

## American Brain Tumor Association Webinar

### Patient Advocacy: Pearls for living one's best life

>> Welcome to the American Brain Tumor Association's webinar series. Thank you for participating in today's free educational webinar. Today's webinar is on patient advocacy, pearls for living one's best life. It will be presented by Erin Dunbar. Please note that all lines during our webinar are muted. If you have a question, type and submit it using the question box in the Control Panel on the right-hand side of your screen. Dr. Dunbar will answer questions at the end of the presentation. Tomorrow, you will receive an email 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. Today's webinar is being recorded. The recording will post to the ABTA website shortly. Registered participants will receive the webinar link in a follow-up email message once the webinar is available. Let's pause for a moment so we can begin our webinar recording.

>> The American Brain Tumor Association is pleased to welcome you back to our webinar series. Our webinar today will discuss patient advocacy, pearls for living one's best life. My name is Emily Lippert, program manager at the American Brain Tumor Association. I am delighted to introduce our speaker today, Erin Dunbar. Erin Dunbar specializes in the governance of care of brain and spine tumor patients with primary and the static tumors. A certified provider of MD Anderson Cancer network. She serves as a director of Neuro-Oncology and is a founding position of the Piedmont Brain Tumor Center. Providing a robust portfolio promising clinical trials to serve the needs of her patients across their lifetime is Dr. Dunbar's passion. She serves as a community oncology alliance patient advocacy co-chair as an active member of the following academic societies where she is involved in the care of primary and static brain and spinal tumors, including the Society of Neuro-Oncology American society of clinical oncology, the American Academy of Neurology, and the Georgia Society of Clinical Oncology. Dr. Dunbar is committed to providing the highest level of compassionate care to patients, caregivers, and referring physicians. Thank you for joining us, Dr. Dunbar. You may now begin your presentation.

>> Thank you for the opportunity to speak today. It is a true privilege. There is nothing that I need to disclose other than educational advisory that I do for Celtics and No Cure.

>> I do Neuro-Oncology, medical oncology and hospice care based out of Atlanta, Georgia. One of my passions is being able to care for people anywhere along their healthcare journey. I really do consider the privilege of being someone's care home. I hope that each of you find a care team that you trust to assist you or your loved ones along your lifetime's journey. We are going to start the educational series. Today will be about patient advocacy: pearls for living one's best life. There are three distinct subsets that I felt strongly about sharing with you. The first are the behind the scenes medical pearls that each one of us specialists want to make sure that our patients and their caregivers know. The second is talking about strategies to optimize your interactions or your loved one's interactions with any part of the healthcare team. Third, we want to talk about advocacy and empowerment tips and how to optimize the lives of everyone touched by brain tumors. To begin the first part, we'll talk about the medical pearls -- pearls of wisdom.

>> There has been an explosion of advancement that we are going to talk about. I want to get each of you to make sure that you are talking with your healthcare team to see if any of these are right for you.



The picture on the top right is reminiscent of the concept of early medicine when we were first approaching any type of tumor, whether it was a benign or malignant tumor. We were either going to crudely cut it out, crudely do radiation, crudely give chemicals and hope that it got the job done. Now, we have gone into a much more evidence-based model where we have individual, clinical algorithms for each patient. We utilize not only best evidence, but also incorporate patient schools, wishes, values and the individual information about their body is trying to tell us. We think of this as a hybrid of what we can do to lower the burden of the tumor, whether that is lowering the volume or lengthening the life as we are best able. Equally important, is what can we do to lower the symptoms of the tumor. That may mean memory, cognition, fatigue, quality of life, or someone's functional independence. What this transfers to is a balance between the risk and symptoms of the tumor versus the risk and symptoms of the treatment and how we stack the odds in the patient's favor for the best and longest life.

>> There have been advances in how we understand the imaging of the brain and how we monitor tumors and monitor treatment effects. We have had an advancement in understanding physiology and how that is greatly impacted by a broken blood brain barrier. Naturally, as we are made, we have a watertight seal between the blood circulation in our body and that of our brain. That is helpful every time we get a rusty nail in our finger or a cough or a cold. It does not translate to an infection that will go to our brain. That means, though that if we put IV dye from a contrasted CAT scan or MRI, that dye does not get into the brain to illuminate the brain. In many disease processes, there is an abnormal blood brain barrier or a broken blood brain barrier that may represent the destructive physiology of that space. Surprisingly, when someone has a tumor, that same abnormal blood brain barrier with the leaky dye in the brain maybe an infection, a trauma a stroke etc.

