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Determining Caregiver Needs and Well Being November 16, 2017

TRANSCRIPT

Moderator Rachel Breidster: Hello and welcome to Public Health Live!, the Third Thursday Breakfast Broadcast. I'm Rachel Breidster and I'll be your moderator today. Before we get started, I would like to ask that you please fill out your online evaluation at the end of the webcast. Continuing education credits are available after you take our short posttest. And your feedback is helping in planning future programs. I also want to let you know that the planners and presenters do not have any financial arrangements or affiliations with any commercial entities whose product, research or services may be discussed in this activity. And no commercial funding has been accepted for this activity. As for today's program, we will be taking your questions throughout the hour by phone at 1-518-402-0330 or via e-mail at phy.ny@gmail.com. Today's program is entitled "Determining Caregiver Needs and Well Being" and our guest is Mrs. Elizabeth Smith-Boivin, who is the Executive Director and CEO of the Northeastern New York Chapter of the Alzheimer's Association. Thank you for joining us.

Moderator: Good Morning. Thank you so much for joining us today.

Elizabeth Smith-Boivin: Good morning, Rachel. Thank you for having me. I'm so grateful to have the opportunity to talk about this important topic.

Moderator: And it is a very important topic so to get us started for today, would you mind reviewing the objectives for today's program.

Elizabeth Smith-Boivin: Certainly, I would be happy to. The first objective is participants should be able to list a minimum of five statistics or characteristics specific to Alzheimer's care giving. They should be able to describe a minimum of five components of a thorough caregiver assessment and lastly, they should be able to identify a minimum of three elements that are contained in a caregiver -- a person-centered caregiver plan.

Moderator: Excellent. Thank you. Now, before we talk with about completing a comprehensive caregiver assessment and developing that person centered plan for the caregiver, I think it would be valuable to define some of the terms that we're going to talk about today. And I think many people use the terms dementia and Alzheimer's interchangeably. But can you talk about what the difference is between those two terms.

Elizabeth Smith-Boivin: Sure. You're right. It's a great point and is a great place to start. So

dementia is not a disease in it of itself. Rather it's an umbrella term that's used to describe a variety of conditions and when an individual has dementia that means that they have a change in memory and a loss of cognitive ability that is significant enough to impair everyday function. As I mentioned, there are many different types of dementia. Alzheimer's disease is a disease and is the number one form of dementia. Alzheimer's disease is a progressive, terminal neurodegenerative brain disease, which means nerve cells die over the course of time. Brains diseases that creates difficulties with memory, thinking, behavior, personality, and ultimately one's ability to manage their activities of daily living. Alzheimer's disease is the number one form of dementia and currently over 5 million Americans struggle with this disease.

Moderator: So in today's program, we'll be talking about caregivers for people with Alzheimer's or dementia. Is it safe to assume that the strategies we're going to talk about today can be used in many or all caregiver situations?

Elizabeth Smith-Boivin: Yeah, great question. So care giving is defined as the act of providing unpaid support to a family member or a friend with either a physical, psychological, emotional or developmental need. And so, sure, many of the principals that we'll be talking about today can be applied to all care givers. However, people that provide care for folks with Alzheimer's disease and dementia are a bit unique and we want to look out for them in a special way. Because, they are on duty 24 hours a day, seven days a week. The safety and security risks present when you care for someone with Alzheimer's disease just never go away. In that way, Alzheimer's caregivers are a little different than in other circumstances.

Moderator: So can you explain -- because the focus of today's show rather than on the patient with Alzheimer's, we're talking about the caregiver. Can you explain why caregiver wellbeing is such an important topic?

Elizabeth Smith-Boivin: Sure. So caregivers are at risk for struggling emotionally, physically, financially. The strains can be enormous. And that's especially true, again, when you have a disease that sort of never gives you a break. And so the burden can be very great. And when a caregiver struggles with any and all of these particular circumstances, not only are they at risk, but the wellbeing of the patient is at risk, as well.

Moderator: Sure.

Elizabeth Smith-Boivin: So we want to make sure that the people with Alzheimer's and dementia being care for at home by their loved ones can continue to receive the best possible care. That's why we really want to look out for the health and wellbeing of the caregiver.

Moderator: Excellent. Now, we recently visited with Moreese and his wife, Maurena about how they've approached care giving. Let take a look.

Maurice Haughton (Caregiver): This is me here, this is my mom here. And this is her aunt, her mom's sister.

Maryna Bilak (Caregiver): Unfortunately, I cannot really say that I know my mother-in-law when she was healthy.

Maurice Haughton (Caregiver): It's very hard for a young woman to walk into a relationship and not just try to build a relationship, but at the same time trying to deal with the fact that the person she loves is caring for somebody else.

Maurice Haughton (Caregiver): Some of the things that we have done to accommodate mom is we have this pad.

Maryna Bilak (Caregiver): We decided to move in together in November 2014 and in February next year Dorothy, my future mother-in-law, moved in with us.

