

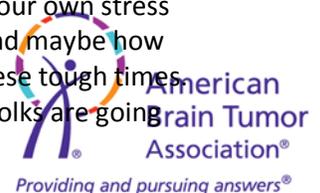
American Brain Tumor Association Webinar

Caring for the Caregiver

Hi everyone and welcome to the American Brain Tumor Association webinar series. Thank you so much for participating in today's free educational webinar. Today's webinar is on caring for the caregiver. It will be presented by Vickie Leff, MSW, LCSW, ACHP-SW. Please note that all lines during our webinar today are muted. If you have a question you would like to ask, type and submit it using the question box in the control panel on the right-hand side of your screen. Ms. Leff will answer questions at the end of her presentation. Tomorrow you will receive an e-mail asking you to evaluate the webinar. It is a very brief survey. Please take a few minutes to share your comments. Your feedback is important to us as we plan for future webinars. Today's webinar is being recorded. At the recording will post to the ABTA website shortly. Registered participants will also receive the webinar link in a follow-up e-mail message once the webinar is available. Let's pause for a moment so we can begin our webinar recording here.

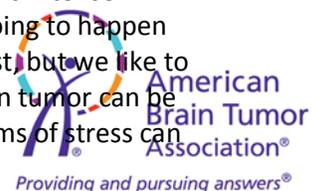
>> The American Brain Tumor Association is pleased to welcome you back to our webinar series. Our webinar today will discuss Caring for the Caregiver. My name is Andrea Garces, program manager here at the American Brain Tumor Association. I am delighted to introduce our speaker today, Vickie Leff, MSW, LCSW, ACHP-SW. Vickie Leff is a clinical social worker for palliative care at Duke University Hospital. She has a long history of working with cancer patients and families, along with other serious illnesses. Ms. Leff has a particular interest and passion in providing support to the caregivers of people with serious illness. She has presented several times for the ABTA over the past few years on this caring for the caregiver topic and other subjects. Ms. Leff has been a clinical social worker for over 30 years. Thank you so much for joining us, Ms. Leff. You may now begin your presentation.

>> Good afternoon everybody and this is Vickie Leff and thank you so much for joining us this afternoon for our talk about helping the caregiver. I am really thrilled to be able to provide this information for you and hope to leave some time at the end of the presentation to answer any questions that you might have. I called the presentation Navigating Rough Waters because we know that this is really difficult stuff for caregivers to go through. And I really hope that today at the very least you can get out of this suggestions and strategies for things that will help you going forward. I have no disclosures to make and today what I would like to talk to you guys about is the challenges that are faced by caregivers for people who have brain tumors. Things like the fatigue that you might feel, this serious role changes you go through, maybe even depression or grief related to how the trajectory of the illness is going and then how to cope with the sudden and significant neurological and sometimes functional changes that folks go through with brain tumors. And some short and long-term strategies to help you manage these challenges. There are things that you can do today even to help you get through this very rough time. And finally how to find some fantastic educational, financial and emotional support that you may need. One of the most important things I want to tell you is that there really is help out there. And I am hoping that the things we talk about today can help you figure out a plan that works for you because not everything works for everybody. It is not once size fits all as you already know. Help you guys to identify support resources, strengthen the coping you already have, but also learn to recognize your own stress that you are having. Figure out when to ask for help. I know that is very hard for folks. And maybe how finding 15 minutes a day can give you a little bit of strength to help keep going during these tough times. So I would like if you don't mind to set the table briefly and to help us understand what folks are going

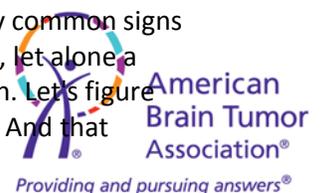


through and my experience with lots of different cancer patients and folks who have gone through brain tumors, as it looks like things are going along just fine and then all of a sudden out of the blue, this disaster strikes. And folks generally, you know this yourself, feel a lot or some or many of the kinds of things we -- on this slide about anger and doubt, fear, grief, hope, it feels like a roller coaster and not really sure where to start. There are specific challenges dealing with a brain tumor, and so the next couple of slides I want to differentiate a little bit between folks who experience a brain tumor as opposed to other cancers. There are specific challenges that are different and I think that is important in terms of when you're talking to other folks who have gone through other cancer experiences and there are lots of similarities but there are some things that make dealing with a brain tumor a little more challenging I think. And that has to do with the cognitive and psychological and behavioral challenges that sometimes come along with dealing with a brain tumor. It is different than other cancers. Sometimes the sudden nature of the diagnosis can feel very different. Some of the treatments sometimes are very intensive and sometimes it is a short trajectory of an illness. And there is unfortunately a high rate of mortality and it does tend to hit a lot of young folks. And I think that is a little bit different than a lot of the other cancers and that makes it challenging. The other things I think make it more different have to do with the emotional and the cognitive piece. The thinking and memory. Emotionally, I think a lot of folks have told me that they experience a lot of anxiety and/or depression, irritability, personality changes. It's hard to figure out, is that because someone is going to a hard time or because of the brain tumor? We will talk about that and a little bit. And then thinking and memory issues that come up. Making it difficult to process information. That has a lot of implications for you as the caregiver. And then short-term memory which has its own problems as well. Concentration issues like confusion, maybe getting distracted makes it hard to plan. And what we call executive functioning, where your judgment is involved sometimes can be impaired and that makes decision-making often very difficult. All of those things – the changes in personality, mood swings that can come along with brain tumors and treatments, the reduced mental capacity at times and the physical impairment, can lead to a decreased quality in life and increased dependence on you, the caregiver at home and that is the challenge. I put in this quote because I like it so much: "I'm sure the health care physician is quite talented but I understood nothing they said." It is so important, the caregiver so important in any treatment of cancer and certainly brain tumors as well in terms of getting the information you need, understanding what people are saying, having that other set of ears is so critical.

