

## Caregiving & TBI: What You Need To Know

**Moderator:** Doris McMillon **Panelists:** Carolyn Rocchio, Sarah Wade, and Dr. Nathan Zasler

**Video Link:** <http://www.brainline.org/content/multimedia.php?id=955>

**Voiceover:** I remember the explosion and waking up on the ground and needing someone to come, come to my aid. Then I started thinking, man I can't die cause my fiancé is going to kill me...

**Doris McMillon:** What's it like to care for a loved one with traumatic brain injury where can caregivers turn for help, find out what care giving is all about next on Brainline.

**Voiceover:** BrainLine is funded by the Defense and Veterans Brain Injury Center, the primary operational TBI component of the Defense Centers of Excellence through the Henry M. Jackson Foundation for the Advancement of Military Medicine.

**Doris McMillon:** Hello everyone, welcome to Brainline, I'm Doris McMillon. This web cast is part of the series of programs about preventing, treating and living with traumatic brain injury or TBI. Today we look at how TBI affects not just the person who is injured, but also the family members and friends who are caring for someone with TBI.

Joining me on our panel is Carolyn Rocchio. Carolyn is a nationally recognized advocate, author and speaker in the field of brain injury. She wrote her memoir, "Ketchup on the Baseboard" about her experiences caring for her son Tim after he sustained a severe TBI in a 1982 car crash. Tim is now 47.

Also with us is Sarah Wade, Sarah is a caregiver for her husband, Army Sergeant Ted Wade, and a mentor for the Wounded Warrior Project. In 2004, Ted was severely injured in Iraq when his Humvee was hit by an improvised explosive device. He sustained a severe TBI that left him in a coma for two and a half months. And I believe that Ted is here with us today in our studio audience, welcome Ted.

Also joining us is Dr. Nathan Zasler, he is an internationally respected neurorehabilitation physician, specializing in brain injury care. He is the CEO and medical director of both the Concussion Care Center of Virginia and the Tree of Life, a transitional neurorehabilitation program and long-term assisted living program for people with acquired brain injury.

And I want to say thank you to everyone for joining us today. We'd also like to welcome our studio audience. We're going to reserve time at the end of the hour for a question and answer session with our panel. But Carolyn let me start with you, let's start with the basics. What do we mean when we say caregiver?

**Carolyn Rocchio:** A caregiver can be anyone who assumes primary responsibility to meet the needs of an injured person, insure their well-being. But anybody can be a caregiver who chooses to devote that time and effort to that cause.

**Doris McMillon:** Alright, what has... what does it mean to you to be a caregiver and if you would just kind of give us your story in a nutshell?

**Carolyn Rocchio:** It's been very rewarding... people question why you say that but I think over the years you've learned so much and it's been, you've met so many courageous people, it's been very rewarding for me and it's really given me a whole new outlook on living each day as it comes.

**Doris McMillon:** Yeah and I think a lot of people think of an adult child caring for an elderly parent when

they think of caregiving. How is caregiving for someone with a TBI different?

**Carolyn Rocchio:** It's very different and having had some experience caring for my elderly mother, it was a very gradual descent... in which I assumed responsibility for some of the things that she needed. But it's one moment in time that your life changes forever with a brain injury. You have no prior experience and there's no preparation for managing a brain injury.

**Doris McMillon:** Now what happened with Tim?

**Carolyn Rocchio:** Tim was injured in an auto crash, he was a passenger... just three blocks from home. Little horseplay on the part of the driver, he was thrown out of the car, he ended up in the grass. He was in a coma for three months, 42 days on the critical list, had five major fractures, the entire skull was eggshell fractures.

He lacerated a right optic nerve so lost vision in one eye, multiple bodily injuries that weren't even addressed initially, tracheostomy, gastrostomy for nourishment. Later a ventricular peritoneal shunt to drain the excess fluid from the brain. But gradually at about three months he began to awaken and we transferred to an out-of-state rehabilitation facility where he began to progress.

At five months he uttered the first sound that he made and six months he was able to stand and support himself and then he walked at eight months. So we... it was a gradual recovery. Later he spent time in a rehab out in California where the goal was very different. It was to reach an optimal level of independence which unfortunately Tim is not independent but has wonderful skills that make him less dependent on me.

**Doris McMillon:** Right, if you would, give us a broader picture of who is sustaining brain injury and then who is caring for them?

**Carolyn Rocchio:** Well the CDC estimates there's 5.3 Americans current living... currently living with brain injury and then you add to that the number of military that are returning from theater and we have a huge population with a variety of needs, both physical, cognitive... the needs are just overwhelming. And those who have support systems wives, mothers generally do much better. Those unfortunately that don't have the support they need are going to end up in nursing homes... adult living facilities, unfortunately some in psychiatric facilities and the judicial system.

