

UNIVERSITY OF ILLINOIS AT CHICAGO  
AAPI ADVANCE CARE PLANNING - STARTING THE CONVERSATION  
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>> MANSHA MIRZA: Good evening, everybody who is just joining. Thank you all for being here today. My name is Mansha Mirza. I want to welcome all of you on behalf of ASIAAN which is a National Assistance Resource Center funded by the administration for community living and focuses on supporting Asian-American and Pacific Islander older adults and their caregivers.

Before we get started, we wanted to get a sense of where everyone is at with this topic, how familiar you are with Advance Care Planning. What is coming up is a poll just to get a sense of what your prior experience and familiarity is.

I'll go ahead and launch the poll and give you a few seconds to respond.

I'm going to close the poll now and let's see what we have. Hopefully I'm sharing results with everyone and everyone can see. So it looks like we have a bit of a mixed bag. Some people are familiar with the topic and quite a bit, and for some people this is new or relatively new, and it also looked like, let's see. We have about half respondents saying they have created an advance care plan for themselves which I think is great. Some of the information that I'm about to share with you in the next few slides is going to be very familiar with some of you, and for some of you it will be relatively new. Regardless, we hope all of you get something useful. We do have an excellent line up of panelists today, and I will introduce them after we are done with this introductory information. So let's begin with what Advance Care Planning is. This refers to the process of planning ahead to ensure that healthcare and financial arrangements are in place before a health crisis or end of life.

And there seems to be a lot of myths about Advance Care Planning and I'm going to try and address some important ones here. One myth is that advance care planning is only important for someone diagnosed with a terminal illness, whereas in reality, it is for everybody, particularly for people who are older, have one or more serious chronic health condition, are experiencing cognitive changes as they age and or are approaching the end of their lives.

Another myth is that Advance Care Planning is an individual's sole responsibility which, again, it not quite sure. Advance Care Planning involves team effort. It involves having conversations with family, friends, legal and financial experts, doctors and other health professionals. There also seems to be this idea that's quite pervasive that advance care planning is a one-time effort, one and done thing, where in actuality it is an ongoing process. If you have an advance care plan, it is important that you revisit the plan regularly and update as needed.

So why are we here today talking about Advance Care Planning for AAPI communities? Why this conversation important? And what we have for you on the slide is data that was published in an C report and come from a survey -- NBC report and comes from a study from 2022. Compared with other racial he ethnic groups, AAPIs were more likely to think about death and dying but far less likely to have a documented advance care plan. So among respondents it seemed like 47% had an advance care plan, but based on this survey, 66% of AAPI respondents said they did not know how to find information about creating an advance care plan, and 63% said this they would need emotional support through this process.

So we looked at the literature on what some barriers would be. And we looked at several studies conducted with a wide range of AAPI communities and the slight summarizes the list of barriers these studies have identified. So it turns out that for a lot of AAPI individuals and families, the idea of end of life planning is very foreign or alien. Also cultural beliefs related to or the idea that it is the family duty to care for elderly family members is quite common across AAPI communities. And there is a sense among younger AAPI individuals that discussing Advance Care Planning with their parents would be considered disrespectful, on the other hand, parents think that bringing up Advance Care Planning with their children will upset them.

It's a conversation that keeps getting avoided. In several AAPI communities, decisions are made collectively with the family's opinion being prioritized over individual autonomy and balancing the two can become quite complicated when Advance Care

Planning is being considered. Also there is a tendency to not really talk about serious illnesses.

The idea being that you don't want to rock the boat too much. You want to maintain harmony, you want to avoid causing possibility of pain so that ends conversation about Advance Care Planning. There is also great value placed on incorrect communication as a way of saving face or minimizing the burden of knowledge on your near and dear ones.

As a result older AAPI's assume they don't have to talk this out or with their younger family members, and that their children and others in their family will just know what their end of life preferences are without having a conversation about it. Research shows that there is language barriers that get in the way for AAPI older adults who are not very proficient in reading or writing in English. We saw based on the survey data that there is lack of information on how to even get this process started, where to find information, who to talk to, et cetera.

