

Thank you for joining the American Brain Tumor Association webinar series. We will address understanding fatigue and insomnia for brain tumor patients. Today we have Terry Armstrong please note all lines are muted if you have a question you would like to ask please type them submitted in the control panel on the right-hand side of your screen. Terry will answer as many questions as possible tomorrow you will receive an invitation to complete a feedback survey please take a moment to share your comments it is important for us for future webinar development we are recording today's webinar that will post shortly as well as a transcription that will be there also. If you received a webinar link you can visit the recorded archive at any time learning and you can use that feature to forward to friends or family members who might be interested in doing the webinar. The American brain tumor association is pleased to welcome you back to our webinar series our webinar will discuss understanding fatigue and insomnia and brain tumor patients I am senior program manager at the brain tumor Association and I'm delighted to introduce our speaker today. Terry Armstrong she is the distinguished professor of oncology nursing and family health of the University of Texas health science Center she is also the adjunct--at M.D. Anderson Cancer Center she collaborates and practices with providing care for patients with tumors her primary interest is--thank you so much for joining us you may begin your presentation.

>> Thanks. It is an honor to be here today to talk to you about two important issues that many people who are dealing with brain tumors face on a daily basis and that is fatigue and a related issue which is sleep disturbances by merrily insomnia and I just shared a quote from a fellow patient who put it into words in a way that we can understand about restoration that people feel and the difficulty if you compare how you feel when you are fatigued to how you felt before you had that problem. So, the definition of fatigue is an overwhelming sense of exhaustion and we recognize there can be multiple components you can have mental batik physical or emotional or have a combination of all of those when you are dealing with a brain tumor and its treatment it can be associated with the brain tumor and its treatment and the most common treatment is radiation and fatigue is the most common symptom that people have as a result of the radiation so you can see how it affects a lot of people trade in addition many people are on other medications that are required because of the tumor itself or because of the effects of the tumor that can contribute to fatigue. So for example people are on anti-seizure medications and the Atlanta phenobarbital, among others have been reported to be associated with fatigue as well as steroids so prednisone can also be associated with fatigue just on their own and finally we know that many people have issues with mood, sadness and depression and anxiety as a result of tumor location or dealing with the effects of the cancer and that has been estimated that up to 50% of people during the early stages of the disease have issues with anxiety or depression and sometimes that is difficult to distinguish from fatigue, tumor or its treatment. Fatigue is one of the most common symptoms with brain tumors and it can occur so what I mean by that is it could happen early on when you are diagnosed during treatment or people find that they can happen years afterward. Dr. Mary lovely did one of the earlier studies and found that almost 50% of patients reported quite a bit low or very low energy levels during the course of their illness and other researchers have shown regardless of tumor or tumor grade patients can have a camera that remains years after treatment has been done and it has been shown that set-students had--patients had severe fatigue eight years after the diagnosis and more recently, we recognize that even in patients who have low-grade tumors such as astrocytoma,