**Doris McMillon:** Okay well you've got your parents, your partners, your children, your siblings, who decides who gets to be the caregiver?

**Carolyn Rocchio:** Well I... I don't think it's a decision that... it has to be carefully made because it is a full-time commitment. I think usually it ends up mothers and wives, after all we're the nurturers.

**Doris McMillon:** Right, obviously every brain injury is unique, but what are some of the common features of taking care of someone with TBI?

**Carolyn Rocchio:** Well it's very different, as you say, it's very unique. I mean some require a great deal of physical assistance with bathing, toileting... all their activities of daily living, while others may regain their activity of daily living, but because of cognitive disabilities, require so much more effort to keep them safe, to keep them appropriate.

So the needs can... and also you can deal with both, the physical and the cognitive.

**Doris McMillon:** How does someone learn how to be a caregiver?

**Carolyn Rocchio:** It's on the job training... and it's a lot of common sense, you know it's not rocket science, but I think you must learn while you're in the setting, the medical and rehab settings. You got to ask questions and believe me the squeaking wheel gets the oil. You have to do your homework and the more you learn, the better equipped you are to do what needs to be done.

**Doris McMillon:** I guess those first few days and weeks when Tim had his accident were pretty overwhelming for you. What would be the most important initial step for a caregiver to take?

**Carolyn Rocchio:** Look at your insurance, look at the funding source because that's going to drive the whole boat and then when you first come home, you have another critical period because I think most people kind of enjoy a honeymoon period where you've been in hospitals for so long, you're so anxious to get home. Once you get home... you better be prepared because the honeymoon doesn't last long. You need a good structure in place, you need to have everything done before you get home and establish who's going to be in charge.

**Doris McMillon:** Now if your child has a TBI, how do you make sure that your other children get lost, I mean how did you handle that with Tim?

**Carolyn Rocchio:** Oh it wasn't really an issue in our family, Tim had an older brother and a sister that was still living at home and another sister that was in an out-of-state university. It waxes and wanes; my youngest daughter didn't deal, she wasn't ready to accept what happened to him. But ironically she lived with him in a condo for a period of time, so that changed dramatically. My older son who witnessed the accident and found his brother in the grass, simply just walked out of ICU one day and said he's never going to wake up and I can't deal with this.

And it took him a long time to begin to accept. Now since my husband died 14 years ago, the two boys have worked together in a little business I've been able to keep, so you know, it changes. They adapt and they adjust.

**Doris McMillon:** Okay, after you look at the insurance, how else can you educate yourself, I mean right from the beginning, about your loved one's injuries?

**Carolyn Rocchio:** Well education is empowerment and if you have some power, you can get the things done you need to do. And I think everyone should resource the best they can, ask questions. There's a wealth of information on the internet, you just got to be careful about the credibility of some of it. A lot of printed material, the Brain Injury Association has expanded so dramatically from 1982 when there was so little available at the time, but education is the key.

**Doris McMillon:** Now what's the range of knowledge that a caregiver will need to develop, what the areas they need to look at?

**Carolyn Rocchio:** A little bit of everything. In addition to the medical aspect, the... financial, the legal, the psychological, it's an injury that affects every aspect of your life.

**Doris McMillon:** Let's talk about caregivers and how they should handle aggressive or other inappropriate social behavior from their loved one who sustained a TBI.

**Carolyn Rocchio:** You got to have strategies, but first, before you develop strategies, you need to know your particular family member's preserved abilities and their areas of deficit. If you know what they're capable of doing, you don't want to exceed their capabilities and result in a failure.

I have a lot of strategies that I use with Tim and he can be very inappropriate in social settings. We do a lot of rehearsal, role playing and because he went through a period which is not unusual, like three to five years post injury, when he became very unhappy with his life, his awareness had improved, he had more insight into his situation.

And he didn't like it and he often ran away and I ran with him always, about six feet behind him. But he wouldn't let me near him, he would get angry until he finally... the frustration level came down. But what I did about that is, he could walk independently in a very prescribed area.

If he got out of that area and was... because he has a wide bait cerebral gait and his slurred speech, I thought he might be accused of being on drugs or alcohol. So I did a story on a picture and I took it to a police station and I did in-services for the three shifts of police.

In other words, you know, you want your children to be friends with the police.

**Doris McMillon:** Right.

**Carolyn Rocchio:** And if they ever saw him out of the area he could walk, they would stop and say, hey Tim, you want a ride home because if they had stopped him and accused him of drugs or alcohol, he would have become confrontational. So a lot of strategies, we have hand signals that help redirect him if I see he's becoming inappropriate.

Aggression, we've been through that too and you get through these things.