Sometimes the economic constraints and mistrust of legal paperwork can get in the way. There might also be concerns about non-compliance. For instance, I might have a plan, but do I trust my family to execute my plan? And finally, what we also know is that there is a lack of culturally sensitive tools and supports for this process that are aligned with the religious values and beliefs of AAPI communities.

So this is why we are here today because of this set of barriers, and we are hoping that through this webinar we get the important conversation started. And to help us kick off this conversation, I'm going to invite our first panelist, Jim Berchtold. Jim is a senior staff attorney with justice and aging, a national nonprofit legal advocacy organization that fights senior poverty through law.

Jim's work at justice and aging focuses on guardianship, improvement and reform. Prior to joining justice in aging, he worked at a legal aid organization where he developed a number of programs to provide direct legal representation to older adults and people with disabilities who are facing or under guardianship. Jim, it's over to you now.

>> JIM BERCHTOLD: Hi, everybody, thanks for having me here. So I'm going to approach -- I'm sorry, just to clarify, am I supposed to -- do you want me to talk right now?

>> MANSHA MIRZA: Yes, absolutely, the floor is yours.

>> JIM BERCHTOLD: I'm going to talk about the legal aspects of Advance Care Planning. So from a legal perspective, Advance Care Planning is fairly straightforward. It really is just a matter of signing, dating and copying a packet of legal documents. Now, these documents are usually standardized,

fairly easy to read, so this is something fairly simple to do. I recommend that people focus on three primary documents. The first one -- so get your pen, write this down. The first one is a Power of Attorney or healthcare.

Now, what a Power of Attorney does, it allows you to appoint an agent who can make medical decisions for you. So that in situations where you are not able to make those decisions for yourself, so that person, the person you appoint can then talk to your doctor, can obtain your medical records, and can consent to medical treatment if the need arises.

This document also usually allows you to state your preferences. What kind of medical care do you want or not want in particular situations? So that's document number one. Document two is a Power of Attorney for finances. Now, similar to a healthcare Power of Attorney, a financial Power of Attorney allows you to appoint an agent who can handle your money when you are not able to do it.

Now, you may be asking, we are talking about healthcare, why is my money important? Well, think about it, if something happens to you, your bills, your mortgage, all of that stuff still needs to be paid. There probably is, someone may need to talk to your bank, someone may need to talk to your insurance company, and there are probably additional financial issues because of medical treatment you are receiving. So document number two, financial Power of Attorney.

Document number 3 is called a living will. It's sometimes called an advanced directive. This document really allows you to state what you want to happen in particular situations. Now, some states have combined a healthcare Power of Attorney and a living will into one document. And that's fine. You may not need an additional living will, but there is also no problem, there is nothing wrong with having that additional document. What you need to be sure of though is that those two documents do not conflict with one another.

If you have a healthcare Power of Attorney and you have a living will, you want them to say the same thing. The next question is where do I get these documents? Usually you can find these documents online for free or for a small fee. Now,, for example, I live in Nevada, if I Google Nevada Power of Attorney for healthcare form, I would get a number of sites. I would probably be able to find the documents for free, but I would also get a number of sites that specialize in creating legal forms that you can buy.

You just want to be sure that the documents that you are downloading comply with the requirements of your state. Now, once you have the documents, you also may be able to find them at your local library or at a legal form store where you can

purchase the forms. They are pretty readily available. Once you have the forms it's a matter of filling them out, signing them, dating them. You probably have to get them notarized or you have to sign in front of two witnesses. It depends on the requirements of your state. Then it's a matter of making copies and distributing copies to everyone who may need a copy. That includes definitely the agent you are appointing to make decisions for you, but it also would include for your healthcare Power of Attorney, you want your doctors to have that. For your financial Power of Attorney, you want to give that to your bank and to your other financial institutions.

