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>> Welcome to the American Brain Tumor Association's free educational Webinar Series. Today's webinar is on Improving the Quality of Life for Caregivers. The webinar will be presented by Margareta Page. Please note that all lines during the webinar today are muted. If you have a question you would like to ask, type and submit using the question box in the control panel on the right-hand side of your screen. Ms. Margareta Page will answer questions at the end of the presentation. In the next few days, you will receive an e-mail asking you to take a brief survey to evaluate the webinar. Please take a few moments to share your feedback, which is important to us as we plan for future webinars. Everyone who completes the survey will be entered into a quarterly drawing to win 50 target gift cards. Fifty dollars target gift card, excuse me. There is a difference, isn't it. Today's webinar is being recorded. We will post the recording at the ABTA website on the learning page within a few days. Registered participants will receive the webinar recording link and a follow-up e-mail once the webinar is available. Let's pause momentarily so we can begin the webinar recording.

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>> The American Brain Tumor Association is pleased to welcome you back to our webinar series. Our webinar today will discuss Improving the Quality of Life for Caregivers. My name is Vince Rock, Program Manager here at the American Brain Tumor Association. I'm delighted to introduce our speaker today, Margareta Page. Margareta Page is a career neuroscience nurse, having spent the last what is six in the field of Neuro-Oncology. She is well-versed in both brain tumor patient and caregiver experiences. She is very proud of her most recent work, which has been working with Dr. Susan trying to launch the UCSF neuro-oncology caregiver program called the first program of its kind, to offer dedicated staff and support services to caregivers as part of patient care. Thank you for joining us, Ms. Margareta Page. You may begin your presentation.

>> Thanks, Vince, and good morning or good afternoon to all out there listening today. It's really wonderful to be here. I would like to start by extending a big thank you to the ABTA for hosting this webinar today on what I consider a really important topic. I have no disclosures. I am here today to talk about improving the quality of life of the caregiver. As a member of the healthcare team who provides care for a patient with a brain tumor, and actually, I think I speak for anyone who is in the immediate family of someone with a brain tumor, we know that this disease has the potential to not only impact the patient, but the whole family and on so many levels. This is particularly true for the family member who is the primary giver. Today I will discuss it with you but it means to be the caregiver of a patient with a brain tumor, which is actually documented to be a little different than other illnesses. We will review some strategies you can use to be a successful caregiver, as well as help bolster you along the way through this journey. Let's start at the beginning. I want to review the definition of who and what is a caregiver. By definition, a caregiver is someone who provides physical, emotional, spiritual, or logistical support to someone with a chronic disabling or life-threatening illness. A caregiver is often the Partner or spouse of the person, but it can be an adult child. It can be a parent, and usually there is one person who is primarily responsible in support of the patient. We call that -- person the primary caregiver. When thinking about caregiving, I think it's really important to understand what happened in healthcare in the last 20, 30 years. There have been several big changes. I think most significantly has been reduction in days patients are allowed to spend in the hospital. Vincent mentioned I have been at this work for a long time. When I started my career, people who had craniotomy's, which is the surgery to

