Cancer Brain Fog

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Melissa Rosen:

I want to thank everyone for joining Sharsheret today. My name is Melissa Rosen, and I'm a member of the Sharsheret team. You're joining us today for an important conversation about cancer brain fog. Before we begin, I have a few housekeeping items I'd like to share. First, I want to thank our program partners on this important webinar. All of these fantastic organizations are ones we work with to accomplish our shared mission. We're partnering with four different Gilda's Clubs in Chicago, in New York City, in South Florida, and in Westchester. We are also partnering on this program with Imerman Angels, Komen LA, and Twist Out Cancer. So thank you to all of our program partners, and welcome to all of you who for you, this is the first time you're joining us.

This webinar is being recorded and will be posted on Sharsheret's website along with the transcript, but I do want to confirm that patient faces and names will not be in the recording. If you'd like to remain private today, we're posting information in the chat box right now as to how you can do that. You may have noticed you were muted upon entering. Because this is such a full room today, please keep yourself on mute. We also recommend you keep your screen on speaker view. This will enable you to see the presentation clearly. You can find this option in the upper right-hand corner of your screen.

I do want to say we receive so many impressive questions that came in through registration, so thank you for that. You will notice that many questions were combined. So be sure to listen for your question and your concern, but not your exact words. We expect additional questions to come through now, so please use the chat box, which you can access from the bottom of your screen. Any questions that we don't get to today will be addressed over the course of the coming week.

So as a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 20 years now. I recently heard someone describe this time as a time of creative connection. I believe that's true, and as we continue to provide the necessary support that we always have, we found meaning in the creative ways we have connected with all of you during this past year.

As a reminder, in addition to the many formal programs to help women and their families navigate different aspects of the cancer experience, I want to remind you that our clinical team, they are available every day 9:00 to 5:00 in each time zone for one-on-one support. They can answer questions, connect you with appropriate resources, even allow you to vent on a difficult day, and so much more. As always, our support services are 100% confidential and 100% free.

As we move into the webinar itself, I want to remind you that Sharsheret is actually a national not-for-profit cancer support and education organization, and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret is not a substitute for medical advice or treatment for a specific medical condition. You should always seek the advice of your physician or qualified healthcare professional with any questions you have regarding your medical condition.

Okay. Let's get to it. We are so very fortunate to have our speaker with us here today. Dr. Kathleen Van Dyk is a neuropsychologist and Health Sciences Assistant Clinical Professor in Psychiatry at UCLA Semel Institute. Dr. Van Dyk earned her PhD in clinical psychology with a specialty in neuropsychology from City University of New York with both a pre-doctoral internship and post-doctoral training in geropsychology and neuropsychology at UCLA.

She has received grants from the American Cancer Society, National Cancer Institute to develop her research program at UCLA in assessing and supporting cognitive health in cancer survivors. Her research program is designed to inform and compliment her clinical work, which includes neuropsychological assessment of cancer survivors and cognitive rehabilitation services locally at UCLA.

In an effort to broadly impact supportive care and cancer survivorship, she is the co-chair of the National Oncology Cognitive Rehabilitation Task Force in the American Congress of Rehabilitation Medicine. So,

you see, her expertise is exactly what we need today. I'm going to turn the floor over to Dr. Van Dyk and look forward to learning alongside you.

Dr. Kathleen Van Dyk:

Thank you. Thank you so much, Melissa, and thank you to everyone at the Sharsheret community for inviting me. I'm really, really glad to be here, and I'm really excited to talk about something that I'm very passionate about, which is the cognitive changes that can accompany cancer diagnosis, cancer treatment, and how do we understand them now, and what can we do about them. So I'm going to jump right in. Oh, hang on. There we go.

Okay. So let me just move this out of the way so I can see. Okay. So first, I was going to start off by giving everyone just an overview of the state of the science. Very, very brief bullet points about what we know about cognitive difficulties in cancer and why they arise, what they look like, what survivors tell us this going on, and then I was going to dive right in to just talk about a few supportive strategies that hopefully some of the people who are watching might be able to implement in their day-to-day life if they feel like they're having any cognitive challenges. Then, of course, we'll have plenty of time for Q&A afterward.

So just to add on to that, let's say, introduction, I'm a neuropsychologist by training, which means that my... I'm a psychologist, and my focus is in brain behavior relationships, understanding what happens when there has been some injury to the brain and what that looks like in terms of behavior and cognitive symptoms. Primarily, right now, I am doing research in cancer-related cognitive issues and particularly looking at the effects of antiestrogen hormone therapies on brain function. I'm also developing... working to develop a cognitive rehabilitation program called Improving Cognition After Cancer and in the process of trying to pilot test that, that program and hopefully develop more programs for folks in the LA area and UCLA.

So I think it's important to start off by recognizing that this is not a small problem and that there is a pretty high prevalence of survivors who report having cognitive changes after their cancer experience. So you can see the LIVESTRONG survey, which was about 2,000-plus cancer survivors across different types of cancer have reported a year after treatment that about 45% were still experiencing cognitive problems.

The Sister Survey Study, which was only breast cancer survivors, about 3,000-plus breast cancer survivors, 60% had reported that they had experienced some kind of cognitive change. What I think was a really striking statistic after that survey came out was that of that 60%, only one-third had actually talked to a provider about it, which means that there's a gap somewhere in our medical community in understanding, addressing, asking these questions, and really getting a good handle on what people are going through.