>> Once we know that it is a tumor, it tells us globally where there is a tumor that has created enough population to be able to see a mass or also where the tumor has created enough inflammation and broken the architecture of the brain to cause a leaky blood brain barrier. Once we Institute treatment, we may have additional reasons why the brain is taking up more dye, because we may have caused more inflammation or injury from the treatment itself. That is an important point that hopefully you can talk with your healthcare providers about. Think about how it affects the monitoring of your tumor.

>> Here are a few examples to describe it. We have many different types of tumors that when we treat them, we make the skin look worse before we make them look at her. The pictures that are on the screen are actually coronal images. It is someone in the first part of the picture is post-operative. The lower picture is after they have endured radiation and chemotherapy. That scan at the bottom looks to be tumor progression to anyone of us at first glance, but in reality, backed is the inflammation and cell kill that we tried to create. Instead of thinking that is tumor progression, we treat patients with supportive care and lots of symptoms support. The overwhelming majority of the time that inflammation process calms down over a period of weeks and the scan goes back to looking like the one above it, which was back to baseline state. We call that increase of inflammation and dye leaking in the brain pseudo-progression because it is not true tumor growth. It is reminiscent of the leaky Blood brain barrier becoming more leaky like a picture that I show before. Now I will flip the scenario to the other continuum and say that there are also things that we can do in terms of treatment and medicine that can make this scan look better even though we have not created a biologic tumor kill. For instance, the use of steroids or certain types of anti-angiogenic therapies actually can make the scan look better even when we don't biologically think we have killed the tumor that rapidly. In other words, it is hiding the tumor. These are very important concepts to talk to your healthcare provider about. What is the best modality to image your loved one or your brain tumor.

>> There has been advances in how we think about personalized treatment over one's lifetime. In my personal analogy, which I encourage you to consider, I think about engaging in a relationship with the patient much similar to us beginning to write a novel together. If I lined up a patient of mine and three



other patients that looked similar to them with respect to the way the brain scan looked, they may have a different experience with respect to their treatment chapters. I think that periods of treatments as being chapters in a novel we are writing together. Each person will have a different experience and -- with each one of those. Some of the things that I can do to advocate for my patients and your healthcare providers can do is to add as many pages to each chapter and help squeeze out as many benefit of every therapy as possible. We can be smart and efficient about changing chapters. We are going to talk in the future about how that might be done with tumor boards or multidisciplinary clinics. We always want to maintain many good options for our patients. That might be routine therapies or clinical trials. The binder of this novel is the patient's quality of life. I will often discuss with my colleagues that it does not matter if we have very exciting vaccine trials or other new surgical tools, if the patient is not well enough to get the therapies or they're not desiring to get the therapies, then they do not matter. The binder of the journey is their quality of life.

>> We have advances in pathology analysis or tumor tissue analysis. On the top right, this is reminiscent of how we used to be able to characterize people's tumors. How much tumor looked alive, how much tumor looked dead. What was the basic cell type and personality of the tumor? Increasingly, we are relying on the -- molecular and genetic abnormalities well below the level of the microscope. We are now looking at RNA and DNA mutations in the tumor or other types of cellular metabolic tissues. It tells us much more about how we can best fight the individual tumor. If we think of the tumor type like glioblastoma, you can take 100 patients and they will all have a molecular genetic profile that is different. The molecular and genetic abnormalities are increasingly being used to be able to get an FDA approved drug. In metastatic melanoma in the brain, if you are going to use one class of drugs, you have to have good receptor mutation or you cannot get better drug approved. Furthermore, these molecular and genetic aberrations compass sought treatment for each individual patient and help us select a trial or help prognosis and prediction. The picture down on the bottom right is an example of those two factors. A good analogy of prognosis and prediction is very similar to nature versus nurture. A prognostic factor is something that is inborn in the cell or in the individual. Even if there is external events, it does not change the outcome because it is already faded. That is similar to nature. On the other hand, you have the concept of nurture which is more an analogist to prediction. That means there is some outside external event that can turn the outcome in that individual or tumor cell. You can have examples of prognosis that can affect outcome and things that are predictive. You can apply an external event and change the outcome and be able to predict it. The last comment I want to make about advocating for brain tumor patients is that each one of us are the guardian of our own tissue or that of our loved ones. We have to make sure that our providers are as well. That means prompt and thorough analysis of our tissue. Are the right things being done with our tissue that will give each of our patients the best information to make a real-time treatment decision? Also, only use what is necessary. Don't run every test we can possibly think of. Do tests that are actually applicable to real-time management or will help with the factors that we just talked about. Save the rest for potential future use. We have patients all the time that have brain tumor tissue who have no immediate need for it. But a new marker came up for a new drug came up and we were able to use their older tissue where it was originally archived in the hospitals pathology department to be able to retrospectively test it and figure out that a particular trial or treatment or drug is right for them. Wherever you get your tissue analyzed, consider doing it in a place that contributes that data to a larger research goal. There are some private labs that mostly are in the moneymaking program. There are other places you can get your tissue tested and donate the knowledge to research.