remove a brain tumor, they would stay in the hospital at least five, and often seven days. Today, that has been reduced down to two or three days for a brain surgery like that. Really, what's happened is caregivers have been out to step in and take over what used to be done in the hospital. Second, other switches in the healthcare system have caused patient and families to have fewer and shorter interactions with the formal healthcare system, in the outpatient setting. People don't get to go to the doctor as frequently. Usually those visits are much shorter than they used to be. Finally, we capped that all off with another reduction, reduced number of resources for those who need help in the home. Now, we're left with this patchwork, fragmented support for caregivers in the home setting. This combination has really led to an expansion of the role of the caregiver. Truth be told, healthcare system is now relying on the family to provide care. In the end, caregivers become an extension of the healthcare team. For many of us, that is really a tall order. Let's talk about what a caregiver does. Caregivers are called upon to do something called multidimensional care. We are asking you to do that with little or no training. And then you are also being asked to do it on top of all of the other things you are already doing. One might look at all of these things and it's not you are providing all of these things, but may be some of these aspects. Let's talk about physical care. I think this is what many people think about when they think about caregiving. At its most basic level is providing help with bathing, dressing, maybe meals and nutrition on a more complex level, though, it's acquiring and managing medication. And then perhaps assisting a patient manage their symptoms or cannot be giving them medication for a headache, or providing some sort of therapy for certain symptoms. And even on a bigger level, you have to know when something is significant enough to contact the doctor. That's physical care. Emotional care is actually the support a caregiver provides to a patient as they come to terms with the diagnosis and it's impact on their life. Usually, this is at the same time the caregiver is coming to terms with this themselves. This can be really difficult. I think of what's even harder and a surprise to many caregivers is that they often find themselves supporting there extended family and all of their friends who are having similarly difficulty coming to the grips of the impact of the illness. It's sort of an extra level of care. The spiritual care refers to helping a patient find hope and make sense of the disease, and maybe find meaning. This is all going on while caregivers are doing it themselves. I often hear caregivers talk about they have a tremendous responsibility to maintain hope for that patient. That is one that I hear very often. Financial support involves managing that income stream and/or managing the bills, all of the disability paperwork, insurance. For many people, this isn't something they were doing of the family before, so it can be a whole new field one has to navigate. Finally, there is the logistical aspect of care, the overall supervision of the patient. It can be -- you can kind of be standing back, but many caregivers feel the need to ensure the patient is adhering to a medical plan. Maybe you are just helping them navigate the complicated healthcare system, or maintain communication with the health team. A lot of caregivers spend time working on scheduling and attending appointments and keeping all of the calendars. As I mentioned, people usually aren't doing all of these things at once, but usually some combination, and again, always on top of the things you are doing before your loved one got sick. Not that it's a competition, but I do want to acknowledge the work that the caregivers a brain tumor patients do. I wonder if any of you ever wonder if caring for a brain tumor patient is different than maybe caring with someone with another kind of cancer. I would like to tell you, yes, it is. It's documented that caring for someone with both, I life-threatening illness, and then one that causes neurological symptoms that can affect their mind, body, or personality, combined then with the fact most of us have little or no training to provide this kind of care causes higher levels of distress and burden. The caregiver population of brain tumor patient actually exhibit higher symptoms of distress

and burden. That's because this combination of life-threatening with the neurological illness can be very challenging. Some of this distress actually comes from the comment and emotions and feelings a caregiver experiences as a result of a diagnoses, and/or the symptoms the patient experiences. First, there is a tremendous amount of grief and loss around the diagnosis of a brain tumor and it's meaning. This is common with caregivers of many kinds of cancers. People our struggling with the loss of the plan for their life, or perhaps even the loss of a future. Secondly, for some people, this disease so often really does affect the essence of the person that they are caring for. The caregiver may have lost or will lose the person that they knew. They are chatting and animated husband may have changed to someone much more quite with flat affect. Or your cool and collected mother has become quite depressed and anxious. I think this is really a painful loss for caregivers a brain tumor patients, and one often that is sadly invisible to the outside world. It can make one feel very alone. Third, I want to mention that caregivers are human, and human responses include times when we lose our patients, we get angry or resentful about a situation. It might be to the patient. It might be to others around us. Then because we are human, we vacillate, and then we feel guilty about having that emotion about maybe losing our patient, or maybe even maintaining are own life. It's really common to have strong feelings of guilt when you are taking care of someone. This can cause a lot of distress. Finally, for those who our taking care of a brain tumor patient where their disease is considered noncurable, there is something known as anticipatory grief. Just anticipating the loss that is coming can be so distressing for some people, and they wonder, how will I live fully while I'm waiting for the other shoe to drop? This can be so challenging for many to live as they did before with this living loss. For some people they can really get lost in this place, and very much unable to live in the moment. They are so worried about the sadness at the end. This is not a great place to be. Some people need help moving through this emotion. These kinds of emotional reactions are quite common when caring for someone with a a life-threatening and neurological illness like a brain tumor, and they do contribute to this higher level of distress that caregivers feel. I want to talk a little bit further about how being a caregiver has the potential to impact all aspects of quality of life. Each one of these bars here is an aspect of your life. And each one of these contribute to your overall quality of life. Let's just think about how being a caregiver can impact these, both in a positive and a negative way. Certainly, finances and employment can be affected by being a caregiver. You may have to reduce your employment so that you can provide care. Or maybe you are -- you or the patient may have had to retire and finances are limited. Emotional health, as I mentioned, is particularly at-risk, particularly ones boot. Caregivers a brain tumor patient have higher incidences of depression and anxiety. This is documented. We really need to pay attention to this. When you think about your physical health, think about this, any kind of stress impacts one physical health. Caregiving is truly a stress, and you need to pay extra attention. Just by paying attention, you can begin to think about how you can offset that stress. That would be stress management things practicing, relaxation, trying to eat well, sleep and exercise. We know that social relationships are really important to us as humans. We also know when a big illness like this comes along, many social relationships suffer. A lot of patients report that there are people that they thought would show up that don't. On the flip side of that, other social relationships might strengthen. You have to always the kind of looking for the positive there, and also acknowledge being a caregiver does put you at-risk for isolation. Certainly our sense of self, or your sense of self can be affected by being a caregiver. Again, this can be positive or negative, but sometimes people identify by who they are and what they do. If you give up your job as a lawyer, or you are having to delegate some of your duties as a parent so that you can focus on caregiving, that can impact people in a negative way. It's important to be aware of how you identify yourself, and then how