Maurice Haughton (Caregiver): Maryna and I were the hands on caregivers at the time. We were doing everything by ourselves. It became very stressful. Extremely demanding of us. And it just seems like the more we gave mom, the more she needed and we had to keep stepping it up, the expense of our relationship in a lot of ways.

Maryna Bilak (Caregiver): It was extremely, extremely stressful. Our relationship was very, very young and as a woman, I still is wanted some romance. But then all of this was happening. And I felt like all of the time, all of our energy was consumed by care giving.

Maurice Haughton (Caregiver): We learned a lot from the caregiver assessment. We really did. We absolutely learned a lot from it.

Maurice Haughton (Caregiver): We learned about a lawyer. We also learned about the catholic charities which helped us a lot. Catholic charities provided us with aids that came over for a certain amount of hours which gave us time to go out food shopping, do the little things that people take for granted because we couldn't do those things before connecting with you. We had to take mom everywhere we were going. We had to take her with us because we couldn't leave her by herself here. So a lot of that changed. We also connected with the Eddie and they provided volunteers who came over to give Maryna and I a chance to go out on a date and kind of refresh our relationship. Things changed for the better for us. We really had a chance to get help and accept help and it was such a blessing to know that there was help there that was available to us. And we tried our best to utilize it. And in a lot of ways, that did save our marriage, our relationship at the time.

Maryna Bilak (Caregiver): I really remembered that day when people came to our house and with all the paperwork and they started asking questions. And at some point, I realized that all the questions were pretty much about me and Maurice as the caregiver. And I was shocked because for the first time, somebody came to our house to ask how I

am doing as a caregiver. And it was so helpful.

Maurice Haughton (Caregiver): We started spending more time reading about the disease.

Maryna Bilak (Caregiver): We tried to educate ourselves as much as we could, but meeting with the professionals who really knew what they were talking about it give us hope and a sense that we're not alone and even that was so, so important.

Maurice Haughton (Caregiver): I have the to remember that I have two women who need my attention and my love and my first concern is to take care of the future while not letting go of the past.

Moderator: Wow. Well, Maurice and Maryna certainly did a wonderful job describing their situation and how the caregiver assessment plan for well-being really impacted their relationship. Just how many additional people are really providing these kinds of invaluable caregiver services?

Elizabeth Smith-Boivin: Yes, indeed. I'm grateful to both of them for sharing their story and grateful to my colleague, Molly, for the work that she's done with them. In addition to Maurice and Maryna, there are more than 15 million Americans, believe it or not, providing unpaid care and support for people with Alzheimer's disease and dementia. And to take that a step further, in 2016, Alzheimer's caregivers provided an estimated 18.2 Billion hours of care. At an estimated value of \$230 billion. Which to put in context is nine times the revenue of McDonald's for the same year. So we know, Rachel that caregivers are not only contributing to the wellbeing of the folks that they're caring for, but they're really contributing to society at large as well as our economy.

Moderator: Absolutely. Now, do we have any information about who these caregivers are?

Elizabeth Smith-Boivin: We do. We have a lot of data, a lot of great caregiver data. We know that approximately two-thirds of caregivers are women. We know approximately two-thirds of them are 65 and older. We know over two-thirds are married. More than two-thirds are non-Hispanic white with a small population of folks in our country that are African-American, Hispanic and Asian or at least report to in their care giving duties. Almost half of the caregivers have an annual household income of less than \$50,000 which speaks to the financial strain issue we talked about earlier. And, again, about 66% of our caregivers live with the person that they care for.

Moderator: Which certainly creates -- it's probably needed to live with the person, but creates that situation where they're not getting a lot of relief.

Elizabeth Smith-Boivin: Sure. It can be helpful, but probably sometimes tense.

Moderator: Earlier, you mentioned the physical, emotional and financial challenges that are associated with care giving and Maurice talked about them a bit, as well. Can you provide more specifics about those things?

Elizabeth Smith-Boivin: Sure. I think that the number one item that we hear so often from people and that certainly comes through in the statistics is that approximately 40% of Alzheimer's caregivers report suffering from depression as compared with only about 5% to 17% of their counterparts that are not providing this work. Almost 40% of Alzheimer's caregivers describe the physical labor involved in Alzheimer's care giving as high or very high. And then, of course, we have all of these caregivers that are working, that are employed caregivers. And approximately 10% of them have reported that they have had to leave their jobs to provide care. That's a large number of people, 54% reporting having to go in early -- excuse me, leave early on go in late and then we have another cohort of people that report that they have had to take a leave of absence to provide for care giving emergencies. So this is affecting a lot of people about you think back to that over 5 million Americans number.

Moderator: Absolutely. Now, is it fair to say that caregiver challenges are specific to each individual situation and, therefore, we really need to have an individualized caregiver assessment?

Elizabeth Smith-Boivin: Sure. And that's really the biggest part of this. So every family is unique. Every care giving situation is unique. And that's really the reason that we want to do a caregiver assessment. The assessment is that systemic process of gathering the information about the care giving situation. It helps us to identify the problems, the needs, the challenges, but also the strengths and the resources that a caregiver has at their disposal. And then it really helps us to determine what the caregiver's ability to provide care and support to the recipient is. Sometimes we learn through the process of caregiver assessment that more help is needed and it's needed imminently.