>> One of the things I would like to challenge you to think about as we go through this discussion is that balance between hope and uncertainty. I mention this because this comes up in a lot of my discussions with patients and families of, how can they coexist? How can you hope for something at the same time as you are uncertain about what is going to happen? I think this is a huge challenge and it is very hard to balance this. I'm not sure it ever gets quite balanced, but I encourage you to think about this as we go forward about how you manage that balance of hope and uncertainty. Let's talk about recognizing stress for caregivers because it is certainly out there and I'm sure that all of you can tell me a lot about the stress that you are experiencing. I wanted to write down a couple of things that both patients and caregivers face. The psychological physical and financial stress that the caregiver and the patient feel. I suspect that many of you have had experience with feeling anxious or depressed, had some sleep disturbance, fatigue, frustration, isolation. One of the things I think that is unique and challenging for folks who are dealing with a brain tumor is the role changes that it can cause because of some of those physical, psychological and cognitive changes that people go through that are quite sudden and very difficult to deal with. For the patient of course it is a huge sudden change and often means intense treatments, surgery, chemotherapy, role changes. That uncertainty of knowing what's going to happen in the future. And here and palliative care and at Duke we like to say we hope for the best, but we like to plan for the worst. Some of the stress in the physical symptoms that go along with a brain tumor can be really confusing. And I really want to stress something about this. Some of these symptoms of stress can

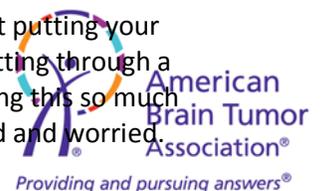


be irritability or anxiety, depression, feeling overwhelmed, memory and concentration issues. And I've heard from a lot of people that what is difficult is trying to figure out what is a normal reaction, what is due to the stress of having an illness, and what is the result of the brain tumor itself and/or the treatment? I put at the bottom of the slide how important it is to get a differential diagnosis. And what I mean by that is that if the person with the tumor is experiencing some of these symptoms and you are not sure whether it is from stress or a result of the tumor, we want to be able to rule out what is what as much as we possibly can and so I really encourage you to bring those symptoms, maybe even taking a log of it, bring it to the Dr. to the oncologist and have them help you sort that out. It's really important in terms of what treatments can be provided. If someone is anxious because they are dealing with this serious illness, the treatment for that is different than someone having a neurological reaction that manifest that looks like anxiety. It is important to get that differential diagnosis. And differentiating between the symptoms and reactions really makes it hard. But we always want to treat it, so I guess the reason I am focusing on this a little bit is because symptoms should always be treated as best they can and not just pushed aside because reactions can be helped as well. The reality for the caregivers can be equally devastating and difficult. You're having to put the patient first, you are probably exhausted. It can be very rewarding a meaningful of course being able to help someone that you love or care for and helping them through something difficult, but it can also at the same time feel lonely. And there is a lack of focus from the team on the caregiver. I certainly want to admit that right up front that in medicine, we are really focused on the patient. And sometimes, I think it's hard for us to remember that it's a team sport. And the caregiver is going through their own difficulties and that needs to be tended to as well. There is hardly any preparation for this new role for you as a caregiver. There is not a lot of ramp up time, things probably happened really quickly and all of a sudden here you are, you are having to be a caregiver and it's not something perhaps you have done before. Or maybe it is for somebody else. You are very little personal time. This is from an article so I am not just making this up. This is from a study that was done specific to primary brain tumor patients that the caregivers have no personal time. Generally only three hours a week. Which is nothing. They're finances are stretched, 41% reported reduced hours working or needed to stop working and I'm sorry to report that this particular study noted that 50% of caregivers, folks who had a primary brain tumor, experience depression. I hope that maybe we can provide some ideas for you so that we can at least tend to that a little bit better. I don't think we do a very good job as a medical profession about that. This is from another study that was done, forgotten voices, lessons from caregiver of persons with a brain tumor. Knowing that you are ready know: physically exhausting, expressed feelings of anger and frustration and guilt for losing their patients. I hope that one of the things that if you're listening, that you walk away with is knowing that the feelings that you have, which vary quite a bit, are very normal. And that anybody would have them. And that everyone does the very best that they can. I picked up this quote, this next one from the ABTA website. They have a wonderful form. A lot of resources and one of them is a form where caregivers can share some of their thoughts with each other. And this one was particularly striking to me: "I think seeing my soulmate change a little more everyday is the hardest thing I've ever had to experience. I miss my best friend so very much and he is still here." So the signs of stress that I would ask you to look for as the caregiver, we are talking about you all, trying to figure out what's stress, what is normal, when do I need help. Normal signs of stress, things like feeling tired and rundown, like all of us do from time to time, having trouble concentrating, feeling more resentful than you might normally in the day, difficulty sleeping, overreacting to minor issues, being irritable, your own health problems getting exacerbated, getting worse is something to look for. Anxiety, that feeling of not being able to think about anything else, depression, feeling really sad and isolated, wishing for this to end. Those are all very common signs of stress. I would expect any caregiver of anybody dealing with someone who has cancer, let alone a brain tumor, to experience some of these if not all of these. I hope not all at once, though. Let's figure out maybe what we can do about some of those as well because stress leads to burnout. And that