**Doris McMillon:** Right and you've been very strategic.

**Carolyn Rocchio:** Well, very structured household, everything is... is structured, all meals are at set times and we have some flexibility, but we're very structured and he cannot initiate so it helps him with that kind of structure.

**Doris McMillon:** Okay, thanks so much Carolyn. Dr. Zasler, let me turn to you. What kind of correlation is there between the quality of care that a person TBI receives from family and friends and that person's long-term outcome?

**Dr. Nathan Zasler:** Well again, I think it depends on the patient as we've discussed in prior to coming on the air. There's a great difference and across patients and a great heterogeneity in brain injury itself. So you can have people who able to walk independently, but have cognitive impairments as Carolyn was saying, who may have visual impairments or judgment impairments.

And other people who are fully dependent for care, but cognitively quite with it. So there is quite a range and those are just two examples at the extremes of the spectrum. So I think that as a general answer, my response would be that the more support one gets, whether it's from family, significant others, or even caretakers, regardless of whether it's facility-based, home-based, wherever, I think the better in general people do if it's positive support.

Obviously if you have people there who are living with you who aren't really involved with your life, who aren't really encouraging you to remain motivated, to remain hopeful, I think that's not a positive even if you're living with family. So family as caretakers, regardless of location, who can provide those kind of positive supports, generally what I've found over the 20 plus years I've been doing this, is that only serves as a plus in terms of getting people further faster and maintaining gains that are made during the rehabilitation process.

**Doris McMillon:** Okay, Sarah let me turn to you, I can imagine that this could be motivating, knowing that what you do has impact or does it feel like to much pressure for some people?

**Sarah Wade:** I think sometimes it can be too much pressure, I think being a caregiver is a lot of pressure, knowing that someone's well-being is riding on your shoulders. I think probably what's more difficult is that sometimes helping others or being an advocate is a luxury because people are so bogged down taking care of their loved one, they don't have time for that sort of thing.

**Doris McMillon:** Okay, well I want to say thank you to everyone and we're going to be hearing more. What we're going to do now is take a look at a critical connection for anyone dealing with TBI. This clip comes from Understanding Traumatic Brain Injury, it's a video produced by the Defense and Veterans Brain Injury Center. It shows the powerful impact that a mentor can have.

**[Video]**

**Voiceover:** TBI awareness and education are key factors to a successful recovery and have proven to diminish symptoms and anxiety for patients. Often the best advice comes from someone who's been there.

**Lt. Col. Tim Maxwell:** I do remember walking, I was in that tent. Did I tell you I was in that tent? I remember walking out into the impact area.

**Lt. Col. Tim Maxwell:** I tried to talk to youngsters sort of different level, I'm not a psychiatrist, I'm not a chaplain, I don't talk about... anything except I tell them about my frustration.

**Voiceover:** Marine lieutenant colonel Tim Maxwell knows about the trials of injury and healing. Almost a year and a half ago, he sustained a penetrating brain injury while stationed in Iraq.

**Lt. Col. Tim Maxwell:** We Marines and most sailors, soldiers, airmen, not something you want to complain much about, being wounded, particularly when friends of yours are killed or you've seen multiple guys who were wounded way worse then you.

**Voiceover:** Still on active duty, Maxwell now spends much of his time visited wounded at military hospitals like Bethesda and McGuire Veterans Medical Center in Richmond where he spent much of his early recovery.

**Michael Yochelson, MD LCDR:** Helping patients and families to understand what is ahead of them, I think is probably one of the best things that we can do for them.

**Voiceover:** As a career Marine and officer, used to leading others, Maxwell now struggles with his new limitations.

**Lt. Col. Tim Maxwell:** You never get 100 percent normal and it's very difficult, people have a very hard time notifying that there's anything wrong with me. So... I go to McDonald's and I want to order a cheeseburger, I can't remember the name cheeseburger and I... the other day literally I could not remember, I say French fries.

**Shannon Maxwell:** He has high expectations for himself and others and... that's been a big frustration because he's not... he doesn't feel like he's the Marine that he was, although I see it everyday when he goes and he talks to a younger Marine who's wounded, whether it's a brain injury or a missing leg, he's able to connect with that person and motivate them and lead them.

**Melissa Shaylor:** It really helped to meet Colonel Maxwell who was an inspiration for us. To see that they've went through this actual... trauma and they're returning more to a normal life. It gave me hope, it was... it was something that was really needed.

Not every day's easy, we just take it one day at a time until then, you know, just wakeup smiling everyday, lucky that we have another day together.

**[Studio]**

**Doris McMillon:** Well Dr. Zasler... you've got nearly 25 years of experience in the field and you're currently the chair person of the International Brain Injury Association. From your perspective, what role can a mentor play in helping caregivers?