that might be affecting your caregiving. This relates to promoting your identity outside of caregiving, which we will talk about further in the lecture. Certainly confidence and self-esteem. Let's think about this. When you are confident and have been self-esteem, that improves your quality of life. In this situation, actually, all of you have probably been asked to step in and cases overnight with little or no training. You have been asked to learn a whole new language with words you had never heard of before like [Indiscernible], or [I ndiscernible], [Indiscernible], [Indiscernible], made her, and none of this has been by choice. Most importantly, it's on top of all of the things you're juggling in a day whether it's work, being a parent, or taking care of the house. It's important to allow yourself opportunities to become informed around the illness because that will make you feel more competent and increase your self-esteem. Interestingly, of course, we have opportunities for positive growth, that can impact our quality of life in a positive way. I want you to know that caregiving can give you opportunities to work on things like this, things like staying in the present moment, rising and meeting a challenge, or accepting and forgiving. There are some things that are positive that could come out of caregiving. I think would think about quality of life, I want to acknowledge that we can't change the problem. We cannot take away the brain tumor. But with support, I think caregivers can strengthen their ability to solve their problems; to cope, respond, and be resilient so that we can offset some of the negative that caregiving on many of these aspects we talked about in your life. How are we going to do that? I put this slide up here because I want you to know that society and the health profession are paying attention. I want you to look here. We have headlines from the New York Times, Wall Street Journal, New England of the New England Journal of Medicine. These represent organizations that are here to help caregivers. We have this aging population, and we have these shifts in health care. I can guarantee you that are system recognizes now that caregivers need help. Certainly, those who have been in the field of Dementia care have been leaders in this area since the 1980s. The rest of us really are just starting to catch up. I'm going to talk about one of these organizations, national alliance on caregiving. It's an organization that is dedicated to both the legislative and political advocacy for the caregiver. They have made some recommendations now for care and how it should be provided. I see it as a Call to Action. They are calling for a shift on the emphasis of person-centered care that we should not be shifting it to focus on the person and family centered care. They are also calling on your health practitioner to formally assess a caregiver's needs, strengths, and preferences, as part of patient care. Their calling on help professionals to provide education and skills training so that caregivers feel more confident, and able to manage there day-to-day activities and daily care challenges. And then they are asking health nationals to provide or encourage counseling, self-care, relaxation training, and respite programs, both to improve both the caregiver and the care recipients quality of life. I think that's encouraging in my mind. In addition to this call-to-action, we now have a whole body of research that has been published about the caregivers a brain tumor patients. This is what we have learned. This is all scientifically documented now, and it will not be new to you. Caregivers one acknowledgment. They need information and guidance. The any connection with similar others, and emotional support. And it's very important to recognize that we vary by individual, and things change across the illness trajectory. What this means is it's not necessarily always a one-size-fits-all approach. That's what we know so far. And then I want to talk a little bit in case there are health professionals out there listening, whether it's a nurse, social worker, or support staff or even a doctor. I think we can just say in response to that Call to Action, and what the evidence tells us, there is a few things you can do. First and foremost, you can formally acknowledge that caregiver is a member of the healthcare team, and integrate them into the plan of care. Another thing you can do is just begin by increasing your awareness of caregiver support that is