almost 80% of those have the cheek of any severity and 40% reported it as severe. Now we try to identify if there are other factors that seem to predict who is going to have more of a problem with fatigue in our study we found that most important characteristic is what we term the performance status of the person and the performance status as a scale that we used to identify issues people might have with being able to walk on their own or care for themselves and we found that people had a K PS of 80 or lower had a higher incidence of fatigue so what that means is if you are someone that has weakness in your arm or leg and makes it difficult for you to walk or use your cane you may have more fatigue than someone who is not and it is not uncommon with other solid tumors as well there is a debate if women are predisposed to fatigue or maybe more comfortable every porting and we do know that the tumor status if you are diagnosed or the tumor has recurred you are more likely to have fatigue at those times that that illness a grouping of cancer centers around the country that puts together some guidelines for care of patients with cancer and these guidelines relate to treatment and symptom management and put together a nice guideline for clinicians so the nurses and physicians that you see, help us understand what we should do to look for people who have fatigue and what we need to assess and manage it so I thought I would share some of those guidelines with you because we have limited data and brain tumor patients but a lot of this can apply to your situation as well. The first thing I want to point out in these guidelines they asked the clinical team diversity and there are other issues if you have fatigue and you're able to see your physician they may ask you some questions that you wonder why they're asking and that would be fine if we could manage the other symptoms or issues that sometimes we can make the fatigue better and things like pain, if you have uncontrolled pain we are having issues with anxiety or you may be anemic or have a nutritional deficiency these are important things that the physician will try to evaluate because by treating those we can make the fatigue better. Sometimes it is hard to distinguish if the fatigue is from these issues or not but we recognize that with a lot of these problems fatigue is a symptom of the issue so if you are anemic you may be fatigued so by treating that anemia sometimes it can make the fatigue better the second part of the guideline is intervention that has been shown to be helpful for people with any kind of tumor in terms of treating their fatigue and the way the NCC and group seizes by pharmacologic or medications or non-pharmacologic which are things other than medications that can help and I thought I would go through each of these with. And give you some guidance based on what they found. One of the things it does, they review all of the clinical studies that have been done to evaluate the efficacy of these interventions and they grade them in terms of category score in which the level of evidence is assessed. So if there has been what is called a randomized study where people are randomly assigned to one intervention or another in a large study that carries more weight than if someone just reports on one person they may have tried an intervention with so it is a way to grade the intervention in terms of how it has been evaluated by the medical community.

>> The first area I thought would be important to review in the guideline is in terms of types of interventions and these are rated on the slide according to if they have been used in people that are on active treatments such as chemotherapy or radiation if they have been shown to be helpful in those aftertreatment at the level of evidence so if there is a bold color that means there is randomized controlled studies showing the impact of that particular intervention and finally if these have been shown to be helpful at the end of life as well. So the first is activity enhancement and that has been

shown to be with people on active treatment and posttreatment and it really involves exercise that is prescribed by medical professionals and monitored throughout the course of the therapy and we will talk about it in terms of physical-based therapy massage therapy is one type of treatment that has been shown to be helpful with people in active treatment and was psychosocial interventions having counseling session, with cognitive behavioral therapy in which a counselor works with somebody and provides directed guidance related to management of fatigue has been shown to be helpful in the meeting with a nutritionist to optimize diets and meeting with a sleep specialist to optimize sleep have also shown to be helpful.

>> Let's talk in more detail about exercise. It seems almost counterintuitive if you are tired that someone should say go out and exercise to make it better but there is increasing evidence to show if you are able to maintain exercise that you can actually make the fatigue less severe and this has been shown with several randomized controlled trials in which those who had prescribed exercise regiment as opposed to those that did not be ported significantly less cheek in general we talk about the impact of that in terms of the effect size so how much the intervention impacts the fatigue and overall those have been moderate in the effect and that we should consider it a good outcome and a clinical study and when you think about using exercises first it is important to talk about your individual care provider and you never want to initiate it without talking to your medical care provider and some components seem up organs it includes walking and resistance training set not type of one exercise or the other but it has been shown that the person is able to pick the exercise, they do. So they enjoy bicycling or walking and they can choose that, that is more helpful and usually it has to be something people can do at home to some degree. If it is an exercise you have to go out to a place people are more likely--less likely to stick with it and you have to do the exercise for eight weeks or longer and it is not something that if you exercise for a few days you're not going to see a big impact but you have to stick with it for eight weeks and it has been found if you start early on it is going to be more helpful than if you wait until aftertreatment to begin exercise so one thing we recommend we see patients starting therapy is to consider a walking exercise regimen. Continuing to walk three times a week during the course of the therapy. Some tips when you are thinking about exercising to manage fatigue. It is important to exercise to moderation. What that means, you said not exercise to the point were you can't have a conversation going to the person next to you. You don't want to be winded when you exercise that you exhaust your reserve.

>> A good metric is too, if you're exercising with someone, be able to carry a conversation and not get to the point of feeling winded. Talk to your health professional about their specific recommendations. Some people think rest is a key component and it is not uncommon for healthcare providers to recommend napping as a way to manage rest him parsing out your activity throughout the day and rest is important but you should make sure they are short mass because if you are taking a nap of an hour or two, sometimes you can disrupt your sleep and wake cycle and have difficulty sleeping at night. In general, 30 min. or less are recommended to you don't end up disrupting your sleep cycle at night and additionally it is important to plan ahead and accept help so if you look at your days activity if there is something you need to get done that day like going with your children after school to an event and you

know if you do more in the morning you're not going to be able to get to that point, you need to prioritize your activities so you have the energy when you need to add your priorities are what matters.