means that you would be feeling constantly exhausted, neglecting your own needs, your life is revolving around your caregiving, no time for anything else, can't relax even when you have help, getting more impatient and irritable, feeling helpless and feeling hopeless. And those are not good things to have to feel. I'm sure perhaps some of you are already feeling this way. It's also important to take a moment, I want to take a moment to talk about signs of depression. And I'm not talking about that kind of having the blues sort of thing. That every person on the planet feels from time to time. But a little bit more significant feelings that last a little bit longer than normal and are a bit more severe. And that's what as a clinical social worker I would be looking at trying to diagnose if someone had depression. It's about the severity and the duration of these symptoms to think about. Changes in sleep that last more than two weeks. Changes in your appetite that might last for more than two weeks. An overwhelming feeling of sadness and finding no joy in anything that you do. Feeling terribly isolated, withdrawing from your friends and that everyday feeling of just not having a good day, never leaves you. And these symptoms start to interfere with your daily functioning and then it's a problem, but it's also something that can be treated and that's really important to know. And I also want to spend a moment talking about the difference between grief or anticipatory grief, worrying about losing somebody and depression and there is a difference. So grief has a little bit more to do with feeling sad or thinking about anticipating adapting to what it might be like without someone even though things may go perfectly well, it's very normal for folks to think about what would it be like if things don't go well? Hoping for the best but planning for the worst. And grief in general tends to come in waves. One moment you're feeling okay and the next out of the blue, you are just hit with this, oh my gosh, I don't know what I would do. Depression generally speaking has a little -- it doesn't come in waves as much as ongoing feelings and the reason that this is important to differentiate is so that first you know that these feelings are normal but also if they last a long time or like we were talking before about the duration that there are things you can do and it is help that you can get. And I don't want you to feel isolated or feel like there is nothing that can be done about this, "this is the way I am supposed to feel." I just wanted to differentiate that. It is really so important to know when it is time to get help. I don't know about you, but I know it's hard for me to ask for help because I like to think I can handle everything. And sometimes you can't. So if those feeling start to get in the way of your day to day living, keep you stuck or frozen and you are the best one to know that, then I think some help is probably would be useful for you and that can come in a lot of different ways and the ABTA has a lot of fantastic things that can help you as well. Three of the things are come to my mind are thinking about medications for anxiety or depression, therapy or counseling, and as a mental professional I am a huge proponent of this. Time to yourself with someone who has no prior history with you, no judgment whatsoever, a place that you can go that is just for you to unload and think through and process what is going on for you can be enormously helpful. I realize while I say that though that finding the time to do that is extraordinarily challenging. I throw it out there as a great idea but I do realize how hard that is to put into a day that you are already slammed and up 24 hours a day anyway. A support group if you have the time can be a wonderful thing as well, especially in terms of helping you not feel as isolated as you might feel. It is a time issue. What do you find the time to go to a support group? Thanks to the Internet there is a lot of stuff you can do that you can fit in when it works best for you. I would encourage you guys to take a look and see what works best for you. There isn't one thing, there isn't one magic pill or one magic counselor. It depends on what will feel best to you and you are all different. But I do want to encourage you to think about asking for help. When you are feeling overwhelmed. And remind yourself that it is not forever, that we can all use help at times. It is not going to be always.

>> I want to spend a moment to talk about what doesn't help. I put this cartoon up about putting your head in the sand and just ignoring it. It doesn't really help for terribly long. It can help getting through a day but it might not help you in the long run so that negative self-talk of "I should be doing this so much better, why can't I be positive and perky all the time," and it's because you are exhausted and worried

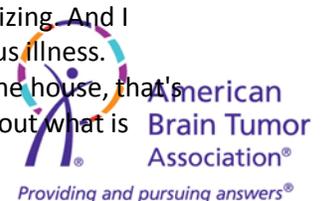


What doesn't help is isolating yourself and the feeling that generates from that, saying, "I am the only person going through this, no one can help me." And your situation is of course unique to you but you aren't alone out there, there are people that can listen and be present with you and help you in this journey. Avoiding feeling with your emotions -- generally speaking, kind of like not dealing with a clog in the drain. It just gets worse. And so some of these suggestions I have later on have to do with getting those emotions out on the table. And not asking for help is never something that will be helpful. And why it matters - I love this quote from this great article for psychosocial care for family caregivers. When the patient caregiver dyad is treated as the unit of care, which we should all do, it contributes to the well-being of both the patient and the caregivers. It's like this saying of putting your mask on first to help the person next to you. It is just as important for you to take care of yourself in order to do what you want to, to care for your loved one. Let's talk about what can help. Now that I painted this picture and I am worried about you guys being depressed and anxious. The most important thing that I hope you walk away with today and learn about is that you are not alone. And I think that's really important.

