

>>JODY: Welcome. My name is Jody Krainer and I work with the Wisconsin Alzheimer's Institute. One of my roles is to manage our program called Wisconsin Dementia Resource Network, otherwise known as WDRN. So WDRN puts on webinars that highlight creative services, programs, and ideas in the space of dementia. Today's webinar will be on connecting those impacted by young onset dementia to essential services. We have two guides that we developed through a collaboration that we'll be going through. As we go through the slides, I would encourage you to think about one or two individuals that you have worked with that have lived with young onset dementia and their spouse or significant other. We'll be using the term young onset and younger onset dementia interchangeably as we go forth. So, I would like to have our collaborators introduce themselves.

>> JENNIFER: Hi everybody. I'm Jen Harders. I am one of the dementia care specialists here at the aging and disability resource center in Waukesha County.

>>HEIDI: Good morning, I am Heidi Neeley. I'm with the Alzheimer's Association and I am a program manager and research champion with the Alzheimer's Association.

>>TRISHA: And I'm Trisha Witham, a dementia care specialist with the Aging and Disability Resource Center for Barron and Rusk counties.

>>JODY: Thank you for uh joining us today. So WDRN has an advisory board and about a year ago at one of our meetings several of the members brought up an observation.

They had more and more frequent contact with individuals living with younger onset and said that the prevalence had gone up. And a lot of the work they were doing with spouses and significant other really reflected the large gaps and the lack of connectivity for those individuals, as the journey for someone living with younger onset and their their support system is a little different than those that have later onset dementia. And so I agreed to the board that I would try to find a work group to develop a caregiver map for those living with young onset. And so this was inspired by this caregiver map that I had learned about at the Alzheimer's Association conference a couple years ago. Carly from the ADRC of Portage County, she's a dementia specialist. She actually had presented on this tool. I love the image and how they were utilizing this caregiver map. So I started off with the vision of setting up a workgroup to develop a caregiver map for young onset dementia and their support system. And so I put out a call and said who would like to work with me? Hence Heidi, Jenny and Trisha stepped forward. And so we've been working for just about a year on trying to develop this caregiver map. When we first met, we started to talk about the young onset journey is not a linear process. It's not a 'one and done.' It's not the same for everyone. And so because of the difficulties with getting a diagnosis, people enter the journey at different points in time. And often they need to, you know, revisit a specialist or

their attorney or other services. So it wasn't linear. So I spent an extraordinary time. I won't tell you how much it was trying to think of, oh well, it's a roundabout. You can go round and around and then you can kind of like go off and the group said, "Jody, how do you get back on? This is really confusing. This is going to make people feel like they're spinning in a circle on this journey."

I'm like, "Okay, okay." So, at the dinner table one night, I was talking through this saying, "I'm trying to come up with an image. It's like a caregiver map, but it's not linear." And my adult son said to me, "Have you tried looking, you know, asking AI?" And I'm like, "No, I don't know anything about it. I've been on the sidelines." And so we went on my computer and UW has Co-Pilot. And so we put in a prompt in co-pilot to kind of come up with an image for this caregiver journey and those living with younger onset. What kind of resources? So AI came up with what I thought was a very creative solution, a hiking map. And so I brought this to the group all excited. And as we talked about it, comments were kind of it's kind of busy, Jody. And you know what? It may look like someone's off in the wilderness by themselves with no support. And I said, "No problem. We can make it in a city." And so we did try to - I did try to put it in a city map and it really just didn't work. And after dialogue after dialogue about this, Trisha referenced that she had been using a tool that was very successful with some of the clients she had been using with and so she will talk to you about that right now.

>>TRISHA: Yes, thanks Jody. Yeah, so you can see it was a process to really get to where we were at. I don't know how many of you are familiar with this form, but it's the 'Now what? Next Steps after an Alzheimer's diagnosis' developed by the National Institute on Health. And I utilize this as a dementia care specialist with many customers. And it's not necessarily, oh, we got to complete step one to the next one. It's just kind of more: I use it as a guide to kind of figure out maybe where the family wants to start, what things have already been accomplished. And it also helps me to kind of remember, oh yeah, what other points do we need to get to here? Um, if you're a professional and you're working with families living with dementia, I'm sure many of you can agree that it's very overwhelming. It kind of is that like where do we start? And sometimes families are coming to us with multiple things and we're helping to guide them into what is most important. So I really do use this 'Now what steps' for most of my folks that are living with dementia and their care partners and it's a great guide to start. But we took our inspiration from this also realizing that when you're dealing with young onset that journey does look a little bit different and that there were things that - pieces of this puzzle - that were missing and that we needed to add into it. Next slide Jody.