Moderator: Sure. So it seems that the assessment can help to maintain the caregiver's wellbeing and then, therefore, enhance their ability to provide care. So it's kind of a win-win.

Elizabeth Smith-Boivin: Absolutely. That's right. So by doing a thorough caregiver assessment, we really do enhance the caregiver's wellbeing, particularly when they take our advice. But we also with, then, have the ability to see definite impact positive impacts in the ability to provide care. Sometimes all the caregiver needs is a break. And when we're able to help orchestrate that for them, they really are able to do a better job. The other good news for us, as we think about health systems and the cost of health care, is that we know that positive caregiver wellbeing really does reduce the number of hospitalizations that a person has and it often postpones or prevents altogether a long-term placement. So for those reasons, it's important, as well. In addition, the family caregiver alliance supports what Maryna said earlier, when she spoke about how much it meant to her that somebody asked about her wellbeing. And, again, that's support themed in the data and I think it's really important when health care professionals take the time to ask about the caregiver, it means the world to the caregiver.

Moderator: Sure. I would imagine when you're dealing with that level of responsibility and what can sometimes be a burden having somebody stop and ask about you.

Elizabeth Smith-Boivin: Ask about you, right. So you can imagine probably nine-tenths of the visit is addressed to how is the patient, what's happening with the patient, and for someone to take pause and think about the caregiver is a monumental step.

Moderator: So, let's talk about the assessments themselves. What should the assessment consist of?

Elizabeth Smith-Boivin: So we really believe that a good assessment contains two parts. I think the first part is a caregiver self-assessment. And that can often be done with a simple tool that a caregiver can complete. For example, while you're talking with the person who has Alzheimer's disease or dementia. But, then it's a comprehensive assessment that is done by the health care practitioner.

Moderator: Okay. And can you recommend any self-assessment tools?

Elizabeth Smith-Boivin: Yes, yes. So as a representative of the Alzheimer's Association, I'm going to go ahead and make a plug for our on tool. The Alzheimer's Association has a very nice caregiver self-check and is that's a nice, simple, brief form. I'm also very happy to report that several years ago, the AMA identified the need to really address caregiver health. And they have come out with a terrific assessment tool that not only assesses caregiver burden, but it also can be a great screening tool for the risk identify depression in caregivers, as well. So it's a very valuable tool.

Moderator: Excellent. It's good to know we have those tools available.

Elizabeth Smith-Boivin: Absolutely.

Moderator: So in addition to self-assessment, you also mentioned an assessment interview. So before you describe the elements of the assessment interview, what should someone consider before really engaging in this?

Elizabeth Smith-Boivin: Sure. I think the one thing I would advise health care practitioners to do is be very open-minded. And nonjudgmental as you enter into the assessment process. Care giving situations can be very challenging. One of the things that is so important that we look at in the beginning of the caregiver interview is the relationship.

Moderator: Sure.

Elizabeth Smith-Boivin: And its overall quality. I can remember not too long ago having a woman in my support group who had been attending for quite some time and at one support

group session she broke down and explained that one of the things that challenged her most was that she and her father never had a good relationship, that he was never an easy man to live with. And now she found herself in a situation where she was the only one responsible for his care and wellbeing. So I'm sure that it's challenging to provide 24 hour a day seven-day a week care for somebody that you are deeply committed and connected to. Imagine how much harder it is when the relationship is strained. So I think we have to listen to that and not judge that. We also have to look at the family's environment. Do they live in a place that is conducive to care giving? What is the household composition? Is this an 85-year-old caring? For an 85-year-old? Or are there adult children or other people that are in the household that can contribute? And lastly, we want to look at the financial resources and the employment status. So another scenario I'm thinking about is one where we had a single mom and she had several children. I can't remember if it was four or five. One was a teenage boy. And she was caring forever dad at home. And in her particular circumstances, the space was tight. Finances were tight.

Moderator: Sure.

Elizabeth Smith-Boivin: And in addition to that, she was quite uncomfortable handling some of the personal care items for her dad. Particularly showering. And so she asked her oldest teenage boy to take on that responsibility. And I'll say asked in a loose way. He was kind of expected to help with that. And he began to act out. This was really a great challenge for him.

Moderator: Sure.

Elizabeth Smith-Boivin: So while I understand it was difficult for her, it was also difficult for him. So, again, looking at all of these elements in the care giving situation in an open-minded way thinking that it's really our role not to judge been but to problem solve.

Moderator: Gathering information so you can help people make the best decision.

Elizabeth Smith-Boivin: Right.

Moderator: So what's the next area you would recommend for assessment?

Elizabeth Smith-Boivin: So after we look at the caregiver's financial ability, I like to look at the caregiver's -- sort of their understanding of the overall situation.

Moderator: okay.