>> You may not be able to get done all things that you normally would have been able to do but you can prioritize and get the ones done that you need to do that if there are certain tasks that are difficult for you to do those of the ones that you want to accept help from family or friends you don't want to push yourself to do more than you can manage because often you are more fatigued and you can get into a vicious cycle with doing less and less.

>> Food and fluid are the fuel that help you get through your day and it hasn't been shown that any supplements or megadoses of vitamins are helpful and these actually may interact with some of your other medications so in general, recommendations are to eat a well-balanced diet throughout the day and try to avoid sugar or have the fat containing foods and really feel your body with the food you eat and not try to overdo with supplements or megadoses of vitamins. An exception to that is if you want steroids this can actually influence your ability to have calcium and vitamin D in your body and often times supplements are recommended.

>> In terms of psychosocial interventions, there have been many studies on this. Over 119 studies in patients with all kinds of solid tumors and in general it has been shown if you have an intervention where you can sit and talk to someone about your fatigue and what your activities are and how to manage those often times that it can lessen the impact of the fatigue on your daily life and those sizes have small to moderate the similar to what we have seen with exercise and in general the most promising approaches if you are able to have a specific time or you're talking to your counselor about the fatigue and what are your goals and what is important to you and it should be brief and delivered following treatments are not during the active part of treatment when you might be too worn-out to focus on the intervention and really focused on the test as the primary outcome. There have been many studies looking at pharmacologic treatment for fatigue in patients with other solid tumors and there is a Cochrane review in which a group takes a look at the literature and summarizes the clinical research studies that have been done.

>> They reported studies on patients with a variety of solid tumors and they included a number of types of medications including stimulants, growth factors, antidepressant medications as well as the steroids. And in general the most effective of these would be a medication seems to have some impact, the psychostimulants in the most studied have been Ritalin. Which has been shown to have some improvement of Teague and people with other solid tumors. And there is a small study in patients with brain tumors in which they took Ritalin or modafinil and the Zrich 24 patients and they found that either one of these drugs patients reported improvement in fatigue by two separate patient reported measurement instruments so patients stated they felt better when they were on the medication in terms of fatigue self you are thinking about medication that you want to talk to your healthcare provider about to see if it is indicated and if there is any restrictions for them to make these medications there may be some others that have been evaluated and if you go online you can read about the types of agents. Ginseng is one agent that has been used in patients for breast cancer and patients take a very poor form have reported less fatigue there is currently an ongoing study run through the alliance clinical

trial group looking at the impact of ginseng on patients with brain tumors. So we will not specifically how this works for brain tumor patients hope Lima next two years. Other medications have been tried including antidepressant medications, corticosteroids, donepezil and amantadine and most of these have limited effect advocacy so they are not medications that we were too late recommend for people to take for fatigue because the response has not been seen or it has been temporarily--and there are many others and there is a lot of information that you can, pond but I think there are important questions to ask in terms of can it interact with my other medications? What are the potential side effects and are there any studies that have shown the fatigue for somebody like me. So looking at modafinil and I want to review a couple things a will be a Ford. The first is the most common type is Ritalin. It can cause some agitation and problems with sleep and people that take itself if you are prescribed it is important medication to take in the morning you don't want to take it before bed because it can keep you up. It is a controlled medication and what that means is often times your physician may be able to give you a month supply at a time so this can be an issue with keeping access to the medication going if you are on it for an extended time and modafinil is another type of stimulant medication that can be used it doesn't have the issue of being a controlled substance which means you can get refills on that prescription some people report headaches nervousness and anxiety with this as well and I have listed some standard doses.