So in general, in the field, I know that there's a lot of confusion about what brain fog is. In general, what we think is that there are plenty... there are many people. I shouldn't say plenty, but there are many people who experienced some cognitive fogginess while they're undergoing cancer treatment and probably around a quarter of those folks end up having more lasting problems. By lasting, I mean a year, two years, three years after the fact. So it's not a small percentage, and I think the field itself is getting a better understanding about why this happens and what's going on, but we still have a long way to go.

One point that I think is really important is that when these symptoms, the cognitive changes that survivors were reporting initially started with breast cancer survivors who were really raising red flags about having these symptoms, and the researches at the time said, "Well, it's probably the chemotherapy because there's... Chemotherapy is toxic, and that's most likely what's going on." So that

was really the focus of the research for a long time was people who had undergone chemotherapy, and that's where the term "chemo brain," coined by patients, came about.

Dr. Kathleen Van Dyk:

So I think that an important aspect, important kind of paradigm shift now is that it's not just chemotherapy that can lead to cognitive problems. What we're finding in the literature and in studies is that people reporting cognitive effects of radiation treatment. Some studies have shown that even before any treatment, so after a diagnosis, before any treatment, that some patients are performing worse than their non-cancer counterparts on cognitive testing.

Like I said, I think there's a big question mark around endocrine therapy because we still don't have a good handle on what the different anti-estrogen endocrine therapies are doing to the brain. So I say this in an effort to be inclusive of anyone who's having problems regardless of their treatment exposures that we're learning more, and more, and more that it's not one thing. I think that that's an important message that doesn't always get communicated.

So at the end of the day, and this is a very simple slide of a lot of different research areas, but at the end of the day, what we're likely looking at is that there are a few different factors, a few different components that go into cancer-related cognitive decline or what we call CRCD. So yes, it's the cancer treatments themselves. It's the cancer itself potentially. There are some studies out there that are looking at the actual effects of having cancer cells in your body.

Other comorbid conditions like heart disease, obesity, frailty, stress, and depression, which I'm going to talk about a little bit later in more detail. Sleep disturbance, which I know can accompany just various cancer treatments themselves, and so that can certainly be a component that contributes to cognitive problems. What we call cognitive reserve in the aging literature, which means someone's ability, cognitive resilience to any insult to the brain.

So the point of this slide really is to get across that it's not just one thing, and there are different ways that these risk factors can interact with each other and contribute. So what our goal is as clinicians and as researchers is to better understand what we can do to identify and address all of these different issues that might be contributing to someone's cognitive functioning so that they can have the best quality of life and best cognitive functioning that they can.

One of the going models right now in the research world of cancer-related cognitive decline is the idea of accelerated aging. It was put forth a few years ago, and we're still learning more and more about it. There are some evidence to suggest that this might be the case, but we know just vis-à-vis normal aging research that there is some decline. Typically, it's things like processing speed, attention. To be honest, that decline starts around 35 and then accelerates more in later years, but there is some mild decline.

So the hypothesis with this model is that the various different risks that could be contributing to cognitive problems or brain changes are causing that person to look like they might be a little bit older cognitively, to push them a little bit forward on the normal aging scale. So it's still a hypothesis, but I think it's the going one. It's the one that researchers are focusing on, and it helps, I think, potentially helps patients understand to have a better footing about what might be going on with them that it could be that there's just a little bit more advanced aging in terms of cognition.

There's plenty of neuroimaging evidence of cancer-related cognitive impairment or cancer-related cognitive decline. Sorry, I didn't change the slide. So what we're looking at here is just a summary of some structural brain changes. So this is just a structural MRI looking at white... Sorry, gray matter changes in the frontal lobe and cerebellum, looking at the white matter tracts in the brains, the highways of the brain, and so we see degradation in the white matter tracts of the brain, the information superhighways in this picture. Then, the last one is an FMRI task, which means that

someone was doing a task, and they were trying to see where the brain was lighting up and using energy. You see differences in the frontal areas when people are doing tasks. I'm going to show you one more slide in that regard.

Dr. Kathleen Van Dyk:

So this is [inaudible 00:15:09] that was done a few years ago by some of my colleagues at UCLA where we looked at... They looked at. I wasn't at UCLA. They looked at what happens in the brain when someone is doing a very straightforward working memory task. So they took pictures while people were engaging in this working memory task. Basically, what they saw was that people who had been previously exposed to chemotherapy, their brains were lighting up more than people who weren't. What that means is that they were using more energy to do the same task than people who weren't exposed to chemotherapy.

What's interesting about this is that this is very similar to what you see in aging. The aging brain works a little bit harder to do the same thing. So at the end of the day, they're performing the same on the task, but the energy that they're using in their brain is a little bit more. So I think this is a really important point because oftentimes, not to get too in the weeds about it, but oftentimes, you'll see people who are able to perform better... pretty much the same way that they used to be able to, but they're telling you that they're having problems. So it could be this experience of this increased energy use and this increased need for the brain to work harder to do the same things.