So we developed the 'now what guide' a guide for young onset dementia diagnosis in Wisconsin kind of following that same template or model. So this is again where we got our inspiration from. We also wanted to make sure that it was again not overwhelming but that positive approach. There is hope. It is about navigating through this journey but also recognizing that there's um different roadblocks or different things that can get in the way here. That's different than if you're 65 and over and maybe retired in your life. Um, so we started out with this guide and we had also included in my role what I had found was that, in some of my calls or contacts with folks that were younger, even I was having a hard time and the families were having a hard time really differentiating out, you know, is this mental health, is this dementia? A lot of families were getting a lot of kickback from doctors and the health systems themselves. And you know so we're kind of struggling in this together and we had originally added in you know how do I get an evaluation for cognition here, if I am 45 you know and I want to, and I think that there's some symptoms here: what does that look like how do I know? Again it's not really mainstream education um what's what might be going on in your 40s could possibly be dementia, you know, and it does take a lot longer for people with young onset dementia to get that diagnosis. So, we originally put it in this guide, but we decided that we were going to break this out because there was a lot more information into just getting a cognitive evaluation for a younger person. And recognizing even though some of those symptoms might cross into just late onset dementia that again some of these symptoms might be occurring and look differently in people that are younger, still working, have kids at home. Some of those symptoms that we talk about when you're 65 and over it, it might be appearing differently when you are again have a family or you're at work. So some of those signs and symptoms might come from a different area than just the care partner realizing it. So we created these two guides. And the thing too - when Jody was talking about the caregiver road map - is we wanted to make sure that it spoke to both the person that might be suspecting that there's cognitive issues or has been diagnosed and also to their care partner. So both guides are are written and directed to both the person with the diagnosis or concerns and their care partners.

>>JODY: So the remaining of the time this is the agenda we'd like to cover. We want to talk a little bit about what young younger onset dementia is, what the gaps were that inspired the guides, and then the actual two guides. The guide for getting a cognitive evaluation and the guide for young onset dementia diagnosis in Wisconsin. And then we'll have time at the end for question, comments, and thoughts.

>>JENNIFER: So, we thought we should probably pull back and just provide kind of this basic diagnosis of dementia. Just kind of start at the beginning. So when we're talking about dementia, just general dementia, we're talking about changes in someone's memory and or thinking skills that are sign severe enough, significant enough to impact their daily life. So that's that general term of dementia. Also, you may hear it referred to as major neurocognitive disorder. That's that's kind of the new diagnosis that's being used in place of dementia. Okay, Jody.

So, more specifically, we're here to talk about younger or or young or younger onset dementia. So, as we've already has already kind of been mentioned, we're talking about dementia that is diagnosed prior to the age of 65 can be as young as 30. So significant changes in how somebody's um thinking skills are in a much younger group of people. This younger onset dementia impacts about 5% of all dementia cases and the most common types of the younger onset dementia that we see are are located on the screen. So we do see Alzheimer's disease as a form of younger onset dementia as well as frontal temporal dementia, vascular dementia, Lewy body dementia, Huntington's, as well as a traumatic brain injury. We know that that diagnostic process, as Trisha was talking about, is very challenging for people. It can take up to four years on average for someone to be diagnosed with a younger onset dementia. And we also know that people often are seeing many doctors in throughout this process. Um so it can be a very complex time consuming process for someone to be diagnosed with younger onset dementia. Okay, Jody. So the unique challenges this form of of dementia this younger onset dementia is very different than late onset dementia in many ways. Um the and Trisha talked a little bit about this when she was talking about the guides. What we see for people who are younger, it can impact them, as I said, in many different ways. That employment impact, many times people are still working. If they're under 65, they may be in the prime of their career. And so that can involve a loss of income for a household. A disruption in their career and the trajectory of that. Which is is very disruptive to that family unit. It also often means that there could be children at home or children who are at the college level as well as parents. So often times these folks are not only trying to navigate their own disease process but also um it interrupts that caregiving or the family dynamics. We know that people are often misdiagnosed. We don't assume that someone in their 30s, 40s and 50s are experiencing dementia changes and so it is often misdiagnosed. The symptoms can be misdiagnosed as things like mental health issues, depression, other other health issues. And again, that's where people can be bounced around from doctor to doctor throughout their process. And then the social stigma of this younger onset dementia is really significant because the resources are often um fewer and not as accessible for these folks as well as people not