available in your area so that if you see a caregiver into stress, you can provide the resources or facilitate them accessing those existing resources. You could offer education on the symptoms of the disease, what to expect, how to navigate. If you do not want to do that in an educational setting, you can make sure that the resource examples or ABTA Pamphlets are there in your office. Finally, this is something we found really interesting at UCSF. You can look for themes in your patient population. What are the common questions coming up? Then you will be able to have a sponsor with an anticipatory guidance, information, and connection to resources. Something we realized when I started work in the caregiver program in 2014 was that we had very limited information, or even knew exactly what to tell people when they said, how do I talk to my children. That was something we were able to develop and put a packet together. Now, when we meet people with children we are able to put them in the right direction. Those are things you can Institute in your own practice wherever you are. For the last 30 years, research about caregiving has helped us understand the plight of the caregiver, and people have begun to test interventions to help work we know that caregivers need help. More often, they need help more than they are usually get them. With that in mind, I would take a moment to share a novel approach were using at UCSF. That is our UCSF Gordon Murray Caregiver Program. This was to honor a patient whose family gave us a gift allowing us to hire dedicated staff,, a doctor, nurse, social worker and Coordinator so we could offer individualized assessment to the caregivers, and tailored interventions. The guiding principles of the program are that this is integral to the care of the brain tumor patient. You know the quality caregivers the quality care. We know that needs change across the disease trajectory, and neurological impairment adds to caregiver burden. We also know that caregivers don't always call for help. Some proactive outreach might be helpful. We also talk about this thing we borrowed from the stroke literature called timing it right. It's making sure people get the right information at the right time. We don't want to be offering everything when we meet people at there very first visit at the clinic. You have to dispense it when people are ready to hear it. This care is now integrated into the care that it patient at UCSF receives. Caregivers get additional resources specific to that. We have developed educational materials very specific to the time point and the illness. We spend a lot of time with caregivers offering anticipatory guidance and what to expect. One of the other things we do is go out and educate others about caring for a brain tumor patient always with that caregiver lands, making sure people realize how this disease impacts the caregiver, as well as the patient. We are offered to -- able to offer caregiver [Indiscernible], educational workshops and retreat, and we are able to offer bereavement follow up. In the last year and a half we have had tried the other big centers come to ask the University of Pennsylvania and University of Alabama. Both are looking at getting their own versions or parts to this program up and running at their centers. This is really exciting because it's starting to spread. It's from this work now that I want to move on. I want to spend a little time to focus on some practical things for you that you can do for yourself. I want to start with what we know doesn't work. There are four big things trying to do it all; not allowing time or room for your feelings. A lot of people push everything down and do not let themselves feel. Pretend nothing has changed. This is a good one. A lot of people like to move in that direction. Distance yourselves from those that can help. If I could see you all, I want to ask you now, how many of you actually think maybe you have used one of the strategies? I bet if we could see each other right now, I bet a lot of us would actually be nodding. And I even see one or two things on this list, even with all of my training that I think our what I call my default settings. I think that we need to think about them that way. Sometimes are default settings need to be reset. Because if you ignore your needs, it's going to lead to your own health problems. That includes physical and mental exhaustion, which is then going to lead to you not to be able to attend to

