

Dementia 101 with Ellen Platt

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SPEAKERS

Announcer, Ellen Platt, Ashley Biggs

Announcer 00:02

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Ashley Biggs 00:22

Hi, everyone, my name is Ashley Biggs, and I'm the marketing and outreach librarian for the Maryland State Library for the Blind and Print Disabled. And I am so excited because one of my good friends is here with us today. I actually met Miss Platt during my very first year at lbpd. And she is someone that I've kept in touch with because she's just a wealth of knowledge. Ellen Platt is actually the founder of the option group, the people who are presenting this webinar seminar on dementia 101. And she is a Certified Rehabilitation Counselor. She's a care manager, certified aging life manager, like care manager, actually, with over 30 years of experience working with individuals in providing care management, advocacy, placement, care, conditioning, all that all this awesome stuff that really helps our community continue to grow and expand. And under her leadership, the the option group has really taken off, they've gone and become a trailblazer in the community. And so it's really cool to continue to see her and to see her organization grow. She is actually here today to talk to us about dementia, and dementia. 101 is the title of this particular podcast. And I'm gonna let Ellen take it away.

Ellen Platt 01:53

Well, thank you, Ashley. Good morning, everybody. I I'm thrilled to be here. I'm Ellen Platt, founder of the option group. This is our 11th year providing care management services and advocacy for families

who are trying to figure out how to navigate certain circumstances, whether it be just a decline due to aging or because of some type of catastrophic injury, or disability. And so what we do is we work with a wide range of families to help them just navigate longevity, whatever that looks like for them. So you can imagine there are a lot of different circumstances out there. And we really tailor a care plan to that individual and their specific needs. So as a care manager, I do work a lot with people who have dementia. And we're going to focus our conversation today on dementia and kind of the just the basics so people can understand there's a lot of terms that we hear that are thrown out there. Sometimes it's a little bit confusing. So I hope to be able to simplify some of that today. So I'm going to talk a little bit about, you know, we hear dementia or Alzheimer's, we we hear all kinds of terms. And what I'm going to try to do is clarify that dementia is an umbrella term. And so that is kind of a generic term that we use when people start having difficulty with processing in their brains and their thoughts. So dementia is is the umbrella term and there are over 200 Different kinds of dementia. The one that we hear about most is Alzheimer's, that is a type of dementia. And it's really is about how the process happens in the brain. So there's Alzheimer's, dementia, vascular dementia, Lewy body dementia, Frontotemporal dementia, there's all kinds of dementia, and some of it may even be as a result of a disease like Parkinson's, that as the Parkinson's advanced, dementia also becomes part of that. And there may be mixed dementia, which may or may mean that we've had we have more than one kind of etiology, how the dementia started. So I just wanted to clarify that because when you hear to match, it doesn't really mean just one thing. So the difference between Alzheimer's and dementia is that dementia, again is used as a describe a set of symptoms. But Alzheimer's is a specific disease that is a type of dementia. And it's one of the most common. About 50 to 75% of the cases of dementia are related to Alzheimer's. And about 5% of those cases are considered early onset. Now sometimes people get confused the difference between early onset and early stages of dementia. So early stages, you could be any age and you were just starting to notice the beginning stages of decline and cognitive issues. But early onset is actually its start So with people who may be in their 40s, and 50s, sometimes we've even seen them in subpopulations as early as 30s, and 20s. But that's pretty unusual. But early onset is in the 40s, and 50s. And that tends to be a quicker progression of the disease. In the other regular cases of Alzheimer's or dementia is, you see the early signs of kind of forgetting things, or forgetting names or starting to forget how to do things that really are very common routine kinds of things that you have done, but then you start realizing that it's more difficult to do them because you forget the steps or you forget where you're going now might be someplace that you've gone to 100 times that you just kind of forget how to get there. And then we start seeing some depression or withdrawal from activities because people start realizing that they have a little bit of a deficit, that they're not quite understanding, and maybe withdrawal from being around social people, you know, social situations where they might have to explain or it might kind of present itself and they feel uncomfortable about that might have a little bit of confusion, you might see some mood swings, maybe some difficulty finding particular words that we're looking for. And it's really as the brain cells are dying, or there may be some plaques and tangles in the brain that make the processing a little bit more difficult. When we talk about vascular dementia, that's the second most common of dimension is probably about 30 to 30% of the cases. And the main symptoms, again, are memory loss, impair judgment, decreased ability to kind of plan that executive functioning, where we're talking about organizing things in your brain and, and making decisions and kind of complex problem solving. That becomes much more difficult. And usually vascular dementia is from something like