>> A related issue for people that have fatigue is increasingly recognized that problems with insomnia and fatigue go hand in hand and people tend to not have one problem without having the other so we thought it was important to talk about your sleep cycle as well and any type of insomnia is perceived or actual alteration with resulting daytime impairment and some people may say my wife or daughter tells me I am sleeping throughout the night that I wake up and I do not feel refreshed I do not feel like I am getting good sleep tonight and I can be a form of insomnia as well and it can still impact you and how you get about your data has been read ported almost 20% of the general population have insomnia and those with solid tumors including brain tumors and we know adults are--survivals of childhood brain tumors those that have radiation and those with a--tends to occur in the base of the brain and things that can be controlled like fatigue and sleep there is more risk for having problems with sleep disorders so there are a number of types of sleep disorders that can occur. People can have movement, restless leg syndrome, you can have circadian sleep disorders, you can have excessive sleepiness but I'm going to focus on insomnia because that is one of the most common problems we see a people with brain tumors. This is information of American Academy of sleep medicine which is important in understanding insomnia and the impact it may have. The first is, there are a lot of types of insomnia you can have insomnia that occurs acutely.

>> Something happens to you, like you were just diagnosed with your tumor, you may have trouble sleeping because you are thinking about what has happened or you can also have insomnia from another medical condition and if you have a tumor or on another medication this can lead to insomnia because of the effect of the disease or the other medication and you can have insomnia that is short-lived or transient or it can become more of a chronic problem and if you see a sleep specialist these are the questions they're going to ask to determine if you have a diagnosis of insomnia and in general you need to have a complaint or difficulty of falling asleep, maintaining sleep or getting up early and you

need to have difficulty despite opportunities for sleep so if you are somebody that has a small child that is waking up frequently that is not insomnia because something else is waking you up. If you have the opportunity but cannot sleep you might have insomnia and at least one of the following conditions occurs and number one is fatigue that difficult with memory and concentration difficult completing tasks at work irritability or anxiety daytime sleepiness difficulty with motivation tension headaches, or thinking a lot about or worrying about sleep so a general you need to have the first two and one of the third to have the diagnosis.

>> It is important to identify and treat the underlying cause and sometimes if you can treat that the sleep and fatigue can get better and you could fix everything by treating the underlying problem. One of the most common difficulties is with timing of medication and in particular the steroid medicines you may have prescribed for you. Prednisone or Dick Adonis prescribed to control brain edema and one of the side effects is that can keep you awake and make you feel anxious if you take these late at night so often times you can adjust the timing of these and have a big impact on your sleep. For example if you have been told you need to take your steroid medication every six hours like they did in the hospital and you are setting your alarm to get up it is important to talk to your healthcare team to see if you can adjust that because often times you can change the timing to where you are taking the bulk of it early in the morning and often times you can sleep better. Medications like Xanax or Valium during the day sometimes can have you--make you sleepy during the day in the new have difficulty sleeping at night and people that have chronic need for steroids because of their tumor can sometimes have weight gain and the type that you can have is increased fat distribution in areas of your body like your neck or your throat or the top part of your back and sometimes with that excess weight gain you can have difficulty with sleep apnea as a consequences of you are having time when you have reduced breathing at night excessive snoring, it is important to see your healthcare professional to evaluate if you have sleep apnea that needs to be treated. If you are sleeping a lot during the day you will have difficulty sleeping at night and we find if you are sleeping more than 30 min. during the day, often you disrupt your cycle at night so you should try to not map an excessive amount of time during the day.

>> Bowel and bladder function isn't ported so if you're someone has to get up a lot at night to go to the bathroom, M.D. you're about-bladder before that are limiting the amount of fluid you drink could help so you don't have that issue and emotional stressors we recognize happened particularly if you are dealing with your disease and treatment and finding ways to manage those structures and some things you can do the first thing is have a fixed bed and wake time. If you have a set time and routine that you do, often times that will help. In edition you should relax before bed. Exercise is important but right before bed tends to not help with sleep. You want to avoid clock watching and a good rule of thumb, if you are in bed for 20 min. and you are not going to sleep, it is time to set up and not turn the light on and to do something restful to do before going back to sleep. It could be reading, it could be meditating, something restful and you should avoid caffeine and exercising--time out to exercise right before bedtime. Some other interventions that have been evaluated, the same cognitive behavioral therapy were you have a session with a trained psychologist in which you talk about management strategies for particular issues. This seems to be effective for some people and maybe health will he have ongoing issues and had done the other things and we have made the effectiveness and meditation, and if you're

considering trying them talk to your healthcare professional and have clinical studies and it will be helpful to you on a larger scale. So reading about how to sleep listening to your tapes. So far has shown not to be effective and is not been shown to improve insomnia.