**Dr. Nathan Zasler:** I think mentors can play a very valuable role, again I think we need to distinguish between a peer mentor and a professional mentor. Certainly in most contexts where peer mentorship is present, there's a training process, so you don't just go in, naïve to the process, and expect somebody to be able an effective mentor.

But generally in the context of an acute care setting where someone's just injured, I think peer mentors can play a very valuable role in decreasing anxiety, educating families and loved ones, significant others, about the process, some of the things Carolyn spoke to earlier.

So I think that can be a very positive phenomenon in their early setting. As you move along through the continuum, there are different issues that people face and peer mentorship can continue to be helpful in terms of guiding people through those different points in the continuum because there are different challenges along each of those points, including over the long haul, once people are hopefully back in community and trying to reintegrate within their own communities.

I think professional mentorship really is a separate kind of issue and deals with more education about medical phenomena such as prognosis, what the medical process involved in caring for a patient who is the loved on in question might be and that will be different depending on the injury and the... specifics of that injury. But typically in most of the settings I've been in, that's typically a nurse-educator who provides that kind of professional mentorship.

**Doris McMillon:** Okay, let's more about the medical team, how should caregivers approach the relationship with the doctors?

**Dr. Nathan Zasler:** I think this is a very important question because over the years, I certainly and other physicians, certainly get the sense that often families feel like physicians are omnipotent and omniscient and that we have all the answers. And the reality is that we don't.

And I think it's important for people to realize that there is a knowledge that we do have, but there are limits to that knowledge and that includes our ability to say whether someone's going to live or die, at a very basic level, to what someone's outcome is going to be after a significant brain insult.

I think it's very important for people to know that they can ask questions and physicians should be accountable to the care of their patient by making themselves available to answer questions. And when you have physicians who don't do that, I think they're not standing up to their accountability, given their role as a healthcare professional.

**Doris McMillon:** So let's, if you would, tell us about the holistic approach that you take and then how a doctor like you would interact with caregivers.

**Dr. Nathan Zasler:** Sure, my background is in physical medicine and rehabilitation. Philosophically I think the... basic tenet of that subspecialty is really looking at a person holistically as a whole person, understanding that brain injury affects various aspects of function and approaching care for more, of what we term, now to sound trite, a bio-psycho-social approach, understanding the biological implications of the injury, the psychological and the social, is important.

And... in order to do that, one really needs to one, take time in order to get that information, understand that one is not just there to prescribe medications or therapies, but really be... an asset to the patient by looking at all those components that really are important in reintegrating people into the community and their family.

**Doris McMillon:** Now what are the biggest challenges that you see that doctors and caregivers face... trying to work together?

**Dr. Nathan Zasler:** How long do we have?

**Doris McMillon:** Not that long.

**Dr. Nathan Zasler:** I... I think that as a short answer to a complex question, the biggest issue is that with severe injuries... like many that we see and deal with on a daily basis, there are often multiple physicians and healthcare professionals involved. And oftentimes that kind of divergent care isn't particularly productive and in the best interests of patients because you have multiple physicians prescribing therapies, medications, making recommendations, giving opinions.

And that often leads to disparate information and recommendations being provided. So as much there can be convergent care and if it is divergent, communication between the different treating healthcare professionals, I think that optimizes the quality of care being given as well as decreases the level of potential risk for complications, confusion and... anxiety on the part of the caretakers and the patient.

**Doris McMillon:** How would you suggest that caregivers deal with the medical staff who may not be as willing to answer questions and explain things?

**Dr. Nathan Zasler:** Well that's again a challenging question, I think one needs to go to resources that are responsive so if someone that you talk to isn't giving you the answers you think you deserve, you need to go higher up the ladder 'til you get those answers and not stop 'til you have the answer that you want.

So I think part of it is an issue of the degree of persistence and advocacy that the family member can muster and not just settling for we don't know or I'll talk to you later.

**Doris McMillon:** Exactly... I think one other point of contention between care givers and doctors is that word hope, talk to us about hope.

**Dr. Nathan Zasler:** Sure... it's always been big on my list of important things. I think that... how one approaches care as a physician is important and the degree to which one can continue to inject hope in the context of comments about prognosis, progress is very important because once you remove hope and say, he'll never walk again or he'll never talk again.

One, we don't have the knowledge to be that dogmatic about prognostic opinions. Two, when you do that, you take away a large degree, not just of hope but of motivation. And I think both hope and motivation are very important in the context of expecting continued ongoing progress.

And I think the patients that I've seen do best over the years are those who have maintained optimistic but realistic attitude about their injury and their potential for improvement as well as families who have continued to maintain an optimistic view. And that helps maintains motivation in the injured person.