So it's a simple process, but where people commonly make a mistake is they assume that if something happens to me, someone else will have the legal authority to make decisions for me. And that is not necessarily a correct assumption. This happens frequently with married couples. They assume their spouse can make decisions for them. That is not necessarily true. Even if your state allows some types of decisions, it probably does not allow the breadth of decisions, the breadth of powers that your spouse will need in order to handle your medical decisions and your financial decisions.

So I would, so across the board, everyone, everyone should engage in Advance Care Planning. And they should do it as early as possible. Many of these legal documents require something called legal capacity to sign them, meaning that the person who is signing them needs to be able to understand the contents and the effect of these documents.

If you wait too long, you wait until something happens, then the person may not have the legal capacity to sign these documents and take advantage of these really powerful tools.

>> MANSHA MIRZA: Thank you, Jim. That was helpful information, and I'm sure as Jim was talking some questions may have come up for members of the audience. As you are thinking of your questions, please put them in the chat and we will take them after all panelists have had an opportunity to talk. I'm going to go ahead and invite our next panelist.

Our next panelist is Mary Fus who is a caregiver and has been a volunteer for the Alzheimer's Association for 11 years. She is also the mission chair for the Chicago Walk to End Alzheimer's. She has been a caregiver for her mom since her diagnosis in 2009. Mary, please go ahead and share your experiences.

>> MARY FUS: Thank you so much for having me. I'm just going to answer a few questions that was presented to me and just talk a little bit about that based on my experience. So one of the questions was what are some of the recommendations for service providers to initiate culturally sensitive

conversations with Asian families about advanced care and end of life planning.

I think basically you start out with the healthcare provider determining what stage the person and I just want to go back a little bit because my experiences with someone with Alzheimer's, dementia that I might throw in a lot of those examples. So a person with dementia, you want to know what stage they are at. If they can understand and even contribute to the conversation, and just set up an appointment with the key individuals.

And you want to explain and acknowledge that there may be cultural and traditional relevant issues that may affect their decisions, and as their caregiver and healthcare provider, they just want to make sure they understand what those may be.

And then in terms of language, you want to make sure that they address whether they need a translator. In my instance, I understand Chinese more than I can speak it. So I would need somebody there to help translate because some of the terminology I would not be able to explain, and so you want to make sure you have a translator. And even for the healthcare provider as well as the translator, make sure that they are trained on how to interface with someone with dementia. For instance, you may need to speak slowly or use less complex words. And sometimes people with dementia, they may have problems understanding what is being said versus not hearing what they are saying.

And I can give you an example, my mother, she would say ha? After you say something and you would say something, and she would say Ha, so most people would think that she is just not hearing it or she has hearing issues, but in her case, she was actually not able to comprehend what you were saying. So that's something to keep in mind. And there also may be faith-based beliefs that affect decisions, especially when it comes to DNR, you know, whether they want to prolong their life or just have comfort care. Cultural aspects, each family is different. For instance, who makes decisions in the family? Some people they have like the eldest or maybe a male, or some people don't follow those traditions and anyone who is capable of doing it will help make the decisions. And if you have that Power of Attorney, those decisions will already be made.

And then a lot of Asians are brought up as mentioned before to take care of their elders. So some people may want to keep their loved ones in their home as long as they can, or they may want to bring them into their own homes versus going to a long-term facility or rehab facility. But something to keep in mind is that if they do need to go to a long-term care facility, Skilled Nursing Facility, rehab, that what they may need is a facility that takes into account cultural appropriateness,

activities, food as well as language.

And then another question that was asked is what do caregivers need to know about advanced care end of life planning? I would say that you really just need to educate yourself. Do your own research online, talk to healthcare and legal representatives, use community resources such as the Alzheimer's Association, AARP, Department of Aging, but be informed and do your research. And then you need to have those hard conversations and discuss what the person wishes are so that their wishes are known and decisions can be made based on that information.

And the last question that was presented was how can we get American, Asian-American communities talking about wishes for care at end of life? There never is a good time to talk about end of life, but I would just say it just needs to be done. And I'm going to give dementia as an example is that it's a progressive disease. And over time someone with dementia may no longer being capable of making decisions on their own. Every family knows their own dynamics and can help get the conversation going. There may be someone who automatically takes charge or someone who knows what to say just to set the tone.