Okay. So this is probably not a slide that I need to tell this audience, but I think that's always a good idea to bring in some of what people report and some of the things that are out there in the literature. These may resonate with some of you, but some of the things that we've heard patients say are that it's a fine degree of memory or speed, that they struggle to remember things. They feel that no one is offering any kind of help, which I've heard often. People have said that they're not as sharp as they used to be, that their edge is totally gone, that they feel mentally spent, that they have trouble doing more than one thing at a time. They have trouble finding the right word, learning new things, and that it just takes them overall longer to do this.

I think this is a good survey of what I hear clinically as well, and it represents an important problem, but it's not the same as someone who may be was in the later stages of Alzheimer's disease. They're concerning and they're troubling problems, but they're typically a little bit more subtle than what we see in more severe cognitive disorders.

We do know that there is a significant impact on a person's functioning, which is in quality of life, which of course is really the goal of all research is to help support patients' quality of life and functioning. I've heard this clinically, and the literature describes it as well that breast cancer subscribers have told us that they're having concerns about their job performance. They're worried about losing their job. They have reduced self-confidence at work, that they feel overwhelmed, and so there's a potential for withdrawing socially. They just can't get it together. They feel like they can't get it together to engage in social engagements.

What I think is also really important that has come out in the literature is that many people have said that they would've thought it would have been helpful if they had known about these problems beforehand. So if they had been prepared, if it wasn't a surprise, and so that they could've better equipped themselves afterwards. That's one of my areas of focus in research and in clinical work is how do we help give patients a pillow after treatment to land on and not cement floor in terms of cognitive functioning and day-to-day functioning?

Okay. So that's the overview of cancer-related cognitive decline in terms of the facts and general states of the research right now. I want to jump into cognitive strategies that have been developed both by

myself and by others in the field in terms of helping people who might be experiencing these problems. So one possibility that unfortunately isn't widely available to everyone in the country, but if it is, it could be an option, is cognitive rehabilitation.

Dr. Kathleen Van Dyk:

So cognitive rehabilitation basically involves cognitive exercises, so doing things that exercise the brain, that help to strengthen networks and compensatory strategies. So what I mean by compensatory strategies is that if a person used to be able to just remember to go to the store to buy milk. So they've got from Point A to Point B via Path 1, right? They just remembered to go to the store and buy milk. Maybe if they can't do that anymore, they develop a strategy where they still get to Point B, but now they have to use a memory. Now, they have to write it down or set a reminder for themself. So the idea is that you're not changing your brain necessary, but you're functioning at the end of the day the way that you'd like to function.

Oops. Okay. So the strategies that I'm going to talk about are grouped into cognitive domains, and these are neuropsychological domains, just to orient you to what the next few slides are going to look like. So I'm going to start with attention. Now, I'll talk about what that means. Executive functioning, memory, and language. All right. So let's talk about attention. So when I say attention, as a neuropsychologist, it's not the same as other non-neuropsychologists, and so it's important to understand what I mean by attention.

So attention is the ability to work under distracting conditions. So it's like your mental filter. If there are things happening in the background, you're still able to write that email, and send it off, and not pay attention. Like I said, ignoring information that's not relevant or important to what you're doing. So again, that filter, being able to focus your, what I like to call your spotlight, your attention spotlight.

Keeping your train of thought. So you're going into the kitchen to get a glass of water. On the way to the kitchen, you see the laundry, and you decide that you want to go for the laundry. Then, by the time you finished the laundry, you forget what you were doing to begin with. So the idea of keeping track of your train of thought is part of the construct, the domain of attention, and then not mind-wandering when you don't want to. Mind-wandering in and of itself is not a bad thing, and lots of research suggests that it's a good thing. But it's when you don't want to, when you want to be focused on something and your mind is wandering, that can be a problem with attention.

Okay. So let's talk about some basic strategies when it comes to attention. Clean off your desk. By desk, I mean your physical desk. So if you have something that you want to be doing, clean everything else off, and I also mean your mental desk. So cleaning off your mental desk means that if you want to focus on one task, then have... Write down all the other things that you need to do so you don't have to think about them and keep them active, and so your mental desk just have that one thing on it that you're trying to get done.

Also, creating an environment that's distraction-free, and so this is very hard to do in this day and age. So we're all getting dings, and emails, and tasks, but it involves turning off arriving emails, turning off your ringers, silencing your phone, really creating an environment that will help prevent you from being distracted by other things. Another strategy could be telling other people that you need uninterrupted time. So really, really carving out that desk space, carving out that time, and telling other people that you need this mental desk space time and not to disturb you or ask them if they can wait. I'll talk about that in a sec.

Another strategy is organizing your time. So what I found talking to patients who've had some problems, some attentional problems is that we're all used to thinking about 25 different things that we have to do at once during the day. But if you can take back those to-do lists, if you can take those to-do items, that

tasks list, and put it in your calendar, then you don't have to think about it anymore. You know it's somewhere. You know you'll get to it. You know you'll remember it, but... vis-à-vis looking at your calendar, but you don't have to keep it up here. So you're cleaning off that mental desk by really taking advantage of your calendar. Another question might be prioritizing, not doing things as soon as they come in, which again is not really our culture right now. Our culture is, right, "Ding, ding, ding, ding, ding." But it's really, "Can this wait? Can I finish what I'm doing now?" Then, wait and reply to that email later.