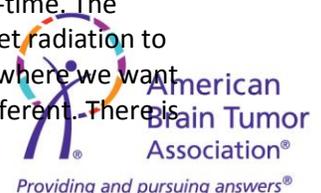
>> I want to talk a little bit about advances in surgical treatment. There has been some phenomenal advancements including intraoperative frozen sections to make sure that we get the right negative margins or help tell us what type of tumor it is early so that we can decide if we need to collect the



tissue subsequently during a surgical experience such that we can make a tumor vaccine from their tumor tissue or be able to get them into a surgical or clinical trial. Maybe we put in wafers or treatments into the brain. Knowing what it is as early as possible helps make sure that we are not doing surgery when we don't need to and that we are maximizing all the value of the surgery and getting the most from it and being able to do a surgical type treatment when we are in the middle of the surgical experience. We can enhance the amount of recession by using things like narrow navigation, where we can create a 3-D model of your CAT scan and your MRI. While the patient and their brain is moving through blood vessel flow and breathing, and the surgeon is being able to touch the brain tissue, then you can be able to approximate that with the imaging. The picture that you see on the left with a blue turquoise ball and the two colored lines that is an example of using functional imaging to see where a tumor is with respect in 3-D space to delicate motor sensory tracts. An important point to know ahead of surgery is if the tumor is invading delicate structures or if it is adjacent to delicate structures or is it just pushing on delicate structures? That makes a tremendous difference in terms of the goals of surgery like how much we can cut out but also it makes a difference in terms of preoperative consenting. Should be done awake? Should be done asleep? What are the outcomes expected? Some pictures on the right are different types of tools and equipment that may be available to your surgeon. Importantly, not all the tools need to be used on every patient. You might have heard that if someone needs intraoperative CT or MRI or someone needs awake surgery. Talk to your neurosurgeon and get a second or third opinion and figure out what are the tools that are needed for my type of tumor. Not everyone needs each one of these.

>> There has been tremendous advances in imaging. Talk to your healthcare team to see if these images help make real-time treatment decisions for you. Sometimes they don't. Sometimes they might be false positives or false negatives. Let's make explain some goals. The pictures on the left are physical MRIs that you see in black and white. They are developing the pictures looking at a surgical cavity and what you see below that surgical cavity as image abnormality. A question comes up of is it tumor growth or radiation treatment or necrosis? Is it an inflammatory reaction? Is it an infection? It is important. The colored picture on the bottom right shows a cold or an absence of imaging. The example to that is that you can have dye leak in the brain or fluid or tissue characteristics be worrisome looking on certain images and then if you develop the picture using the right computer programming and the right sequences, you can get additional images that may clarify what the other ones were trying to describe. The colored picture at the bottom really just describes that even though you see red and yellow and green normal brain blood vessels, there is an absence of brain blood vessels where we are worried there might be a tumor. That shows it instead of being a life by logic area, that area is not alive and more reminiscent of necrotic scar. From pictures on the right, the gray and white one is an example of structural imaging we can do. The next photo is an example of connectivity. If we want to see if there is a delicate structure that we will traverse with a knife or a scalpel or radiation that can be helpful. The third picture is the functional MRI. The fourth picture is the PET and examples of being able to evoke function. If the area of the tumor is area -- near the area of speech or physical motion, that is good to know. The picture on the right often tells us how hot and cold metabolically is a certain abnormality. Is this area a live? Is it dead? Is it growing? It is extremely important concepts. Once again, not all of these imaging legalities are needed for every patient every time. You want to talk to your healthcare provider to see if these are right for you.

>> There have been tremendous advances in radiation therapies. You see at the top, one of the examples of the less claustrophobic machines that can move around each patient in real-time. The pictures along the right-hand column show different dosing strategies and how we can get radiation to go where we want. There is so much of the color. We can paint the amount of radiation where we want it. We can even bend it around structures that we don't. Radiation could not be more different. There is



traction aided radiation. It is done in many different smaller doses. There is one time radiation that can be done in different strategies like stereotactic radiosurgery. Each one of those are specific for the goals of each patient and each tumor. These are worthy of discussion with your clinician. The picture on the bottom left is an example of photons versus photons radiation. I know you have heard about the different modalities. There are two different energy waves that do different things. Neither are better or inferior. It is just about matching the treatment to your tumor and your need.

