Hadley Presents

Tips for Living with Vision Loss and Dementia

Presented by Ricky Enger

Ricky Enger: Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, we discuss dementia concurrent with vision loss and our guests are Teepa Snow, Founder of a Positive Approach to Care interviewed by Hadley's Chief Program Officer, Ed Haines. Welcome to the show, both of you.

Ed Haines: Thanks, Ricky.

Teepa Snow: Thanks. Great to be here.

Ricky Enger: So glad to have you both. Now, it's interesting Ed because you are Hadley's chief program officer. Before that, in another life you worked out in the field. So why don't you give a brief background of what you do now and what you did before?

Ed Haines: Yes, I am the chief program officer at Hadley. But for many years, I spent most of my time in the field working with older adults with vision loss. And one of the situations that I would often find my clients facing is vision loss and dementia. And it wasn't something that I as a vision rehab therapist really knew a lot about and really knew how to mitigate. So, I was really fortunate to hear Teepa several years ago now at a conference. So, I'm just thrilled she's here with us today.

Ricky Enger: Yeah, me too. I did not have the privilege of hearing her. Thankfully, we all will now. So, before we jump into that list of questions that you have, Ed, Teepa, why don't you just give us a brief overview of who you are and what you do?

Teepa Snow: Yeah, thanks, Ricky. Well, I'm an occupational therapist and I've been in practice over 40 years, which means I'm old, I'm in the category of aging. And I have been working in the field of dementia well over probably 30 of those years in one capacity or another. I also had family members and friends, some with developmental disabilities, some with vision impairment, but a lot with cognitive change that came with dementia. I also had worked with the Alzheimer's Association and taught at medical schools, nursing schools, and ran a practice where we did hands-on care just as Ed was describing. So, I learned a lot from some of the best teachers I've ever met. That's people living with dementia and folks who we're trying to help.

Ricky Enger: I can't wait to have you share the knowledge that you've gained over that time with our listeners, because I think this is a topic, dementia, and vision loss, that doesn't get as much attention as it needs to. So, it's really wonderful to have the opportunity to do our part to raise that level of attention and just provide these resources and things that people can think about, strategies that they can employ. Why don't we then get into that discussion? Ed, I know you have lots of great questions. So, let's do that.

Ed Haines: Teepa, we recently had a presenter from the Alzheimer's Association talk to one of our discussion groups and it was apparent there's just a huge amount of interest and confusion related to the relationship between Alzheimer's and dementia. Would you like to just offer us some basic clarification on those two terms?

Teepa Snow: It is frustrating as someone who's been in the field a long time to still use the specific condition's name for the general condition that people might have. If you think about it, an umbrella, think about an umbrella. An umbrella is the thing that goes over. So, dementia is the word that encompasses all conditions that meet certain criteria. So, it's called a syndrome, it's a collection of symptoms. And what it means essentially is that at least two parts of a brain are starting to die. The second is that we haven't currently got a way that we can stop it, or cure it, or turn it around or make it quit. And the third is that it is progressive. It will continue to change and change and change. And ultimately, anything that's a dementia is considered a terminal illness because it will progress to the point where your brain can't run your body, which is we think about brains as just being inside the skull. But in fact, they're the master control switch for everything we do and everything we perceive and how our bodies work are controlled by the brain. So, dementia means that your brain is no longer working the way it did and it's changing and it's changing and it's changing, and the cause varies. So, Alzheimer's is one of the specific dementias. It's a very common one. It's what we used to think was the major one. But now we're understanding it's related to beta amyloid plaques. You'll hear a lot about beta amyloid plaque and tau pathologies. We estimate at this point there's over 120 forms, causes and types of various dementias. So, it's one of a large group, but it's under the umbrella.

Ed Haines: When folks lose their vision, sometimes it's hard just to locate objects in their home as easily as they used to, particularly if someone's in an assisted living facility where other people are moving their stuff around. And if someone's capacity to remember things is changing that can make finding their stuff just even harder. They can't see it; they don't remember where they put it. Are there strategies that someone can employ just to keep themselves from being frustrated by losing stuff all the time? And I recall many occasions where individuals lose things and then start to feel like other folks are stealing them. And that interferes with their relationships, with their family, their caregivers, et cetera. It's really important.