your relationships and/or provide the care that you want too. If we know what doesn't work now, then I think the next question is, what does work? The truth is, not the same size approach works for everyone. Not everybody needs the same support. Some people may need practical support. Maybe help getting their loved one to and from an appointment. Some people really need emotional support. They are having a hard time dealing with the diagnosis of the grief. Others may need and that additional meal or bag of groceries. There may be someone else that needs round-the-clock assistance. No matter what, I think it's really important for all of us to remember that it's really difficult to do this 100% on your own. I think that's why it's crucial to seek and accept help. This is why, because first and foremost, really, it's true. You're physical and emotional will being depend on this. From that, your ability to take care of your loved one is tied to your own health. I think a lot of caregivers are really hard on themselves. I think we had to go back and be gentle with ourselves. Most of you have stepped into a role you haven't been trained for. It really does require a significant extra demand and responsibility, and other things that you had to do. Many people don't even know what they need. Finally, I think this is one of the key things, and it might not be for everyone, but I think many of us are going to need to develop or enhance new skills and strategy to adapt to a new normal. I think, again, this is not necessarily our default mechanism. As human skull we don't change. I think the sooner we acknowledge that there has been a change, the sooner we can adapt in a positive manner. Where do we start? I would like to say the first thing goes back to making yourself informed. I think access to resources. Find out what's available. Does the doctor's office have anything available? Is there a social worker you can connect with? Is there a council of that may have resources? I think that's a good place to start. Another thing, and one of the strategies to reset the default mechanism is you're going to have to talk to yourself. It's going to be super important. You have to tell yourself over and over, you do not have to do this all. It's really important to recognize that it's not realistic to do so, and that you will need some support or help. Just keep reminding yourself of that. The other thing is, there is a big focus on self care. I am sure many of you have heard it in many of you think, how will I fund time for that? I want you to remember every little thing you do, no matter how tiny, it does add up in a positive manner. I will go through pretty good list of things you can do. I want to remind you, you don't have to do all of these, but remind yourself any little thing you can do in a day does add up. It's really important to be flexible in how things are done, and it might be true that you are going to have to let a few things go. This is harder for some people than others. I think it would be great if maybe one of those times when you are waiting in a waiting room, think of what are the things you can delegate to a friend or family? People want to help you. The ABTA on their website has an ice sheet caregivers can access to help you think of the kind of jobs you do. It helps you to think about what you can offload to others. I thought of a good one just for this. I was thinking if someone asked if they could help and you were feeling, how will I ever locate the caregiver resources in my town, you could ask you want to do the research for you. Let them find out what's out there for you and let them bring it back. Finally, the whole thing about not being hard on yourself. You have to be gentle on your cell. Knowledge is power. I think of becoming -- yourself. Knowledge is power. Becoming informed to so many p eople. The truth is not every one is being treated in a big center. You may not have access to a social worker, Cancer Center, or any of this information. That's why it's a good idea to access what I call community of resources where you can learn more about the disease. Maybe you can learn about an upcoming clinical trial. You can learn about caregiver skills and report. You can find out what financial resources are available. This page I put my favorite resources on there. Certainly, ABTA is on there. It's a great place to go for information. There is also an organization called IBD a, our global network. They are doing similar things to ABTA, but they have a

great publication and a great website. They also put on seminars that are helpful for patient and caregivers. Say would national brain tumor society. This is an organization that is an advocacy Agency. They funded research and advocate for public policy changes. It's important to know about them, but I also wanted you to know about their website. They have good information about what's going on politically and in the research world look at the bottom I put virtual trials. [Indiscernible] website has a lot of good brain tumor information on it. I then through some other places I thought important to know. My very favorite where caregivers is Family Caregiver Alliance, which is an organization dedicated to improving the life of the caregiver by offering information, services, and advocacy. The neat thing about this place is they have offices or connections in every State of the U.S. They well do an intake and can connect you with the resources that are in your local community. Sometimes they have free counseling to help caregivers should they need a little counseling. They also offer in some areas some small financial respite grants, which are great. I put on here American Cancer Society. Again, another great place. They have great information about talking to your family and friends. They also offer a little financial support to patients but I wanted you to know about that. I put our cancer resource center on there, but this would be for whatever town you live in. If there is a local Cancer Center, it's worth checking out what kind of support services they have for you in your area. These are just some strategies to get the lay of the land and become informed. Now I will move on to the next part of the talk and focus on things you can do. What can you do? Not just a reminder that you don't have to do all of these things. A piece here and there will keep you nourished for this journey. I think the most important thing that underpins everything else to ensure that you are as emotionally strong as you can be. I think I mentioned earlier that caregivers of patients with brain tumors are at-risk for depression and anxiety. We already know that. We are now at a higher risk than anybody else. It's also important that if you are depressed or anxious, it actually undermines your ability to do anything else. I think it's really important to State in tuned. You may say, how do I do that? I think you have to take charge of this and connect with resources. First and foremost, how are you doing? Certainly, if you are distress, I think you should be seeking professional help. I think it's not a bad idea even if you are not distressed, just to have someone to talk to that you can bounce things off of, keep up with good coping strategies, as will be helping to make you more resilient. You can get a referral from your primary doctor and/or some of the caregiver support agencies offer free counseling. I almost feel I would ask everyone just to consider that. Certainly, you can help your emotional health by just staying connected with friends and family, and/or attending a support group. There is power in community. There is this whole thing we talked a little bit about. It's resetting the default mechanism, but it's managing yourself talk. You are going to have to give yourself a talk now and then, which is true. We tend to go back to the default mechanisms. Use good, positive self talk. Another practice you can do that is scientifically proven to help people with their mood is a gratitude practice. This is something you can focus on at home. You can do this any time of day. Take a moment, five minutes, to think about four or five things each day you are grateful for. I know sometimes with all going on, that might feel difficult, but focus on things such as, I had a good nights sleep. I do not have to wait of the doctor's office to long today. A really great cup of coffee. We know a gratitude practice can improve your emotional well-being. People also feel like if they can't get out, it's okay to use self-help books or podcasts for similar reasons. The next thing is going to be a theme in each domain. This is critical. This has to do with every aspect of your body, but learning how to relax. Not even just learning how to r elax, but developing a practice for it. People can go to formal relaxation methods. You can take a mindfulness class, go to yoga. Some people get an app on their phone. I heard of one. I'm not endorsing it but I heard about it. It's called headspace. There are others. Some people

