

## Avoiding Caregiver Burnout

Welcome to Avoiding Caregiver Burnout, my name is Melanie Ordonez and I'm one of your moderators. I am also here with Jeannie Keeler. I want to introduce our guest speaker. Sylvia Nissenboim received her Masters degree in social work from St. Louis University in 1981 and until 2005 managed and developed programs for older adults and their family caregivers. She has a private practice focusing on issues related to work and life transitions, such as aging and caregiving. She is a certified strategic intervention coach. She is a published author of the positive interactions program. She has provided training at local, state, and national conferences on a variety of topics from aging to dementia care, marketing, coaching, and many other topics of relevance. I will now turn this presentation over to Sylvia.

Thank you, Melanie. My name is Sylvia. What we are going to do is go over quite a bit of content. I'm going to be asking you for feedback. There will be questions so it will give me a feel for the issues that people are dealing with through this journey. And I will be guiding you. I have an exercise that I will be asking you to do with me. That will be a five minute exercise, and I want everyone to allow themselves to close their eyes and do the exercise with me. It will be an important take away, and I believe Melanie is recording this, so you can refer back to it. The objectives we will cover today is talking about symptoms of burnout and the most common situations that arise when you are taking care of an aging loved one or a loved one who needs care that can often lead to caregiver burnout. I have a lot of caregiver experience and things that I have learned from them in things that work best. I will be providing tips. We will be reviewing a variety of tools, as I said, and strategies that you can employ to reduce the likelihood of reaching burnout. If you are already experiencing some of those symptoms, you can learn to get back to a healthier balance as you provide care to a loved one. That is the work we will be doing in this hour. At the end of this session I will go over benefits that are available to you through the employee assistance. Let's move on. We will talk about identifying it and this is where we are going to ask you to share things with us. Let me give you the web MD definition of caregiver burnout. Make a note if anything speaks to you. Caregiver burnout is the state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help that they need. Caregivers who are burned out can experience fatigue, stress, anxiety, and depression. And separate from this definition, with COVID-19 overlaid on this, it notches up the likelihood of burnout, which is why it is important that we go over this. If you look at what these, you know, ways to identify caregiver burnout is stress, physical and emotional and behavioral -- physical is you have headaches and your back hurts, your neck hurts, you feel tight, you're frustrated and that is a stressed individual. Someone feeling pressured by the responsibility on them. Emotional could be perhaps you are sad or unhappy or guilty or feeling an emotion related to caregiving, and the richest information I get is what was the quality of the relationship you and your care receiver had prior to caregiving. That will help you understand if there are patterns that need to be changed from way back. To make this process better. Behavioral is you are not eating or sleeping or you are eating a lot and you have physical reactions and you don't want to be with people. With COVID-19 overlaid, what are you doing to express yourself behaviorally when you feel the most stressed. Do you pace or fret, what do you do? And then change aversion is another question, you know, sometimes what we know is better than what we don't know. Being in a bad pattern, people don't realize they are stuck and what would it look like if I was not in this place. And overall overwhelm

meeting the resources that you have are not enough to supply the need. It is supply and demand. It is good to notice it because you know where you need to layer in support. Here is the first question.

The question is I know I am reaching burnout when. I will read some of these comments off. People talking about being tired and easily irritated.

Losing patience.

This is really valuable because hopefully, not only what you entered into this answer section, but maybe you will notice other things that you experience that someone else wrote that you do not realize. This broadens out -- you have to notice what is going on in order to change it. That is why we are looking at what are the stressors and how do you experience them. Read through all of these. Is there a way to hold onto these? Can that be saved?

We will see if we can do that. [ Indiscernible - Multiple speakers ]