>> I am going to talk about advances in medical therapies. These pictures are cartoons to describe the treatment that need to be individualized to each person's tumor and treatment. They get called terms like small molecular inhibitors that may affect a particular receptor on the outside of the tumor cell or a marker inside the tumor cell. If the tumor cells DNA as opposed to the rest of the person's DNA, they may need a therapy where we are implanting antibodies to fight the tumor. That would be an adoptive therapy. We can do other types of immunotherapy that are stimulating your own immune system to fight the tumor. That's might be using a sample of your own brain tumor or it might be using a proprietary set of chemicals that mimic the unique features of a brain tumor to be able to stimulate your own immune system to fight the tumor. On the top right, we have examples of anti-angiogenesis therapy where we are trying to not let the tumor go through blood vessels or be able to lock into your brain tumor blood vessels or to be able to normalize the blood vessels so that they have less extracellular leakage of swelling and edema. If the blood vessels are normal, it allows the chemotherapy or other things that we get to get to the tumor tissue without it's leaking out before. Lastly, we have an explosion of nanoparticles in which we have been able to make radiation and chemotherapy and other types of treatments like immune therapy so unbelievably small that not only can we get them to the target tissues better, but we can often use a fraction of the dirt and it is tremendously better tolerated. Each one of these are advances that we are making in medical therapy. Some of the pearls in this situation is understanding the goals, the safety, and the tolerance of each of these medicines. If you are on any of these medicines or radiations or surgical strategies, talk to your healthcare provider about these promptly. Remember that if we are dealing with advanced emerging treatments, your providers are learning about these treatments in real-time just as you are. You can partner with your healthcare clinician to make sure that each of you are learning these technologies as quickly as possible.

>> This is a cartoon to describe the explosion of new ways to get local drug therapies, local radiation therapies and even real-time detection of what the tumor is trying to tell us. Is it sending out signs that it is dying? Is it creating more chemicals that we can measure? We are able now to put microchips in catheters that can tell us things in the tumor bed or dispense chemicals or chemotherapy into the tumor bed. Each one of these are emerging technologies that may be part of a clinical trial for you or your loved one in the future. If you have any questions about how these may or may not apply to you, go to [www.abta.org](http://www.abta.org) and talk to your clinician.

>> There have been advances in treatment modalities. We just talked about surgery, radiation and medicine. Now there is a fourth modality. Now, as we think of each cell, each is subject to gravity. Each cell in our body has a positive and negative charge. Those charges help our cells to do good, normal things like that chemicals to the cell surface to be able to be utilized by the body or make sure that the chromosomes line up for division in mitosis. Tumor cells have a polarity as well. What we have been able to find is that by giving unbelievably low doses of energy, we can ever so slightly perturbed the energy of the cells to get it to act less like a tumor cell. In many times, it won't be able to grow and divide and ultimately go into a death signal and die. We deprive the energy through a noninvasive way by putting a very small non-warning ceramic plate using what is very similar to a Band-Aid. We can put those on the outside of one's shaven head and be able to apply and external, wearable, portable, removable treatment that can be targeted specifically to one's tumor through the use of very sophisticated



computer planning. This can be started in the comfort of your own home. You can have a certified clinician be able to modify and optimize your treatment plan. This is becoming available to glioblastoma patients and those that are newly diagnosed and those that are progress. You can find where a certified provider may be and find out if a treatment like this is right for you or your loved ones.