understanding. Really not having that awareness or that understanding or that empathy for what someone might be going through and also impacting the person's social system. If I am younger and my spouse and and my um friends are still working, where does that leave me as far as a support network? Okay, Jody. So when we're talking about symptoms, they can be very different than someone with late onset. Some of them certainly there are are some there is some overlap and to keep in mind that the symptoms can vary from person to person. The things that can be different for them are it doesn't necessarily always impact someone's memory. So depending on what type of dementia the person has, their memory may be very much intact. It might have more to do with what we call executive functioning. So the trouble with planning and organizing and making good decisions. We can see that um again we talked about the fact that sometimes it is assumed that it is a mental health issue or a midlife crisis or something going on with that person. We do know from the family standpoint that it can really impact a couple if this is someone who is married or has a significant other. In working with some of these families, we do know that divorce can be a topic of conversation because that person can seem so very different. The caregivers that I work with will talk about the fact that their loved one seems to be very unconcerned about them. When that person becomes apathetic, they don't seem to be concerned about what might be going on with their significant other. and that can really change that relationship. We do know that sometimes people will develop behaviors and habits that maybe they didn't have earlier in life. Things like gambling, drug use or substance use can become a problem again because of the changes in the brain, the changes with judgment and problem solving. Individuals can fall into some of these risky behaviors. Along with that, if there is some interaction with law enforcement, these individuals are less likely to know how to handle that interaction. They may end up arrested. They may end up - I we've worked with a caregiver that actually was tased and was thrown into jail because he didn't respond to what he was being asked to do. So really significant changes in and risks for these individuals. The individual may not know that these changes are happening. So if they're having difficulties at work or in other relationships, that may not be communicated to the spouse or to the significant other until things are very much out of control. So, um, kind of just the symptoms again can vary. They can be very impactful. And sometimes as support individuals, we aren't aware of how significant things are until it's too late. The person has lost their job or they've had some sort of interaction with law enforcement. Okay, Jody.

>>HEIDI: So when we talk about younger onset dementia, we have to talk about the gaps that are out there. In 2018, my family was gathered in Yellowstone at a family reunion. And none of us knew that this trip was absolutely going to change our life. And like Covid, that's