Dr. Kathleen Van Dyk:

So the self-talk is a very simple strategy, but it works. So the self-talk aspect of keeping the train of thought is repeating your intention to yourself while you're doing it. "So I'm going downstairs to get a glass of water. I'm going downstairs to get a glass of water. I'm going downstairs to get a glass of water." So you're literally holding on to that thread of your attention. By the time you get to the kitchen, you still have the thread of what you're trying to do.

Another piece of the attention component that I alluded to a little bit earlier is the idea of creating your attention boundaries, protecting your attentional space. If someone wants to interrupt you, just say, "Hey, I'm in the middle of something, but can it wait? I can focus on you better in a few minutes," so that you can finish the task that you're doing. I know somewhat as a parent this is incredibly difficult to do with children, but it's certainly something that can help you finish that task that you're doing in order to switch your focus the way that you want to switch your focus and not be distracted.

When you're socializing, when you're having dinner, when you're out with friends, I know we're not socializing very much, but hopefully that will change in the near future, but turn off your phone. Choosing quieter restaurants and spots to meet. I don't know about the rest where all of you are, but I know in Los Angeles, it seems like every restaurant is like a cement cube that bounces sound all over the place. So really finding those spots that allow you to be quieter that don't have a lot of distracting sounds.

Okay. Let's talk about executive functioning. So what do I mean when I say executive function? Executive function means the ability to plan and organize, organize yourself, organize your thoughts, organize your tasks, and carry out those tasks effectively. So imagine you're planning to go on a trip. Planning all the different components for the trip, getting everything in order, keeping track of budget, yada, yada, yada, so those. That's what I mean when I say ability to plan, organize, and carry out behaviors.

Multi-tasking, so doing more than one thing at a time without losing sight of the first thing. So you're cooking, the phone rings, you answer the phone, talk to them on the phone, go back to the stove, and remember what you were just doing at the stove. So being able to go back and forth between two different tasks. Organizing. I often use the idea of just organizing your sock drawer. How do you do it? How do you start? What do you do first? So it's this, applying an organizational principle to things. Another aspect of executive functioning is reasoning, and judgment, and decision-making, so laying out two outcomes and just making a decision using your judgment.

So again, just thinking about some examples of what this looks like in day-to-day life. It could be budgeting, paying bills, like I said, planning a trip, planning the weekly schedule, or scheduling meals and cooking is a very high, highly executive functioning taxing activity. So just to start thinking about in your life where you might see executive functioning and if you're having problems, if this is what's popping up for you.

Okay. So let's talk about some strategies. I think that a very simple and straightforward one that sounds too simple, but is honestly very effective is the idea of using checklists. So taking a few minutes at the

beginning of the day or before you start engaging in a task or engaging in a project, and writing down everything that you need to do so that you have a document where you can check things off and you know that you have... and you can keep a record of what you've done that day.

Dr. Kathleen Van Dyk:

This is a simple executive functioning strategy called stop-think. The idea behind this strategy is if your mind is going faster than you'd like or you're doing things before you really have the chance to pause and organize your thoughts, write out a checklist. Then, just envision a big red stop sign, and just take a few seconds. Say, "Stop thinking." Ask yourself some questions. "Okay. What am I doing? What do I need to do next? Are these steps that I should be writing out?" Giving yourself a little bit of space to organize your thoughts, and it just takes a few seconds, but it can be really effective when in life, we're going 50 miles an hour, and things keep coming at us, and we need just a few seconds to stop, and reorient, and get ourselves organized.

Goal management. The idea of goal management is you have a goal, and you write out the different steps that get you to that goal. So first, you define the task at the start. "What is my goal?" Maybe it's planning a vacation. Maybe it's buying a new refrigerator. Then, you ask yourself, "What are the steps? What are the very specific steps that need to happen?" By steps, I mean they're logical. They're actionable. Meaning, that you can check them off. "I need to lose weight." How much weight? Or, "I need to budget out, budget, create a budget." What exactly do you need to do? It takes advantage of those some natural breaks in the flow so that you stay on track to what you're doing towards your goal, even if you can't complete the goal that day.

Like I said, using the stop-think strategy. Just stop and think, "What am I doing?" as you're doing the task. So I think this is a really important... Another really important aspect of this strategy of the goal management is that you get to pat yourself on the back and check things off, and that's really important. We get to celebrate your accomplishments. You did that one step. Great. That brings you that much closer to what your goal is. Then, at the end, looking over the steps, asking yourself if you completed your goal after the fact.

Okay. So imagine that you had a task that was settling health insurance bills. You might look up the phone number, get out your insurance card, locate unpaid bills, write down a list of questions, make the phone call. Oops. So this is just an example of what a goal management... what the application of a goal management strategy might look like because a lot of times in day-to-day life, we have these nebulous, unformed things that we need to do. If we take a few minutes and write down very concretely what needs to happen, then it helps to organize you and helps you to keep record and move forward.

Okay. So let's spend a little bit of time talking about memory. I'm just keeping my eye on the time. So what is memory? So memory is a task of receiving information. So you have to attend to the information first, learning it. Meaning, you are processing what's coming in, and then recalling it over time. So if someone tells you a phone number, you first have to attend to that person telling you the phone number. You have to pay attention to what they're saying. You then have to process the number. So you have to mull it over. There are circuits in the brain that help us to mull over information we want to learn, and then three days later, you want to use that phone number. You have to pull it out from your memory bank. So you have to retrieve it. So this is a very simplistic model of what memory is, but just to give you an understanding of what we think of, we meaning neuropsychologist think of when we think about the domain of memory.