Okay. Let's talk about stress a little bit very shortly. This is the foundation for what is going on right now. Stress is the biggest culprit to setting the stage for feelings of overwhelm and exhaustion. I don't want you to think I'm saying stress is a bad thing. You know those blowup things that move in the wind in front of car dealerships, their knees you have to have stress in order for him to wave around. It is important to manage the stress that causes us to feel overwhelmed and exhaustion. Our health is completely affected. Our physical health is affected. Chronic stress is an unhealthy behavior. Your flooded with cortisol and that is what exacerbates a lot of pains and aches and noticing things on our body and being self focused. Our brain is saying where angry or frustrated and we cannot set out to do what we want to do. So there is anger and resentment . There could be siblings that are not helping her siblings that over help or this hoe over help and under help situation. We will learn ways to reduce stress whenever we feel the demand. We get caught in frustration and exhaustion and we are less able to attend to our lives. There is a quote I use all the time in my practice. I use it myself when I catch myself doing this. This is from a French philosopher. He said, I lived through many terrible misfortunes in my life most of which never happened. How often do we invent a future and imagine, oh my gosh, if this happens or that happens or she does this, we create a future story and then you go ahead and believe it as if it has happened already. You are living in that disaster before it has even happened even if it does happen. It is important to notice what you do and what you say to yourself. If you are scaring yourself and forcing yourself into high stress for something you are imagining, you're wasting a huge amount of resources. The reality is when you reduce the stress, we cannot change the reality of what is out there , but what changes is our ability to deal with it in a balanced way. When we are stressed, our thinking and reactions are exaggerated or minimized. When we are stressed, reactions are severe. They are not modulated. Working on your stress will affect all the other areas in your life that relate to caregiving and relate to other people in your family. When we are challenged we feel depleted. We talked about

fatigue, and we tend to do the familiar and avoid changing things. That was the change aversion. It is easier dealing with it. This is part of it and you can change that. A feeling of overwhelm, and I often think of overwhelm as an ocean and if you have ever been to the ocean and you walk in to your knees and the waves begin to hit you, I get knocked over in the waves. And if they keep coming before have gotten by grounding to stand up, that is what overwhelm feels like to me. You might have a different metaphor that is more descriptive of how you experience it, but it overwhelms you. I talked a little bit about these already. These are some of the potential issues broken down. Physical. We talked about chronic stress on your immune system and health changes. When I was my mother's primary caregiver, she passed away now five years. From the time I was maybe 57 to 62, I was the primary caregiver in terms of working full time and I get it from that and. We are aging and our bodies will do what they're going to do anyway, but you don't want to add to it with stress. The emotional aspect, we talk about guilt. I should've done this and something that I heard which is really powerful is the difference between guilt and shame. Guilt is what did I do bad and shame is I am bad. Sometimes we talk about one or the other and I think it is important to differentiate because they are different approaches to, I feel bad that I'm not taking more care of my mother and that my sister is mad at me because she does more of the work or whatever the guilt would be. A lot of families and siblings are troubled during this period because it is not a planned thing. No one knows who will step in or who has the ability. The relationships get tangled up in this as well. And grief not only for your parents or your spouse or your family member, but grief for you. Grief is not just about death. It is about losing something that you hoped for that you had. The story you tell yourself that you are grieving and the loss that you are experiencing is how you experience grief. It is denial and depression and anger. All of these things are tied up in grief and that could be going on. Spiritually they say that people who are connected with their community do much better. It is about relationships and the quality of our lives. And especially with COVID-19, making an effort to pick up the phone and make a zoom date and pull together people that you like to see. Initiating. Waiting for things to happen, we may be more isolated than we need to be. Connect yourself to people and to your community and church or synagogue. You are watching a loved one age and it tells you what aging looks like in a very personal way. There is nothing wrong with that. That is being aware that we are mortal and everyone is going to have an end of life. Behaviorally these are the emotions and more that you might be experiencing. I hope as I'm talking you will circle things that help you remember what you are dealing with. And I talked about relational with siblings. Relationships change. A parent who is controlling and now you're taking care of a parent, it is hard to that person to have a changed relationship. There are so many different dynamics that happen among siblings related to this. Role reversal. Now I'm taking care of my mother and this is a personal thing for me. If you ever hear anyone or you yourself say I feel like my parents are the child. You will never be their parents. You will always be their child taking care of your parents. It is a completely different mindset. What happens if you feel like you are the parent to your parent, there is an authoritarian tone that is wired to come out when you're in charge of something. And that affects the relationship. They say 93% of communication is your body language in your tone. Not even what you say. We read that. And relational meaning demands on time and you spend more time with your parent than you are with your family you feel pulled between those. These are some of the causes of caregiver burnout. Decision overload. When we feel stressed, we feel decision overload. Our ability to think clearly and be productive when we need to be productive is clouded by the constant flooding of cortisol. That is the stress hormone. It affects our thinking because we are in a mindset of survival and not balanced thinking. It is important to notice that. Your less efficient and less clear and less able to make decisions in a negative mindset. There is a fabulous Ted talk and it is only 12