the year now we look at the before and after that year. Just like Covid, before and after Covid. One evening my sister-in-law, who I will call Jeanie, asked if she she could talk to us and to bring our spouses in. So there was five spouses and five siblings with the five spouses. And for quite some time she shared with us that her and her husband were having having issues. Um we we'll call her husband Steve. He was convinced that Jeanie had issues. She was um overreacting. She's misunderstanding things. That she was imagining problems. She really needed to see a counselor. And Jeanie's like, "No, Steve, you're having issues. You're being more physically abusive, emotional abusive." Just different things that were causing marital issues. Well, Jeanie, of course, wanted to keep the peace, find answers, and so she went to a counselor. And in fact, it was a counselor that Steve had even suggested. So, Jeanie went, she went again. And on the third time, finally, the counselor said, "You know, Jeanie, I don't find anything wrong with you. Let's bring Steve in. Um, I really think he's an probably a narcissist or I think he's just really controlling." So, that matters because this conclusion wasn't careless at all. It was reasonable based on what the counselor had heard and what he had learned. Um, and when somebody is in their 40s, when they're in their 50s, they're still working, they're parenting, they're functioning properly: dementia is not your first thought. We think about mental health of course, but we think about, oh, do they have a personality change? Um, we think about relationship dynamics, etc. And so often families are sent to counseling long before anybody even looks at the brain. So the counselor suggested to bring Steve in. And about 15 minutes into that session, the lens did begin to shift for sure. And the counselor turned to Steve and said, "I think you need to see a neurologist." And from that moment, their story changed from blaming each other and behaviors issues to 'let's look at the brain.' Steve did see a neurologist. And within 10 minutes, they heard the words that neither of them were prepared for. Just like, Steve, I think you have Huntington's disease like your dad. Um, five years earlier, my father-in-law had passed away, which what we had believed was from a tragic accident. He had slipped in the shower, had hit his head, and had a massive brain bleed and had major brain surgery. And then he had a lot of dementia symptoms. He had a lot of movement symptoms and eventually did pass away. But what we learned that about that was that dementia had not been caused by the accident. It was the accident had been caused by Huntington's disease. And this distinction matters clinically, emotionally, systemically. Our parents had chosen not to tell us about Huntington's and the diagnosis because they were trying to protect us. They wanted to protect us from the stigma, from insurance barriers, from fear. Of course, it was a heavy weight that my mother-in-law was holding on her shoulders and did not want to pass on to us. So, it was a decision made by love, but still there's pros and cons for sure. Um, but the biggest con was that we were absolutely not unprepared for this. Also because Huntington's disease is genetic. It can occur to people in 5 years old, 6 years old. I just talked with a family, their loved one, she

died at 16 last week. So younger onset can be even younger than - way younger than 30 - for some of these genetic diseases. Each child has a 50/50 chance of inheriting the gene of the mutated gene. And with each generation, the symptoms will appear younger and lives are then shortened because of that. So with this, um, this wasn't just Steve's disease. It was now my husband's risk, my children's risk, my granddaughter who was just born's risk, nieces and nephews, cousins, etc. Um, it just opened up. At the time, my husband, Brian, was 54. He was healthy, successful, working. I was 49. Our son was engaged, was going to be married in 2 months. So excited. But we knew at this time we needed to hurry and tell our son about this possibility, that if my husband has it, then our son Austin could have it as well. And we needed to let his fiancée know. And so we shared the news. And something still brings me tears is she says, "I don't care if Austin has Huntington's, I still want to marry him."

He ended up having it as well, or he will. He's a gene carrier. But a few months later after this discussion, my husband Brian went to see his primary care doctor as normal. Shared that his brother had been diagnosed with Huntington's disease and his doctor asked him the simple question. 'Do you want to take the blood test?' So for Huntington's disease, the test is just a specific protein that they look on at the fourth chromosome. It's a a protein repeat. It says CAG CAG CAG. For normal repeats, you're in the 12, 13, 14, 15s. Once this repeat starts mutating and gets into the 20s and 30 repeats, it starts to mutate, gets sticky, long and sticky and kind of basically sticks to your brain cells. They they destroy. And if this in the 20s and 30s, you could be a carrier and the next generation, this protein repeat gets longer and you can pass it on to the next generation. And once this protein repeat is over a 39 repeat, the person will develop Huntington's at some point in their life. But Brian was confident. He was healthy. He was working. He truly believed he didn't have it. And more than anything, he wanted to prove that he wasn't a gene carrier so that our children wouldn't be at risk. So he told the doctor to order the blood test. There was no genetic counseling first. There was no discussion of that emotional stab in the heart and deep depression dive. No road map and we would were told that the results would come in about 2 to 3 weeks. Well, those weeks ended turning in 2 months. We after the weeks of waiting, we checked the portal daily to to find those results. What is the repeat number? Is it over 39? We ended up writing back in the portal. We emailed. We called. No one seemed to know where the results were. They didn't know who was supposed to give us the results. Eventually, we were told, "You need to make an appointment with a genetic counselor." It's like, "Okay." So, now we waited for that appointment. Um, when we were finally able to sit down with her, she sat there and in her hands held a folder with our results, but then she had to explain, "Well, we're really sorry. This wasn't done appropriately. You should have seen a genetic counselor before any of this. Primary care should not have done the blood