So what are memory problems typically? Difficulty learning something new, having a really hard time learning new names, learning new information, remembering what someone told you the next day in detail. It can also be difficulty remembering old information, not being able to remember things from way back when, forgetting how to do something. So you used to be able to ride a skateboard, and now

it's impossible. Now, it's very difficult and you're not sure how to do it, or getting lost. So not being able to navigate. The way our brain works is we have a mental map that leaves breadcrumbs so to speak when we go somewhere, and so we create a trace of where we go. So if it's hard for someone to create that mental map, then they're more likely to get lost.

Dr. Kathleen Van Dyk:

So one thing that I wanted to bring up that I know was something that some folks had raised as a concern is that we... Cancer-related cognitive decline is not the same as Alzheimer's disease, and I see that a lot clinically and a lot of worry clinically right now. So first of all, Alzheimer's disease has a very common cognitive profile. Meaning, the cognitive symptoms are typically mostly related to memory or, though they can be related to other things, and it's much more severe than what we tend to see in cancer-related cognitive decline.

The underlying causes of cancer-related cognitive decline are not the same as Alzheimer's either, and so they're distinct things. I know that there's a lot of concern out there, but I can say that we are actively investigating if cancer-related cognitive decline is putting people at greater risk for later getting Alzheimer's disease, but that is not conclusive. That is not something that we know. If anything, the evidence that I've seen is that it doesn't. So we're actively looking at this question, but I just want to be sure to make the point that cancer-related cognitive problems are not the same thing as Alzheimer's disease.

Okay. So what are some basic memory strategies? So when we think about... Earlier, when I mentioned compensatory strategies, it's really what we want to think about doing is if you don't have to have it up here, you don't have to keep it up here. Put it out there. So using external memory aids, using your calendar to keep track of appointments, keep track of reminders, using a notebook, and I would suggest keeping one notebook so that there aren't random notes all over the place, which I know can happen even with myself or random sticky notes. You can always put sticky notes in your notebook, but keep things in one place so that you know if the information was going to be somewhere, it's just going to be in one place. Even if it takes a little while sorting through it, keep one notebook for it.

Depending on how fluid and fluent you are with your smartphone, using your smartphone saying, "Siri, remind me in 10 minutes to check the muffins in the oven." Siri will remind you in 10 minutes to check the muffin in the oven. You don't have to do anything else. So I think really getting to know the advantages of the smartphone because you're saving space. You're saving space, you're saving worry, and you're saving time and the potential to make mistakes if you just use the strategies that are available around you.

Another thing is to really pause and think, "Is this something that I should probably write down?" and take the time to write it down, and tell people, "Hey, give me one second. I'm just going to write this down to make sure that I have everything correct." Getting into that habit of taking the time to record things outside of just trying to keep it in here.

I wanted to talk a little bit about learning names also and remembering names because I know that's something that... I've had many, many people tell me it's become more of a problem. So a couple of strategies for how to better remember names. One, I think it's important to recognize that names are just labels. So there's nothing inherent in my face that says, "Kathleen." I mean, although on Zoom now, it says my name underneath. But if we were meeting in real life, there's nothing inherent on my face that says, "Kathleen." It's just a label, and so what you need to do is try to connect these things. Try to connect the face with a name. Try to connect it with information that you already know.

So a couple strategies are, first of all, repeating the person's name after you meet them so it doesn't go in one ear and out the other, right? So it stops in the middle. So repeating the person's name after you

meet them. Getting a business card if that's something that is appropriate in the situation. Thinking about what their name sounds like. So again, connecting it with information. Learning something about the person and linking the person's name with someone you already know. "Nice to meet you. My name is Kim." "Kim, like my cousin Kim who also has brown hair." So you're connecting that name with information that you already know. You're making it a little bit stickier.

Dr. Kathleen Van Dyk:

I want to switch gears a little bit and talk about word-finding difficulties. How am I doing on time? So again, this is something that I've heard many patients say has become a much bigger problem for them, and that's coming up with the word that you want in the moment that you want it, and so why does this happen? So briefly, we know this because of aging, the aging literature. Word-finding problems are one of the number one things that people complain about in aging. By complain, I mean report to their doctors. It involves being able to pull out that one word that you know is going to accurately represent the idea that you want to express.

So what's important to understand is that the... Again, thinking about that words are just labels, the idea is connected to a label. What can happen sometimes is that that network, the sound of the word coming out of your mouth and the idea that you want to express, that network can get a little fuzzy. So it's not the case if the person loses the word. I'll have patients tell me that they used to have extensive vocabulary. They still have extensive vocabulary. If they saw the word, they'd know what it meant. It's just that connection between being able to use that vocabulary the fluid way that they would like to, and so I just put a simple example here of... A very, very simple example of the language network.

The way that our brains are organized are by meaning, by similarity and meaning, and so here's a picture of an elephant, and it may be that all of these other words pop up in someone's mind when they're trying to pull up the word "elephant." For some reason, that connection to the word "elephant" just isn't crisp and clear, and right there at their fingertips. So what do you do?