minutes. I show it very often. We also have seen caregivers struggle with maintaining balance, like how much to give and are we overdoing or are we under doing it. Is your parent overdoing it or under doing it. A real assessment of how people are showing up right now affects the balance in our lives. I talked about the supply and demand issue. Who in your network, and I would ask you to do this right now, draw three concentric circles. The inner circle is your most intimate family members who you speak to and you trust. The second circle is your very close friends. You would share things and they know what is going on in your life. You've known each other for a while. And the third circle is acquaintances and other networks. And that speaks to the concentric circles of relationships. You can always move someone from an outer layer to an inner layer by reaching out to them. You can control the interactions and relationships, which is hugely important during this time. Family support, friend support. Care options. This is a very difficult time. Knowing that placing a parent in a nursing home means you will not visit them. It means people are taking care of people for longer at home because they don't feel like they have an option. Financial demands. Very often the caregivers paying out of pocket for resources that help a parent or spouse but help themselves. There is a outlaying of money. The last point is when we notice. Who is in your most intimate circle, and do you have acquaintances are good friends that you need to bring in more? That is a good thing. Look at your whole network. Which out to someone that you have likes that you never spend time with, but you think that, I like that person. We tend to go inward when we are depressed and that is the loss of intimacy with friends and family. Cognitive behavioral therapy, which is what most generalized therapists are trained in is helping you notice what you think affects what you feel , affects what you do. There is a lot of study around the stories we tell ourselves as they compare to the entire story. And so I talk about, you know, the story you tell yourself is one small piece. And the question you need to ask yourself is, but what is the whole truth. Let's say the story is, I am the only one that takes care of my mother. That might be true. You may feel that at times, but the whole story is, my brother is a doctor and he is in a COVID unit, so he's not available and maybe my sister has a disability, so she is not available. Maybe I am the only one in the family that has the ability to do this as opposed to being angry at siblings because they can't help you. Changing the way you look at it. If you're focusing on what you are not getting, you will experience anger and resentment. If you focus on what you can control, you will feel better. Habits of thought. Real quick, think quickly. What do you think in your head when the person that you provide care for calls you. Here we go again, or wonder what happened? You can look at those thoughts and shift them if they are taking you to a place of anxiety. You have to be careful with what you are seeing, but are you telling yourself a story. Habits of thought and maybe, why just me and I can't handle this. Those automatic thoughts can be shifted. Positivity increases effectiveness. Shawn Aker talks about the impact of a positive mindset that affects your ability to perform. You not only feel better, but you are a better decision-maker, you have more energy, and you have more focus. You're better at the things you are struggling with when your attitude is, I am doing the best I can. Even if you have to tighten up some things, remind yourself you are doing the best you can. It changes your attitude and how you perform when you are providing care or making arrangements. Notice the things that you are grateful for. What are things that you are grateful for? I wrote down a few of my own. I'm doing right by my parents. I feel proud of my intention. I have a job. I am working to reduce my stress by meditating. I am owning the feelings that I have, but I am saying them in a way that her true and that expands your thinking. Expand your thinking to what is also true so you are just telling yourself the bad story. It could be part of the story, but it is not the whole story. If you can raise someone's level of positivity in the present, their brain experiences a happy advantage. That advantage is your brain operating on positives and it operates significantly better. Your