>> How to strengthen the coping that you currently have is also really important. I am sure you are all doing the very best you can. Some things work better for you than other things but I wanted to go over how these certain coping strategies can really help you and why they help you. We talked about a minute ago not letting your emotions just be untold. Acknowledging how you are feeling helps you not just to get it off of your chest, which can sometimes feel great - more importantly though, it helps you know what you need. And I think that is critical. Then you can come up with a plan for yourself. Prioritizing, what is important for you. Maybe even hour by hour, afternoon by afternoon, day by day is really important so that you can have a sense of knowing what your limits are. I know you are all Superman and Superwoman but we all can't do everything and we need to know what our limits are to be able to set those priorities and set goals for ourselves. And have success. I can't stress this enough. I know that being a caregiver in a serious situation is so overwhelming. And perhaps it feels like, "I can never get anything done, I don't have any time, things are going well," but setting some small goals for yourself and experiencing success with that even if it is something like, "I am going to walk the dog for five minutes today," doing that and having success with that, you would be surprised how much energy and focus that can help give you. I know that sounds trite, but give it a try and see what you think. Asking for and accepting help can help you not to feel isolated. And reevaluating often. Thinking about what worked a month ago is probably different than what works today. The situation has changed, maybe medications have changed, lots of things can change in a short period of time. It something you really have to reevaluate over and over again. What is working now? How did I cope then? Do I need to change it because things are different? And rinse and repeat. Do it again. Accepting that there are gonna be ups and out. It will be in waves. And taking a look at what works for you.

>> Acknowledging your emotions is really critical. Because you can't fix or change something if you don't see if it is there. Admitting scary feelings and thoughts, putting it out there to think about can be really helpful. It doesn't mean you have to do with your partner or love one. You can do it by yourself by writing it down. But by acknowledging that they're there is a really help of thing because it will help you think about what you can do about that. And by the same token, acknowledging that your role has changed makes it possible to think about how to cope with that. So writing it out, back in the 70s we called this journaling, but now it is called reflective writing which sounds a little bit nicer. Taking a few minutes once in a while doesn't work for everybody, to write out what is working and what isn't working as a way to identify your emotions is really helpful. We talked a minute ago about prioritizing. And I think this is really critical when you are dealing with anybody who is dealing with a serious illness.

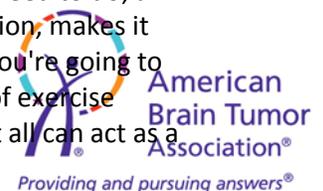
Figuring out what is the most important thing. When I first saw this, I saw, oh, cleaning the house, that's really urgent. Well, it's not necessarily in the face of maybe having a seizure. Thinking about what is



important, what can be put aside, what needs to be focused on and revisiting this often because things are going to change and looking at day to day, even writing it out, helping you think about what is important right now, what's important today, and how we can solve that problem. I hope that make sense a little bit.

>> I really encourage everyone to think about bite-sized goals. And by bite-sized I mean, sometimes we are all thinking about the big picture a lot. And hoping that things go well and I hope they go well. But also, setting ourselves up for some success in being able to manage things on a smaller bite-sized level. And maybe that means setting a goal that is just one thing for the day. Walking your dog. Using your organizational skills, and I like the graphic in this, I'm a big Post-Its person. And writing down what you need to get done and what you can prioritize and making sure that you are putting things out there that actually can get done. Curing the brain tumor, I wish we could put that down as that is the most important thing. And it is, but let's break it down into things that we can do on a day to day basis to get through this together. Asking for help, I know this sounds so simple and you're probably thinking, come on, everybody knows how to ask for help. But I can't tell you how many times I've heard how hard this is to do, but I want to remind you people really want to help you. People want to know a little bit about what you need. When someone says, "How are you doing today what can we do to help you?" You've probably got a thousand things in your mind like, "I need to do this and this and this." Maybe being concrete is exactly what they need to know. "I need someone to pick up my dry cleaning. I don't have time to do that." So think about and write down somethings people can help you with – there are some things folks can't help us with and that's ok. And I want to encourage folks asking for help is not giving up. And it does not mean that you are helpless or that you are not doing the very best that you can. It takes courage I think to say, "I need someone to help me with this. I need them to help me and maybe that will help me feel stronger."