But bring your family, significant others, friends together and just explain why it's important to have this discussion for both the person with the dementia or with the healthcare issue, and their family. You want to make it clear that the goal of having the discussion is to be able to honor the wishes of the person with the dementia as best as they can, and the only way to do that is to know what their wishes are. And then explain that if it isn't done while they can make decisions and communicate their wishes, that waiting too can be too late when the progress of the disease may limit or even take away their ability completely. And then the last thing is within a family unit there may be disagreements on plan of care, but if everyone hears from the person with the disease what their wishes are, then it just makes decision making easier.

>> MANSHA MIRZA: Thank you so much, Mary. We understand this is a difficult topic to talk about and we appreciate you sharing your personal experiences.

>> MARY FUS: You are welcome.

>> MANSHA MIRZA: Time for the third panelist. I'm going to invite Pooja Patel who is the founder of aging together. She specializes in proactive holistic care planning for older adults and their families through a self-developed framework with a background in occupational therapy, she has experience in dementia care, fall prevention and geriatric health. She also hosts a podcast focusing on supporting underserved communities

to navigate aging confidently.

Pooja, the floor is yours.

>> POOJA PATEL: Thank you for the introduction. Similar to a lot of the points that Mary made, I'm going to kind of base this off of some of the questions that I received preemptively. So as a healthcare professional in the geriatric care world, there is a lot of strategies that I picked up over the years to really help older adults and their families understand their options to create these proactive care and end of life care. One of the first things I do with these individuals within our Asian community is try to understand family dynamics. I try to understand am I working directly with the older adult or will I be including family, and if family needs to be involved in these conversations, then can we get a system, a system set up to make sure that everybody's voices are heard.

A big cultural, a big cultural consideration for working with this population is that in many cases there will be family involved. In some of these families it's likely the oldest child or the older daughter. Generally it varies, so it's important to identify who the key point person is. Then something Jim mentioned it's important to ensure that that person then has healthcare Power of Attorney to make sure if they are making decisions for the older adult that that has been identified and that the rest of the family is going to be on board with some of those discussions and decisions.

Secondly is education. There is a lot of misinformation and just a lack of awareness of what decisions someone might need to make at that stage of life, and I think a lot of that comes from just lack of conversations, we don't have these difficult conversations, right. A lot of points that Mary mentioned earlier, we grow up with this sense of filial piety, which is a sense of obligation, sense of duty to our family, and we don't really have those in depth discussions around what are we going to do at end of life, who go is going to take care of us what do you want us to do.

And it's important especially as the generations change. I'm an American born Asian daughter, and so a lot of those values sometimes differ from what a first generation immigrant may hold close to their heart. So I can appreciate a lot of those values, but a lot of them sometimes differ from what I might bring to the table. But I have a very practical approach to this. It's everyone is going to experience end of life. It's not an if you will. Everyone will, and so why not plan ahead for it? So I come from a very educational lens of here are your options, here are some of the things you should think about and consider.

And then based on family dynamics, the older adults' goals



and wishes and the family's goals and wishes come to together into a written plan of care that I have created personally. Then they have a written tangible plan. It's really important to have these things written down whether in a legalized, formalized matter such as a healthcare Power of Attorney or living will, or just a document where you have had a conversation with family members, and you have written down what your goals and wishes are.

Now, I mentioned some of the barriers that I have observed to why a lot of families in our communities may not approach the subject as much. What I have noticed in working with these families over the years it first I mentioned lack of awareness, and often poor health literacy in general, but then also poor communication within family units where some of our communities aren't known for good communication. So a lot of times it's purely communication related. Family dynamics, especially if there is language barriers or difference of values, difference in beliefs, then that can create a very challenging family dynamic to have some of those deeper conversations around difficult topics.

And then beliefs and values, again, especially religious values and beliefs, if they play a role in end of life care. Sometimes that can be a very, it can be a very implied decision without communicating about it, and I think that that's where I see a lot of barriers.