Elizabeth Smith-Boivin: Do they understand the diagnosis, do understand where their caregiver is right now. One of the more common things we hear is the report their loved one is in the moderate to severe stage of the disease. And then will asks do your love is still ambulatory? Are they still content? Are they bed ridden and the caregiver will say no, they're still walking, they're using the bathroom and we inform them in a gentle way this is still the early stage of

the disease and entering the moderate and they have a long way to go. So their perception of where they are in this process is really important because we want to make sure that they do understand what lies ahead. We also want to see what their perception of personality and behavioral changes might be. What their perception of the safety considerations are. I mean, we find some people with Alzheimer's disease who still have guns in the home, who are at risk for wandering. Does the caregiver understand the importance of assistance with medication administration when that time comes? Do they understand the need to provide support for activities of daily living? I had somebody one time say to me, my husband manages all those things just fine. And then I said, you know someday you should just take a peek and see how he's doing. And she came back in a very tearful way and informed me she didn't know how long this was happening, but when she did take a peek, her husband was brushing his teeth with her face cream. Sometimes we have expectations that are too high and sometimes we have expectations that are too low. And it's really important that we help people understand this disease. So we need to start by understanding their perception of what's happening.

Moderator: Absolutely. That's a really good point. So now how do you address caregiver values and their preferences in the assessment?

Elizabeth Smith-Boivin: Right, so again when we think about that for some people, they may have a very close relationship and be fine with providing the care. Others may not see themselves as caregivers. And they may not embrace the role. In addition to that, they may have a loved one who is resistant to the care. It's also important to know whether there are cultural, moral or religious issues at play here. Sometimes we find people from various cultures that would benefit from respite or long-term placement in a short-term way, but because of their own cultural beliefs they're not comfortable with that and that is important. And then whether or not there are restrictions or preferences in care. So I mentioned earlier the teenage boy that was uncomfortable with the thought of giving his grandfather a shower. Some care recipients want a same-sex caregiver for more intimate tasks and we need to be mindful of those things.

Moderator: Absolutely. Now turning our focus back to the health of the caregiver. Let's talk about while the caregiver is having to do these things such as: providing assistance for activities of daily living and making sure they're not brushing their teeth with the wrong implements. What do we do and why is it so important to address really the health of the caregiver themselves?

Elizabeth Smith-Boivin: Well, again the caregiver's health is so important because an individual with Alzheimer's disease or dementia depends greatly on the caregiver. So the health of the patient can only be as good as the health of the caregiver. So we really want to look beyond just whether or not the caregiver has chronic health conditions or do they have any acute health conditions. We want to look at whether or not there is a plan in place for if an acute health condition occurs. And we will talk a little about that when we talk about putting together the caregiver plan. We also want to look at caregiver fatigue. I can't tell you how many people come to us and say my sleep is always disrupted and it's so difficult. We've talked about depression, but the emotional effects of care giving need to be addressed and the sooner the

better so we can ensure that the caregiver treats those things, as well.

Moderator: And I would imagine, in addition to receiving caregiver's health and any conditions, we also want to look and examine what are their strength and what are their weaknesses that they bring to the table, as well.

Elizabeth Smith-Boivin: Of course. So there is all of those partial considerations. And many caregivers enter into this journey eyes wide open, willing to learn all that they can. We'll see a little bit on of that in a clip coming up soon. And that is terrific. But not everybody entered in that way. Some folks want to self-learn and that's not always the best way, as well. So the skills and abilities that the caregiver are really important not only for today, but for the future, as well. So we want to know what the caregiver knows about the disease, about the symptoms, about the progression that's to come. And then we want to evaluate their competencies, their skills and their confidence in providing care giving. Because that is important as well and then their coping skills. For some folks, every small thing can be a crisis. And again we don't want to judge that, but we want to help people grow their strength and confidence.

Moderator: Absolutely. It really sounds like this assessment looks at the big picture for the entire family or household that affected by the disease.

Elizabeth Smith-Boivin: It does, It's important that we look at the whole picture. So we want to look at all of these things that are kind of specific and personal about the caregiver. We also want to look at what resources and what that are the things they are using. We want to know for example if there has been financial burden for the family, financial strain, and if there has, what are they willing to do. Are they willing to access insurance policies, look at county grant programs to provide respite or state grant programs that provide respite hours, volunteer service agencies? So there are lots of possibilities there. It's also critically important, Rachel, that we look at family dynamics and family strain. I used to work with a physician who I admire greatly and who always said that dysfunctional families don't ever get better when the diagnosis is Alzheimer's disease. And boy, was he right. I think most commonly, we find differences in families about those big issues. Can mom or dad continue to drive? And you'll have one person think yes and another no. Can mom or dad be alone? So those kinds of things can really create very divided families and family strain never helps the care giving situation. It really is another great challenge we need to address.

Moderator: I am sure. Now does the assessment address who or what resources the caregiver has utilized as well?