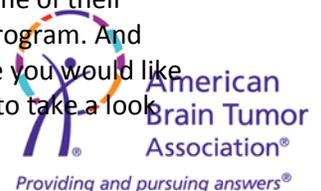
>> I will stop preaching about that. I think it is worth thinking about reevaluating over and over again because things are going to change, they can change quickly, your role may change several times and if it's not working, that's okay. Reevaluate it. There is no one way to do something. I know this is intuitive, but I wanted to take a moment to say to be kind to yourselves. You all are going through a lot. It's overwhelming, and I suspect that sometimes you beat yourself up with how you're doing but it is important to be kind to yourself. And I will preach a little bit more here, it's really important to spend a few minutes to talk about exercise and sleep. If you can, just have a few minutes a day to do some exercise. It actually really does help a lot. If you can, just try. And sleeping. Sleeping and your mood are really connected and I'm sure you know, when you don't get a good night's sleep, you don't have the strength and the clarity to deal with a lot of important things. So it's really, really important and it can make you irritable, adds to your stress, it can actually add to feelings of depression and anxiety. But it can be helped through improving sleeping habits. Even partial deprivation can have a really significant effect on your mood. They did a study - cumulative sleepiness - subjects were limited to only 4.5 hours of sleep at night from one week reported feeling more stressed, angry, sad and mentally exhausted. When they resume their normal sleep, they reported a dramatic increase in their mood. I can hear some of you saying, "I don't have time there is too much to do." I think it is so important to remember that you need to take the time to do this so that you can be and take care of the person that you are caring for as best you possibly can. And you've got to have sleep to be able to do that. Not only does sleep affect your mood, but your mental states can affect your sleep of course. I suspect that some of you and I have experienced this, get into bed and you just keep thinking about all the things you need to do, all the things you're worried about and you cannot make your mind stop. It increases agitation, makes it really hard to sleep. And if you are under constant stress, as many of you probably are, you're going to tend to have sleep problems. So there are things that you can do about that. A little bit of exercise actually goes a hugely long way to help with your sleep problems. Any kind of exercise at all can act as a



stress reliever. I'm not a huge proponent of sleeping medication, but if you talk to your physician and that's what they think might be helpful for you, this is an individual thing and then that's what you need to do. If you're not getting any sleep you will not be able to be the caregiver that you would like to be. Just a note about the exercise thing. Any form of exercise, yoga, anything, can act as a stress reliever. It pumps up your endorphins, it helps you to meditate, and it can improve your mood dramatically.

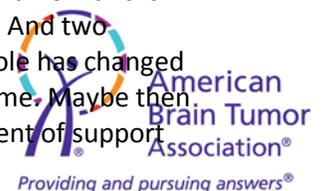
>> I have a couple of suggestions for you. One is to think about journaling or a.k.a. reflective writing. Being able to spend a few minutes writing down what you might be thinking about. You don't have to show this to anybody. This is your private thoughts. Sometimes getting them out of your head onto paper can help you to clarify what it is that you are worried about. And think through how you might be able to deal with some of those worries, maybe even come up with some solutions about them. How you're feeling, maybe some of those scary thoughts that you are having that you don't want to share with the person that you are caring for, you can write them down and feel like you have been heard in a way. Without having to bring them up to the person because it might feel emotionally charged. I think this is really helpful. The second thing is using reminders, the Post-it's. And also little inspirational things to put on your refrigerator. I know that doesn't take the stress away, but if there is something that you can say to yourself that helps you to keep going or something that you want to remind yourself, then put it up there, post it. I know that folks don't have a lot of time, but I do want to challenge you to find at least 15 minutes a day that is just for yourself. Whether it is doing a crossword puzzle, walking outside, talking to your dog or your cat, I told you I was a dog and cat person, I think that everyone can find 15 minutes for themselves. Maybe you will say what the heck is that going to do? 15 minutes will not do anything for me but I think you would be surprised. And the act of carving that time out for yourself, I think is extremely therapeutic. And then finally, the other thing and these are things you can do this afternoon. Do them tomorrow if they work for you. You don't have to do all of them and they're not always going to work in the same way. It is just something to keep in your back pocket as things that might be helpful during times when you are not sure what else to do. Be writing down three good things before you go to bed. There is actually a couple -- lots of articles about this and a book on this. Martin Siegelman I think wrote this. It's an exercise in gratefulness. Which makes it sound like it has to be Susie Sunshine, but it's not. The idea of this is to write down three good things, I do it at the end of the day just because it is easier, you can do it anytime - the idea is to make a habit of it. Write down three good things that happened to you today. These do not have to be monumental or things that you would call into a news station. It can be something like, I really enjoyed my lunch today. I had a good conversation with my daughter today, or I really wanted to yell at somebody and I didn't. Or, I put the right shoes on. It can be anything, but the idea is to take a few moments when you wake up or before you go to bed to think about your day and just identify a couple of things that went okay. They don't have to be fantastic.

>> The idea is to cultivate a feeling of gratitude, not to whitewash or put rosy glasses on something, but to take a moment and take a little bit of solace in some of the little things that happen to you or maybe it was a big thing. It's a really nice strategy for you to try, and it might feel good to you, it might feel like that didn't do too much for me but give it a shot and see if you think it is helpful. If it is and it becomes a habit, I think it can be a really useful tool to help you think about things. 15 minutes. Will it fix anything? Nope. Will it change the reality you are going to what? No, not at all. We'll give you a little more strength and focus? Maybe to help you deal with what you have to? I think yes. And it really can be anything at all. Like I said, it will not make a huge difference, it doesn't make things go away but it gives you a few minutes to yourself to think about what might be helpful. One of the things I wanted to also tell you guys about, which you may already know is the ABTA, and we will go through some of their resources because they are really outstanding, one of the things they have is a mentor program. And maybe for some of you out there who have been a caregiver for a long time, and feel like you would like to be able to share your wisdom, share your support with others, I really encourage you to take a look