**Doris McMillon:** Okay, let's talk about depression. I think for people with TBI as well as the caregivers, it's seems like a... a very natural, a very common response to a time when everything is changing. How do you counsel families on dealing with depression?

**Dr. Nathan Zasler:** Well as you said, I think it is a common phenomena, there are different types of depression, certainly in response to seeing a loved one injured catastrophically, reactive depression in caretakers is common and it can be more acute or it could be longer term after they realized that someone's not improving the way they thought they would and... the message sort of hits home, as been mentioned earlier, then you may see that even several years after the injury in a caretaker.

Within the population of patients who get brain injured, depression is probably most common in the first year to two post injury on an organic or brain injury basis and ultimately it needs to be recognized by the people taking care of that patient and addressed through not just medications but also non-medication interventions such as psychotherapy which has been shown to also be effective even in people with brain injury.

**Doris McMillon:** Now one of the caregivers key roles is to assess the medical care that their loved one is receiving, so how does a caregiver know when it's time to search for a new doctor or a new team?

**Dr. Nathan Zasler:** No easy answer to that one, you're asking me good questions. I think that certainly one should feel free to look for other opinions and get other opinions. Many physicians have a problem with patients requesting second opinions, but I think you have a right to do that as a caregiver, as a patient.

And all too often physicians take that as a slap in the face to their own opinion, but I think ultimately we as physicians need to facilitate those kinds of requests not in anyway inhibit them. I think that we need to encourage people to educate themselves and some of the resources have been mentioned already.

So if you see things about new treatments for... for example vision loss or perceptual impairments, you need to broach those kinds of questions to the treater and if the treater's not aware of that intervention, they need to refer you to places where you can get information about that treatment.

**Doris McMillon:** Okay, Dr. Zasler, thank you. Sarah, let me come back to you. Ted had an incredibly complicated medical situation, which included amputation along with its severe TBI. So what strategies worked for you best in trying to sort through that medical maze?

**Sarah Wade:** It's still incredibly complicated. I think currently Ted has roughly 15 people involved in his care right now. I think the most important thing for me to admit was that there weren't enough hours in the day for him to do everything everyone prescribed and again I think this is what Dr. Zasler was talking about, that it's really important to get teams to work together and talk to one another.

Each individual involved in Ted's case seems to think their area is the most important.

**Doris McMillon:** Of course.

**Sarah Wade:** And that's not necessarily always the situation. Finding a good physician if you can, a good physiatrist to take the lead and prioritize is every important. And sometimes it means just keeping a laundry list of what needs to be dealt with and deciding in each phase of recovery, what is more

important and what can take the back burner for awhile and come back around to those things.

**Doris McMillon:** Okay, Carolyn let me come back to you. What can caregivers do to help their loved ones' doctors do a better job?

**Carolyn Rocchio:** You have to be a very good informant. A lot of people don't like to discuss some of the issues they're dealing with that maybe in areas of inappropriate behavior, things like that when you need to be very honest with your physicians.

**Doris McMillon:** Alright, well I want to say thank you all and we're going to move on. For caregivers, rehabilitation is the path to having their loved one re-enter the community. I want to talk about strategies for re-integration in just a moment, but first let me introduce you to Arlene and Alan.

This next clip was produced by the University of Washington TV and we want to say thanks to the University of Washington's Living with TBI Program, we're able to see a bit of what it's like to care for someone who's living with a traumatic brain injury. Let's take a look.

**[Video]**

**Arlene House:** How many?

**Allen House:** Nine biscuits.

**Arlene House:** Nine biscuits, okay. So I'll get the milk out.

**Voiceover:** The success of treatment depends a great deal on the individual and of course on the nature of the injury. Another important factor is support from friends and family.

**Mary Pepping, PhD:** Coping with this kind of injury is one of the toughest things any person could ever be asked to do because they're really coping with an alteration in such basic components of who they are as a person that it creates a... a huge challenge to their identity, as a human being, and their sense of meaning and value. It can challenge all of their roles within a family and in the community and in a workplace.

**Allen House:** Place on a surface, generally sprinkle with Bisquick...

**Arlene House:** Okay, so I've got the board over there for you.

**Voiceover:** It's been four years since Alan House crashed his motorcycle, his helmet saved his life but it didn't entirely prevent brain injury.

**Allen House:** Short term memory comes and goes and... when it goes, something else fills it up and then it goes. And it's hard to recall... what was there before. And she has been very good in keeping me on track to do different things... she... uses a computer to print out a list from our calendar that today is Tuesday and at 10 o'clock you... walk the pups.

At 11 o'clock and on, when you eat lunch and take a rest and... so that gives me an idea of what... what her expectations are or what's on the schedule for the day and... sometimes I stick to pretty close to that and sometimes I don't.