outcome improves, your brain at positive is 31% more productive than at neutral or stressed. You are 30% better at sales. Doctors are more accurate at coming up with correct diagnoses when positive instead of negative, neutral, or stressed. He says we can reverse the formula. If we can find a way to become positive in the present, our brains work more successfully and we can work more intelligently. We need to be able to reverse the formula so we can start to see what our brains are actually capable of. The dopamine that floods into your system has two functions. The cortisol is the stress hormone, dopamine is the positive. It makes you happier and it turns on all your learning centers in your brain and allows you to adapt to the world in a different way. Positive thinking -- not happy face. What is the truth. I love my mother, I'm doing the best I can. Those kinds of statements. We will talk about resiliency skills. Imagine a firefighter dressed up and standing in front of their fire truck. This will help you learn the skills that you can expand or deepen. These are skills that highly resilient people have. They report these items. Safety and self-care. Imagine the helmet on the fireman. That is, I take care of myself. This is how I am resilient in my life right now. I am working and caregiving. Or I am isolated at home and caregiving. I have not seen my mother and I'm still trying to be a caregiver. How do you take care of yourself in this mode? Get a massage. That will help enormously. How do you take care of your body. The next one is grieving and relaxing. A matching imagine a fireman. Breathing and relaxing is how you calm yourself. Were going to do it right now. Lean back in your chair. And feet flat on the floor. And arms resting on your lap and breathe then for the count of three, expanding your chest and your belly. And now blowout like you're blowing out a candle. And let's breathe in. One, two, three, and blowout. Just this is a relaxation breath. There is a whole exercise you can do and you can find a zillion of them on YouTube. This will be your go to thing. It will become a best friend. It is free and you have it. I think during times of COVID-19, breathing is a valuable commodity. Be thankful of your breath. Communication. Connecting with people. So normally we go out with friends. Maybe arrange a dinner out with your friends, but do it on Zoom and everyone has dinner. Reach out and initiate relationships. You may feel like you don't have the time for this and that is the point of being overly stressed. The reality is you have to reach out to get the benefit of relationships. You might be talking to people who upset you more, but you need to find people who do get it and talk with those people. Network implies how many different selves you have. Me in my neighborhood, me and my family, me and my church, me and my book club. How many different separate groups of people are in your network. Highly resilient people have multiple. If you have one or two, invent a third. Reach out and say, let's take an class together and paint together or let's knit or let's just catch up. Make it up and reach out to people. Networking is very important. And sose optimism. Talking about the positivity advantage. I love the visual. The optimism is the fire truck. Why would that represent optimism? Well, I think the fireman believes he or she will be able to affect change. So they raced toward it. That is optimism. The fire truck gets them to where they can do the work they will be successful doing. It might look different than what I thought, but I will be successful. That perspective is present in people that are highly resilient. They can shift their thinking to feel hopeful. Language. We have a couple slides of tips and things that I want to talk to you about. How you talk about yourself. When you're telling someone about what is going on, are you like, oh my God, I am dying. And do you talk about it at all? How do you language about yourself during this time and that will set how you feel about it. If you can, it is easy to say. Be aware that cutting out talking negatively about yourself to yourself and to others is kind of like an incantation. You begin to believe it. You can change the negative talk. Again, I'm doing the best I can. You can say that I did not expect this. So give yourself a break. You don't know what the future holds. Now they would say it is like taking yourself to a scary movie. Turn it off. Don't scare yourself about what will be. Be educated , but don't just scare yourself.

And the present talk is what you want to focus on. When can we start. Make a call this afternoon and get that resolved. I'm really sad today, but I'm going to be okay. Talk about now. Not what is going to be. Stay in the present. Helps with the feeling of overwhelm. Creating positive habits. It is kind of like knowing what you like. Do like to take a bath at night, are you are walking in the woods person? Are you a dog person? No what makes you feel good and celebrate that. Get yourself a hammock and get to know yourself. You will be proud of what you are doing. Are there things that you can tweak? Of course there are. Immerse yourself in new relationships. Reach out. Right down three names of someone you haven't talked to in a long time that you think about. Learn self calming techniques. If we took a minute or we see how we run and we can take a minute at the end and just go online and find a meditation or put on and at. There's insight, there is calm, their great things on YouTube you don't have to pay for. If you like the rain or the waves, just do what makes you feel good. But what are you grateful for. We are dealing with a pandemic and political upheaval. People are angry. We don't know how it will play out. People are upset about what is going on. And you can say, this country has been through huge transitions before. We will somehow get through this. Is coming up with something that feels honest to you and saying, I'm going to use my strength to get myself through this. This is going to be a life-changing time. Don't you find yourself saying things like before COVID? This is a period in our lives. If you can exude optimism and just faith in yourself, you're going to reach out and manage, that is you taking care of you. This is actually about taking care of you. We talked about relaxation. It could be sitting in the woods or taking a walk. But doing something that you like that feels good to you. Insert that into your day. Shift your focus from pain to purpose. What is true, what is the whole story, and what can you do about it. And what can't you do about it. If you cannot do anything about it, let it go. Work at recognizing when you cannot affect the change. You cannot turn back the dementia. You can make it as bearable for yourself as much as you can , but you cannot change some things, so how do you live with it? Stay in the present. Not what will I do in the future or what should I have done. That will limit the anxiety that we build around focusing on the past or the future. Tell yourself the best you can do is the best you can do. Can you do better? I'm taking this class right now and I'm going to learn something. You can learn from someone. You're not doing it perfectly. The optimism. We talk about optimism, if you want to write down real quickly, three things that you are grateful for right now. You've just begun a gratitude journal. Every night before you go to bed, reach over and write down three things you are grateful for. It can be one word or sentence, but be specific. Say, the sun felt great. Pick something that gives more texture to it and that trains your brain to look for things that are good and the gratitude. As hard as your situation is, and I don't mean to minimize it, learning how to be in it in a way that you will look back and be proud of yourself and you will maintain if not enhance the relationship with your family member. That is a big one. It is not always easy. Taking care of yourself means accessing resources. There are agencies on aging that can provide free resource books. What in the community are resources? With COVID-19, some may be open and some may be closed, but know what services are available to you. Maybe you can afford someone to come in four hours once a week more or less, but you will know that you have those hours to go out for a walk or do something out, but taking the time for yourself. Taking a class, closing yourself off in your room and not being interrupted. Exercising. It is harder to take walks outside. Take advantage of the weather when it turns, or do you have an exercise routine at home that you do now. There are 1 million free yoga things. There are a lot of good exercise programs that are free that is good to follow. Taking care of your health. For the person you are taking care of, if they are looking for ways to busy themselves or they are obsessing about something, have them begin to face out. Have them face out. Get a birdfeeder, put up chairs there so you can watch the