Ellen Platt 06:55

bleeding clots in the brain of stroke, Tia with transient ischemic attack. So there are different, again, different etiology, but it relates to the vascular portions of our brain. We mentioned before that there may be some disease states that cause dementia, and some of the common ones for that would be Parkinson's, or Huntington's disease, Wernicke Korsakoff syndrome, or CTE, the chronic traumatic encephalopathy, which we hear, you know, a lot of concussions, you know, frequent or repeated concussions can cause later in life can cause some dementia. So that would be another way that, that dementia appears, a lot of people wonder if there's a test to check for dementia, and there really is no one test to determine if someone has dementia or not. They are looking at some blood tests and some things that might have markers. And we hope that that may be coming and be really affirm indicator to be able to confirm the diagnosis. But right now, it's pretty much diagnosed by a thorough review, maybe some testing, monitoring, following you know, digging into the medical family history, is there a history of Alzheimer's in the family, they may do some laboratory work, blood work, brain imaging is a really important way that they are able to disguise or identify some of the things that occur in the brain as dementia progresses. Also, maybe doing some neuro cognitive or neuro psychiatry, some testing, really kind of think about characteristic changes in thinking things that were able to happen for you before may be more difficult to do now. And we're really just looking at day to day functioning, things that used to be easy may become more difficult. And we're really intentional on looking at how can we make the functioning easier. Maybe it's doing using cues or notes or things that might kind of trigger how to do something. And then sometimes we will also see some behavior. So sociated with dementia is and we'll talk about that in a little bit.

Ellen Platt 09:08

So what is it? What if it is Alzheimer's? What do we do? How do we manage it? What What can we do to kind of stay as independent as possible, make sure their loved ones are safe, and really continue to function as best as we can. So dementia or Alzheimer's is one of the top 10 causes of death in the US. And it's the only one that cannot be prevented or cure. So death rates from Alzheimer's have increased 89% since 2000. And as you've probably heard the term the silver tsunami or the baby boomers are aging 10,000 people a day are turning age 65 We are gonna see an increased prevalence in Alzheimer's. We also have more accurate ways to diagnose it, and we're diagnosing it early. Some people can start early on with stages of dementia, or Alzheimer's, even 10 years before we're actually diagnosed with it. So it's really important to know that these things are long and progressive, and may be experiencing some, some of the symptoms, but you may not even have a diagnosis. And a lot of people think, Gosh, I'm normal, or I have dementia. And it's not really like that either. You, you may, there's this wide range in between being normal and having dementia, that's called MCI mild cognitive impairment. And that could be really mild, it could be moderate, or it can be pretty severe, even before you get that diagnosis of dementia, sort of like a pre dementia phase. And so it's really important to distinguish that, that you can have the ability to make decisions and can make, you know, decisions to function in your life. Before you even have that diagnosis, you just may need some assistance. So some of that, and we want to make sure that people understand that it's a kind of a fluid thing, that you're not normal, and then suddenly have dementia, but you may have good days, you may have bad days, you may have days that you're more lucid, and clear. And there may be days that are just really

difficult to function. So Alzheimer's is one of the most expensive diseases, it's going to cost an estimated a quarter of a trillion dollars. This is these are 2017 statistics. So we know that it's much higher now, we're finding that about \$1 Out of every \$5 that is spent by Medicare is spent on some form of Alzheimer's or treatment related to that. And for every \$100 spent on finding a cure, more than \$16,000 is spent on care. And so as you can imagine, with the caregiver crisis and shortage, there are a lot of people that need care out there. And it's been difficult to find. And so a lot of family caregivers have become the actual caregivers. And so there is a big economic impact not only on the families who have to stop working, because they're taking care of loved ones, but also people who are just trying to fill in the gap for the professional caregivers that are not available. So with the early signs of dementia early on and the beginning stages of dementia, you might start noticing some memory problems or remembering events that usually are or routine for you maybe a family member's birthday, something that you always remember, but it's fine, if you find that it's difficult to kind of retain that information might have increased confusion, or if there's a lot going on, it might be more difficult to follow conversations. If there are groups of people talking around you find that you know, the focus is not there might have reduced concentration might start seeing some personality changes or behavior changes, when we mentioned earlier about withdrawing from activities that you used to enjoy because it's either harder to focus, or again, those conversations are hard to track, people might get a little bit embarrassed because they're not able to kind of keep up with the pace around them might start losing interest in things they enjoyed. Because it's harder to follow the directions of that, that puzzle or that, you know, activity that they're doing, and might start slipping in terms of managing medications for getting a ticket or getting to go get something refilled. And then that's when we start seeing problems with bill paying or keeping up with regular bills and finances. And and this is where we worry because there may be some people who might not have good intentions that start coming out of the woodwork and taking advantage of somebody who might be slipping cognitively and still managing their finances. So the early stages, they may look normal, they may be doing most of the things that they normally do, they could still be driving. Some people may even still be working, but they start losing recent memory. And what you'll see is that short term memory starts going first. So the most recent events are forgotten. But they may remember something that happened back in 1950 of you know, special event, they could tell you absolutely every detail as if it were yesterday, but that's fairly normal. So you could be at the early stages of dementia, but remember those details to the umpteenth degree from long ago, but you might start forgetting what happened recently. Whether somebody came to visit you last week, or what you had for breakfast or if you even had breakfast, might start forgetting appointments or things like that, that were usually easy to track or forgetting to put things on the calendar so that you can track it is just difficult to pay attention or focus. Understanding abstract concepts might become more difficult. might be harder. had to balance your checkbook or, you know, know whether you got the proper cash at the cash register, and things like that. So it gets to be a little bit more difficult. And you might have to adapt or start bringing in people who maybe can help with the finances or help remember that you have that doctor appointment. So a lot of times the changes are subtle at this stage, but then they might start becoming more pronounced. The onset of symptoms are usually gradual, they're usually progressive. But I'd like to note that if something happens very suddenly, and there's a huge change in somebody's cognition, seem really confused one day are really just totally not what you're used to seeing. There often is some underlying medical impact, and it's usually unrelated to the dementia. So something like a urinary tract infection or some other type of infection, can really magnify those early progressive dementia symptoms. And we want to know that if something is significantly different one day, it's

