advance, you want to be talking with your provider and letting them know this is what's important to me.

So first to talk about I want to talk about medical aid in dying or MAID you may also you'll hear us interchange made with death with dignity or DWD. These are interchangeable. In medical aid in dying allows someone who is terminally ill to control the timing of their death, to reduce anxiety, pain, and/or suffering. Death is inevitable. So these individuals simply choose to die using a medication to have control over the date and time of their death. What we find is that so many will as I mentioned earlier, many will, many people who choose medical aid in dying are also involved with hospice and palliative care or palliative care. We find that there's two statistics that I want you to know. One is that, so we're serving over 600 people annually in the state of Washington. I'd say 95% of the people in the state of Washington come through End of Life Washington for support. And we find that 20 to 30% of people who sign up as clients and go through the process of obtaining the medication don't use it. For many people just having kind of facing all the unknowns that come at the very end of life, having that safety net, or just having medical aid in dying, the medication available to them really reduces stress. That's important.

The qualifications to access medical aid in dying, death with dignity is you need a terminal diagnosis, terminal diagnosis with six months or less to live. You need to be a resident of the

state of Washington. You need to be 18 years or older, you need to be capable of self-administering. This is a really important criteria and that's really is a safeguard in the law that protects against euthanasia which is it protects providers and individuals from euthanasia, which is when a provider administers the medication. So with death with dignity, with this law, an individual needs to be able to self-administer, very, very important, and that self-administering can come in a variety of ways, can be orally and other ways, but an individual needs to be able to self-administer. We have, this is where our volunteers and our physicians really help individuals make these decisions, need two doctors who can and will support death with dignity. Of our clients we support, 70% of the people who come to us need help accessing one or both physicians. So we definitely help people with this and individuals accessing death with dignity need to have decision-making capacity, right? So the timing really matters a lot. The disease matters here. So individuals, which I'll talk about in a minute, so individuals with Alzheimer's do not qualify for death with dignity.

Again, this law was passed in 2008. There, currently Washington is one of 10 states, entities, including the district of Columbia who support medical aid in dying. And Montana has a court decision that says, doctors can do this. But it wasn't passed by, like it has been in other states. Washington was a leader when it comes to advancing death with dignity, we were the first state that had initiative before a ballot measure, a bill, a ballot measure for people to vote on, back in, I think it was the nineties. So a leader in this area.

Let I just look at my notes real quick here. See if there's anything that I'm missing. You can see here, we have worked with people as young as 18 and up to 104 years of age, you can see that cancer is a primary diagnosis. There is a waiting period, so there's a 15-day waiting period. There is a very involved process for people to access death with dignity. And oftentimes, you know, because we, facing our mortality is hard. Many people wait till the last minute and are not really able to go through the process that it takes to sign up and go through the steps to access death with dignity. I really want to encourage you, I'm gonna say things over and over again. I really want you to encourage you if this is a, if you qualify for death with dignity, if this feels attractive, just because you go through the process, just because you get the medication, again, doesn't mean that you're going to use it or that you have to. Going back to that first choice, accepting, and stopping treatment, you can change your mind at any point in time.

And I think it's important for all of us when we're thinking about end-of-life choices, to realize that individuals are in control of their choice all the way through. So the choices that we're talking about are very, very patient or person centered all along the way.

Let me take a quick drink here, but as you can see that medical aid in dying is not an option for all people. So when someone does not qualify for death with dignity, someone has a neurodegenerative disease, like Alzheimer's, ALS, Parkinson's included with long trajectories of

decline and potential loss of decision-making capacity the end-of-life decisions are more limited, but they are available. And we want to talk about what's available to you. So one option we talk about is called voluntary stopping eating and drinking, or VSED. VSED has been around for hundreds of years, although it hasn't been called VSED. It is a natural death. It's a natural supported death that's legal and is really, really important to have a care team in place. So it's a voluntary choice to hasten your death, it's by removing nutrition and hydration.

So when we're not eating and drinking both, our body's dying naturally within one to two weeks. Managing this process of dying naturally in one to two weeks, really requires a support team. From palliative care, hospice, medical providers, family members to support this process. Again, someone choosing to VSED is in control of their choice to stop food and drinking food and water and their caregivers are following their instructions. That's articulated in a healthcare directive throughout the whole process, the individual can change their mind. And again, at any point in time, VSED is not a decision to be chosen lightly. None of these decisions are, but it does require tremendous support and a good plan. And it's very effective for people experiencing present and eminent suffering who do not qualify for death with dignity. Again, VSED is a voluntary choice by the person with decision-making capacity, right? So you can see that decision-making capacity is a core protection in both MAID and VSED. For someone making this choice, they're making the choice while they have decision-making capacity, in advance. So it is advanced planning.