We have a lot of implied beliefs in certain communities that, well, this is what you should do. And that may not necessarily translate down to the children. They may not understand that, and if it's not communicated well, it leaves a lot of room for error.

And so those are the barriers that I have noticed, and one example I have is an Indian male married in his 50's, he approached me to create a plan for his father who was in his late 70's, had Parkinson's and wanted to know how to prepare for end of life.

And initially we had a conversation with the whole family. It was my client plus the three siblings plus the parents, and we had a family meeting about all of these different aspects of care, and then the mom, she didn't want to participate because it was too sensitive, it was too emotional a topic for her and she was very comfortable with letting the kids have that conversation. And so we had a separate conversation with just the kids involved, and it was just like, okay, here is what we need to talk about. And ultimately, I had a one-on-one with the child who is healthcare Power of Attorney and who was going to be making the decisions. We had a one-on-one, and I explained the difference aspects of Advance Care Planning and what

important decisions need to be made, and he had that one-on-one with his own father instead of involving it as a family unit because he felt he could get a better understanding of what he truly wanted versus in the family setting environment.

So it really depends. You have to understand the family dynamic, whose decisions matter, and also what everyone wants. But the main point is you need it written down because when the time comes, and if it's not written down, then the hospital is going to do what they need to do.

>> MANSHA MIRZA: Thank you, that was really insightful. Moving on last but not the least, is Edie Yau. Edie Yau is the Senior Director of diversity, equity and inclusion engagement for the Alzheimer's Association. And leads strategic initiatives to reach underserved communities in the pursuit of health equity.

She leads national partnerships to increase access to resources and support for all those affected by Alzheimer's and other dementias. She was an appointee of the California task force on family care giving, a member of the California master plan for aging, equity Advisory Committee and currently serves on the AARP California Executive Council. Edie, the floor is yours.

>> EDIE YAU: Thank you for the opportunity to present on this panel. So I am also coming from the Alzheimer's Association and Mary when I come to Chicago, I would love to meet you in person. I am in California, and I certainly do more nationwide work. I'm kind of wondering what else do I have to add to this conversation because our panelists have covered so much. You heard what are some of the, what are some of the issues around this topic for Asian-American communities, and I don't, I feel like, well, you might think, well, there is nothing really pinpointing to it.

It's the general stigma is what we keep hearing over and over. It's lack of communication. It's not, these are not conversations we grew up learning how to talk about. I often think about when we are talking about Alzheimer's or other health conditions that I may have a college degree, a graduate degree, but the stuff that I grew up understanding around health issues, healthcare-related things coming from immigrant parents, that's very different from what I learned in college.

So a lot of these conversations happen in the home, happen with our family members, and through multigenerational conversations, intergenerational conversations, and so I don't think we know how to have these conversations is what I'm hearing and what I gather from my own experience having worked in this space for over 25 years.

And so when the question is, you know, what are some of the

unique challenges around Advance Care Planning for people with Alzheimer's Disease, I think first and foremost we have to think about Alzheimer's impacts nearly seven million Americans. It is the most common form of dementia, and then you think about over 11 million Americans provide unpaid care for people with Alzheimer's or other dementias. Most of those individuals are family members. A lot of family members do not consider themselves caregivers. It is simply what I have to do. When we think about our Asian-American communities, often it is the daughter or daughter-in-law or the wife, but it's also we see a mix of multiple family members all contributing in some form or fashion. But they may not talk about these things. It's just what we do.

But Alzheimer's specifically, it's an unpredictable disease in terms of the life span of how long someone might survive after a diagnosis and so someone could live from several years to 20 years, and so, yes, it is really important to talk about end of life care and do some of that advance care planning with the person with the diagnosis. So that's the thing I would emphasize if we are talking advance care planning for people with dementia is that over time individuals, they lose the capacity to express themselves, and it would be ideal to have that person's wishes carried out. So knowing what that person's wishes are when they can still express them is so critical.

There are some links to our website that I can share when I'm finished talking because I can't do that at the same time, but I think you heard that talking about death and dying and that talking about even planning is taboo. We heard that. And also the notion of filial piety, the respect and the Asian culture is very much around family preservation.