>> I will now tell you that there have been advances in how we approach helping patients come up with an individual treatment that is right for them. I call it a starting and stopping rule. How do we know what and when to start any treatment? We talked about new treatment chapters. Your clinicians will do everything they can to narrow a treatment down to what is most likely to be equally safe and how it helps the patient feel. Let's say that we have narrowed down five or six options that are equally safe and equally likely to work. There's a lot of other things we need to figure out. Your goals and wishes, the strategy and order of therapy, would one treatment now exclude you from another later, etc.? Is it inpatient or outpatient? How often would you have to do it? What would the cost be to you? Is there a trial you could be a part of? What would be the support needed by other people in your life? Where is it located? Once you go on treatment, there are many tools to help see how you are doing in that treatment and that treatments chapter. This includes bloodwork, health, symptoms, and imaging. Of course, there are stopping rules. Stopping rules include do you want the therapy? Do you feel well enough and think it is worth it? Do you think it is safe? Does your clinician think it is safe? It can be related to the tumor and the treatment or it can be unrelated. It can be related to a general medical flair or a car accident. Is it getting the job done based on the preselected goal of why we started the treatment to begin with? If one of the things are no longer relevant, then maybe it is time to stop that treatments chapter. Are you interested in a clinical trial? A trial is a good idea, but not proven. It is another option for patients and their families. It is not necessarily guaranteed to be a better treatment. When we look at the National Cancer Institute and the clinical trials that have been hosted in America and internationally, and overwhelming number of trials have been negative. Patients either do just as well or less well than the standard. I wake up every day with my entire goal of providing patients options including clinical trials. There is a humbleness to knowing that they are not for sure a better option. They are not right for every patient. The goal is to be able to put the potential role of a trial into the balance of your overall care. Maybe is not right for one chapter. Maybe it becomes good for another chapter. Importantly, there is lots of different types of trials. There are trials that are therapeutic. There are more supportive care. There are other types of trials that your clinicians may ask you to be part of that are ways of looking amongst outcomes of groups or testing your tissue to donate it to science. There are different levels of trials. These are extremely important for you to know. They involve phases. Is their safety? Doesn't show any signs of working? -- Does it show any signs of working? How does it compare to existing therapy?

>> There are many well backed search engines to help you find trials. I want to direct your attention to the ABTA trial connect which is an outstanding resource. There are clinical trials websites as well. I want to talk about strategizing for optimizing interactions with your healthcare team. I want to help you prepare for a new patient visit. Some of the things to do would be to send in your new patient paperwork, bring in all of your doctors names and faxes and phone numbers where you want things sent. Make sure you have medical record releases on hand from where you have been and where you want to go. Make sure that you bring CD-ROMs of your images and that you absolutely have made sure that they have been sent ahead or that you bring them. Make sure that the clinician looks at them themselves. Make sure that the final path report is with your new Doctor. Make sure you bring your insurance cards and your prescription cards. Bring information about your pharmacy and specialty pharmacies and ask about the possibility of talking ahead with a nurse navigator. Are there ballets to help you Park? Are there volunteers or transporters that can help you get around or optimize your visit? Update your contact information often. It is very important that as your cell phone changes or you have



new loved ones who you want to make a point person for your care, make sure that the information is updated in your medical record. Make sure you allow for blocked numbers. Many times doctors try to call patients and family members from blocked numbers through the hospital system. Make sure that your voicemail identifies yourself so that we know it is you so that we can leave a message. If we can't tell it is you or your loved one, we are forbidden to leave a message. Please make sure that your contact information is in all those areas.

>> Prepare for every visit. Have your questions ready or send them in beforehand if you can. I want to direct you to an awesome resource through the ABTA called questions to ask your team. It is a great primer on things you can do to make sure you have all the questions ready to go for your healthcare team. Make sure that you are keeping up with what the timeslot is for your visit so that you can prioritize what you most want to get across. Then make a date through a portal or through a next visit of when you will have the remaining goals and questions addressed. Make sure you know what medicines you need refilled and keep your contact information updated. Review your imaging with your clinician. You can put photos on your cellphone so that wherever you are you have your own recent pictures on your cell phone. Make sure that you request CD-ROMs of your images and ask ahead before you get your MRI done. Make sure that each of your doctors that are important see those images and have a copy. Ensure your provider has looked at your images and is not just read the report. It is only the clinician that can interpret that scan, not just the radiologist. Ask about multidisciplinary tumor boards, especially if you are told worrisome news. Make sure that the collective wisdom about your individual situation and all of your options are available.

>> Use your electronic portal. I can't stress that enough. They are unbelievably helpful to lower the communication challenges between providers, clinicians, and caregivers.

>> Use technology and telemedicine. Ask ahead. Use speakerphone, FaceTime or Skype. There are extraordinarily helpful ways to lower the bar of communication and maximize the information and outcome of your healthcare.

>> I want to talk about advocacy and empowerment tips to optimize the lives of everyone touched by brain tumors, not just patients, but their caregivers and their neighbors and their family as well. I want to encourage everyone to utilize patient centered and caregiver centered resources. Visit sites like [www.abta.org](http://www.abta.org) for social support resources and other online community resources. Look in your community and state for support groups, social media outlets, etc. Some of the examples include fertility preservation, chemotherapy teaching, memory and emotional well-being, or relationship services. Find financial and social services, wellness centers, genetic counseling, cancer screening programs, and survivorship programs. Each of these can be tremendously impactful in a living your longest and best life. Patient and caregiver assistance programs can be available through pharmaceutical companies, pharmacies, they can transcend between accesses to drugs, co-pay assistance and nurse navigators that can help you monitor the safety and tolerance of the drugs once you are on the drugs. You can look of different state, national and local social works or financial assistance. Ask about transportation around the hospital and around the clinic. Ask about other medical associations, civic or community or government resources that you and your loved ones can tap into.