Elizabeth Smith-Boivin: Absolutely. And so in terms of resource utilization, we want to look at two things. So we define resource utilization as informal and formal. When we talk about informal, Rachel, we're talking about your friends and your family and those things that aren't paid or secured outside of your home and family environment. And truthfully, there are often some great folks there and willing the to help. Sometimes we just don't know how to engage

them. We're going to talk a lot about that this morning. But then there are many, many formal support networks, too. Many of which have Alzheimer's and dementia expertise, so we want to make sure that our caregivers, if they're not utilizing them, will know about them. In addition financial planning is so important. So we want to make sure that financial and legal plans are well in place. And the earlier the better. Because this is a disease where folks will lose cognitive abilities if they don't articulate their legal wishes and their health directives early, they may lose the opportunity to do so. And we think that that is tragic. Lastly, we want to ensure that all of our family caregivers understand the volume of resources that are available in their local communities.

Moderator: Excellent. And are there any other things that you really include in the assessment interview?

Elizabeth Smith-Boivin: so we want to make sure, again, that we have done a good job kind of gathering all of the data that exists and that can affect the caregiver at all. So, again, we want to look at what plans are in place in the event of an emergency. We talked a little bit about that. And we want to make sure that everything has been accounted for in the assessment.

Moderator: and I would imagine you're looking at things like stress the caregiver is going through, if the stress is putting an impact on them, as well.

Elizabeth Smith-Boivin: Yes, thank you for the reminder. All of the emotional effects of care giving, and I apologize, we talked about them earlier but I wanted to go more deeply into that. So for some caregivers, denial is a huge problem. We talked about some caregivers who may over exaggerate where their loved one is in the process, but for others, they really are in denial about this. We talked about the depression and it is significant. And it's troubling for all of us. But anxiety, irritability, anger, they're also significant problems. I also feel badly when I see my caregivers and consequently persons with Alzheimer's disease withdrawing from social situations. Fatigue and sleeplessness is another situation we talked about earlier that is so important, again, to the caregiver's health, not only physically, but emotionally. So all of these things come into play, as well.

Moderator: Thank you. So once a health care provider asks the caregiver to complete that self-assessment that you mentioned and then has conducted the caregiver interview, what's the next step?

Elizabeth Smith-Boivin: Right. So then we want to take that data and we want to take a few Minutes, at least, to look at all of it. Where does the individual believe that they are and what have we gathered from our assessment? We want to collect that data, put it all together and then thoroughly analyze it, create what we call a person-centered care plan for the caregiver. Now, we talk a lot about person-centered care for folks With Alzheimer's disease. And I suspect a lot of our viewers are quite familiar with that concept. The concept really has to extend to the caregiver, as well. Because the person's centeredness of this means that the care plan is going to be individualized for them and that caregiver situation. That caregiver plan is what we use to

promote the wellbeing of the caregiver.

Moderator: Excellent, thank you very much. Now to learn about the value, the assessment and creator of the plan, let's hear from Howard Cohen caring for his wife, Barbara.

Howard Cohen (Caregiver): Barbara was at an appointment with her primary doctor. This probably happened 3 1/2, maybe 4 years ago. And after the appointment, he pulled me aside and he says, I think Barbara is starting to have some memory problems. Why don't you get an appointment with a neurologist. The neurologist came up with -- that she might have early stage Alzheimer's. That is how it all started and it's progressed. So I was sort of reaching in the dark for answers. I called up the Alzheimer's Association and they said that they would do an assessment to see if there was a situation where we could join their EASE program. That was an 8 week program once a week and it was more of a support group, but we learned an awful lot. We had speakers every week, different speakers, and it just really gave me a lot of help. The caregiver assessment was very valuable to me because they told me what I should be looking for and what the future might hold, also. I've done a lot of different things since the assessment. One of the things is I've learned to become a little more patient with Barbara. But I've also done things where I've helped her along. We have had a whiteboard that I put up every day where I actually put the date and I put the day and I put down what we have to do that day. So she knows as soon as she gets up in the morning, if she looks at the whiteboard on the refrigerator that that will tell her what we've got to do. And also, we have a monthly calendar. Monday, Eric was coming. He was the dietitian that we had an appointment with. So we're going to see then. And in working with some of these support groups, the other participants have told me what they are doing to improve their personal life as a caregiver and I've tried to follow some of their examples. One of the things that I do and I've always done my whole life, I'm still working. And I enjoy that. I work out of the house. I have to go to Rochester for a sales meeting, but Barbara Zeller is coming to stay with you for the day. I find that that keeps my mind going and it's really -- it's been advantageous for me to keep working. The Alzheimer's association helped a lot and they gave me guidance. We eventually joined some other groups and it's been a great thing for me, anyway, to help get through all of this.

Moderator: So I think Howard is a great example of the value of the assessment and the plan and it would help to illustrate how all that comes together. So once the assessment is complete, what is the first item to address?