So I guess the way I would suggest that we think about if we are trying to move this forward and have more people talk about Advance Care Planning in Asian-American and Island Pacific communities is framing the discussion in this way. What do I need to know in order to respectfully honor my mother's wishes or so and so's wishes and preserve cultural desires. The Alzheimer's Association puts out a facts and figures report every year, and this past year we talked about dementia care navigation because that's an important piece of having someone who can help the family navigate all of the different care options that they might want to consider and certainly Advance Care Planning should be a part of that discussion early on, not waiting until late stage, not waiting until middle stage, but early stage. We need to start having that conversation.

One of the things we learned from a survey that was put out and breaking it down by racial ethnic groups was looking at the cultural competency piece, and how cultural competency is

fundamental to dementia care navigation. I think we see this in general even for healthcare providers and so one of the polls showed that Asian-Americans in particular felt very strongly that cultural competency is really important to us. It's important that we feel like our healthcare provider has some knowledge about our racial or ethnic background, and the other question was do you feel like you have access to dementia care navigator, healthcare providers who have that cultural competency, and that was under 50% of AAPIs who felt that that was available to them.

So I think even if we don't have access to people who share the same racial or ethnic background, that at least our healthcare providers and those around us who are helping us navigate this have some understanding of that. And so asking those questions, taking the time to understand the family dynamics as our earlier presenters talked about, some families are very complex and so understanding those family dynamics and not making assumptions of who is the primary caregiver because in many families it's the whole family unit that makes these decisions. It's not just one person who makes these decisions. It's the whole family unit and so really understanding that.

The other question how can we get AAPI communities talking about wishes for care at the end of life. I think it really is about normalizing the conversation. So, again, taking Alzheimer's as an example, talking about dementia, and right now is such a great time to be talking about Alzheimer's in the sense that we know that there is now this new treatment, the third F.D.A. approved treatment for Alzheimer's that has such potential to slow the cognitive decline that is specific to Alzheimer's. And so it's hopeful.

And so having these conversations about do you understand what dementia is, and what if, what if you had dementia, would you want me to express some concern? Would you want me to express that I notice any symptoms? And so starting those conversations early helps.

I'll give you an example of my own parents, I have been in this space for a long time. I studied death and dying and I would bring up to my Chinese immigrant parents like, well, do you prefer to be buried or cremated. And they shunned me thinking like how could you ask us that question? But to me, it was such a normal question because I want to know. And at the time they didn't want to discuss it. Now that they are, you know, my father is over 80 and my mother is in her mid-70's, and they are very open to talking about this they are really comfortable. We are having normal conversations about this, and they've made certainly legal plans and everything, and so I think you start somewhere, you have got to start somewhere, and

it may not go as planned the first time, but you have planted the seed, and then that seed hopefully will grow.

You can bring it up again another time, and so you have just got to start it and knowing that your intention is I want to be able to honor your wishes and I want to be able to carry out your wishes. And I think that intention is always first and foremost the most important thing.

The other question that was asked of me is what is being done to educate AAPI communities about advance care planning? Is there anything different than we can do in this space. Again, I would cite statistics that Asian-Americans when surveyed over half of Asian-Americans believe that significant loss of memory or cognitive ability is a normal part of aging. Almost half of Asian-Americans also say that they are concerned about developing Alzheimer's or dementia. So there is this worry and there is this belief that it's normal, and so I think we are doing people a favor by opening up that conversation and relieve some of the worry and assurance that it's a hopeful time when it's detected early. There are things that we can do early, and that that planning piece needs to happen early as well.

At the Alzheimer's Association what we are doing is certainly partnering with Asian-American organizations to build that trust in communities to be able to have these kinds of conversations. So, for example, with the Philippine Nurse's Association of America, with Tzu Chi Foundation, which is a Buddhist organization. In many communities chapters have partnerships with South Asian organizations and so really partnering with trusted organizations in Asian communities to be able to bridge that gap of dementia care and cultural values. I'll also just point out a couple of tools that are useful in having these conversations. Coda, which is an organization that helps with end of life conversations. They have these Go Wish playing cards. And so these playing cards are things that you can buy a deck, and I think there are different questions related to end of life care.