**Voiceover:** Alan always remembers that he's loves his wife Arlene and they both love their pets. The strong bond they share has made it possible to work through the changes in Alan and in their

relationship.

**Allen House:** I was depressed because of the accident and how it had affected me and... I didn't want to be a burden. I know that I made her feel bad a lot and I found that the worst thing that I could do was say that I wish I was dead because she didn't like that. But it was a real thought that crossed my mind because... I didn't feel good about myself at all.

**Arlene House:** He certainly has gotten better... but it's been... you know, it hasn't been all sweetness and light, it's been tough. But I think that for me personally, it's been... a journey that... you know I certainly didn't ask for, but we've done it together.

**Mary Pepping, PhD:** It's one of the most daunting things to say to someone, you know, you've... you've had all these injuries, physical and cognitive and behavioral, and now you get to try to tackle the toughest set of symptoms you've ever had with a compromise in your intellect or your memory or your attention or your endurance or your speed. But we still want you to try to get it fixed and we want you to take a productive place back in society and not be overwhelmed by what's happened to you.

**Kathleen Bell, PhD:** People may seem to have problems with get up and go. They... have difficulty with initiating activities so that they look lazy and it's not that they're lazy, it's that the brain is not giving them that impetus to do what needs to be done. They can tell you what they have to do, but getting to do it is a whole 'nother story.

**Arlene House:** While you're doing that, I'm going to... see that the soup is cooking.

**Allen House:** Okay.

**Voiceover:** As Alan relearns the tasks of everyday living, there can be frustrating moments.

**Allen House:** I think I usually cope by, you know, banging my head against it or getting into it more to... see if I can figure it out and... sometimes I can and sometimes I... I think well I guess I'll... try that later or...

**Arlene House:** Well sometimes yeah, you just walk away from it. We do a time out and you just kind of... walk away from it for awhile.

**Allen House:** And sometimes I get tired of walking.

**Arlene House:** Yeah. But I can usually tell and I'll come in and distract him.

**Myron Goldberg, PhD:** For the family member, my main message to them in the course of recovery is... patience, is patience. Recovery from traumatic brain injury takes time and takes treatment, but oftentimes time.

**Kathleen Bell, PhD:** Sometimes the families kind of take it on the chin because all of the frustration and the maybe anger or disappointment that people have is sometimes directed at the people that they feel safest with, which are their family members. And it's important for families I think to... to understand this, to... remember that... a family's job is to provide and support and to help someone get professional help, but not to do it all by themselves. They... they can't carry the whole world on their shoulders, they have to get help.

**Arlene House:** This is the timer right there.

**Allen House:** What's that say, eight minutes?

**Arlene House:** Yeah.

**Arlene House:** Ask for help, ask people, ask your friends because if you're not taking care of yourself, you're not going to be able to take care of your survivor, you're... you're loved one.

**Kathleen Bell, PhD:** Recovery is possible and I think that's important for everybody to know, that as hard as it is... people get better, people get a lot better and life doesn't stop after a brain injury.

**Arlene House:** Join a group when you're ready, you have to be ready to do that. Join a survivor group... or a support group rather to... to have other people to talk to. You have to talk to other people.

**Allen House:** To be exposed to other people and to learn about their injury... and be able to compare it to other people, I mean... I think that's... been very help to me.

**[Studio]**

**Doris McMillon:** Sarah, Ted's a clear example of life not stopping after a TBI. Tell us about the mentor that you and Ted found.

**Sarah Wade:** Ted, I know this going to sound strange, but in a lot of ways Ted was very fortunate to have lost an arm, to be an amputee. When he was at Walter Reed, there was already a program in place for peer mentoring for amputees and Ted was very fortunate to find a man, Jim Mayer, who's known as the milkshake man at Walter Reed, who became his mentor as an amputee and since has branched out to other types of injuries.

But Jim was someone who was severely injured in Vietnam who's been very successful throughout life. And... he kind of showed us that there was, could be light at the end of the tunnel and has really helped Ted and I both understand that it's... it's okay to go through your ups and downs, that that's natural and still be able to succeed.

**Doris McMillon:** Okay, so we'll have a sense of just how far he's come, tell us briefly what happened to Ted in 2004 and then what his life was like the first year after his injuries?

**Sarah Wade:** How do I be brief about this? Ted... when he first got injured, he was... he was taken to Germany and was not expected to live. I was given the option to withdraw care, his dad and I were given that decision. And one of his friends in Iraq was pulled off of a patrol and was going to come to Germany to escort his body home to the States.

Ted... took a very good turn and improved, he was in a coma for a couple months... probably about two and a half months and was in the hospital for I think 10 months consecutively, so the first year for Ted was a lot of what Carolyn was talking about, learning how to talk again, learning how to walk again, learning how to get dressed.