put their headphones on and enjoy listening to music. It's trying to figure out what can help you relax, and they commit to practicing it. I want to tell you about something that is so simple, and is something you can do anywhere. You can do it while waiting outside of MRI. You can do it if you are having trouble sleeping at night gets a very simple practice of breathing. This is an exercise will practice white now. We call it [Indiscernible] breathing. You breathe in and out slowly. Prevent for half the amount of seconds that you breathe out. We will start with in Fort four and out with a. At that feels to big of a breath, it can be in for three and out for six. We know with this type of breathing, it settles your nervous system down, as does active counting. If your mind is spinning, sometimes active counting and slow breathing can get your mind off of all of the things it wants to think about. They do say we should do this for five cycles. We're going to practice for a moment. It's important to sit in your Chair, feet on the ground. Relax your upper body. Put your hands in your lap. I would like you now to take a minute and close your eyes. We are going to breathe in two, three, four, out, two, three, four, five, six, seven, eight. In, two, three, four. Out two, three, four, five, six, seven, eight. In two, three, four. Out two, three, four, five, six, seven, eight. In two, three, four, five, six, seven, eight.

>> Did that help you relax?

>> You can do that anytime. The other part besides emotional health is physical self. Caregiving is a stressor. It can affect your health. I would recommend just as soon as you take on this role, it's important to see your Primary Care Doctor. Not only see the doctor for a checkup, to let them know what you are dealing with, making sure your blood pressure is okay. If you want they referral for mental health of this would be a great opportunity. Let your doctor know what you are dealing with. Exercise is good for physical health. The recommendations are for 150 minutes of moderate exercise each week. The nice thing is it can give you a chance to connect with a friend. It by yourself, it can give a chance for you to clear your head. Most importantly, you can do it in small increments. You can do 15, 10 minute exercises if that works. Tie to maintain or keep up some form of exercise during you're caregiving. Certainly, as mentioned top eating healthy is important. We know that. I like this picture I put on here. You don't have to focus too much on what to eat, but if you eat all of the colors of a rainbow each day, you are ensuring you get all of the proper nutrition. Finally, sleep. I think this is something many caregivers struggle with. One, people our staying up to get their chores done, and while the patient is sleeping that is always a good time to get things done. Two, the patient is up all night and your sleep is disrupted as well. Remember, sleep is essential for your physical and emotional health. It should be a priority. Just prioritize it. If you can't graciously at night because the patient is up or down, make sure to allow yourself to take a nap during the day. That's not a bad thing. At least 45 minutes. If your sleep is disrupted every not because the patient is up and down, it may be we're to ask a friend or family member to take a shift at night so you could occasionally get a full nights sleep. Something to think about. Now we will move on to your social health. We talked a little bit, if you remember, one of the aspects of the quality of life was sense of self. It is important to remember that caregiving can impact who you are and how you see yourself. It's worth taking a moment to think about who you are. We identify ourselves in ways of doing things, as well as being. Doing might be an exerciser. Being might be loving, generous. Again, think about new you are. I want you to look for ways that you can maintain that sense of identity in small ways. People can do that by keeping up with outside activity. During the week we do say do something once a week. It to be exercise. It could be going to the movies, PTA, or even back to work. It's really important to you prioritize yourself once a week. Do something for yourself. Again, that could be getting a massage, but it could be going to a movie or getting coffee with a friend.