Elizabeth Smith-Boivin: Great question. Howard is terrific. One of our longtime supporters and friends. And he really speaks to kind of the place where we start. And that is to develop a stronger understanding of the individual's knowledge about diagnosis. Before we can do that, though, Rachel, we need to make sure that the care recipient has been diagnosed. So often times we hear from caregivers that they've recognized a memory challenge or changes in behavior or other things at home. And yet no diagnosis has been made. So they think something is going wrong or maybe they interpret this as a normal consequence of aging, which Alzheimer's disease and dementia is not. So if our folks have not had a proper diagnostic workup, the very first place that we want to start with the caregiver is recommending that they

have that thorough diagnostic assessment and we want to make sure that we give them the resources to do that. There are many neurologists who are able to do this and, in addition, New York State has ten centers for excellence located across the state that provide excellence in diagnostic services. So the ability to get a good diagnosis is out there and we want to make sure that that is done. After someone has the diagnosis, then we want to make sure that we provide them with disease-specific information in a manner that they can understand. So its one thing if we provide them disease-specific information that only a Ph.D. can understand. We want to make sure that this information is delivered to caregivers so that they know what to expect today and what to expect tomorrow.

Moderator: Absolutely. So you must also have to integrate information about the different resources that are available into the plan, as well.

Elizabeth Smith-Boivin: That's right. So we talked before about the importance of assessing for all of these resource utilization. Have they accessed legal and financial planning? Have they accessed -- have they thought about safety and emergency planning. So talk a little bit about that for a minute. If they haven't done those things, then its incumbent upon the health care professional to provide them with the resources to get that done. so the legal and financial, well, that's pretty easy because, you know, we can turn to any number of financial advisers, elder care attorneys to provide those services. The safety and the emergency planning part is really where the health care practitioner comes into play. Because we want to ensure that we deliver some kind of a safety checklist or provide some resource for the caregiver to be able to assess and identify. I think this is particularly important when we're in a spousal situation. It's very hard for a couple that have been living together for 30, 40, 50, sometimes 60 years to now begin to think, oh, boy, I have to really protect the chemicals in my house. I have to lock away medications in my house. The gun that's been in a cabinet for 40 years now has to be otherwise secured. I can't have any loved one drive any more. It's a complete change in the way that that couple has functioned for so many years. So we have to think about that. And the other -- the last element here, that emergency plan that I've spoken about a couple of times but that I find caregivers almost never have. And what the emergency plan is really designed for is that situation where we have one particular care recipient. Who's dependent on once particular care giver and again that typically a husband and wife situation as well. Sadly, I've witnessed far too much situations where a caregiver has a health emergency, an accident, a heart attack, needs gallbladder surgery and there is no plan in place for their loved one. So the caregiver has had to deny or postpone emergent care because there's no one there in an emergency to deal with their loved one who can't be left alone. So we want to make sure that the plan is in place ahead of the emergency.

Moderator: Absolutely. So once you have provided the caregiver with disease specific information and the resources they can use. What's the next step?

Elizabeth Smith-Boivin: The next step is to make sure they are going to access or utilize those resources. It's one thing to give folks these tools and services. It's another thing to ensure they're using them. And I think that's kind of a challenge. So think about times in your life,

maybe, where somebody said, is there anything I can do to help? And it's so common for us to say, no, no, no, with I'm fine. Right. ? And I think the same is true of Alzheimer's caregivers. And afterwards I think they feel so regretful or remorseful that they didn't ask for help. And I think part of our role is to help people know how to ask. Number one, what are the informal resources that are there, whether it's adult children or siblings or somebody else and what are the formal resources that are there and how do I ask or how do I accept the ask? We have a terrific brochure at the Alzheimer's association that helps caregivers do that. And one of the key things that that brochure suggests is that every care giver is ready with a list of small things that a person can do. Don't get caught off guard. If an individual comes up to you and says, what can I do to help? Be prepared to a response like bring up lunch once a week or call me twice a week and ask me if I need milk or groceries. So be ready with your response and that will help people. The people who offer, I find, really do want to help. But if we turn the help away, then we kind of don't have anyone to blame but ourselves. So we want to arm our caregivers with the tools to make the ask or accept the offer. And then we also want to help them help their loved one to accept that care. That's particularly tricky in the early stage of Alzheimer's disease where the care recipient has great skill sets and a great desire to want to have a productive life and a great desire to want to do things independently. So we want to work to help caregivers balance that, trade off the things that are needed and important with those things that we can let go a little bit and leave independently to the care recipient.

Moderator: Are there other types of support that are important to include in the plan?

Elizabeth Smith-Boivin: Sure. So, again, we want to make sure that the informal network is being utilized as best as possible. And, again, because typically folks respond best to receiving care and support from the people they already know and love.

Moderator: Sure.

Elizabeth Smith-Boivin: Those folks are familiar and comforting. So that is a good thing. And we want to continue to engage that. But those community resources are important, as well. Support groups and volunteer agencies that can, again, either provide that ongoing support. We talk about this in two fashions. So a moment ago, we were talking about the support that one can give in terms of making lunch or picking up groceries, but that emotional support for the caregiver is equally as important. So, again, that's where we want to tie in that informal or formal network, as well. Howard is a great example. He has a relatively small family, but boy, he's grown his family because he and his friends at the Alzheimer's support group have become very, very close. So he grew his informal support network and everybody has the ability to do that.