>> There are a lot of medications you can try for insomnia as well these are a partial listing of sleep aids available for you to try and some side effects and issues to think about. Things like Ativan, Halcion, and one issue with this is you can get a sedation and the hangover effect were you feel sleepy the next day so we try not to recommend the use of the first-line treatment because of the impact they can have on the person on the waking daytime life. nonbenzodiazepine Hypnotics that I have listed have less daytime sleepiness and problems like Ambien, Lunesta, Sonata, and resurrect my medications that your healthcare professional may want to try but some do have some effects. And if we are not going to get a hangover effect from the next day with Lunesta and in particular, high-fat foods can affect the absorption so if you are on any medications be sure to talk to your healthcare professionals about any specific side effects or issues that might be pertinent for you. In terms of other interventions, there have been no randomized controlled trial and oncology that shows one drug is more beneficial than the other say can't say this is the medication that you should take that in general, most people recommend that you start at a low dose and bring it up if you needed and that way you will have less side effects and the benzodiazepine and we don't like to use, early on in long-term it does have the potential for abuse. You should not stop any of these medications cold turkey. Sometimes you can have withdrawal insomnia and you have to slowly taper off the medications that we oftentimes think about everything going on to see if the right medication for them, for example if you are somebody that lives in the Southeast, sometimes an antihistamine can improve congestion which has a secondary effect of improving sleep. There are like with fatigue and other agents that are out there that you read about him people recommend to you. And a lot of these are not designed to treat insomnia but have a secondary effect of making people sleepy or they may not be medications routine medications the more supplement medications so melatonin is one of those it is available in health food stores and online pharmacies around the country and usually the dose is 3 mg but there are differences in brands because it is not fully regulated as other medications may be. See may have an effect with one brand and not with another. It tends to be a medication that works slowly over time. I mentioned anti-histamines in the most common one is Benadryl. Which tends to have a secondary effect of causing sleepiness and controlling congestion as well as antidepressants are often prescribed although we have limited clinical data to support their use.

>> In addition you may read about people using copper, which is a supplement that we suggest you not to use because there has been reported liver toxicity associated with it and the Larry in, a newer medication which has some efficacy with other medical conditions and it takes two or three weeks to see the effects of it is not a medication you can start and see the effect right away.

>> We have begun to explore why people with brain tumors have fatigue and I just wanted to share some of the research we have been doing to concede some of the things with I mentioned earlier 80% of patients during radiation have fatigue and we recognize that has a particular pattern more people get tired near the end of radiation and slowly the fatigue gets better and this has been described in several studies and one thing we are trying to figure out during treatment the fatigue and other symptoms get

worse, we could start the intervention early and make the fatigue not so greater in the course of the therapy.

>> We did a study which we evaluated the patients reporting their fatigue and symptoms, sleep, measuring sleep with an active graph watch they would wear at night and looking at urine and blood test to determine what the underlying analogy was and we had patients report before radiation throughout the course of radiation and after to see if we could identify the pattern or the underlying cause and what we found was that fatigue at the end of radiation correlated with the amount delivered to the part of the brain called the pineal gland where melatonin is produced and we saw this as a very direct relationship between fatigue and radiation so we decided to look at the levels of melatonin in patients undergoing radiation therapy.