probably a good time to go back to the primary care physician and have an exam to see if there is some underlying medical condition. Sometimes it can be a vitamin deficiency, it could be polypharmacy, it can be interaction between medication. And it could be some type of infection or underlying condition that can be fixable, but should be assessed by a physician. So it's really important to know that it may not be just progression of the dementia, it might be something else going on. And it's really important to get it checked out. So the progression can be very different from person to person. And a lot of it depends on the underlying etiology depends on underlying, you know, lifestyle, or if you're doing brain games or engagement or, you know, you're not isolated, all those kinds of things we have found adds to the impact of dementia. Early onset we talked about earlier, when somebody is diagnosed early, their progression of the disease tends to be more, more severe, and much quicker than regular dementia. So it can be much faster onset. In the middle stage, we might start seeing comprehension of written or spoken language deteriorates, it might be more difficult for them to express themselves, they might start forgetting words or making up words or kind of putting together sentences that don't quite make sense. They might start repeating things that they heard or repeating words, multiple times in the same sentence. And then sometimes they might have difficulty understanding what somebody is telling them might have to repeat it a couple of times, or change the way that you're saying it to help them understand better. And sometimes it just might be using other senses like taking their hand and showing them what you're talking about, or, or helping to show them a picture of something that you're trying to refer to. So sometimes it may be a little more difficult for them to understand. So slowing down the speech, repeating it in different ways.

Ellen Platt 18:27

You know, the tone of voice also makes a difference. Whether you're talking loud or talking soft or getting agitated, it's really important to be calm, and simplify your instructions or simplify your sentences, maybe break them down into smaller components, so they're easier to understand. And so sometimes there's behaviors that we see at the middle stage where it starts to become problematic. They might get their days and nights mixed up. Because there's not the structure they used to have when they were going to work. They might start sleeping during the day or nodding off so at night, they're not, they're not sleeping, they may be up, they may be wandering, they might sharp start showing agitation easily or frustration with their inability to communicate, or frustration or argumentative when there's things that they don't remember. And they get agitated because they think they should remember them or they might lash out at someone that's trying to talk to them, or even help them. And what we need to remember as caregivers or friends or family, that the person is not being argumentative for the sake of being argumentative. It really is frustration to their dementia. And it's the disease talking and especially as we get to the middle and later stages, we need to really be supportive and understand that they're not lashing out of us intentionally. It really is part of the disease. So some of the behaviors you might see is that there are more Totally labile, which means they may have dramatic shifts in their emotions or their mood, they may be kind of happy one minute and get really agitated very quickly. And that's not a traditional pattern that you would see in this person. So they may have up highs and lows and ups and downs and really seem to come out of nowhere we seem to change pretty quickly from from one extreme to the other. There may be delusions, false ideas about something or that somebody's calling you or, or that somebody is looking in your windows or, you

know, they saw somebody in the bathroom, and it may be their reflection in the mirror, because they're not processing what they're seeing as well. And so they might, it might plant some kind of false ideas.