birds come. Make it something they do. It will take them out of themselves and into the world again. Bring them out and put out the paint set. How about you sit with them and you paint just for the heck of it. Not to produce and not to criticize. Just to mess around. Put on their favorite music. Exercise with them. Do one of these YouTube exercise classes with them. Let them do for you. Thank them for clearing off the table. Thank them for calling you this morning. Thank them for whatever they do so that you give them the opportunity to be thanked as well. We've gone through these very quickly. I'm happy to answer any questions. And I can take one minute and do one minute of a relaxation thing to give you a sample of it that you can find online. Find something that you connect with.

Do you want her to go through a progressive relaxation exercise right now, raise your hand. If we get a majority of people saying yes, we will go ahead and do that. It looks like we have about half of the people. So if you want to walk through that quickly.

I will do one minute and then I can answer any questions. Sit flat and sit in a comfortable chair with your feet on the floor and hands on your lap facing up the breath is in for 3 your nose expanding your chest and your belly. The breath out is through your mouth like you're blowing out a candle. In, two, three, eyes closed, out, two, three, four. In, out. With your eyes closed I want you to squeeze your fist really tight and now slowly release your fist breathing in. Now out. In for 3. And out for four. One more time. Do your shoulders up to your ears. Squeeze and be really tight. We hold a lot of stress here. And then slowly release down breathing in. Now breathe out. And in 43 and out for 4. We would be tightening shoulders and your arms and tightening your legs. Each time releasing the tight muscle with the breath. It coordinates loosening your muscles with your breath so that just doing the breathing helps to loosen up a little bit, but doing it with your body helps train your brain to do that. Do it with all parts of your body. Just tighten and release. Open for questions?

I'm going to real quick remind everyone before we do questions that you do have your EAP as a benefit. It is already prepaid that your employer has gotten for you so you can get this information like what we have today. If you want to know more about these topics, please call and on your company's toll-free number. You can reach us on your company website. Please reach out to your HR department and they can provide to that information. There are a lot of different companies on today. Please reach out and get that information. This is available to you all the time. The information that you give is never given back to your employer without your permission. We do have a few minutes for some questions. A couple comments came in, but I'm not seeing questions right now.

I see some with Michele. She's asking how you respond to apparent who is staying, I cannot wait until I get to go home, but they are not going home. They are in a care setting that they will not be able to go back home. Let me respond to that. I think what you do is you validate the feeling. I know you want to come home. I want you to come home, but right now the doctor does not think you are ready and that becomes the story. I'm not suggesting that you tell them ally. You have to connect with their feelings. You cannot talk them out of their feelings. You just want to say, I know you're sad and I would miss

being in my home as well. Go along with the feeling. But say that right now it is not going to happen. The doctors not ready to release you. And you don't have to go further than that. Anything else? So my mom is taking care of my dad who has Alzheimer's and leukemia. How to encourage her to get her outside? Even if a family member or sibling or someone in the family can up front the money, hire someone to come in and you pay them for the two weeks that they quarantine themselves. They test before they come. You have to get help. You have to get help somehow. You learn enough about them that you are ready to hire them and maybe you have them, and you are there and you show them what you do. Take videos of yourself doing what you do so they can see how you do it. But absolutely try to figure out a way to get someone to help you so you are not carrying this all by yourself.

You have given some great advice. I wish we could continue, but we are out of time for today. Thank you so much. And I want to let people know, please rate your overall satisfaction with this webinar. Click the radio button next year response. You will not be able to see everyone's responses. But know we will get your response. Please click that. If she could not get your question today, please feel free to call into your EAP and get a consultation. They can help you with resources and answer questions you may have. Thank you, Sylvia, for such a wonderful presentation and thank you, everybody. Have a wonderful rest of your day.

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