>> We found that patients had a very high increase in the level of melatonin around week six and this is around the same time they had the worst fatigue reporting during that time and other symptoms like neurocognitive symptoms during that time so we began to think about this pattern of melatonin production and we know typically in most people you have a peak in the melatonin around 9 PM and then it goes down around the nighttime troughs and circadian pattern to melatonin production and we looked at patients with brain tumors and we just wondered if they had an increase of melatonin or did they have a change in the melatonin to where the level was higher during the day and this is what we found. People with melatonin, it was peaking in the middle of the day which made sense that people needed to take a nap in the middle of the day. So we are continuing to explore this because there are ways we can shift this to get it later in the day their interventions and our goal is to try to improve that so the fatigue doesn't occur at all or is less for the individual patient. So I just would like to say that fatigue and insomnia are, and so you are not alone and it occurs in primary brain tumor patients throughout the course of the disease. It is very, during radiation but it has been reported eight years after people have completed therapy. There are guidelines that exist on how we manage fatigue and cancer and it is important for you as an individual that your healthcare professional make sure there are not other contributing factors such as anemia or nutritional deficit or other issues that can be controlled to make your fatigue better. Often times the interventions are trial and error. We try something to see if it works for the individual person and if it doesn't we move onto the next one even though the data shows certain things like routine exercise talking to someone and finding specific ways to measure daily activities or ways to improve issues with insomnia have been shown to help the general population if they don't work for you talk to your doctor to find an intervention. Don't give up. There are things that can be done to help make it better and we recognize that we really need to focus our studies on understanding symptoms and make it better for people and I hope I have shown you that there are trials looking at medications and supplements as well as trials looking at the underlying biology so we could try to make this better for everyone that is suffering. I want to and by showing some references. These are a number of studies that you could talk about some of the things that I mentioned and with that I will close and I'm happy to take questions.

>> Thank you that was wonderful. A lot of good information. We are going to have time for questions if you have a question you would like to ask type it in the question box and submit it. Using the webinar control panel on the right side of your screen.

>> So we had some come in. Are there any treatment differences for children? My daughter is 11.

>> That is a great question. In terms of treatment for insomnia can be very different for kids for example if some of the medication that I mentioned that we use in adults can sometimes have the opposite effect in children so psychostimulants are often used to reduce activity during the day and have children be more focused which may not improve fatigue and kids so definitely there are different considerations for children. However things like exercise have been shown to be important in children as well for fatigue so the nonintervention medication tends to apply across kids and adults as well as the cognitive behavioral therapy the medications are a different issue and I would encourage you to talk to her healthcare provider if they feel like any of these particular medications would be helpful.

>> Someone had benign tumors removed a armed they are talking about taking Benadryl for sleep and wondering if this is okay to do if they are taking other medications talking about the acid reflux around the neck problems and wondering about Benadryl and other drugs.

>> That is a great question and I don't want to make any specific recommendations to individuals because you always want to consider other medications you are on, other illnesses she may have say you want to talk to your doctor. I can thought you that Benadryl is a common medication that we often use in our practice because of the shorter half-life and the impact on the patient and improving sleep and it is nice because it is available over-the-counter and tends to be fairly reasonably priced but there are some contraindications. People have particular heart conditions cannot take Benadryl. People that are elderly sometimes I recommended not to take it so talk to your doctor but I can tell you it is a common medication.

>> I know you went over some studies but someone mentioned that they were diagnosed with idiopathic hypersomnia. And I did not know if there are any studies related to that.

>> I am not aware of any studies in brain tumor patients related to sleep disorders there are many types of sleep disorders and I chose to talk about insomnia because it is the most common sleep problem that we see. But we know people can have tumors that affect the part of the grain-brain. The hypothalamus, that the two Terry people have tumors in those areas sometimes they can have disorders that result from their tumor and if that is the case it is important to see a sleep specialist so there are physicians out there that specialize in sleep and they are able to evaluate patients and are well-versed in the causes and the treatment and that is a situation where you want to CNX per who sees those particular issues routinely and can make specific recommendations.

>> Okay. Does fatigue or energy level--connected to the location of the tumor?

>> That is a great question. We explored that in the studies that we did so we look to see if tumors in the frontal, temporal, brainstem, cerebellum, there was an impact and we did find that so probably people who have tumors involving those parts of the brain of the center part of the brain probably have more of a problem but that is rare as most tumors occur in adults in the frontal and temporal lobe and most tumors and kids are currently cerebellum and the brainstem we don't find that those locations are associated with fatigue.