>> Rate your experience. Satisfaction surveys that you sent matter. They can be things that are sent by your provider or hospital, or they can be things that are private surveys. They can also be social media outlets like Facebook and Twitter. Your clinician and your team and your hospital use them for things that make a huge difference in your care. They may impact reimbursement to your hospitals and clinics. They may impact reimbursements to providers such as quality bonuses. The better the job the clinician does, the more they are reimbursed or given a chance for incentives such as more educational dollars. What are the areas of unmet needs that we can go out and be able to enhance services for? We want to serve the community for different groups. They can be used for policy change in committees at the level



of each doctor's clinic. The larger clinic group, the hospitals or state and national levels can be affected. If we hear that there is a trend of an unmet need or a burden or a request or a dissatisfaction, we can channel our energy and our dollars to improve your life. Rate your experience.

>> Vote and participate at the county, state and national level. Know the issues and dates and methods of how to vote. You can do email campaigns. You can be at in person events and vote. It matters. I want to direct your attention to an advocacy site through the ABTA that is a wonderful way to get involved and make a forever positive impact on the care of you, your loved ones and future generations.

>> Donate your time, talent and resources. So many of us come in to each one of our healthcare challenges and it seems like we can't see past it. When we exhale and when the sky is clear, find ways that we can give back and pay it forward in our community. Sometimes it is by volunteering. There are sites through the ABTA the link you up with a fit for you to help with. Consider joining as a patient representative on a hospital or community board. Consider utilizing the things that we have that people don't always use to their fullest like airline and hotel points or gas cards and store cards. Look for avenues to share them for other people in need.

>> We have talked today about patient advocacy. How can patients, their caregivers, and those who love them live our best life? It is partly about medical pearls of wisdom that each specialist wants you to know. It is about how to optimize your interactions amongst the healthcare team. It is about advocacy and empowerment tips for everyone touched by brain tumors.

>> With that, I want to thank each of you for participating and welcome any questions now or in the future. You are welcome to contact me anytime if I can ever be an added value to any chapter in the novel that you or your loved one are writing. Thank you so much.

>> Dr. Dunbar will now take questions. If you have a question that you would like to ask, please type and submit it using the questions box in the webinar control panel on the right-hand side of your screen.

>> The first question I have is what steps should one take if they do not feel comfortable or agree with their doctors suggested type of treatment?

>> That is an excellent question. One of the biggest reasons that can occur is because the clinician has not spent the time to explain what their rationale for that treatment may be. If that exchange has occurred and the patient and their family truly don't feel that it is in their best interest, I strongly encourage each patient and family to feel much empowered to get a second opinion. Clinicians fully understand that life is a team sport. I encourage everyone with grace and full empowerment to approach the clinician and say that you would like to get a collective wisdom. I want to make sure that I have turned over all the stones so that I feel that I'm doing the right thing in this treatment chapter. That clinician should jump at the chance to meet your needs. Should they not, that is a warning system that they are not open-minded to making sure that it is the right decision for you as an individual. Overwhelmingly, as soon as you let that clinician know that you would like to broaden the opinions to get a collective wisdom, it almost always is a benefit for the patient and for the clinician. I encourage you to do that.

>> Thank you, Dr. Dunbar. That segued into our next question. What are some signs that a patient should get a second opinion?

>> If the patient or their loved one feels that the clinician does not have a large volume of experience in the type of tumor that they are being treated for. There are different practice environments. There are different experience levels with different people. Ask how many of these you have treated and how comfortable you feel. Are there people who do just this or similar things that are dedicated to this type of tumor? Another would be if there is just not a good hand and glove fit between the patient and the clinician. If it just is not feel like trust that can be an indication that a second opinion would be beneficial. I would also say that a very important reason is if you are told worrisome news and you are



thinking that you may need to go to a new treatment center, that is a time or pause. That is a time to say unless I am being told that the situation is extraordinarily urgent, then let me take some time to collect my thoughts as a patient and be able to explore what other things might be out there to make sure I am getting collective wisdom myself. Maybe there are three or four options that are excellent options immediately available to you. Definitely experience and sophistication of your treatment team or if you are told worrisome news or whenever you are told that a new treatment may be needed, take time to collect your thoughts.