Socially, I want you to think about the relationship that you have with the patient. Make changes when someone becomes a patient and you become the caregiver. These are a bit out of balance. One way you can sort of get back to the way that you were before the illness, so it's not all about the illness is think about things that you enjoyed. Try to build in someday nights, activities, or things to nurture that relationship outside of the context of a patient/caregiver situation. Here it is again. It's important for your social health, is being able to reduce stress. Again, it is that learning and practicing some sort of stress reduction technique. I would like to remind you how simple that paste breathing was. Again, you can use that at any time.

>> I have on here spiritual self. Some people ask asked what that means. We'll be think about our spiritual self, it's recognizing that, week, as humans, all have the need for purpose, meaning, and fulfillment in life. I think sometimes when people are in the midst of caregiving, they report feeling that their lives lacked meaning. How do we support are spiritual self while caregiving? First and foremost is recognize you are not alone. It's really important to seek support. It might be a support group. It might be a peer. It might be some other community, but I cannot underestimate the power of community. It's really important for people. Another thing and another community, if you have a faith community, we recommend you stay connected with the faith community. I think a lot of times people get busy and stop going to services or whatever because they are taking care of the patient. People do derive a great sense of strength and/or community from their faith community. Just remember that. I think it's important to recognize not all relationships are perfect. Sometimes they were not perfect before caregiving. That one should be open to the healing power of love in a relationship top and know that healing and reconciliation are possible. And know the importance of embracing and acceptance of the way things are and forgiveness. Another thing when we think about spiritual self, and I think this is hard because it's a lot of our default mechanism, but it's giving up control. The sooner we can do that, that will help. A great resource for some of these things I want to mention today is the greater good science Center. This is an organization out of Berkeley. It's science-based insights to help people with meaningful life. I like it because it has articles, tips, and even classes to enhance some of the meaning making activities that we can do in our lives. That is a good resource. You can access that from home it's important to express your feelings honestly. Remember how we said it doesn't help to type everything down. You have to find a way to get things done. It can be positive and negative things. It might be talking with a trusted friend, family member or Clergy. Some people find journaling a great way to let it all out. That is something to think about. Other people find prayer or meditation can also work. It's really important to think about balancing between doing and being. Again, just being there for the patient, trying to give up the busyness of doing can be challenging, but something to think about. Be sure to maintain time to rest. Again, take time for q uiet/meditation/prayer. We are almost done. I think in summary, I want to borrow a phrase that you have probably all heard. I think this applies. This experience is a Marathon not a Sprint. Just like a long race, not only do you need to get ready, because if you don't you will plug, but you need to nourish yourself along the way. For those already in the race, do not hesitate to pull over and stop for water or nourishment, or even medical tent if needed. I want to say that I think there's no one way or write way to be a caregiver. Everybody is different. Just remember, different things work for different people. Choose what works best for you. I think it's important to accept you are likely going to have to learn a new way of doing things. I think it's important to get support early. Support certainly learn as much as you can about the disease, but also work on coping, problem solving, and communication skills. I'd like to give a shout out to the caregiver resource center at abta.org. They have great things for caregivers. If there are people not primary caregivers listening

today, I hope some of the things we have talked about you can use to support those people who are primary caregivers. Finally, I would like to ask you all to be kind to yourself, and know that we support you can do this. I think you can do it will. Thank you, very much.

>> Thank you, Ms. Page. We will now take questions. If you have a question that you would like to ask, please type it and submit it using the question box in the webinar control panel on the right-hand side of your screen. The first question comes from someone who attended the webinar.

>> As I am sure you well know, very often both caregivers and patients will put on a brave face for the sake of the other person in their life or their family, and maybe not be as vulnerable or as honest as they could be about how they are doing. One person asks if you have any suggestions for speaking with a patient, or encouraging them to be more honest about how they feel?