You can think of a word that sounds like the target. I just, for example, eggplant. You find a way to access the route that will get you to that word. You can think of a word... Ooh, sorry. Ah. There we go. You can think of a word related to the target word. So, meaning, you think of a word that is meaningfully connected, and that can be a route that gets you there.

Nine times out of 10, it's going to be important to let it go because the frustration of finding that, just that right word can sometimes be so overwhelming. The harder that we're pushing that area of the brain to get it that one word can overwhelm the system and make it even more difficult to remember that one word. So I always tell my patients, "At the end of the day, let it go. The idea is just to communicate, so express the idea another way." Even though you know that there's a word that perfectly encapsulates what you want to say, express the idea another way just to get the idea across. Then, when the word comes to you later, which inevitably does, then you think about that word and you draw more connections to that word. So we'll talk about that.

So doing things like word exercises, using synonyms, rhyming words, homonyms or homophones, fill in the blanks. The same types of word exercises that we did in grade school, but the idea is to strengthen the connections to the word. Oops. I think reading out loud can be beneficial because again, we're strengthening the sound of the word with the meaning of the word. Then, when the word comes back to you later, think about it. Spend a few minutes thinking about what that word means, what other words or concepts that word connects to in your mind.

Okay. Now, we're getting a little bit close to time, so I'm going to go through this a little... I'm almost done, but I wanted to spend a little bit of time talking about stress and trauma because this is certainly a

significant aspect that I've seen clinically and I think in the research is getting more and more attention. So what is the connection between stress and trauma, and cognitive problems later?

Dr. Kathleen Van Dyk:

So this is a model that comes from a few different studies and literature, but it's very simple. First of all, cancer diagnosis. So just focusing on the green lightning bolt over on the right side. Receiving a cancer diagnosis, and undergoing treatment, and all of that related psychosocial distress can cause the brain to experience trauma, psychological trauma, and psychological trauma is accompanied by lots of different biological processes afterwards.

So the trauma that some people have experienced, just vis-à-vis their cancer experience, can contribute to cognitive problems later because of real changes that happen in the brain, real elevated hormones that happen after the experience of trauma. It is also a hypothesis that for people who may have had earlier life trauma, earlier life stress, so when they were kids, that early life experiences or adverse effects can make the brain more vulnerable later. That's something that's born out in the literature outside of the cancer field, but you add in... Then, you introduce the cancer diagnosis and the trauma that could be associated with cancer to that vulnerable brain, and that can make someone more susceptible to cognitive problems later. Does that make sense?

Melissa Rosen:

Yes.

Dr. Kathleen Van Dyk:

Another thing that I've seen quite a bit is that cognitive difficulties then can lead themselves to distress, so this. There can become an internal monologue, and I've heard just these very verbatim quotes from patients. "I'm so stupid. I can't do anything." There's an undercutting of someone's self-esteem, and if the experience or they have the experience that they aren't remembering something that they should or they aren't coming up with the word that they should, then it can spiral and snowball in their mind as not being good enough, not being able to do their... be as effective and high-functioning as they used to be.

So I want to talk a little bit about what you can do, and again, this is an educational side. So this can involve a lot more treatment, but just some quick strategies to think about. So the idea of catch and replace. So trying to notice if you find yourself saying harmful things like stupid, dumb, worthless, fail, terrible. Seeing if those are popping up in your mind. Stopping for a minute and saying, "That's not helpful," and then replacing it with something that's kinder to yourself.

So having some positive self-talk mantras in your back pocket. "It's okay. I'll use another word to express my idea. I'll ask for her name. I'll think of it later." "Nobody is perfect." "It's not a big deal, NBD." "I just need to give myself a beat, and I'll remember." "I'm smart. I can do this." "it's okay. I'll make mistakes. I'll learn from them and keep trying." So having just some positive, kind things in your back pocket to buffer that experience of distress when you feel like your brain isn't working as well as you'd like it too.

Another part of this process is the idea of reframing. So what would you tell a friend in your shoes? How would you reframe something for a friend? If your friend said that they were having cognitive blip or having a cognitive lapse, what's a more accurate way to assess the situation? Is this true? What's more specific? I think I got cut off. Even if you believe... Sorry, it's just like I cut off. Even if you believe that you're accurately judging the situation, is this helping you? Is this a helpful way to think about it for you right now? Is this helping your quality of life and your mood?

Okay. I'm going to zip through coping strategies because they're pretty straightforward, but just in general, coping strategies related to stress, so coping. The idea of coping strategies means that we

introduce something when the demands, or the demands of stress, the demands of what's going on in the world, of your situation are outweighing your available resources to cope with them. So you introduce coping strategies to help support the demands, the stress demands.

Dr. Kathleen Van Dyk:

Deep breathing, as I'm sure many of you are familiar with. The idea of breathing and slowly holding your breath for a couple beats, and then breathing out slowly. Cold water. Really cold water like ice cold water on your face can be a reset button when someone is feeling high levels of stress. Soothing touch. Touching a pet, touching something soft like soft fabric, a family hug. Using imagery, going to a place in your mind that you find peaceful and where you feel calm, and of course, self-care. So being sure that in your calendar, you're carving out time to take care of yourself, to do things that you enjoy that aren't just perfunctory, that are truly feeding your spirit.