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They may have hallucinations, they may see or hear or taste, or smell, or touch things that aren't there, they may be talking to somebody that's not there, you might see sundowning, which is a very common behavior or symptom of dementia. And that is later in the day, we're talking in late afternoon or early evening, or somebody may show increased agitation or restlessness or pacing back and forth, or they may start getting really anxious, wanting to go home or wanting to wait or waiting for a loved one to come home. And that may be somebody that has passed, but they're in a different stage of their life in their mind. So they're waiting for their loved one to come home from work, or they're waiting for somebody, their father to pick them up. And these people have been gone for a long time from their life, but they don't remember that they don't have the timeframe of where they are. But they may be very agitated, very upset, you may see a lot of tears. You may see at this point, some people may try to escape or elope leave their home go wandering looking for the people that they're looking for. So it's really important to keep an eye out when people start exhibiting sundowning, because we worry about their safety, we worry about them leaving the house and just wandering and getting lost. And this is quite quite frequent. And as you can imagine, late in the day, we're all more tired. And we we start you know getting exhausted and having decision fatigue of all the decisions we have to make during the day you can kind of equate it to that for somebody with dementia, where they're really struggling and keeping it together later in the day. And they really need some rest needs a quiet time and pretty soon going to be going to bed. So you'll see agitation, you'll see aggression, sometimes where they get physically aggressive or verbal or they start lashing out if you're trying to restrain them from from going to wander. And you know, sometimes we use emergency response system or tracking devices that might keep tabs on someone or alarms on the door. So it alerts the caregivers that somebody may be leaving, but we want to distract them and find other more more constructive ways of getting them to kind of get off of the thought of finding that last person and really kind of engaging them with activities and kindness. And maybe that's time to eat or you know, we're social beings, we want to be together with people. So distracting them with activity or engagement or, or reminiscing about something a long time ago that they used to enjoy. So those are some of the behaviors that you might see throughout dementia, but you see them more in the middle and in the late stages. So when we get to the late stages, even the recent, the recent events are pretty much gone. And people really are not remembering if somebody came to visit them this week or last week, but they might start losing those longer term memory. So they may not remember, you know, grandchildren because they were more recent, they might remember their children. And when they see their grandchildren, they might think it's their own child because they're kind of reverting back to their earlier days in their life. Long term memory is more significantly impaired. Communication may be more difficult, whether it's expressing or communicating their own needs and desires, but also understanding what's coming to them from people in the outside world. This is where we want to watch things like not having the the TV news on at night because some of the news is very disturbing. And people with middle or late stages might have difficulty processing what they're hearing, but they can understand that what they're hearing is very upsetting. So it may be you know, bring out this inner turmoil in them and really get them distressed

and upset because these these terrible things are happening. They may not understand that it's happening somewhere out in the world which is disturbing enough, but they may not think that it's happening to them or a family member, somebody that they care about. So really is not a good idea to have disturbing distressing news or even violent shows and things On, even if it's on in the background, they're not sitting there and watching it, they're picking these things up. They're having a hard time processing them or putting them into context that you and I might be able to do that. They still can understand emotion, and tone of voice and body language. So it's really important that we're paying attention to our emotion and tone of voice and body language. When we're working with someone with dementia. You may be their daughter, they may not remember your name, but they know how you make them feel. And that's what we need to remember as caregivers are people who are in circles with people with dementia, that we need to understand how we're, we're presenting to them is going to impact the way that they are going to react to us. So we're upset and stressed and agitated, you can imagine that they're, they're going to be the same way. So you want to mirror what you want to see from them. And that's a calm, tone of voice. It's a smile, it's body language that's not closed off, it's really open. You know, being helpful being pleasant being cheerful, all those things are really important to kind of get somebody to stay on an even keel and not get agitated. asking their their questions, not rushing their answers, not hurrying them to do something quickly. You need to allow extra time to do things like getting dressed in the morning, getting baths if you're taking a bath before taking somebody to a doctor's appointment, allow extra time, so you're not rushing, and both getting stressed and both getting agitated, it really is important. And when somebody is starting to have incontinence or accidents, and they need to be changed or cleaned up, we've got to remember that it's just going to take longer to do it. And to allow extra time. So going out into the world or shopping or going to a doctor's appointment, or even traveling we need to allow extra time. So it doesn't become this really stressful thing. Eating also takes longer, sometimes they may need help cutting, they may need help, finger foods are really good and it's gets becomes more difficult to use utensils at this point. So something that's easy to eat by picking up with fingers. And somebody who can help them cut it into smaller pieces. So it's easier to eat. Because this is really important to pay attention to nutrition, because that's when we start getting the downward spiral of decline. If they're not eating, they're not getting the caloric intake, they're not getting the nutrition they need, all the other stuff is starting gonna start to decline too, and they may start losing weight. And at this, at this point, we really don't want them to

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they may, again, start not recognizing people who are familiar to them. And that may be disturbing to that individual because they think strangers are there in their home, and what are they doing with, you know, going into my room or going into my checkbook, whatever it is. But it's also very distressing for family. And again, it's important for family to understand that, that one day they may go in and their family member with dementia may recognize them. But another day, they may not because it may be different day to day. But you'll just have to, you know, keep that in mind and kind of work around. To try things one way one day may not work the next. But try try again, either try the same thing another day, try a different approach. But really, we will just want to make sure that they're safe. And they're not a danger to themselves by wandering out or danger to others by driving a vehicle when perhaps they