Moderator: Excellent. Now, in addition to emotional support, I would expect that you address self-care and that's something that really we all deal with, whether we're caregivers or not. Why do you emphasize the need for self-care and the caregiver plan?

Elizabeth Smith-Boivin: Yes. Thank you for raising that issue. We talked about it briefly before,

but it is so critical. I have -- I find Alzheimer's caregivers to be some of the most self-less people I've ever met in my life. They commit so much and oftentimes it's at the sacrifice of their own physical and mental wellbeing. So keeping up doctor's visits, exercising and making good lifestyle choices and managing the emotional stress that comes along with care giving is so important. Having spent about 30 years in this field, I've seen far too many caregivers expire, pass away before their loved one. And their loved one is lost without them. So I need those caregivers to stay healthy and well so they can provide the care giving. Last year, about a week, a couple of days before our biggest event of the year, one of our caregivers who was a new support group facilitator, she had really battled to take care of her husband at home for as long as possible. She did everything right, but she didn't take care of herself and she had a massive heart attack and passed away within a couple of days. And it was heartbreaking for all of us. And certainly for her husband, who lost his best friend and his best caregiver.

Moderator: I think it's wonderful to hear that your organization and the folks in the field are putting such an emphasis on that to try and make sure that the caregivers are getting the care that they need, as well.

Elizabeth Smith-Boivin: Thank you.

Moderator: So before we ask for your concluding comments, are there any specific resources you would recommend for our audience on this topic?

Elizabeth Smith-Boivin: Sure. There are several great things out there. There are a lot of different organized that are more and more attentive to caregiver health. And that's wonderful. The Alzheimer's association, as I mentioned, has a variety of resources. There's a brochure called taking care of yourself that is great and it can help health care practitioners, it can help be a resource to the caregivers themselves. The caregiver self-assessment questionnaire that I spoke about earlier is also available and a great resource and when the AMA created the tool that they created, they also created a great article, wrote a great article, published a great article, I should say, about why it's so important to assess for the needs and the caregiver health. So all of those resources I think are great for the health care practitioner to understand this point about why it's so important that we provide this assessment and then ultimately the caregiver plan.

Moderator: So, Beth, do you have anything else to add about the caregiver plan or assessment that you'd like to share?

Elizabeth Smith-Boivin: Well, I guess in summary, there's a couple of things. First of all to embark on this, again, in a nonjudgmental way and as we heard from both Maryna and the data from the family caregiver alliance, please understand how important it is, health care practitioners that you ask about the wellbeing of your caregivers, provide them with your support and acceptance. It means the world to them. Remind them that the job that they're doing is immeasurably important, but that their overall health and wellbeing is so important not only to them, but to the wellbeing of the person with Alzheimer's disease. I find myself so

often stressing that to caregivers and they look at me and give me the yeah, yeah, yeah, I'll go to the doctor, and then I ask them, what would happen to your loved one if something happened to you? And when they take a moment to think about that, they recognize that their loved one in some circumstances couldn't be there for an hour without support. So we really try in every way possible to drive the message home that it's critically important for the caregiver to care for themselves. But I don't think anybody can stress that point as well as the caregivers that we heard from already today.

Moderator: Absolutely. Now, before we turn to questions from the audience, let's hear from these caregivers one more time about their experiences caring for their loved ones.

Maurice Haughton (Caregiver): This is a picture of her dancing at our wedding with my wife and I, the traditional mother/son dance turned out to be the mother/son/daughter-in-law dance. It all started for me back in 2012, I would say. Mom was bouncing checks, depositing money but not realizing that she was depositing the money. I would ask her what happened to the money and she would say she got mugged. As sure enough I would check as she did actually did deposit the money in the account. So I took her to her primary care physician at the time and I told him something was definitely wrong and he said, no, this is part of natural aging progression and I said, no, this is not a part of natural aging progression because today is my birthday and my mom, for the first time, forgot to wish me happy birthday.

Howard Cohen (Caregiver): Not every day is a great day. It's just you never know. I tell people that ask me, what's it like? I said it's like turning a light switch on and off. You never know at 1:00 in the afternoon everything could be fine and at 2:00 something is just affected Barbara that I just really is a test of my patience.

Maurice Haughton (Caregiver): I was still working at the time, so Maryna did a lot more of the care at home and I would do the best I could to get home and relieve her and help her.

Maryna Bilak (Caregiver): Yeah. We had a very personal interaction with Dorothy because, you know, even though she was still mobile and she could express herself, but it was a lot of work. I was cooking three times a day, trying to figure out what she likes to eat. I was helping her to shower. I would do her hair, massage her feet, I would cut her nails. Back then, I was ironing her clothes, as well. And I also did some artwork at the apartment and I remember she really liked to follow me just working. I got this commission to create a relief of a very beautiful woman and there was a chunk of mud. For Dorothy, it was just mud. It was clay. And I would take a little bit and creating a portrait of a lady. And she was sitting in the back of me and it made her so happy. At some point, she started laughing. For me, it was so nice to see her enjoying herself and smiling and laughing because as I learned later on that ability to smile is something that some patients lose.