and see if this is something you would be interested in - becoming a mentor. So ABTA-- American Brain Tumor Association feels strongly and I agree with them and thousand percent, that there is nothing like the support that you can get from somebody who has gone through something similar. That's why support groups are sometimes helpful and sometimes the online forms are really helpful to talk to someone who has been through something similar to what you are been through. And as we are talking about earlier, although dealing with any cancer is obviously devastating and there are a lot of similarities between anybody dealing with a cancer diagnosis and a caregiver of a cancer patient, I do think that there are real differences and challenges that go along with being a caregiver for someone who has a brain tumor that is quite unique. That I think that's a little bit lost if you're just talking to a general population. So this mentor program through the ABTA hooks you up with someone who has been a caregiver themselves for someone with a brain tumor. You can use it as becoming a mentor or talking to a mentor. And I would really encourage you to think about doing that to share your experiences and help someone get through what you have been through. It's also a great, interestingly enough, it is a really great stress reliever to do something altruistic. One of the things - I was just talking with a group of nurses here at Duke, and I was doing a talk on burnout and self-care strategies that can help them have a long career as nurses, and one of the things I suggested to them is in the middle of the day if you put your hand on a shoulder of a colleague and say something nice about something they have done, that that act of altruism, that act of saying something nice is actually going to reduce your stress, which sounds counterintuitive but try it sometime, it's an interesting phenomenon.

>> I would like to talk to guys for a moment about resources in the time we have and then leave some time for questions. I will focus on the American Brain Tumor Association's resources because I do think that although there is a ton of resources out there for cancer patients, I do think the unique challenges that face folks with brain tumors and their caregivers that the ABTA has some of the most phenomenal resources for you. I hope you have discovered some of these yourselves, but if you haven't, there are a couple things I will point you to. This is a screenshot of their primary page, the ABTA's primary page. And if you can see on the right, there is great information for folks who have just been diagnosed. This is the program I was just talking to you about, Becoming or Finding a Mentor and this Connections piece and Support Groups and the Caregiver Resource Center and the ones with caregivers that I think you might find most helpful. This is the caregiver center website. And on the side you can see I wanted to highlight, look at all this information that is available. Depending on what your question is, like one of the things that we talked about earlier is managing some of the physical symptoms of a brain tumor patient or the cognitive symptoms, this is where you can get even more -- lots more information than what I have given you, managing those cognitive symptoms, being able to identify them, differentiating them from stress reactions, what other people have done to help them with that, when to ask for help, when to go to the Dr. and when should I ask the oncologist. Is there something we need to do some testing about, safety issues, getting the help that you need, tips for extended family. How to talk to your extended family about what can be most helpful. Maybe they're coming over a little bit too often and you want to tactfully tell them what would really be helpful. Navigating the healthcare system, huge. Huge issue since we don't make it easy for folks and I'm sorry that we don't. This is a fantastic resource and you can use it in the privacy of your home, no one is watching you and no one is taking notes. And get more information. This handbook is something that you can download and print. The main sections of it over here is your role as a caregiver, the impact on the family. Navigating the healthcare system, symptoms and side effects and some of the things we were talking about in terms of caring for yourself. So you know today, maybe what you are interested in is, "I am really worried about my family and how this is going to impact my family." Maybe just open the handbook to the family impact section. And two months from now you will have different questions. You will have questions about, my role has changed a lot. I am not really sure how to handle that. I am confused by it and it is frustrating for me. Maybe then you will turn back to it and read it a little bit more about role changes. I am a big proponent of support



groups, I do realize as I say that it is really hard to find the time to do this. So ABTA has online support group communities but there's also a lot of value in that face-to-face contact that you can have with somebody and they have if you see down here, you put in your state and it will come up with what support groups are available to you close by. I would encourage you to do that. And up here is that mentor program and then there is an online forum, that quote that I read to you about watching someone lose their best friend is from that online support community. Use it when you feel it would be helpful for you. If it is not helpful don't use it. I hope if nothing else this webinar has been helpful to tell you that all of your different reactions are very normal. And that there is no one, best way to get through this difficult journey. Everyone is very different. And I hope that I have been encouraging you guys to think about what works for you as an individual. Not what worked for Aunt Jane or Uncle Lou or the neighbor down the street because everyone is different. And yet at the same time, there is a community of shared experiences as well.

>> This is my favorite slide. I am a very visual person and I like to think about caregivers standing steady in a thunderstorm. I think of you guys as this very strong oak tree, standing steady in a storm. Sometimes maybe it abates a little bit and the rain stops and other times it comes on strong and it is really difficult. I wish that we did more for caregivers as a medical community and I think we are starting to do that a bit more. Because it is a team sport. The better you can take care of yourself the better you can take care of the person you are caring for. And that is really critical. We appreciate the fact that it is a very difficult journey. It's a little bit scary sometimes and I hope you know that there are lots of things out there that can help you when you choose to do that. And hopefully revisit what you need when things come up. There are a lot of things online. I suspect many of you have already been looking online and trying to access resources. Here are just some of them and I understand from the ABTA that they're going to send you a link to the YouTube recording so you can revisit some of these resources, but there really is quite a lot out there. I think that is one of the benefits of the internet these days is that people can talk to each other. I would really encourage you to go to the ABTA website particularly for their caregiver support, it's really outstanding. I gave a couple of references for articles if you are interested. There are a fair amount written about caregiver stress, what helps and what doesn't and we are still working on it because there is no magic answer. I wish that there was. Except that you are not alone. There are people that can help you. To be careful about asking for help when you need it. And to lean on each other when you need it as well. I hope that that has been helpful. It is about 2:46, so I would like to open it up for any questions that you guys may have and see if I can answer them for you.