Teepa Snow: Yeah, it surely is. And one of the most important things to really consider first, Ed, is if I'm acknowledging as a support person that my partner, my person that I care a lot about who's living with dementia is starting to have both problems remembering where things last were, but additionally, even how to get to the place where the thing was, because what we know about many forms of dementia is there's a part of the brain called your hippocampal area. And it's deep inside the brain and one of its jobs is to help you learn new things and remember what you learned. But the second job it has is a little different. That job is to find your way in the world. So how do you get from here to the kitchen? How do you find the sink in the kitchen? How do you find the glass that you fill? Now, I have to go back to the sink once I get the glass and then the water and all of that is built into the brain's ability to find things. And then ultimately, go back to the living room where I was when I wanted the glass. All of that has to be sequenced.

So, one of the things about dementia is it also takes away, frequently, your ability to sequence. What it means is now I would have classically used going through the doorway to the new place. If I had vision, I would use my vision to find things. If I've not had vision, what I would have done is count steps, or remember the sequence and remember by number of steps and left versus right, where things were located. So, I'm robbed of that method because I don't have the hippocampal area. So, what you might want to think about doing as a supporter is being careful that we do not move things and say, so for instance, I might say, "Hey, Ed, it looks like you're looking for something. Is it something you were wanting, a cup or was it something else? What did I do for you? I notice you're looking. I notice you're in a seeking mode." And rather than getting frustrated, what I said is, "Hey, Ed, it looks like you're looking for something. Cup or something else?" And you say-

Ed Haines: Yeah, cup.

Teepa Snow: Now what I need to do is as I move towards you, I'm going to keep going, "Oh, you were moving looking for the cup. What I want you to realize is I'm coming closer." Because your ability to judge how far away from you I am, might also be affected by this new thing called dementia.

And when I get to that place, what I can do is use my body cues of using my hand and gesturing, it's the one with a handle on it. Look over this way. And I have to now recognize, wow, number of steps to get somewhere no longer your way of doing it. And it's that internal mapping that is also missing. If someone says, "Did you move my cup?" You're looking for the cup. "I don't think I did." "Is it the one with the handle?" So, I start to recognize, "Man, I need to be tuned into this."

Ed Haines: Yeah, I've seen it happen an awful lot. And it does cause problems with relationships because people seem to default to the idea that someone's taking my stuff. And this is a related question really. Often, if my vision's changing, I'm obviously going to be more anxious about going to church, or potluck suppers or wherever I tend to go socially, because there's just issues of worrying about falling or maybe eating out in public. But I may becoming just more anxious in general, maybe even about things that are unrelated to my vision and folks are willing to help me, but how do they know when I'm having a problem related to my vision or whether my anxiety really is a result of perhaps some dementia.

Teepa Snow: Or whether you're developing a third condition, which is anxiety, which can happen in about 50% of cases of people who develop dementia. You also get an anxiety disorder because your brain becomes anxious in that it can't settle because it's not getting the data it likes, and wants, and needs to figure things out. So, it aggravates the symptoms of your dementia, which makes it much more difficult for you to use the thinking part of your brain.

So, one of the really important things to do is say, "So Ed, you're feeling a little uncomfortable about going to the church happening. And would you rather go with me, or would you rather meet maybe just with a couple people instead of going for the whole big group activity?"

Okay. So, what I'm doing is I'm providing an either/or option for you. And I want to be careful that I don't go, "Well, do you want to go or not?" Because when you're anxious, guess what the more common answer will be? You start limiting your social connections which actually reduces your capacity or resilience. And then you get more anxious even just with going out one-on-one because now you haven't had a lot of experiences.

Ed Haines: As a vision professional, just from that perspective for a second, the gut response always is to, "Okay, I'll solve this as a visual problem, and I'll solve it and then the anxiety will go away." So, when you do try to solve that visual problem and the anxiety doesn't go away, then how do you differentiate when there's a problem with vision or when there's not?

Teepa Snow: So what we have is we have somebody who is starting to be more anxious in social situations, in unfamiliar environments, in larger groups. So, what I would say is, "Okay, well, let's look at the variables we can do something about without losing the entire ability to engage in those situations." Let's say unfamiliar space. Well, I wonder if we're going to be more comfortable meeting in the fellowship hall versus that new part of the church or will we prefer a smaller space where people are seated versus people are up and moving around. What if I said, it'll only last for 15 minutes? So sometimes we can look at how long something's going to be. I could also be preparing you. And as we enter the door, I say, "Oh wow. There's about three people here. I think you know two of them, but I'm not positive. One is Sarah. She is the lady I think who does the organ for the choir? Does that sound familiar to you?"