And later on getting a little closer to maybe learning how to manage himself again. As Ted has described it, it was a lot like being born all over again, except it was an accelerated childhood, that all the things he had learned in the first years of his life, he had to relearn again.

**Doris McMillon:** What are the biggest challenges for caregivers when their loved ones first come home?

**Sarah Wade:** Not having the support of others accessible all the time. There is a great comfort being in a hospital, I know that sounds strange, but... knowing that everything wasn't riding on my shoulders. I think the hardest challenge when you first come home is knowing that... how much is riding on you and that there aren't other members of a staff around to call on.

**Doris McMillon:** Ted has a life coach, how's that person helping him and in turn, how does it help you?

**Sarah Wade:** Ted was very fortunate at the private practice he goes to now to... come across someone who... she's... she's a life coach, she's a case manager... she's really helped him to troubleshoot everyday problems he runs into and honestly some of that was and is still, breaking the rule of Ted being the patient and me being the caregiver and really learning how to be a husband and wife again.

And... it's nice for someone else to be able to give Ted advice... and in turn it's helped me because it can be something little like Ted hopping in the car one day and said me saying that we need to go to the grocery store cause we need something to eat and him saying, hey, honey you want to go out to dinner?

It's... it's helped me to... I guess get that role back of being a wife and just not just a caregiver.

**Doris McMillon:** Right... Ted's got a part-time job coming up this fall, he's going to start this fall, tell us about that.

**Sarah Wade:** I think actually he's going in next Tuesday. Ted is going to be working at a... market, a little market in our neighborhood. One of the rehabilitation counselors that he works with at the private practice where he does his brain injury rehabilitation will be going along as a job coach. But what I think what's important about that is that really what Ted needs in terms of assistance to perform a job is more how to learn... I guess to adjust to memory issues, learning how to communicate with an employer.

**Doris McMillon:** How important is it for Ted and then other people with TBI to be able to get back into the community, back into the workforce and how important is it for the caregivers?

**Sarah Wade:** It's very important for a caregiver because a lot of times we're very isolated... and we ourselves can be homebound because of our family member. It's important for someone with a TBI to get back out into the community that's where you learn socially appropriate behaviors.

That's how you learn age appropriate behaviors is by interacting with people. Sometimes though the supports aren't in place for someone to be able to do that. If, like Carolyn was talking about, sometimes if you need someone to supervise you for safety and you don't always have those resources, it makes it very challenging to be able to go out and live again.

**Doris McMillon:** What are some of the other challenges that are... of returning to the community and to the workforce... that are faced by members of the military who sustain TBI?

**Sarah Wade:** I think one of the things that's different about... someone in the military... with a brain injury is that... they a lot of times joined the military during the early days of their adult life. And their adult life has been spent in a different community, in a different culture.

Even down to where you lived, was where you were assigned, not necessarily where home might... might be. So I think what's different sometimes with people in the military is that we're actually talking about reintegration, we're talking about integration. They're having to, while learning to negotiate this injury, also having to learn to negotiate a culture that they're not used to and maybe a community that's not theirs.

**Doris McMillon:** For caregivers who want to support their loved ones in returning to work, what are some of the steps they need to take?

**Sarah Wade:** That is going to be a very case-by-case basis, for us, it was identifying when is the right time to do that. I'm still not sure of the answer to that question. But also finding somebody who understands brain injury, there are a lot of people out there that can do vocational rehabilitation with someone with a physical, well I guess brain injury is a physical injury, but physical impairments.

Because a lot of times that's using an assisted device... maybe different computer equipment or an employer making accommodations for that individual. But finding someone who understands brain injury, that's... that's got to be the first challenge.

**Doris McMillon:** Alright, let's talk about returning to work... a structured environment is one thing, but how can a caregiver make it easier for a person with TBI to return to unstructured environments, like your social circles?

**Sarah Wade:** For us, it was a matter of... finding somebody else to support Ted, to give Ted a community support other than myself. A lot of times when a family member is the person that helps an individual do that, Carolyn was talking about this, it creates conflict.

There's a different dynamic between a mom and a son or a husband and a wife. A lot of times an adult doesn't want to be told what to do and treated like a child. For us, it was a matter of hiring a person to go out and be Ted's buddy, to be his community support and take me out of the picture.

**Doris McMillon:** Well obviously this whole thing has probably had an effect on your relationship with Ted, but what have you found to be some of the most surprising things about the way things have changed?

**Sarah Wade:** One of the things that we really had to learn to do as I said, was make a conscious effort to be a husband and wife and learn how to be a husband and wife again. Obviously one of the things that's definitely changed is that my husband was a very, very independent person.