test. Um, so then she told us, well, here's the risks of knowing. Here's how it's going to impact your family, the life-altering weight of a genetic disease, etc. And then she finally asked us, now do you want to see the results? It's like, yes, tell us, are we over 39 or not? And Brian, unfortunately, was a 41 repeat. So, we knew he would develop Huntington's, some part of his disease, and our children were now at 50/50 chance. And as I mentioned, Austin did eventually test a couple months later and he's at a 43 repeat, which means he will develop a bit younger than my husband and he will pass away younger, too. Um, one happy thought I'll throw in here is since we do know the cause of Huntington's um, which is wonderful, it makes it a kind of a gateway disease, to helping throw research at it so that if we can prove that it works, then we could throw that research at other dementias as well. And one thing we can do is IVF. And so I am very happy to report that our son Austin and his wife have two healthy babies that they did through IVF that are Huntington free. And so it has completely stopped it in that line. I have three nieces and nephews who have also tested positive, and all three of them have one to two Huntington free babies as well. So it is slowly, you know, halting. Thank you for the love. Um, it is very exciting.

So the genetic counselor, she referred us to a neurologist who worked very closely with Huntington's. She was an absolute expert with it. Truly understood it. And we made now that appointment and waited for months. And when we finally met her, it was immediately clear how knowledgeable she was. She was calm, confident, deeply experienced. She knew Huntington's. She knew the science, the progression, the patterns. She spent time with Brian. Um, she did all the baseline testing. Explained what the diagnosis could mean medically over time. But yet, as thorough and competent as she was, we were still standing at the edge of that dark cavern of not knowing what is next. Because we were given information, but we weren't given guidance. We were handed facts, not a good path even like the one Jody was trying to lay out. There was no path uh for us. We didn't have anybody to really take us by the hand and say, "Hey, here's what you need to do next." There was just a spiral of emotions just going down. We were shown charts, um, age projections of when things should happen and eventually about here's about where you should expect to die, and then follow up with us in 6 months. Handed a, you know, a stack or so of folders of information about Huntington's. Again, this was not negligence at all. It was a system knowing what it knew to do at that time. Um, so again, there's the gap. What is missing the family, we were way too young to look into a dementia world, but now be living in it. So, I went home. I did what many caregivers do. Yeah. Panic. And then you do a lot of research up till many 2:00 in the mornings. Just researching, learning a lot. I've learned what Huntington's disease is, all the aspects of it. But I didn't see anything. How do I learn what how do I learn to live with it? How do I deal with it myself? I needed to know what about my husband's work? What do I do about his work? What about our house? I know he's going to

end up falling downstairs. Do I need to move now while he can help pack? What about our finances? Do I need a trust? do I need a will? Um, there was so much information that I needed to do while he could still help me, but I couldn't find anywhere. Someone suggested I call the our wonderful ADRC, the Aging Disability Resource Center, and so I did, and they genuinely wanted to help me, but they didn't know how either. Um, the symptoms really hadn't started yet. And so, I didn't know what questions to ask. They didn't know what to share with me either. So again, I was 49 and dementia was not supposed to be a part of my life or my husband's. This is not the way we wrote it. And within a year at age 55, my husband had to quit his job. And looking back at his performance reviews, we could absolutely see that the dementia had already been progressing and it had been misinterpreted as performance issues instead of neurological issues. And that's again another gap in the workplace. Um this is where the dementia hides.