>> There is a question about a patient's--and how much sleep is too much? My name talked about short Napster in the day this is realistic for a GBM patient.

>> That is a great question and something that we talk about every day with people so you are not alone in your question. It is dependent on the person and where they are in their disease and the treatment they're going through. When you feel fatigued and wanting to sleep during the day it is your body's way of re-energizing itself and you don't want to totally ignore the need for that so the problem comes in when you sleep too much and you get into a deep sleep during the day and you are not getting restful sleep at night so what we found in our studies with people slept during the day for longer than 30 min., sometimes they were not realizing they were waking up as much as they were so they weren't getting the restful and restorative sleep so a general rule of some that we use is 30 min. There may be a particular time or day when someone is exhausted and they really need a three-hour nap or they need a nap in the morning or night but if your loved one is sleeping, longer than 30 min. every day, it is important to talk to your doctor because there may be things that can be adjusted in medication that can help Laura can make them more awake during the day and help them sleep better at night.

>> Perfect.

>> You talk about radiation and fatigue and people are wondering about chemotherapy and teak and sleeplessness.

>> Great questions as well. Most of the studies in brain tumor patients is during radiation. We don't have a lot of studies with chemotherapy however, many of the larger clinical trials find that fatigue is one of the most common symptoms that patients report and we know from work done with other solid tumor patients, breast cancer and lung cancer that it can happen with chemotherapy and for most people it tends to be cyclic meaning it is worse than they are on the treatment and they have some recovery and they go to the next cycle and the fifth cycle sometimes there is more fatigue than the first cycle so that is something we recognize can occur and it can be cumulative during the course of the treatment and those of the interventions I talk about in turn of planning your day's activities and targeting the objectives you have for that day and focusing on that and asking for help and also exercise can help manage fatigue for the long course of chemotherapy and in addition it is the time when studies are looking at the use of stimulants have shown some effects who is also a time when stimulants can be something to talk to your healthcare provider about if fatigue is an ongoing issue.

>> So there is another question. You recommend only one 30 min. nap a day. Correct?

>> In general that is true. In general. That is true and for the individual they may find that they need more but if you are doing more than one 30 min. nap during the day, it is important to talk to your doctor and something else going on that you can fix and make it so you don't need more than that.

>> Someone writes about his life gets surges that go through her body and it contributes to her fatigue and sleeplessness have you ever heard of this and how did she manage this?

>> There are a list of things that it can be and it is not something I would ignore and anyway it is something I would talk to your doctor about. There are a variety of things that can cause that. For example, people that have a particular type of seizure can present it in the way were they have this type of sensation throughout their body. That is one thing in the list we would think about. People also have other nervous this and can have that sensation as well so if it is happening often talk to the doctor about it because it can be something they can pin point what the cause is entreated. This patient is in remission and having problems saying words correctly. Is this normal? What can she do about it?

>> It sounds like you are talking about aphasia which is saying the words you want to say and although people are doing well and it is great that she is in remission. Sometimes even though the tumor is doing well, the symptoms status of the aphasia stays. Talking to your healthcare professional and they may recommend that you use visit with a speech therapist who is an expert that can give you tips to work with the existing issue with speech.

>> People are very grateful to answering questions.

>> Good. And also a couple of people asking if the slides will be available the presentation transcript yes we will have a posted at our website usually within a couple of days so for those people that asked those questions just know that we will have that under the any time learning section. The next question is about restless leg. There are several different medications for seizures but suffer from restless leg any tips for that?

>> So that is a whole separate diagnosis and not something I covered because it tends to be specific I am hoping if they have restless leg is saying a sleep specialist because they are experts in managing restless leg and is not like there is one thing to do with it it is like many issues where it is trial and error so they try a medication and they increase that benefit is not working they tried the next medication so for you in particular since you mention Iran some other medication it will be a balance between potential interaction with your medication and the impact you are having so if you are not seeing a neurologist or a sleep specialist who has experience in restless leg I think it would be important to talk to your healthcare provider about seeing someone.