In California we have the Chinese American Coalition for Compassionate Care, again, I will put this in the chat. But these are Chinese playing cards. They are called Heart to Heart, and they are playing cards that also foster that discussion around end of life care and linked to that is certainly advanced care planning.

So some creative things that people are doing, organizations are doing to help make this conversation easier. I'll go ahead and stop there and turn it back to Mansha.

>> MANSHA MIRZA: Thanks so much. In you could drop links to the resources in the chat, we will be sure to add them to the

resources we plan to send to attendees after the webinar. We are doing pretty okay on time. And it's time now to address questions from the audience. I know that the chat has been on fire. I will try and sift through all of the questions as they are coming in. So let's see, and also everyone please take note of the resources, et cetera, being shared in the chat. I think one question that came up was can anyone posit two or three specific issues that would apply differently to AAPI people than to Anglos and how those differences can be addressed? So I think Pooja you have taken a stab at that. I will ask you to unmute and say everything out loud so we can capture it in the captions for accessibility.

>> POOJA PATEL: So I outlined to specific issues that could apply differently to our community specifically. First is something that Edie mentioned, and that's understanding individual versus collective decision making. We do have a very individualistic care system. Oftentimes decisions are made by asking the individual and not the family, and it's important to understand that in a lot of our communities it's important that the family is involved, and so understanding that dynamic once again. And then, two, this is something I address a lot, and it's learning, understanding and addressing that familial piety we talked about and all of its implications for the caregivers and family unit as a whole. Oftentimes if the caregivers or the family units' values beliefs and goals don't necessarily align with the care recipients' goals values and beliefs there is often a lot of guilt involved with that, and that can impact what that advance care plan looks like.

So it's really important in my perspective, and I try to address this as much as I can if I notice it that there might be guilt involved for the caregivers or the family unit when they have to make certain decisions or help guide certain decision making for the care recipient that they may not necessarily agree with.

>> MANSHA MIRZA: Thank you, and related to that there is a question from Terry in the chat. Do we address the individual or do we address the wishes of the family?

>> POOJA PATEL: If you are asking me again, I think it's both. As long as the individual is, has decision making capacity, is cognizant of the decisions they are making, it's important to highlight what the individual's goals and wishes are, and then to find a way to get the family or the caregivers on board. If the individual is unable to make appropriate decisions or has been deemed not to have capacity, then that's where the family is more at the forefront of that decision making. With it, you don't want to forget, you still want to ask what would they have wanted? Have you ever talked about

that? Have they ever mentioned something, even if they don't agree with it? But at that point it's probably likely the family that you are addressing and less the individual. Just because someone has a diagnosis of dementia, whether it's early onset or early stages doesn't necessarily disqualify them from being able to have decision making capacity and making caring decisions for themselves.

It's important to identify that and get a capacity assessment and then as soon as the initial diagnosis comes through, make these decisions. Don't wait for the dementia to progress and get worse to then have to try and figure out what they would want. And make those as soon as it happens. My goal, my hope is that everyone does it way earlier than that. But if you notice, if you have a parent who is getting diagnosed or is starting to lose their cognitive skills in some capacity, then start having those conversations, start making the decisions before the person loses decision making capability.

>> MANSHA MIRZA: Here is a question related specifically to dementia. What documents does the neurologist have to give me in order to be able to complete these documents since my mother was diagnosed with dementia?

>> JIM BERCHTOLD: From a legal perspective it varies from state to state. So in Nevada, for example, the only time you need a certificate from a doctor when executing a Power of Attorney is if the person is currently in, the person signing is currently in a care facility. So there are different requirements, but ultimately, you want to make sure that these documents are legally sound, right, that they are going to be upheld should anyone challenge them for any reason. It's not a bad idea to get a doctor's certification that the person has decision making capability sufficient to sign the documents. Now, that can be tricky because sometimes the legal definition of capacity is different than what a doctor considers to be capacity, so if you are in that situation it may not be a bad idea to talk to an attorney and have that attorney and the doctor all in one conversation.