People are - they're coached, 'you need to try harder, you need to put more time into it.' Or they're demoted or let go, like in my husband's case. So again, the gap instead of being needing to be evaluated through a neurological lens. Now, I had to become the primary benefit and bread winner. And I was blessed to find a job at UW-Madison in the neuroscience training program. And it was there that I learned so much about the brain and I worked with the PhD students who were in the research labs, almost 100 labs at UW-Madison in neuro and research, and it was just absolutely amazing. So I learned a lot about the brain. And four years ago then I was able to join as an educator here at the Alzheimer's Association, and and I wanted to be with people who were living what I was living, and it was here that I needed to learn how to be a caregiver finally and I have learned so much about communications, behaviors, about planning, all of that and serving other people that were in my situation. But again it was the gap, everybody were decades older than me and I was still lost. It's like, okay, that works for you. You're retired. You don't have kids at home or or whatever it was. There was no resources for me. And there were support groups. I'm over support groups, wonderful support groups I work with and partner with, but they weren't for me. They again were decades older than me. They weren't - they didn't get it. And I love them, but it wasn't for me. Um, and so the gap was there still. And so almost about a year ago at the Alzheimer's Day conference as Jody mentioned, she came up to me and asked a simple but a very powerful question. It's like, "Hey Heidi, do you want to build something specifically for families affected by younger onset dementia?" And I'm like, "Absolutely." And Trisha was sitting there and she's like, "Trisha, join us." And then Jen joined us. I have, it has just been a year of excitement as we've gone through these and finding the resources together. Of learning what's getting the answers about that journey when you get the heart stab. You know: 'what do we do now?' What are the resources? What are the steps? And that is what these are for - because families deserve a pathway, and that is what this is. And

then about 6 months ago, I took another step and started a younger onset dementia support group in Dane County because there wasn't one. And as we've looked across the state and realized there just aren't any other options and Jen is the only other younger onset support group that we're aware of. So, we would love to know if any of you guys are aware of any. And so, the gap is real, very real. And that's what brings us here together today to talk about this. Because a lot of the families, we're too young. And the ones that you work with may seem too young and they're functional. You know, often families are already, they're in the blaming stage. They're blaming each other. They're blaming the changes. They don't understand the relationship strain, problems that feel like personal failures. There's stress. There's conflicts. People don't know what to do. And they're asking, "What am I doing wrong?" long before somebody asks, "What might be happening in the brain?" So my ask is simple. When the story doesn't fit, when the behavior looks like, you know, major personality changes or controlling, or narcissism, or when stress looks like conflict, or when somebody feels just, oh, too young, just take a pause and just think about the brain like, hm. Because that pause can be the moment a family stops blaming and fighting and finally actually looking at the neurological issues. And then realizes they don't have to do this whole spiral by themselves, that there is resources and there is understanding out there and we can start to fill that gap that has just been way too wide far too long. So thank you for letting me share my story.

>>TRISHA: Thank you Heidi. That was so well said and again thank you for sharing your story. Um as a professional dementia care specialist for the last 11 years in the beginning of my role I could count on one hand the number of people that I was working with that had young onset dementia or their families, even you know doing memory screens out in the community. It wasn't very common that somebody younger would have a positive memory screen to send to the doctor. In the last 3 to four years, I have noticed a a huge increase. And so, in the last 3 to four years, I've worked with at almost 8 to 10 families or customers, living with dementia and just their whole situation, whether just trying to get a diagnosis or they've been officially diagnosed. And so, I think I was on that call with Jody where I said, "Hey, is anyone else seeing this?" And I know Wendy from the Alzheimer's Association said that the calls to the state line for young onset have also been increasing. So again that was our observation and I was, even as a professional as a dementia care specialist for seven or eight years. I was finding difficulty with some of the symptoms that I was hearing. You know talking with my own supervisor. I'm not sure if this is mental health. I know one of my customers she was seeing a counselor in the same way too and the counselor's recommendation was divorce. You know that a separation and a divorce at at this point over so much counseling, when the person was in the midst of getting a diagnosis there

was a lot of work issues happening as well. But for that spouse, they couldn't call, you know, there wasn't this ability to call and talk with the employer about what symptoms they're seeing versus what she's seeing at home. You know, there wasn't an ability to kind of get all of those facts. And so, it was very kind of piece-meal. It was difficult for myself. Um, especially when it came to the workplace. You know, I know about the ADA and reasonable accommodations, but gosh, where do we go with this? There's not a diagnosis yet. What do we do if there is a diagnosis? What is the next best guidance? Um, many younger people also don't have their POA for healthcare and finance completed. So, um, all of those issues occurring. Um, many families have young children at home, still working, navigating. It's just a lot. So, even as a professional, I found myself struggling to help these families kind of navigate both the symptoms and the resources that are available. And as Heidi mentioned, a lot of the resources that might be in person or local aren't necessarily geared for somebody um that's in their 30s, 40s or 50s. They're geared towards older adults. And so that also makes it difficult. Um so that is kind of just in my own professional observation, one of the other reasons too that I teamed up with Jody, Heidi, and Jennifer to say, "Hey, what can we do? What kind of resources are out there? How can we put it together?" And by no means is this an a comprehensive resource. These are meant to be guides with some different links and tips on where you go and what to do, but there could be lots more. And I know that will only increase over time too with the resources.