You can see that a client suffering from various diseases, such as Parkinson's, ALS, early Alzheimer's, severe arthritis, muscular dystrophy, other diseases, this is a good choice. And there VSED is a, so the last, End of Life Washington has been supporting people with VSED for many years, this past year, we supported 12 people, there's a growing awareness and a growing level of support for people to VSED. Let's see if there's any other things that I want to say. Let me just look at my notes here, again, when it comes to VSED, I just want to go back to this for a moment. So for both medical aid in dying and VSED, we help you through this process. If these are processes that you want to explore, again, many people call us, we provide support and consultation. Some people become clients, some people don't, and all along the way, you get to change your mind. You're always a decision maker all along the way.

So when it comes to end of life choices you know, you can see why we started with what's important to you. What matters, how do you want to live until your last breath? Like what's important to you, how that builds into a health care directive, healthcare agent, and then understanding what your options are, kind of reinforces or informs particularly those documents. So you always have a choice of stopping, continuing treatment, medical aid in dying is a choice, as well as VSED. We want you to, so not all hospitals or providers will support your decision to access medical aid in dying, or to VSED. We have access to a team of providers who do across the state to support you with your decision.

We have client advocates, we have support people. We have relationships with hospice. So, so we also want to be on your team to support you in your process. So in review, going all the way back, that first act of what's important to me, how do I, what does quality of life mean to me? And talking with documenting that and talking with people about it, documenting in a values worksheet, and also documenting legally and a healthcare directive, director of power of attorney for healthcare. And it's really important talking with people and sharing those documents is how you create your team.

This slide, I like this slide because it includes both the formal and informal lists of people who's who you need to work with to support your end-of-life choices. So you can see that advanced directive, POLST, refusing or stopping treatment, hospice, palliative care, death with dignity, VSED, these are choices on the left. Here in the middle column is the required facilitator. So you need notary, two witnesses. Some things need to be, your doctor needs to sign off on and improve. Death with dignity requires two supportive providers. And we really encourage to have medical doctor hospice involvement in voluntary stopping eating and drinking. Hospice gets involved with VSED after your, after you stop eating and drinking whether you have a six-month diagnosis or not prior to that, as soon as you stop eating and drinking, you become eligible for hospice.

It's important to put that in place in advance. But when you stop eating and drinking, you become eligible for hospice. Other supports include ourselves, friends and families, other healthcare providers, death doulas, spiritual leaders. It really helps to create a team care pod, we all call these things different names, but it is about, although death is one of the most individual things that we do having others with us and supporting us is really important and really a key motivation, early motivation for End of Life Washington came from individuals who didn't want anyone to die alone. And we support a significant number of people without family every year. We become people's families.

So we want you to check the boxes, really know what's important to you, help using that, to create a support team, identify your healthcare directives, complete your health care directives, evaluate the need for POLST and most importantly, discuss and provide copies of your advanced directives to your core team. So a lot of information, there's no test. You never have to understand all of this. We want to be a resource to you at any point in time. And if you go to our website, so end of lifewa.org, we have a host of resources that you can access. There's videos, there's documents. We have healthcare directives, you know, we have support for physicians. If your doctors, you know, is supportive of you, but doesn't understand the process we can support your provider. We get, another way is to call us. So we get over 1500 phone calls a year. We will talk with you and consult with you. What's important, what you're wanting, what you're needing and help to connect you with the best resources. You don't have to figure



any of this out on your own. We want to be here for you. And again, all of our services are free of charge.

So you heard me say earlier that I would love it if everyone completed a health care directive and understood their end-of-life choices. And again, this is about quality of life, quality of death is about quality of life. And so we want everyone to know, everyone to be able to access, and so help us find people to educate, whether it's friends, community groups, organizations that you're involved with, let us know, help to connect us with other people so that they can also get this end-of-life ready campaign, this end-of-life ready presentation. We do tailor the presentation for the group. So let us know, and that's it. I wish we could talk and ask questions. Again, I will collaborate with that Davis Phinney Foundation, folks, staff, to identify how we can get some, your questions answered.

So thank you so much. I guess the other thing I want to say is an easy way to stay in touch with us is to go to our website and to sign up for like, stay in touch, we send out a monthly, mostly a monthly e-news that we know what's happening, how to get involved, changes in laws, what's happening in other states, we tell stories. So you get a sense of things. We also have an active, End of Life Washington is active on Facebook as well. So thank you so much. And I look forward to connecting with you further.

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