>> MANSHA MIRZA: Thanks, Jim. Edie and Mary if you have anything to add to that based on your own experiences?

>> EDIE YAU: I do not. I'm curious though, Mary, if you as a caregiver, did you receive anything from your mother's doctor?

>> MARY FUS: When my mom started to have signs of dementia, she actually realized it herself, and so she started to go to her physician at the time, but anyway, when I got involved it was shortly after she had that diagnosis. And what they did do, and given this is like 15 years ago, so the tools to diagnose was mainly sort of like a can you do this, can you answer these questions, can you, for instance, draw a clock. So those are

the types of things that they went through, and also did lab tests to make sure it wasn't anything else that may be causing the dementia, any other diseases.

And at that time they weren't doing the scans of the brain and things like that.

>> MANSHA MIRZA: Thank you, Mary. I think we have time for a couple more questions. I saw a few technical questions in the chat that might be directed at you, Jim, and I saw you try to respond but if we could capture this for the Captioner. Would a Power of Attorney for finance override a representative payee for an individual's Social Security benefits? This is an important one. We have been asked similar question in the AAPI communities we work with.

>> JIM BERCHTOLD: It is important. So for anyone who doesn't know, so a representative payee is someone who is authorized by Social Security or by the Veterans Administration to receive, to receive Social Security or Veterans or other governmental benefits and to pay bills on behalf of someone. Now, this is a separate program. This is totally a program within Social Security or within the VA. Those organizations, those government organizations do not accept a financial Power of Attorney, meaning that if I have a Power of Attorney for someone and I go to try to work with Social Security, they really don't care.

So you may end up getting a representative payee anyway. So you may have a financial Power of Attorney and a representative payee. Now, one type of advanced planning that you can do though if you are already receiving Social Security, you can go onto the Social Security Administration's website and you can designate in advance who you want to be your representative payee should you need one at some point.

So that allows you to select who that person is instead of Social Security selecting who that person is. So I would really recommend everybody do that if you are receiving Social Security it's an easy process.

>> MANSHA MIRZA: Thank you so much, Jim. I think we are almost out of time. We do have one more poll that's essentially a feedback survey for us. So I'm just going to launch it. It would be great if those of you who are still present in the webinar go ahead and complete it while we are still in the meeting. In the meantime, I see some really interesting comments in the chat that I will read aloud.

So Hope says in the chat I am an advanced care planning coordinator in Hawaii, and I have worked with Asian-American, native Hawaiian and Pacific high lander communities and the idea of autonomy is not as important as supporting the family and avoiding conflict in the family. It's also very important to



take age and diagnosis out of this conversation as a response is I am not ready to talk about this. Instead we promote the idea that everyone over the age of 18 should have the opportunity to create an advanced care plan.

I also want to mention that several resources and tools were shared in the chat. We are going to make sure that we put all of these together and include them in the resources we already have that will be shared with all of the attendees in an email after the webinar. Some of the resources that we already have include conversation starters, so very similar to what Edie mentioned about the cards just to have a conversation started, address some of these difficult issues that tend to be avoided in many Asian American communities and some of the resources we shared are available in different Asian languages. We hope you find them helpful.

To answer your question, we will send a copy of the slides which will include all of the resources by email. So if you registered for the webinar, please look for an email from us. We will also link to the slides on our website, on ASIAAN website, and you can access the slides and the webinar recording on our website whenever.

If you are looking at the chat, there is information about how you can stay connected with the ASIAAN project at the University of Illinois, Chicago.

Thank you, everyone, for joining us this evening. Thank you to all of our panelists for sharing this wealth of information from their professional and personal experiences. We appreciate it. I hope the attendees found this information helpful and let's get the conversation started and let's also keep them going. Thanks, everyone. Have a good rest of your night and please stay in touch with us.

(Concluded at 7:58 p.m. ET).