>>JODY: So, I want to really acknowledge, Heidi, how special it was that you share your story. Um because I think that was the impetus for this work group is that those of us who don't walk in your shoes but have walked beside totally appreciate the challenges that exist and want to make a difference and so hence I appreciate you're sharing sorry because I think everybody on this webinar has probably interfaced with someone and totally totally want is motivated by to do something and that's what our hope is that these guides will do um as we I've been trying kind of monitor the chat a little bit. If you have a specific resource, like Julie has mentioned, a a group that she's facilitating, feel free to put the information in the chat so others can save the chat and grab that information. We really want you to have the ability to network in our chat. So, go ahead and do that. So, here are the guides. And as Trish mentioned, this is a a companion guide. This was not the impetus for this work group, but it became very evident as you heard story, the challenges that there are in getting a diagnosis, or working diagnosis, or sorting through this. So this guide, this companion guide, the guide to getting a cognitive evaluation is really content heavy and there are five sections in it. It talks about symptom identification. We're hoping to catch people's attention when they look at that list and say, "Oh, yeah, my my husband's experience of that or my mother, I noticed that." Um, we are also um wanting to explain what young onset

dementia is so that that that we can kind of address some of the stigma stigma that goes with that. And then why it's such a challenge to get a diagnosis is kind of explained, steps to take and then key points. So this is a very document that's very knowledge building, understanding building and not as many resource connections. There are links within the documents and as a group it was just amazing how many when you go to the web and you start searching all the documents all the websites all the information out there and a lot of them are very credible and so it became very difficult for us just to narrow down what to put in these guides because we didn't want to overwhelm individuals. We wanted to get a starting point, a window open kind so they can go in and get started. And so the the the links in there are ones that we found that we narrowed down that we thought would be helpful. And we made it based in Wisconsin. So many of the resources are Wisconsin-based. Um our goal is to update these annually and house them on the WDRN website. So you can you can go ahead and download them. Now, we invite you if you want to take the guides, go back to your community, adapt them, take part of them or do whatever you want. Again, we were inspired by Carly presenting that caregiver road map. We want to inspire you to do what works in your area. So, you're welcome to go ahead and adapt them and use them. Um, so this is the companion guide. Um, and the date on the most recent updated one will always be on the last page so you can see if you have the current one.

>>TRISHA: All right. So the now what again guide we modeled after the now what from the NIH. So some of it again is going to be repeated. You know, that was the other thing, too, is like some of these resources obviously expand regardless of your age if you have a dementia diagnosis, but we wanted to make sure that we added in um the specific areas that were more pertinent for people that are younger that are dealing with a dementia journey. So, learning about young onset dementia conditions is very important. We did put the links to all of the specific um organizations that we knew of that are online like the Lewy Body dementia association, the frontal temporal dementia or degeneration association, Huntington's disease society of America. Um there's a rare dementia support website as well. In this guide too, and we'll talk about that again, Wisconsin specific. So, when we listed aging and disability resource centers, those are going to look different in Wisconsin versus Minnesota or Illinois. We also know our veteran service officers, right? Or Wisconsin's very county based. You've got that, but it might look different in different states, but some of these links are going to be to those national or even international resources as well. Um, we also wanted to make sure that we added that section of if you are working because again most people will be working at this point. So really not only just HR things, but you know talking about switching a position, consulting the employer's HR or FMLA, getting connected to the disability benefits specialist at the ADRC's, checking out