should not be doing that any longer. So at end stage, and when we're at the end of life, with people with dementia, the physical care, as you can imagine, can be very demanding. It may take a really long time to do just those basic daily tasks like bathing, dressing, toileting, eating, things like that. Sometimes it's really hard to assess whether they have pain. And at this stage, if they're not able to communicate, we want to pay attention to cues, whether they suddenly yell out in pain or they yell or something. Or if you know you might be able to ask them and maybe they could say yes or no. Or you might see grimacing when they do something to facial expressions, just watch if they're doing something that might be demanding. And you see that facial grimacing, you want you want to think that that could be potentially pain, that we want to talk to the physician about whether there's some type of relief or something that we should be doing to make sure that we can manage that pain. Again, eating and hydration may become difficult, particularly if they start having swallowing difficulties, which is something we often see. See at the end stages, where they may be choking, there may be aspiration. This is where we see a lot of pneumonia, because they've, they've kind of breathed in some food or drink that gets lodged in their lungs, and they can cough it up appropriately. And that's where we need to start watching out that kind of thing. Some people may need thicken liquids and things like that. And it's all, again, things that you should be discussing with the primary care physician, who should be your ally and really work with you closely. During these end stages, their immune system may be compromised, or probably more vulnerable to urinary tract infections, because they the cleanup is more difficult, we would want to watch those infections for ammonia, or urinary tract infections. And we want to make sure that they're comfortable. So you can treat, it's good to treat infections and things like that. But there may be some things that we're starting to think about not treating. And that's usually when we start bringing in hospice, we want people with hospice to come in. And really just that added layer of comfort care, because we're not going to be sending them for surgeries. And we're not going to be putting in feeding tubes and things like that. It's all discussions that should be done with the primary care physicians. But hopefully, that you've had the discussion with this person that has dementia, when they were able to make decisions to really know what they want or not formed. So tips for communicating with a person that has dementia, you know, we're, this is not a typical natural thing that we do. So what we need to do is really get to know our person well, what makes them tick, what sets them off? How do we communicate with them, and we start learning things that they tend to enjoy are ways that we can distract them. People are are, they're connected, they like to be connected to other human beings that we're very social. So working with the social aspect and wanting to do things together. And if they're, they're lamenting the loss of a loved one, or they want to see that loved one that they kind of forgot has passed, instead of

Ellen Platt 32:18

insisting that they understand this person has passed, the real important thing is just validating, I know you really miss that person, what is it that's that you really enjoy the most about that person and distracting them, and allowing them to reminisce about that person, even if they're reminiscing as if they're here today, just like I'm talking about that person or trips that they choke or adventures that they went through in earlier years. And it it kind of brings them back to a happier time, that in their mind, they're more connected with their memories are stronger, and they may enjoy telling you about. And this is where we kind of unlock some really neat family stories that we never knew about before.

It's just allowing them to reminisce about their job, or their children or our family they used to take or when they were in the service, there's all kinds of things that you can tap into and get some kind of magical memories that maybe you never heard about before that can kind of go down into the family history. So really improving these communication skills, maybe using nonverbal communication, doing things like not overwhelming them with choices. So would you like chicken? Or would you like a hamburger? Do you want to wear the red shirt? Or do you want to wear the blue shirt? You know, that's much easier than opening your closet door and saying what do you want to wear, because there's a whole closet full of clothing, giving them some options. So they still have the ability to make decisions that doesn't really harm them one way or the other, if they're wearing the red shirt or the blue shirt, but it gives them the ability to make some decisions about their own life. And they can succeed because it's much easier to choose one, rather than choosing from a whole closet of options. So doing things like that, or if you want somebody to, instead of asking them a yes or no question. Because often the answer is going to be no. So it's like instead of saying, Do you want to go to the bathroom, it might be let's go to the bathroom, or come with me, or I have something to show you. Or let's have a meal together. So a lot of times you can distract and kind of get them to come along by taking their hand with a smile with open body language and kind of helping them travel with you. And that's you know, instead of having this yes or no tug of war, we're really kind of just getting them to do the tasks of the day and it's less stressful for them and it's less stressful for the caregiver. So we want to set a positive mood for our interaction attitude. Your tone of voice body language, our feelings and thoughts are, are much stronger, those kinds of things are much stronger than than words. So sometimes they may not understand the words, but using the body language, and that the communication really sets a positive mood, and being respectful, and allowing them to have as much dignity as possible, and allowing them to have little successes and things they are able to do. So if you're getting dinner ready, maybe they can put the napkins on the table, or put the plates on the table, allowing them to do things that they can succeed at, using their strengths. You know, I've had some folks who still love knitting, and they're still able to do it. And so maybe they can knit something for a family member, or we've had people knit scarves and hats for a homeless shelter. So they can still participate and have a purpose. And that's what we want to tap into wherever possible. Other things that we can do is using the other senses, like hand massages, using oils that might have lavender that's relaxing, and calming and soothing, simplifying distractions. So if we're in a room full of people for having a party, maybe we don't want to have as many people to the party, maybe have a couple of different parties, over a holiday instead of one massive party, limiting the distraction and then the noise, not having a TV and radio blaring in the background. Maybe Dimming the lights a little bit or maybe shutting the curtains or the doors so that they have quieter surroundings, things that they like maybe a blanket, something that has tactile, you know, like a nice soft blanket.