>> Thank you so much Ms. Leff for that wonderful presentation. For anyone would like to ask a question, just as a reminder, type and submit it using the question box in the webinar control panel on the right-hand side of your screen. We have a question here, many of the caregivers are balancing being both a caregiver for the brain tumor patient as well as having young children in the home. Can you address some of the issues that are faced both by the children of brain tumor patients as well as the caregiver balancing caring for multiple people within the home?

>> That is such a good question. Thank you for bringing it up. I apologize I didn't put anything in the slides about young children. I apologize. It is a presentation unto itself which we can perhaps do at another time. I want to acknowledge that the multiple roles that a parent would feel being a caregiver for a patient and dealing with their kids at the same time is extraordinary. And concretely, I would encourage you to see if you can ask for some help with some of the more logistical issues that might have to do with kids in terms of pickup and so forth. If the question is more about how to talk to the kids about a brain tumor diagnosis or treatment, then I think that -- I will give you an abbreviated response and that is that it completely depends on who the children are, what they are like and what their ages are. Creating an atmosphere in the family situation that encourages questions is extremely important. You probably already know as a parent intuitively that the things that kids worry about are almost



always worse than the reality. And having -- creating an atmosphere in the home, in the car, driving to and from school, asking questions about how they understand things are going, what they might be worried about, is a really good place to start from. At the same time, and I know this is going to sound difficult, to also allow kids in their own way to deal with this, meaning that a teenager who is 14, maybe a 14-year-old boy may be kind of quiet about this, a 13-year-old girl might be really vocal about what they are worried about and everybody is going to deal with it a little bit differently. My one caveat is that hopefully wherever the person is being treated for the brain tumor is that they might have child life specialists. I know there is information on ABTA, the website about talking with children about cancer diagnosis and treatment. Additionally though, there are sometimes child life specialists who have age-appropriate information, what I would give and what I would suggest for a five-year-old is going to be very different than a 16-year-old in terms of books I might suggest or ways to talk to them about it. Information about how to explain what a brain tumor is really varies on the age. So I would get some assistance if you can from the brain tumor clinic that you are going to. Be sure to include the school and let them know that what is going on. They do keep that in confidence. I would talk to the guidance counselors at this school so they can keep an eye on the kids and be looking for any acting out behavior which would not be uncommon at all. And being able to help you know what is going on at school. That is another presentation talk and I hope I haven't glossed over it and been able to answer the question a little bit. Thank you for the question.

>> Thank you so much for that. Another question we had here was what are some of the ways that the patient or survivor can help the caregiver. What can they do to give support to the caregiver from the patient perspective?

>> What a great question thank you. And thanks for thinking of that and asking it. I think that the primary thing someone who has been through the treatment for a brain tumor can do for their caregiver is acknowledge that it's a really hard job. That they understand that might bring up ambivalent feelings and that that is okay. Meaning that sometimes maybe they might even have felt resentful or angry about it and that's okay and they understand that. Just acknowledging and normalizing the ambivalent feelings and the maybe scary feelings that go along with being a caregiver would be a great gift that someone who has been through a brain tumor could visit on their caregiver. To be able to say thanks, I appreciate that this was not easy, you probably had a lot of varying emotions and thoughts and that's okay and give them an opportunity to share some of those if they feel like they can.

>> Great, thank you so much. Another question is what are some ways to manage if the patient resists help from the caregiver?

>> You guys have a great audience. That's a phenomenal question. I call it rolling with resistance. And I guess I have three parts to the two parts to the answer and one is, if that is something that is normal for their personality, that you are not surprised that they are being resistant to assistance, if maybe prior to their diagnosis they were a little bit stubborn and liked to do things for themselves and not someone for whom it is easy to ask for help, it wouldn't surprise me at all that there would be resistance. Number one understanding the context. Is this something that is normal for them? Are they normally a little hesitant? In this case you are going to have to be really patient about it and share why it is practical for you to help them. In order to help you, this is what they need to do to help you help them if that makes sense. Like the Jerry Maguire film. And the other thing to think about is if it is not in character for the person to be a little resistant, then to see if there is a differential diagnosis of something going on cognitively. That being said though, that might not change it. And I appreciate that that puts the caregiver in an extremely difficult position of maybe having to do things that the person doesn't want to do. And it requires an enormous amount of patience. The other thing I would suggest is having somebody else, maybe somebody on the care team, the Dr. or nurse or maybe another family member make the suggestion instead of the primary caregiver. When we hear things from other people other



than the primary caregiver, it makes a little more sense or it is easier for them to acquiesce to somebody else than to the primary caregiver. Enlist the aid of your medical team. Sometimes folks will come into us and say, can you please help him know that he can't drive. That's a really hard thing for people to give up, but very important to their safety. As a medical team we will write out, these are the things we are concerned about and that we don't want you to do. It takes the burden off of the caregiver to say it, so they don't feel as guilty about it. I would encourage you to use your medical team to give bad news or lay down the law about things that aren't comfortable. Have some patience and put it in context with what the personality is like normally. And if they were always a little reticent to accept help, my guess is they will continue to do that. And it will take and an enormous amount of patience and try other people to be your messenger.