>> Our next question asks, how does one self-advocate when they are faced with the overwhelming feeling of having too many people offering their opinion or advice? Or as race, too many cooks in the kitchen?

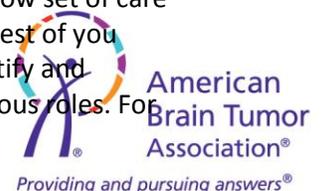
>> That is an excellent question. What I share with my patients and their families are that there are so many people who authentically think they are being helpful. That can do a few things. It can what a patient or the family into PTSD where they have to update or justify or defend what they are doing. They are updating everyone else and they are fatiguing themselves by sharing all of this information all the time. Quiet the madness. Get into a team of healthcare workers and a smaller set of friends or family that you trust. Tell everyone else thank you for your well wishes in your prayers. If you would like an update on what is going on in my life, you can go to my Facebook page and get updates and find out ways you can help me. I will not be individually corresponding to each message I get. I tell a lot of my families to put an out of office message or an automatic reply on a voicemail or email. Try to say that you will not be returning individual correspondence. This is how you can find out what is going on with me. Keep the A-Team type of people that you trust that you can utilize to help make sure that you're making the right decisions close. You are absolutely right. Too many cooks in the kitchen is similar to analysis paralysis. You barely can move forward. It is tremendously fatiguing, scary, and unsatisfying.

>> Thank you. Our next question asks, regarding the treatment team, what is the difference between a neuro-oncologist or a medical oncologist and is one preferred over the other?

>> That is a wonderful question. A neuro-oncologist has done a fellowship program in diseases that affect the brain and spine as well as the symptoms and other nuances that come along with the treatment of patients affected in those organ structures. They can come from the backbone education of neurology or the backbone education of medical oncology. They meet in the middle for the higher-level training. There are fellowship programs around the country that will allow either or both into their training program depending on how the training program is structured. Everyone comes out of the training program equally qualified. I do also want to share that radiation oncologists and neurosurgical oncologists also have the opportunity to have done dedicated sub fellowships or have been able to get extreme experience in the care of brain and spine tumor patients. The goal is, even if you are able to get your care routinely in your community and it is not a dedicated brain or spinal tumor specialist, consider periodically being able to interface with a brain and spine dedicated specialist at least every few months or when a treatment decision is being made. In general, I am a huge advocate for getting as much care as you can as close to your home community as you can. That is right for everyone in so many different ways. Being able to periodically check in with experts really is the perfect balance of helping the patient and their caregivers get the best possible care.

>> Your answer has segued into our next question. What do you do if your neuro-oncologist perspective is limited to just treating the tumor but not the person as a whole?

>> That is a very common scenario where the Neuro-Oncologist is very focused on a narrow set of care goals. Sometimes, that is the piece of the puzzle that they can provide to you. All of the rest of you matter. I would approach through them or through another specialist in your life to identify and articulate the other things that you would like carried out. Other clinicians can serve various roles. For



instance, there might be a neuro-oncologist trained in neurology that feels comfortable taking care of seizures but is a medical oncologist who may not feel as comfortable as taking care of your memory trouble. They could refer you to a neurologist or make sure you can see one on the same day, etc. Sometimes clinicians see patients more innately from a 360 degree perspective. Some take a more narrow view of how they care for patients. The most important thing is that you get all the care that you need. Sometimes, that means that print clinicians -- different clinicians take different parts of your care forward. You may have a clinician expert in the symptom directive care or you may have an ophthalmologist or a counselor or a memory specialist. It is really about identifying and articulating what your needs are and what the things you would like in your life and working with the providers that you had to make sure that all of your needs are met.

>> Thank you. Our next question asks, do you think there is an advantage to getting radiation from a facility that treats many brain tumor patients rather than one that is closer to home that treats fewer?

>> That is a wonderful question. It is very specific to the individual person's tumor. This is a great example of what we would consider a one-time radiation second opinion. Let's say you are contemplating getting a particular type of tumor radiated and you live in a community and you are not sure if that is where you want to get it done. If you ask your clinician if you can go to a closer place where there would be subspecialty care whether at an academic center or a high-volume brain tumor Center, what would your recommendation for radiation be? What would your treatment protocol be? Can you tell me if you feel that that recommendation could be done in my community? If so, would you be willing to share your protocol and your recommendations with my local radiation oncologists and be available to them as needed? It is a win-win for both of those radiation oncologists. That way, at the end of your treatment or the times of radiation is being evaluated with post radiation treatment scans, you may elect to go back to that radiation oncologist at that subspecialty Center for an evaluation of the monitoring. If that clinician says I really do want you to get care for your brain tumor with radiation at a specialty center or a high-volume brain tumor Center because and they articulate why, your ability to get treatment there could provide you with a clinical trial or your ability to get treatment would give you an a bit -- an entire portfolio of other services that you could do at the same time that would benefit your tumor treatment. There are support groups, dietary therapy, and other specialists that you could utilize during the time you are getting your radiation. Hear it from them so that they can tell you where is the best place to get radiation. A similar analogy would be for where you get your chemotherapy, whether or not it is a trial or routine treatment or where you get your surgery. It is about getting a second opinion and asking each of those different providers in fact relationship and saying why here or why there and what would you do if you were a member of my family? Really make them articulate what their best recommendation is to you.