Ellen Platt 36:55

Some people love their pets, if they don't have a pet, there are some really convincing mechanical pets, that give them the feel of having a pet and that comfort of a companion. But you don't have the care and the cleanup that would come with a regular pet, you want to make sure that you have their attention before you start into the direction. So making sure that you're you know looking eye to eye and that they know that you're trying to talk to them or communicate with them. And then going into the

the instructions. But again, you don't want to say well, let's go into the bathroom. But to take off your clothes, we're gonna get in the shower, and we're gonna get cleaned up. That's too much information. So really one step at a time, let's get a shower, and going in and then helping him let's take off your shirt, let's take off your shoes, whatever it is the step by step, and allowing them to participate at the level that they can, but you can help them you can assist them or give them cues, cues are really important for them to know what comes next. Because often that's the problem. They don't know what comes next. And it really gets to be stressful and upsetting. So if you could just kind of walk them and talk them through that process, then they start to understand what they're doing. Using their name is really important because that's something that usually sticks with them. They know when you're talking to them, when you use their name.

Ellen Platt 38:23

Touch is really important. We mentioned that making sure that you're not hanging over them, when you're talking to them, it's getting getting down to their level. So your eye to eye, if they're sitting in a chair, that you're actually you know, looking at them at the level that they are, you want to use very simple words, very simple sentences, speak very slowly and clearly. And in a reassuring tone, so you want to, again, make sure we're paying attention to our tone of voice. You don't want to be too high or too low. You don't want to be too loud, too, when they're faced with it just be very calm and comforting. If they don't understand you try to rephrase it, try to use different wording, maybe use a picture or refer to something that might help her understand sometimes pantomime. Again, they're not processing the way they used to. So they might need a little bit of extra help to understand it. And instead of saying he or she or they use John's name, or Bob's name or whatever name you're going to use, you know who you're referring to. So they know you're talking about, again, simple questions using simple statements. We also want simple questions. So again, we talked about that red shirt or the blue shirt or yes or no questions or rather than No, that's something that they're just going to say no and resist. Maybe it's just like, hey, let's do this. This would be fun. Let's so we want to find the fun and the joy where we can and tap into fun memories and techniques that you have learned that works with that person. So being patient is really hard to do when you're in a rush and you're in a hurry in a hurry, and you've got to get stuff done. But really being patient and waiting for a reply waiting for them to do what they can do to help with the task of getting out the door. If they're struggling for an answer, it's okay to suggest words, or maybe see what they're trying to say, like, give them a word, but you don't want to be rushing in to fill in the blanks of every sentence that they have, I do want to give them a little bit of time to come up with the words of the idea that they're trying to convey. But it's okay to give them a little bit of assistance. And again, watch for their nonverbal cues and their body language. And so you can respond, you might, they might be really agitated, but they're, they're shivering, that might just mean that they need a sweater, they might be agitated, because they need to be changed. They've had an accident in their pants, but they're not able to communicate that. So what we want to do is look out for these clues and cues that they're giving off to you. Or maybe it is asking the question, do you need to use the bathroom? Or can I help you? Or do you need it? Would you like a sweater, or just bringing on a sweater and putting it on them. So always strive to understand that the agitation often is telling you something, maybe they're hungry, because they they're not connecting their brain, to their bowels or their bladder, or to their stomach, their brain is not connecting the messages that we used to get. So we

may have to be detectives in a way and really kind of figure out what it is where this agitation is coming from. Encourage them to do what they can remind them of the steps. You know, we've had people who will put little notes on the bathroom mirror about pickup toothbrush, put toothpaste on brush teeth, and just having that as a simple reminder might be a way that they can still be able to do their teeth themselves. Sometimes they might just need a help with your hand on their hand to show them the beginning steps of brushing the teeth and then they the muscle memory comes back and they can finish the job. And sometimes it's just that beginning cue to get them started, which makes it easier for them to accomplish it on their own and feel like they've had some successes. So if your loved one becomes upset or agitated, or or you can see that something's starting to escalate. What you want to do is change the subject, change the environment, try to find ways to distract maybe as with a meal or a drink, we want to make sure they're they're eating and they're hydrated. So a little snack might be good. Maybe going for a walk or bringing out a puzzle or something that you could work on together. Maybe there is a TV show, that's something a favorite of theirs from long ago, you could find a rebrand, maybe it's some manipulative with her hand or, again, there's lotion, massages, things like that, there's lots of things you can do. Just find things that they used to enjoy. If they used to trove of travel, find a book about the place they used to travel, and you can look at the pictures. And maybe they can start reminiscing about that but different ways to really kind of distract and get them on a different track. Again, they become very confused, anxious, unsure of themselves. And then really, we're going to need to be there to kind of keep them on track and keep that structure around them. And remind them what's going on around them. Remember, we're having friends over, or we're making a meal for a holiday or somebody's birthday. And so there's a lot of hubbub, we need to kind of keep them on track, keep eyes on them to make sure that they have some time for rest or relaxation. And then just helping them stay focused on something present here today that they enjoy. We talked about reminiscing and that's really really important as people progress with dementia and if there are things that they're able to remember from long ago, let them talk about it. Let them reminisce, let them come up with ideas and stories. And it's really important for them to be able to do that to stay connected in their lives. So we want to do that things that are affirming to them. Photo albums family photo albums are a great way to help them stay connected with the past and be able to talk and reminisce about people that were very important to them. So we pretty much talked about these things before you speak just as a review. Make sure you have the person's full attention. Make sure that they can see you clearly. Having eye contact, watching your body language, your tone of voice your nonverbal cues, and then minimizing competing noises like other conversations, or radio or TV Other things that you might do is just think about the time of day, what is an important time of day for them, a good high functioning time of day isn't when they first wake up, where they're raring to go, or maybe they need a few hours in the morning to get going, but the middle of the day is a really good time for them. So that might be a good time to schedule the doctor appointment, or the might be a good time to schedule a family visit, or might be the time to go to the store to try on some clothes with them. Because they're, they're fresher earlier in the morning or earlier in the day when they're not so exhausted, they might be up to that type of activity. So you want to make sure that what we're doing for scheduling is that a good time of day, we don't want to take them out to dinner at a busy restaurant, when they're sundowning late in the day that's just has disaster written all over that, we want to make sure we're picking times of day where it's easier for them to function.