Thank you very much for your time, and here's my contact information. Feel free to email me if you have questions about anything or... In our lab, we have lots of research going on in the alley area. So feel free to reach out if you're interested in learning more about that as well. Just a big thank you to the NIH and the National Cancer Institute for supporting me and my work, and allowing me to continue to do this, this work. Thank you to Sharsheret, of course, and all of you for your attention.

Melissa Rosen:

Wow, wow. That was amazing. We have not a lot of time and a lot of questions, and I'm going to try and get through them quickly. Then, the ones that we can't answer, we'll answer through a blog or something like that.

Dr. Kathleen Van Dyk:

Sure, sure.

Melissa Rosen:

So one of the questions, this one is actually posted by one of our program partners, is, "Does this happen to everyone who has treatment? Are there some people who are more susceptible, genetic predispositions? You mentioned trauma, and ahead of time, is there anything we can do to minimize risk?"

Dr. Kathleen Van Dyk:

Great questions all around, and so I will have to start most of my responses with an asterisk that the research isn't there yet, but from what we know, from what we know. From what we know, it does not seem that everyone experiences these problems. We do not have a formula for who will ultimately experience cognitive problems after treatment unfortunately. There's been some work looking at the APOE ε4 gene, which is the gene that predisposes one to Alzheimer's disease. It's not determinative. It doesn't mean that someone will get Alzheimer's disease. It just puts them at higher risk. There's been some evidence that suggests that there could be some increased risk with that gene, but it's not conclusive by any means.

Dr. Kathleen Van Dyk:

I think the important things to think about are what are the modifiable aspects of someone's brain health, and this is what I tell my patients. So we have to undergo treatment. You can't change it. I mean, the act of receiving a diagnosis and having cancer, you can't change it. But being sure that you're eating well, that you're exercising, that you're taking care of stress, and depression, and anxiety, that you're finding time for joy and meaning in life, you're doing the things that we know in aging are important for brain health to help support your overall cognitive health.

Melissa Rosen:

Very helpful. Thank you. Okay, here's another difficult one. I'm not going to give you any easy ones.

Dr. Kathleen Van Dyk:

Fantastic. That's good.

Melissa Rosen:

How does one understand the difference between normal aging memory issues and cancer-related brain fog? What about the difference between a reoccurrence that might find itself in the brain and treatment-related brain fog? Is there a point at which point we should say, "Okay. Enough worrying. I need to talk to my doctor about getting some additional diagnostic tests?"

Dr. Kathleen Van Dyk:

That's a toughie. That's a toughie. So I think that if it's available to you, it can be helpful to see a neuropsychologist and get objective testing done to have a good sense about where your cognition is compared to a normative group or compared to your peers based on your age. So that's one thing that someone can do. Because these cognitive symptoms can be so mild, it has been very hard for researchers to pinpoint specific thresholds of changes or specific symptoms. At the end of the day, even when I'm seeing a patient, I can't say, "This is aging, and this is not," or, "This is cancer, and this is aging." It's too difficult there. There's too much variability.

But that being said, I think that the concern about meds is something that can be answered by your doctor. So as with anything, what can you do about it? You can get information about what's going on, and the... That wonder is like what I talked about earlier when cognitive problems can cause distress. That wonder, that unknown, that uncertainty. So if you can get the information that you can get in order to address that concern, but other than that, there's no easy answer for that question.

Melissa Rosen:

That is definitely a source of frustration. Okay. Here's a different topic altogether. How can I talk to my colleagues, my boss about this? What do I do about a partner or friends that don't believe my symptoms are real?

Dr. Kathleen Van Dyk:

This is a tricky area because unfortunately, and believe me, I'm working on it, we don't have a diagnosis for these problems because most often, people don't meet criteria for a classic cognitive disorder diagnosis. I think that it is up to the person how much they want to disclose, but first of all, I always suggest the patients that they give themselves a year after completing treatment to recover fully. I know some people want to go right back to work and right back to being on the ball, but I always suggest giving themselves a year, so cutting yourself some slack first. I am happy to share research and literature with anyone who needs something to back up, but I think that depending on the person saying, "I've experienced cognitive changes and cognitive fogginess after treatment, and be kind. Be kind to me."

Melissa Rosen:

Okay. This one came from... This question is maybe an extension and came from another one of our program partners. So how long? You talked about giving yourself a year, and very often, we talk about in terms of five years. But how long really can brain fog last beyond treatment? Could it be permanent for some? Is there any way to hasten the end of symptoms whether it's exercise, supplements, specific foods, the use of apps, and if you could recommend a couple of apps or something that will be good to help us? Finally, can people return to their baseline, or is there always some sort of residual deficit if they'd had it?

Dr. Kathleen Van Dyk:

Yeah. I mean, these are all really great questions that I wish I had evidence to answer more concretely, but I can tell you that for some people, yes, we've seen changes up to 20 years after treatment in the literature. It's not everybody, and many people do return to baseline, but it can take longer than they think. Because treatment is over, it doesn't mean that the changes that have occurred in the brain or in the body, that the recovery that's necessary has also completed. That process can take a while.