>> We have time for just two more questions. The first one asks, what question should patients ask of their treatment team when faced with a reoccurrence signaling that the first treatment type may not have been fully effective?

>> This is a very common dilemma. Almost all tumors that affect the brain and spine are technically things we don't think of as one and done treatments. They may or may not be listed as things that are palliative, but ultimately, we are in a lifetime continuum with our patients. Almost every one of our patients are faced with a potential war real -- or real recurrence and progression. Westerners to ask at that time would be what are my options? What are my best tools at this time to fully optimize my treatment fight? The PowerPoint that I had with the starting rules, that is an excellent example of some of the questions. What is the general science? What is the general safety? What are my goals and wishes? What about the logistics and cost to me? What about the order or the politics of therapy? These are all very important questions. You want to get a sense of what this means for me and my Outlook. Is this going to change my future health and well-being? These are important questions to ask.



very important question to ask is this a recurrence or progression? Could it be pseudo-progression? That is when multidisciplinary tumor boards or virtual tumor boards or second opinions can be priceless. There are many times that the first information that you get may not be the ultimate final collective wisdom.

>> Thank you. Our last question asks, is it equally important for patients to share how well they are doing in comparison to the possible challenges they are facing?

>> That is a very important point. We know that all patients and all tumor types and all states of health and wellness, a more positive attitude and eating for health, daily activity and exercise, lowering your stress, improving your emotional well-being, improving your motivation and your sense of self, all of those are strongly correlated to an improved outcome. It is important that patients and loved ones are able to share and express their joys and their improvements just as much as it is to report symptoms or wonder or worry. Those are not only important to your healthcare team, but we want to celebrate them with you. They improve our sense of well-being. We also want to track the positive systems and outcomes just as we want to know if there is a new trouble brewing. I think it is important for patients to share their stories living with their tumor. A lot of times, if you go in the general Internet, it is full of a lot of things that sound very scary and worrisome and hopeless. If we share positives with our symptoms and our tumor fight, that bolsters all of our commitments to living our longest, best life and creates an environment in which patients and their clinicians have the optimal opportunity to work together.

>> Thank you. That is all the time we have for today. Thank you all for joining us today and thanks once again to Dr. Dunbar for her wonderful informative webinar presentation. To help connect patients and caregivers with information and resources that can help support them in the brain tumor journey, call the ABTA Caroline which is staffed by caring professionals at the number on your screen. 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](http://www.abta.org) for the library of free, on-demand webinars that feature experts addressing a range of brain tumor topics from treatment options and tumor types to diet and coping with a diagnosis. Our next webinar will be on Tuesday, June 28 from 1 PM until 2 PM Central standard Time. It will be on advancements in glioblastoma treatments including tumor treatment fields. It is sponsored by nova care and will be presented by Richard Peterson of HealthPartners Neuroscience and Cancer Care Centers. Please check back for more information on this and other upcoming webinars on [www.abta.org](http://www.abta.org). Join us for our partners in treatment and care, the American Brain Tumor Association's one day educational meeting held in communities across the 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, receive guidance on managing symptoms, and to network with each other. To register, or for more information, visit [www.braintumormeetings.org](http://www.braintumormeetings.org). Again, that is [www.braintumormeetings.org](http://www.braintumormeetings.org). Another event coming up is American Brain Tumor Association's 2016 patient and family conference. It is called the precision medicine and its impact on brain tumors. Low-grade, high-grade and Metastatic which is a groundbreaking opportunity for patients, families and caregivers to learn about the latest advances in brain tumor research, treatment and care from leaders in the field. Join more than 250 patients, caregivers and healthcare providers, researchers and others on July 29 through July 30 in Chicago. To register or for more information, visit the website on your screen.

>> This concludes our webinar. Thank you for joining us and please be sure to complete the evaluation survey you will receive by email tomorrow. You may now disconnect. Thank you.

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