social security disability or SSI and those benefits. The Americans with Disabilities Act. So, giving people lots of resources around if you're working. Um and again, the Alzheimer's Association had a great resource for that as well. We wanted to make sure people are still doing that legal, financial, and long-term planning that they need to do even if it's late onset. Um we added in, you know, a great resource that is more dementia specific is the conversation project. So, instead of, you know, we've got Wisconsin, which is do you want a feeding tube? Do you want to go into a nursing home or a CBRF? This one actually works you through not only those issues need to be dealt with, but you know how if you're in later stages of dementia, how much support and care do you want? So, just adding in some of those extra resources that we had found and agreed were helpful. Um, also adding in the veteran service officers because again, younger, even older, you could be a veteran, but younger onset traumatic brain injuries that could also be leading to a young onset dementia. So, checking in with them. Um, we kept staying safe on the road, finding services and support after diagnosis. One of the ones that we added in here was Lorenzo's House, which has been a relatively new resource in the last couple of years that provides a lot of support for families navigating young onset. So, we made sure to add it in several different places and using some apps, too. So, we included some more technology things. So, keeping families connected through uh an app like Caring Village, Caring Bridge, lots of helping hands. Being safe at home, out and about was also repeated, but we added in some more about firearm safety. And also just a creating dementia friendly home environments and what that looks like. So, um, we also talked about maximizing brain health because we want people to still continue to, um, do what they can to maintain their brain health and the regardless of lifestyle recommendations or even brain games that are on the internet. And again, not a comprehensive list, but a start for people and when they're ready. That's the other important part, too. So, you know, this guide isn't intended to be like, oh, great, you've been diagnosed. Let's go through every section. Really figuring out with people what's the most pressing concern for them, what do they where do they want to start? What have they already done? And then you're using that guide to not only give them as a family, but you know, for yourself. All right, in a few months, let's touch base on understanding the family journey or you know, here's some resources for that. Um understanding the family journey was another one that we did put in that was specific. We wanted to make sure that we connected people with resources to support children to understand dementia because again those family dynamics can be different. A person can be a parent of young children, teenagers or even college age students at that time. And also added in stuff about ambiguous loss which we know crosses age groups. But again, ambiguous losses, super important as your person's changing and especially when we see young onset and those personality changes. You know, Heidi mentioned it, the customers I've worked with, you know, that's really important. That person is is your person or your

spouse or your partner, but they're not that same person that they were that you knew. Um and which probably triggered you to start looking for answers or what was going on. So wanted to make sure that we addressed grief. There is other resources in those organizational websites that also address that. Um and then consider participating in a clinical trial which was the same as the now what too. So local Wisconsin resources along with NIA clinical trials as well. We did get feedback from the two support groups that Heidi and Jennifer helped to facilitate. Had excellent feedback, really good good feedback from both. So we we combined just that input from these family members into these guides as well. A lot of the feedback was wow I wish I had this when my person was first diagnosed or this would have been so helpful. So that was a lot of great positive feedback that we took and then we also had you know some changes and additions from that group as well. Next slide Jody. Um, so we have a little notes page on the back there. And again, some of the the document links are to specific dementia websites. Um, we added veteran service officers, added disability specific resources while working. Made sure Lorenzo's house was in there. Um, home safety, firearm safety, emergency planning, um, the Wisconsin Alzheimer's Association as well. Again, state specific. Um, aging and disability resource centers. You might have several staff within an ADRC that is helping to support a person as was in my case for many of the families that I work with. And of course, the Alzheimer's disease research center.

>>JENNIFER: So, these are the two support groups that have been referenced throughout this webinar. uh the group that Heidi runs um in Stoughton and then the one here in Waukesha. Just a couple notes about these groups. They are for the caregivers or family members of the younger onset um individual. So they're not for the person living with dementia. These two groups in particular are in person, not virtual. We do recognize that other dementia specific groups are available through the Alzheimer's Association, through the association for frontal temporal dementia, Lewy Body association, for example. And in addition to these groups Julie put information in the chat about her group that meets in Kaukauna that is also virtual. Um so Julie, thank you for that information. We will add that to our resources as well. And if there's any um other groups that we haven't discussed, please feel free to notify us of that information.

>> JODY: So panelists or collaborators, any other parting words right now before I open up to Q&A?

No. So, I am going to be stopping the recording, but before I do it, I do really want to thank Heidi, Jenny, and Trisha for a phenomenal partnership in developing the guides and the willingness to step forth and do the webinar. Your passion and commitment is was evidenced through the entire process. So, thank you very much.