In terms of hastening the recovery rate, this is the question I get asked all the time. Again, I wish I could say, "Oh, yeah, just take this." But really, what it comes down to is, again, thinking about how do you care for your brain? You exercise. You eat properly. You do all of the things that we know takes care of the brain. You engage in stimulating activities. I don't necessarily have one app to recommend, but I think anything that is novel, that's new, and that you find challenging and enjoyable, great. It could be things on paper. It could be word games on paper. It could be doing the crossword puzzle. There's nothing magical about crossword puzzles. I will say that. I get asked that question a lot.

Melissa Rosen:

Yeah.

Dr. Kathleen Van Dyk:

But really, you're trying to find something that engages your brain. What you probably don't want to do is be sedentary and passive.

Melissa Rosen:

Okay.

Dr. Kathleen Van Dyk:

So that's the low bar. Not watching TV and sitting all day, but doing more than that.

Melissa Rosen:

Let me ask you another question. You mentioned, and I'm watching the chat box of things that come in. You mentioned already not just chemo, but radiation, and aromatase, inhibitors, and things like that that can impact. One thing you didn't talk about was surgeries and anesthesia, and the longterm effects of anesthesia. Could you mention that for a sec?

Dr. Kathleen Van Dyk:

Yeah, that's a great point. So what we know, again, from the aging literature is that older adults who undergo multiple general anesthesia episodes can be put at higher risk for cognitive problems later. The evidence in younger adults, so people under 65, is not as concrete, but we certainly know that general anesthesia in older adults and particularly multiple anesthesias is incredibly important for doctors for... It's an incredibly important conversation to have with your doctor. That being said, I've certainly seen people who reported... younger people who reported problems and have undergone many surgeries like eight or nine in a year. So it's perfectly reasonable to think that can affect the brain, even younger individuals, but that's anecdotal. I don't have the evidence to back that up, but it's a really important point.

Melissa Rosen:

It seems like this is a field that is continuing to develop, and hopefully, in a few years, we'll have even more information, but we definitely seem to have some strategies to cope. Let me ask you one more question. Even if we're managing through some of the things that you've discussed, or we're not managing, but we know it's normal for a certain amount of time. Is there a benefit to talking to our oncologists about this and why?

Dr. Kathleen Van Dyk:

Yeah, absolutely. I think that I would suggest anyone talk to their oncologists if they're experiencing these problems because there are growing efforts to help support individuals who are experiencing these problems. So connecting with maybe a neuropsychologist in your area, connecting with someone who's trying to develop cognitive rehabilitation programs in your area. I think another very important point is that this is something that oncologists need to know about in terms of symptoms that are happening, like any symptom. What bugs me is the "it's all in your head" excuse, which I've heard time and time again from patients. That's not a helpful or true response to a patient. So knowing that what you're experiencing is valid and true for you. Your responsibility is to bring it up, and their responsibility is to help you.

Melissa Rosen:

Thank you. Michelle just said that she talks to her doctors about everything just to raise awareness. I guess if we do that, the doctor can't say, "I haven't heard of any negative reports like you're giving me," and so they may not have the answer, but at least you feel validated, which somebody also mentioned.

Dr. Kathleen Van Dyk:

Yeah.

Melissa Rosen:

Okay, so a couple of things. It's just after 2:00. We have to come to an end. I want to remind you of a couple things. First of all, we didn't get to all of the questions, and we're going to work with Dr. Van Dyk to get all those questions answered. So thank you, and again, I saw several people ask. This recording, including the slides will be on the Sharsheret webpage sometime before the end of the next week and likely much sooner along with the transcript. If you registered, you will get a copy... an announcement that it is up and ready for viewing. So I know I'd like to actually look at those slides again too. You will have that opportunity. Thank you so much. I know you were talking, so you didn't get to read the chats were coming in, but so many people talked about what an amazing, pragmatic, and phenomenal presentation this was. Thank you.

Dr. Kathleen Van Dyk:

Thank you for having me, and I'm so, so glad that I was invited to come here. I really appreciate it.

Melissa Rosen:

Oh, absolutely. Absolutely. Once again, I want to thank our program partners for their support on this important webinar. Gilda's Clubs in Chicago, New York City, South Florida, and Westchester. Imerman Angels, Komen LA, and Twist Out Cancer. There was a link to an evaluation put in the chat box. I'm going to ask Amy if she can put it in once more. You can click it right now and still listen to me finish this webinar, but I will tell you it's super quick, and it really does impact the presentations we offer and the way we offer them.

Finally, Sharsheret is here for you and your loved ones during this time and beyond. We provide emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. Again, all our free, completely private one-on-one, our clinical number and email were put in the chat, but you could always go on to our website as well. Our social workers and genetic council are available to each and every one of you. Your health, your wellbeing is our priority.

Finally, I want to let you know we have several exciting webinars on wide variety of topics planned over the next few months. Please check out our website regularly to see what topics are coming up, and you can also access those recordings of past webinars in the same place. So that is right up there in the chat

box, and thank you again everybody for joining us. Thank you especially to Dr. Van Dyk, and wishing you all a wonderful rest of your day.

Dr. Kathleen Van Dyk:

Bye, everyone. Thank you.

About Sharsheret

Sharsheret, Hebrew for "chain", is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret's Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer • Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors • Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer • Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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