>> Thank you so much. And this is a follow-up question to the initial question regarding the children. Some of the caregivers have children who are grown and have moved on to their own family lives. What are some of the resources that might be available for those children who are grown-up but are still experiencing some of the fears and stress levels as children of brain tumor patients?

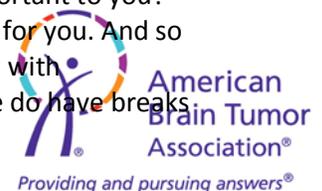
>> Assistance for adult children. That is so well worded because your parent is always your parent, your child is always your child. A lot of the reactions that folks have are in that primary role. If it is the parent going through something difficult, it's not unusual for someone to react as their child, not as the grown up thirty five-year-old. I would direct them to caregiver resources. The ones that the American Brain Tumor Association has on the website about that. Also, if someone is having a lot of difficulty with reconciling being an adult but having a reaction regarding their parent, individual counseling I think can be really helpful to sort that out a little bit. I know it can be expensive and it is hard to find, there is a great website called psychologytoday.com and you can type in the city and find a counselor that meets your needs that has specialties and see what they charge and all that stuff and I think that can be helpful as well, but there aren't any specific websites dedicated to adult children who are dealing with a parent with a brain tumor diagnosis. You'll have to look under the caregiver tabs of the cancer sites.

>> Thank you so much for that. We have another question here of how do you suggest a caregiver address strong feelings or fears and anxiety of the level of care that is needed at the very end stages?

>> If we are talking about the intense emotions that come when somebody is perhaps at the end of life, I would suggest that it's to be expected and difficult and very challenging and overwhelming. To that extent, I think everybody would do well to get some assistance with that through either a hospice organization, through their palliative care organization, hopefully there is one at the hospital, hospice in particular has great family support resources available for people. Both their medical team, social worker, chaplains, volunteers, they have bereavement services as well for when after somebody dies. It is totally understandable and expected that you would have very intense emotions. And at the same time you need a place to put those. So if there is a hospice, even if the person isn't getting hospice services, medically, they can call their local hospice and see if there are some resources they may be able to share or someone they could talk to on that staff who are particular experts at end of life care and some of the issues of emotions that go along with that.

>> Thank you so much. Our final question we have time for and you are more than welcome to add any final comments: What role does faith or spirituality play in caregiving?

>> That is a huge question. I can only answer that by saying it is huge. It depends on what it means to you. So for some folks, it is the most important thing. For others, it is not important at all. One of the things we ask all the time when we meet new folks in palliative care is, what is most important to you? And if it is your faith, then that is one of the ways that you will cope. Great. If that works for you. And so we would support them with chaplain services or encourage them to have conversations with whomever in their faith community. So I think if it works it is great. A lot of times, people do have breaks.



in their faith as well, and I encourage them to go to their faith community to discuss that even though that sounds counterintuitive if you are disappointed or feeling like why has God forsaken me or those types of spiritual existential angst, that they bring it to that faith community for some resolution but that would be a whole another presentation unto itself as well, which we are happy to have and there are plenty of people out there who are experts on that. But it plays a huge role.

>> Thank you so much for answering all those questions, and thank you everyone else for joining us. And we truly appreciate you delivering this wonderful presentation.

>> It is been my pleasure, I appreciate everyone being here this afternoon and I hope it has been helpful. Thank you for having me.

>> To help connect patients and caregivers with information resources that can help support them in their brain tumor journey, please call the ABTA CareLine, which is staffed by caring professionals at (800) 886-2282. Let's pause for just a moment to conclude our webinar recording. We invite you all to continue to check back at our website, www.abta.org for the ABTA Library of free, on-demand webinars that feature experts addressing a range of brain tumor topics from treatment options and tumor types to coping with a diagnoses. Our next webinar will be on neurological complications of brain tumors on Tuesday, April 12, from 1:00 to 2:00 p.m. Central time. Surgery, radiation and chemotherapy have improved the prognosis of many types of brain tumors. Careful management of medical and neurological problems is essential to optimize quality of life during and after brain tumor treatment. This webinar is designed to inform patients and caregivers of all brain tumor types about addressing the complications arising in the course of brain tumor management. This webinar will be presented by Amy A Pruitt, M.D. from the Department of neurology, University of Pennsylvania. Dr. Pruitt will provide key strategies that address problems such as seizures and choice of antiseizure medication, let clot risk and management, infections, as well as the management of steroids and other complications. She will also focus on common side effects of chemotherapy and describe some of the physical and cognitive issues facing survivors of brain tumors. Also please join us for partners in treatment and care, the American Brain Tumor Association one-day educational and network meeting held in communities across this United States. Patients families and caregivers are invited to participate free of charge to gather the most up-to-date brain tumor information from leading experts, recent guidance on management symptoms, and to network with each other. To register or for more information please visit braintumormeetings.org. This concludes our webinar. A cure for joining us and please be sure to complete the evaluation survey you will receive by e-mail tomorrow. Thank you so much and you may now disconnect. [Event Concluded]