>> Have there been any studies regarding a genetic at-disposition and subsequent brain tumors?

>> That is a great question. That is where a lot of the research is going is trying to understand individual person's risk and people with other solid tumors a lot of the work has been done and they have found some genetic changes that predispose to fatigue so seems like there are people that are going to experience fatigue with other types of cancer we are starting to explore that and people with brain tumors so trying to identify who is at risk and also who is at risk for having other side effects from medication like low blood counts or blood clots or high blood pressure so we are beginning to explore that there is not a particular study on brain tumors currently that stay tuned in the next couple of years you'll be hearing about that we have identified what the genetic risk is and in terms of symptoms and the tumor itself so far, we don't have studies that show the same genetic predisposition to cancer also predisposes the person to a particular symptom or toxicity but there are several ongoing studies with

their asking that question. Are there genetic factors that predict who is at risk for the cancer and also does that indicate a risk for particular symptoms? Hopefully we will know the answer to that soon.

>> Exciting. Stay tuned.

>> Also some questions are echoing what we are hearing. They want to know, you mentioned, it could last for up to eight years. Is this a result of the treatment for the tumor and is this how I am going to feel forever?

>> This is a great question and I don't want to mislead anybody to make you feel like if you have fatigue is going to be that long but it just has been reported in people that long and I think five years ago we probably thought you did a treatment and you are fatigue and once the treatment is over you will feel better and there can be some more long-term effects so in general what I would say is that we know there is fatigue with the treatment like that fatigue I talked about with radiation and the majority of people, that gets better so it is not something that is permanent. There are some people who do have their tumor controlled for a long time who continue to have problems with fatigue and other symptoms and we are trying to identify what the relationship is. In our study we found that people that have ongoing issues, neurologic issues such as weakness in the legs may be a risk for fatigue long-term so it doesn't mean you're going to have it forever. There are still some people that have it that wonder why I have it and are trying to understand that and it is probably the reason why some people try to have problems--10 to have problems is related to something about them individually whether it be additional medications they have had to stay on or existing problems that cause it to be long-term. Don't lose hope. I don't want you to feel like I am telling you you're going to be fatigue forever. A majority of people are not fatigue straight years but most people experience some during the treatment and hopefully you can try some of the things that we talked about to minimize the impact.

>> There is a question about gamma nights and wondering if that has any fatigue side effects associated with that.

>> I am not aware of any controlled study looking at that in particular or comparing it to other forms of radiation to see if it is worse. In general, we know that it delivers the radiation to a more focused area of the brains of information I shared about the study where the radiation is delivered to a particular part of the brain that is probably less of an issue because the surgery is delivered to a small area of the brain and also that radiation is given over a shorter time so it is not six weeks that you see with standard radiation that usually it is given in one treatment or two treatments so just overall you would think the fatigue would be less. That doesn't mean that someone who has that is not going to have fatigue it depends on the location of the tumor, how the person is doing otherwise and other medications thereon as well.

>> We will throw in one more question. Somebody experiencing fatigue from the first diagnosis has a reoccurrence and they're wondering how the fatigue symptoms will change and what happens on the tumor grows back?

>> Well. It is hard to tell because for most people when the tumor recurs they have to start another treatment and usually at that point the treatment will be chemotherapy which can have fatigue as a side effect. We know that people with fatigue in a gets worse at the time of recurrence but that may be because they are adding other medications so you may have to go on steroids or increase seizure medicines or start chemotherapy and that can make it worse in the short term but those effects hopefully can be transient for you and related to the treatment you are on and when you are able to get away from the treatment it will get better.

>> That was amazing, Terry.

>> Great questions and great answers and it looks like we will have some nice follow-up so thank you everyone for participating. We are going to posit for a moment and I will stop recording.

>> We invite you to continue to check back at our website [www.ABTA.com](http://www.ABTA.com) for other brain related topics. The next webinar is Wednesday from 2 PM until 3 PM central time it is about fertility concerns for the brain tumor survivor for men and women. It is co-presented and a John Hopkins University this concludes the webinar and please be sure to complete the feedback survey you will receive tomorrow. You may disconnect.

>> [Event concluded]