So, what I'm doing is checking, “What's your memory bank telling you, Ed?” Do you have a familiarity or is this new data? So, I'm giving you the option by giving you small pieces of information now auditorily, but before you hear Sarah's voice, because if we have to wait till, you're in that mix of three people to start taking in data, figuring out whose voice is whose, where is it located, what's the conversat…. Can you feel the anxiety mounting even when I just talk about it? Even with a very mild symptom of dementia, you can become so anxious that you don't want to participate in more without support.

Ed Haines: I'll segue into another question, and this is related to having a partner. Often folks have a family member, if I've got a spouse who's worried about me falling because he knows I don't have any peripheral vision and I've got a partner to guide me everywhere, but I get frustrated with that. Are there specific techniques that a partner can use to do, what we call sighted guide, but in other words to guide someone who's visually impaired, but who also has a certain level of anxiety resulting from dementia?

Teepa Snow: Ed, I'm going to ask you a question back before I answer, which is when you decided guide work, do you provide a fair amount of verbal information while you're doing it or are you typically more quiet?

Ed Haines: Initially a lot of verbal information, certainly.

Teepa Snow: If someone is having trouble processing language, which we don't think so much about, but in fact, when someone is having memory problems, there is almost consistently some difficulty with taking in words, translating those words into meaning, and then being able to respond to them in a timely fashion. And I'm trying to take in the sensory motor data of moving the environmental data and your voice and the data that your voice is supplying. So, we may want to look at how much I'm trying to deliver to you as a support, versus, "So Ed, we're going into the restaurant. Would you rather that I give you some more information about who all is here or shall we just get to the table first?" So, it's really starting to be more tuned into, now if I start to know you well, my goal then is to do the things that you prefer and things that are helpful to you.

The question we always get into though, is we tend to like this, "Do you want me to help you or not?" I want you to help me, but I want you to help me in a certain way. And then the language delay happens. And then it's like, "Well, why didn't you tell me that?" So, we find ourselves almost argumentative without meaning to because we're trying to help. So, one of the most common and purposeful phrases I have is, "I'm sorry, I was trying to help. I'm taking a deep breath because I'm struggling, and I want to try to do something that's helpful to you and I don't know that I am. Can we try something?"

Ed Haines: It sounds like a lot of the techniques you're really talking about really involve slowing down and listening and a lot of patience.

Teepa Snow: It's really hard to have the person who you know is error prone to be the boss. But frankly, it's their life they're living, and my job is to support.

Ed Haines: If it's harder for me to learn new things, unfortunately, when I lose vision, I need to learn a lot of new things. How do I learn what I need to know when learning is difficult? Are there some things that I should prioritize and how can I help other people teach me?

Teepa Snow: So, one of the really important things is to really, for yourself, identify what are some really strong preferences. Like, do you like alone time? Do you want alone time? Well, then we need to create a space and a place where you're going to be okay being alone because you can access things. And then we want, if at all possible, to sustain that environment with its structure as it is so there is very little new you will have to learn as your dementia progresses. In the early state of dementia, in the early stages of dementia, people can still learn new things.

It's just a lot more effort. It's harder for them to hold onto them long-term. If we're going to have you learn one thing, let's say, use a cane, are we thinking that cane is a long-term device or is it going to be something that I'd be better off helping you start to learn to trace around a room to be able to find things in the area by going around the boundaries of an area and having a walking path and objects laid out so that you can access that with minimal effort? Or learn to use a cane and step counting and those kinds of things? Because those things, although short term might prove very, very beneficial.

In the long-term, it may give you a false sense of security as your miscounting steps, or you think you have the cane in the right position, but you actually have it up, maybe two inches. The whole thing is, it's sort of in some ways mind-blowing, but that's what dementia does. It basically blows our minds.

Ed Haines: What you're talking about is really mapping things out with an idea for future needs, not just immediate needs. And that can be tough. Right? Because dementia progresses in different ways with everyone.