Howard Cohen (Caregiver): You know, you want to make sure your loved one still has a quality of life that they deserve. And what you want them to have. So you have to do certain things that maybe you wouldn't be doing normally. I mean, I always cooked, so that was no problem.

But I'm start to go learn how to do the laundry.

Maurice Haughton (Caregiver): I didn't realize how draining it was. And even when we were actually being drained, I didn't realize I was being drained. I thought that I could handle it. I thought that it was, you know, just part of the course. But it's very important to take five and is refresh yourself.

Howard Cohen (Caregiver): what motivates me to be a caregiver is Barbara and I have been married for 46 years and I love her as much today as I did when we first got married and I just want to give her the quality of life that I think she just -- that I know that she deserves and if she has a good quality of life, it makes my quality of life better. She's having a good day, I have a good day.

Moderator: So I think to your point, nobody emphasizes it better than the caregivers themselves.

Elizabeth Smith-Boivin: Absolutely. Sometimes people ask me, you know, why did you choose this field? It must be difficult to work in the field of Alzheimer's disease. But Rachel, as you can see every day I get to work with people like this. So it's a privilege. They really are quite spectacular.

Moderator: Absolutely. So we have some questions that have come in from the audience.

Elizabeth Smith-Boivin: Terrific.

Moderator: The first one that came this the said during the short video, the couple spoke of some services that were suggested to them. A lawyer, catholic charities and that was called the Eddie. What is the Eddie?

Elizabeth Smith-Boivin: Okay. Terrific question, so one of our premier long-term care service providers in the capital region is the Eddie. They have a myriad of services. I think they cover every part of the long-term care continuum. So they provide adult day programs services, they have assisted living environments, nursing homes, rehabilitation services. They are quite a terrific network of services. But they have a terrific program that was formerly called the faith in action program. Where they have volunteers from faith communities all over the region, I think for them it's a 10-county region but it might be a little bigger than that. And these parish communities or church communities rally volunteers together that go out into the home. And provide some hours of respite support. So Maurice and Maryna have some Eddie care team volunteers that allow them to have a date night. Those services are available widely throughout the region. If you haven't engaged in those services and you think you might benefit from them, reach out to us at the Alzheimer's association or reach out to the Eddie and they'll happily provide you with the information.

Moderator: Thank you. The next question, how has physician practices with their often busy

practices successfully incorporated the caregiver assessment when seeing patients with dementia?

Elizabeth Smith-Boivin: That's a great question. I was concerned one of the things folks might ask about today is how do I have the time? And I understand. I worked in a busy medical center for ten years. I understand time is of the essence. But a couple of things, I think. First of all, you set self-caregiver assessment tool as kind of your backbone. And then the other thing I would say is that many health care providers, they already know their patients. Some of these answers are already known to them. Some things -- not to say you shouldn't still ask. We shouldn't assume about everything, but some things you can skim on a little bit more than other things. So I would say be mindful of the time that you have. The other thing is that many people, many physician practices bring in social workers or care managers to assist with this process. And I know that it's an added expense for a health care practice, but when you think about it in terms of what it saves in physician time and in nursing time, it can often pay for itself in a practice. The other thing I would say to health care practitioners and providers is, you don't have to do it all along. If you don't have the time to do it, simply recognize the importance of it and refer that caregiver to the Alzheimer's association or their agency for their caregiver assessment.

Moderator: Excellent. Thank you and I think we have time for just one more question. Many caregivers feel it is within their role to care for someone regardless of the stress and exhaustion it may cause asking for help may be a sign of weakness or they feel they may be failing in their role. What is your response to that?

Elizabeth Smith-Boivin: You're absolutely right. As I have said so many times and we have talked about today. And we have seen here, these are selfless people. They give and give and give. And so, again, going back to something I said earlier, what I often remind those folks about is that without them, the care recipient is at the world's greatest loss. And so the care recipient needs them so badly, that's its incumbent upon themselves to take care of themselves. So that they can be the best possible care giver to that person they love. I remind care givers every day that it's not selfish to care for yourself, but rather it's generous to care for yourself because you will be here longer and you will be better able to provide the care to that person that you love.

Moderator: Thank you so much for answering a question and for all of the information that you've shared with us today.

Elizabeth Smith-Boivin: You're so welcome. Thank you for having me and a big salute to our caregivers during national caregiver month.

Moderator: Absolutely. And thank you very much for joining us today. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available for today's program. To obtain nurse continuing education hours, CME, CHES or social work credits, learners must visit www.phlive.org and complete an evaluation and the post test for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Please join us

for our next webcast on January 18th focused on child passenger safety. Additional information on upcoming webcasts and relevant public health topics can be found on our Facebook page. Don't forget to like us on Facebook to stay up to date. You can let us know how you use Public Health Live! by taking a brief survey at phlive.org. I am **Rachel Breidster** and thanks for joining us on Public Health Live!