Ellen Platt 45:58

So with that, I am going to wrap up. I appreciate your time today. And actually, I don't know if you have any thoughts or things you'd like to add,

Ashley Biggs 46:08

I had a few questions in regards to staying in the home, when it's really hard to make that judgment call. But when should you start making a judgment call as a care provider? That they're no longer able to stay in their home?

Ellen Platt 46:25

Yeah, that's that's a good question. Um, you know, a lot of times, there's no place like home, people would prefer to stay there often, there are a lot of ways to extend your ability to stay in the home with somebody with dementia. And what we're really looking at is number one safety, you know, are they doing things like leaving the stove on? And forgetting it, you know, are there you know, near disasters that are happening? are they letting strangers in the house? Are they wandering out into the street, when we start seeing things like that, we start getting really worried, there's got to be more oversight. But there are ways to do it without going to a facility. And it might be family members it might be bringing in professional caregivers might be having some monitoring systems or cameras or things in the home, that help keep track of them. And then it gets to a point where it becomes a financial decision. If there's 24/7 care, and you've got lots and lots of support, that can get to be quite expensive. And sometimes it's less expensive to actually go to an assisted living facility. So sometimes it does become that financial decision. Which one is more cost effective? And that just depends on how much care you actually need.

Ashley Biggs 47:45

Would it be a good idea if you got a dementia diagnosis to start planning for when you can't make decisions anymore?

Ellen Platt 47:53

Absolutely. Absolutely. Being proactive is so important, even before the dementia diagnosis. But if you are in the earlier stages and the attorney that you're working with to do your planning documents, they feel that you're able to make those decisions to sign your paperwork, you want to make sure that you have an updated Advanced Directive, which says what type of treatment you want, or do you not want? Do you want artificial hydration or nutrition? Do you want to be resuscitated, if that's necessary. So all those kinds of decisions are really important that we make them prior to being far down the road with dementia, because you're no longer able to make them or document them. So you're no longer the

person making those decisions. You can do it early and put it in writing, then those are the decisions that are going to be followed by first responders, by your family members, by the physicians. It's also super important to get power of attorney documents. So who is a person that you absolutely implicitly trust, that can make decisions for you in terms of your health care needs, and in terms of your finances, in the event that you're no longer able to make them. So once you get to the point where you're no longer able to make those decisions, you have somebody in place that you trust, that is able to make those decisions, but you have to have that paperwork in place, or banks and physicians and people like that are not going to be listening to their directives. So you want to make sure that you have all that in writing when you're capable of making those decisions. But also, what are your wishes? What if you want to go to a facility? Do you want to stay home if at all possible? There's all kinds of decisions that you can make now, you just need to clearly state them, document them and communicate them to the people who are going to be making those decisions and making sure that those decisions are carried out.

Ashley Biggs 49:58

I'm sure there's a lot of emotion Shannon for a dementia diagnosis, both on your end and then your potential caregivers that how important is psychological intervention or therapy to deal with the emotional side the psychological side of this kind of diagnosis for you and or your family?

Ellen Platt 50:20

Yes, good question. It's really important for both both the person that has the diagnosis as well as a spouse, a caregiver, or a family member and adult child, it's really important for everybody to seek out the support that they need. And the support might be other family members helping out with the care. Or it might be a professional, a counselor, somebody who can help with just the stress of being a caregiver, or the stress of having a diagnosis. And a great place to start is the Alzheimer's Association. You can go to their website, a LZ, dot o RG. And they have lots of great resources. They have support groups, for people with dementia, as well as their family members. They have Memory Cafes, which is a social opportunity for somebody early stages of dementia and their spouse to have social opportunities with other people who are going through the same journey. So I can't stress enough how what a great resource that is to be able to get people to help you educate you provide you with resources and information to help you walk this journey no matter what stage you're in.

Ashley Biggs 51:34

I recently read an article a caregiving article on dealing with dementia, and one particular caregiver who was the granddaughter of a woman. You know, she's kind of that sandwich ish generation there. But she made a daily book that she wrote down things that had happened the day before, she made sure to print off pictures. And so every week, she's got a new book with, you know, 14 pages or so put together and from her experience, it doesn't stop the progression. It doesn't stop the the I don't remember that.