Teepa Snow: Yeah. And the type of dementia really matters. And that's where that umbrella thing comes in. Someone who has Lewy body disease, for instance, as opposed to Alzheimer's disease often has visual hallucinations, auditory hallucinations. They can think they're in another place, in another time, in another situation or that people are present that aren't present. It can come and go through. So, they could have a problem on Monday evening, but by Tuesday it's fine. Programming for them would and should look very different than programming for somebody who has Alzheimer's that has a more predictable pattern of change. Then there's all the different dementias that we would want to get a little familiar with and how to respond in those situations.

Ed Haines: It impresses upon me the necessity of a really good team of individuals. This is not a single person solving these problems. And in speaking of teams, this is an issue that people with vision impairments confront not just with regard to dementia, but with regard to when they seek mental health counseling, et cetera. Often the problems they are experiencing are attributed by professionals or family members to their vision. Well, you're blind, so you have to be depressed. Someone says, "My brain is changing. Something's not right." And your doctor and your family keeps saying, "Well, you've lost a lot of vision. That's got to be it." What can you say to them to help them to understand and pay attention?

Teepa Snow: The first thing to try not to do, which is really hard to do in that situation is not go, "You're not listening to me," because that actually didn’t, they just say, "Well, I think she might need something for stress. Let's look at a medication." It's like they are listening, they're not understanding you. “I feel like you're hearing what I'm saying, but you're assuming something. So, what I'm really asking for is a good evaluation from somebody who knows both maybe vision loss, but for sure understands dementia because I think what I'm experiencing might be different than just my not being able to see things. I'm having trouble sequencing. I'm having more difficulty figuring things out and making choices than I've had before. I feel immobilized sometimes. I'm really getting to a place where I hear someone, and it takes me a while to figure out who is this person? And I know I should know them, but the voice pattern in my memory are not coming together into a package. And that's not vision problem. That's beyond that.” I think if we have awareness of our change, we do want to say, "You're hearing me, but I'm not sure you're appreciating what I'm asking for."

Ed Haines: And that's hard to do and keep your temper.

Teepa Snow: It is because in those moments it feels like people are not listening. They are hearing, but they're not listing. You're absolutely right.

Ricky Enger: This is such a huge topic and we have asked so many great questions and the answers to those questions to get yet more questions. So where can people go? Are there resources that you would recommend, or things beyond this that people can go to do their research.

Teepa Snow: You want to find someone in the world who matches your interest and your focus so that you're getting the right support. So, we have a lot of free resources at Positive Approach. We have done a couple of sessions for people who either work with people with vision impairment or people who are visually impaired.

You’re looking for a group or a resource person that will listen first, help you figure out what it is you might be talking about and wanting to learn more about, and then be able to point you to those resources.

If you like listening to or still enjoy watching videos, those kind of resources. If you could use modified visual stuff, maybe resource pages that you can go to and the Institute on Health, Institute on Aging has some things. But the tricky part is combining this thing, vision change and dementia when both are incredibly complex and life altering. And there are resources out there, but asking questions is the first place to figure out, “Oh this seems to be somebody you think would like to learn more from because they seem to get what I'm saying and they're offering something of value to me.”

Ricky Enger: And we certainly will have links to Positive Approach to Care in our show notes, along with the Institute on Aging. And anything else that you'd like to leave the listeners with that maybe we didn't touch on, just something people can think about something that we maybe didn't cover that's super important?

Teepa Snow: As with vision changes, I think dementia is... We talk a lot about being person-centered. Who the human being has been they still are, but they're changing. I am who I was, but I'm different. I think when we add in that loss of a huge data set that we tend to use if we've been sighted and we now lose sight, now I've got this other area, at least in my brain that's not sharing with me the way it used to. I have to look for new avenues of getting data and that's uncomfortable. There's a difference between discomfort and pain. What I would always seek out is a way to work towards simply recognizing things should be a little uncomfortable until we figure them out, but we don't want life to be painful. And if life is painful, more support is needed.

Ricky Enger: That's such an important distinction. Thank you for that. And thank you for spending a little time and just sharing your knowledge with us.

Ed Haines: Yeah, I really appreciate it, Teepa. As I said, I could spend hours chatting with you and your website is fantastic. There's lots of great information there.

Teepa Snow: Thanks.

Ricky Enger: Thank you so much for joining us. Got something to say? Share your thoughts about this episode of Hadley Presents or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadley.edu. That's P-O-D-C-A-S-T@hadley.edu. Or leave us a message at 847-784-2870. Thanks for listening.