>> I think that's a common concern between patients and caregivers. I think it's a challenging one. I think we have to start by acknowledging that everyone copes with something like this differently. And that people come to terms with how they are doing and what's ahead at different speeds. I think I would enforce it. I think that's really important. When we talk about doing and being, if you could look for opportunities just to be with that person, and look just for openings, times where they might want to talk. I think sometimes that by attending educational opportunities together or support groups, you may find something in the support group that could be a jumping off place for conversation. Some people, we recommend that may be a professional Counselor, couples counseling to help talk it through. I think that's always a good thing. And then another thought, I suppose, there is a whole special piece called palliative medicine, which helps people come to terms with a have what we call a life-threatening illness. This is not Hospice, it's palliative care. Their focus is to help people think about what's important, and open up with communicating. That might be another option.

>> Thank you. I think a lot of caregivers are very smart people, and they know how to look for information. They often find a lot of great information. What do you suggest for anyone who has tried a lot of these well-known strategies for managing their own emotions, and taking care of themselves, but they still feel overwhelmed? What would you say to someone like that?

>> I guess my feeling is, I think, again, just acknowledging what you are doing is it's hard work. Be gentle with oneself. I guess the two big things, stay at it. The power of community is important. If you can find a supportive community, and I also think, perhaps, again, just sticking with professional help just to keep helping you look for ways to solve problems in a positive manner. That would be my answer. It's hard. I understand that.

>> Yes, yes, thank you.

>> Another question we were asked is about some of the personality changes that can happen in the patient sometimes as a result of the tumor location or the side effect of treatments. Sometimes like you mentioned in your presentation, someone's personality will change drastically, and the caregiver will want to address that but not exactly sure how to talk about that. You have any experience or suggestions for how to address that kind of challenge?

>> Yes, I do. This is a very common symptom. It can be subtle or severe. I think if you are able to, I would just let the patient know that there has been a shift, or that you have noticed a change. If that's difficult, were sometimes patients do not have any insight into the change, you could discuss it

with your doctor. There is a specialty called neuropsychologist who can evaluate a patient, both cognitively and emotionally. They can give you a baseline of a patient's strengths and maybe areas that need support. Sometimes just knowing that can help you. Sometimes that neuropsychologist can actually work with a caregiver and a patient on strategies to tone down, or look for triggers. Sometimes it's just identifying triggers that upset people or get people agitated. They can help you with some strategies to better manage some of these challenging behaviors. I think talk first. And if the patient has insight, that's great. Again, open communication. Of that feels difficult, I would speak with your doctor about maybe having some kind of a valuation done, again, to give you some understanding of actually what is happening, and that the patient is capable of, or understand, or can or isn't in control of. Maybe some strategies on how to work on it together.

>> Thank you. Another question that came in. It sounds like the program you have at USGS is wonderful. As you know, most hospitals don't have programs like that. Who do you suggest that caregivers speak to within a typical hospital system about issues related to caregiving? Who are the point people for that?

>> I think the first thought would be, is there a social worker connected with your Health care team? That would be my first thought. If there wasn't, then I would really look into that Family Caregiver Alliance, that organization, and find out doing the community is supporting caregivers of patients with neurological illness. That's another great resource when you don't have a lot of things like the Gordon Murray Caregiver Program right at your location. I would say the social worker would be one. I think the Family Caregiver Alliance would be another. The other one, you can look at what's going on at the local Cancer Center, even if your patient isn't getting cared for there. They often offer caregiver support. That might be worth just checking in, and seeing what is available. Sometimes they have support groups that people can attend.

>> Okay. That is all the time that we have for questions today. Thank you all for joining us. Thanks, once again, to Margaretta Page, for her wonderful webinar presentation. Aside from our free educational webinars, the ABTA has a variety of programs and resources available to help connect patients and caregivers with information and resources to help support them in their brain tumor journey. We also have publications and other resources for healthcare professionals. For more information visit the ABAT website at abta.org, or call the ABTA care line at 88862282. Let's pause momentarily to conclude the recording for the webinar.

>> We invite you to continue to check back at our website abta.org for the ABTA anytime learning page, library of free on-demand webinars featuring renowned experts addressing a wide range of topics from treatment options for treatment times the quality of life and symptom management. This concludes our webinar. Thank you for joining us. Please be sure to complete the evaluation survey you will receive by e-mail within the next two days. Enter-- you will be entered in the drawing for the target gift card. You may now disconnect from the webinar.

>> [Event Concluded]