But her grandmother had got has gotten into the habit of checking that book. And I guess she's might be in the early to middle stages where she still can, you know, remember to do that. But would things like that, that act of stimuli help keep someone from progressing too much?

Ellen Platt 52:42

Yeah, any kind of engagement and interaction is is great. So not only having the daughter come and visit with her, but also documenting that, you know, eventually there'll be a nice like keepsake for the family members. But right now, it's clearly a tool that helps keep the person with dementia, her grandmother, grounded in the here and now like, this is what's going on now. Oh, I see that I had a visit last week from my sister or I had a doctor's appointment. And sometimes that that decreases the stress because it helps keep them oriented to what's going on. And reminds them Oh, yes, I did see the doctor and the doctor said that it didn't need to change my medicine. So it kind of can help ground them. Especially if family members aren't there to constantly remind them, it might be a really good tool for them to refer to like a reference book, because they're not regenerating the memories like they used to.

Ashley Biggs 53:39

In that that was exactly her thought with like my grandmother will ask me, you know, next time I go to the doctor, and it's like you've just went so. So I'm 38 years old, and I'm pretty sedentary. I'm not exactly a healthy eater. I eat healthy, but I'm not like proactive and like, Ah, I hear that my generation. Those in there, you know, the xennials and Gen X and early early millennial are supposed to be more prone to these things. Uh, what can we do now at, you know, in our 30s and late 30s, early 40s to really help stave off something like this.

Ellen Platt 54:25

A lot of it is, you know, there there are some genetic components that we can't do anything about but a lot of it is really related to lifestyle. So whether it's you know, being super sedentary and not not doing activity exercise, even just getting out and walking they found has really been great to increase, you know, circulation, which is important. But engagement. Learning something new is one of the best things you can do and learning something different than you've done before. So new languages or a new hobby or playing an instrument, the more you can, as we're engaging different parts of the brain, because each of those activities uses a different part of the brain, the more activities or areas of the brain, you can engage with activities, your exercise, exercising them, just like your exercise your arms and your legs, you're exercising different parts of the brain, which helps maintain cognition. We saw during the pandemic, when it was shut down. And people were really, really isolated, we saw a huge decline in cognition, because they weren't having those social opportunities. So being out and about and doing things with people and having new experiences. And even something as simple as going to the store, there's stimuli all around you. And as long as it's not agitating them, it's a way of

engagement, which is really, really important. Having peers I mean, we had, we had some people create zoom rooms for their elderly people, so that they could still, you know, stay connected and have conversations and things like that. So what we want to do is really, whether you're young or old, exercise, nutrition, engaging your brain doing different novel things, you know, all those things that we really know that we've been told, since we were little, you need to eat healthy, you need to cut out the sugar, you watch the intake of alcohol, you know, the smoking, all those things are contributing factors to dementia. So it's just really important, the best you can do to minimize the negative lifestyle habits and increase the positive ones.

Ashley Biggs 56:46

So just a little plug here. As a librarian, I have to say that reading, of course, is one of those fundamental skills that keeps the brain active. And our agency, of course, serves individuals who have visual physical organic impairment. Now, we don't serve the dementia community, per se. But out of curiosity, have you found that dementia patients in the early stages who continue reading are good or happier or more engaged with the world around them?

Ellen Platt 57:23

Yeah, it's just another form of engagement, and especially the ones that were booked bookworms to begin with, you know, it gives them the ability to continue that they may not be able to read as complex material that they used to, or it may be a very complex book, but they've already read it 10 times. So it's, it's comforting to them. But even as people decline, things as simple as picture books, or photo, you know, travel books or things like that, is still a way for them to kind of engage that's, you know, matching picture books, or even children's picture books sometimes or, or some of the books that have tactile, you know, have a little sandpaper and have a little fuzzy thing and you know, the shiny thing and smooth thing. And again, those are great ways to engage people with dementia.

Ashley Biggs 58:11

Awesome. Well, I'm going to provide everybody with your contact information. Because as I said, In the beginning of the program, you're just a great person to know. And, again, this, the person speaking has been Ellen Platt. She is the founder of the option group. They can be reached at 410-667-0266- 410-667-0266. And good news, they don't only serve Maryland, they also have clients in in Pennsylvania and Delaware, I would call the main Maryland number to reach them. She has an amazing team working for her. So you if you aren't able to reach Ms. Platt directly, you can talk to quite a few people. I have met several of them. They blow me away with how engaged they are. So if you have questions, if you you know, just need that, that connection to the managed care community, the option group is the way to go. Miss Platt, thank you so much for being our inaugural event podcast. We really appreciate it especially on such a an important topic that's affecting our community. Thank you. Thank you. The Maryland State Library for the Blind to print disabled is available on Anchor FM Spotify tune in and

more. Make sure you keep listening and subscribe so that you don't miss awesome podcasts like this. Bye, everyone.

Announcer 59:48

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