And not only was he in the military but he was also a volunteer firefighter, so he was always about doing for others and has not always dealt well with having to be the person that receives the help. I think for us though, I think the most important thing was, as I said, making it a conscious effort to be a husband and wife again to find things to do together that were fun.

I think one of the greatest things for us has been... adaptive sports programs. Ted got involved with a group called Disabled Sports USA and he's gone on a couple of adaptive ski trips, he's learned to use a special bike and done adaptive bike riding. And those were parts of his rehabilitation or reintegration that we could do together, that we could actually enjoy.

**Doris McMillon:** Well what happens when what had been an equal marriage relationship, suddenly becomes much less than equal?

**Sarah Wade:** That is... one of the hardest things. Sometimes it's hard and I find myself... sometimes being resentful. That's... hate to admit that.

**Doris McMillon:** You mean being human?

**Sarah Wade:** I hate to admit that but it's... it's the reality of it, that sometimes it's very frustrating to know that I gave up school, I gave up work, I've lost a lot of my friends... and... I have to give myself a

reality check a lot of times and remind myself that he was in the military when I married him and I knew that getting injured was a possibility.

And like Carolyn was saying, remembering that my job now is helping him and it is rewarding cause he gets better everyday.

**Doris McMillon:** How would you advise caregivers to cope with the changes to their relationships and to family dynamics?

**Sarah Wade:** Remembering to take care of yourself, which is easier said than done. People would tell me that all the time and I would get angry because I wasn't neglecting myself by choice, I was neglecting myself because I had no other option. Sometimes it means that the family member that you're caring for has to make some accommodations for you.

I've sat around and waited for Ted at many an appointment and I decided awhile ago that an hour out of every single day would be for me. Sometimes that meant that I wasn't running to Subway at Walter Reed and eating while walking down the hallways. Sometimes it meant that I actually sat down for 30 minutes and... ate my meal.

But one of the things that I also did was, I would go to the gym and Ted would have to sit on the exercise bike next to me because he was just going to have to wait on me for an hour. And you know I... I think it's important to remember that there is a give and take.

**Doris McMillon:** Right, what else can caregivers do to take care of themselves?

**Sarah Wade:** I think one of the most important things for me was remembering to eat well. When you're on the go all the time, when you're at hospitals all the time, usually you eat what's convenient. Yes... I know... but no, just something as simple as learning to eat well and getting regular exercise again.

And what I say be regular exercise, that all has to be taken in context. Sometimes it was me going downstairs and walking around the veranda, around Walter Reed and I know that the people sitting in the command center probably thought I was crazy cause I would pace back and forth in front of them, walk by their window.

But sometimes it was, you know, just going out and taking a walk, I think.

**Doris McMillon:** Yeah, I know that burnout's got to be common, but what do you do... what else do you do to keep from being overwhelmed?

**Sarah Wade:** I am overwhelmed and I am burned out. I think that... I've had to learn to kind of function in that disaster. And I think probably the best thing is to admit that you're burned out and to admit that you're overwhelmed and that sometimes you can't do it all.

**Doris McMillon:** Okay. Carolyn, let me come back to you. It's been 25 years since Tim's injury and if anyone I guess you would know the ups and downs of long-term care. What advice would you give to caregivers to help them find some semblance of balance in their lives?

**Carolyn Rocchio:** I would think you gradually grow into that, probably the worst thing is... the lives of the rest of the family move on, your kids are getting, my kids were getting married and moving on. And Tim was still at home. It's... it's a balancing act and you get through it. You do it a day at a time and... I don't think there's a perfect answer for it. I know what works for me, but it doesn't work for other people. And I've been incredibly fortunate that you know good insurance... other things, financial resources that

have helped us do what we've been able to do.

So I don't think there's a... a good answer for that, you do what you have to do.

**Doris McMillon:** Okay. Dr. Zasler, you've seen a whole gamut of reintegration programs over the years, what should family members and patients be looking for when considering programs following a brain injury?

**Dr. Nathan Zasler:** Well as far as post-acute care is concerned, I think the main things are that you want a program that deals with a reasonable volume of similar types of patients. You want a program where there is hopefully a interdisciplinary or what's termed trans-disciplinary treatment approach, ideally with involvement of a good behavioral psychologist or functionally oriented neuropsychologist and a physician.

Not necessary a physiatrist, but a physician who understands brain injury who might be a neuropsychiatrist, neurologist or physiatrist, I think those are probably the three most common. And I think you need to feel comfortable visiting the programs, talking with staff before making a decision about whether that's the place for your loved one.

**Doris McMillon:** Well I want to say thank you to Carolyn and to Sarah and to Dr. Zasler, this is the time in our program when we're going to take a few questions from the audience and we'd like to have our first audience member with their question, please go ahead.

**Audience Member 1:** What are some strategies for dealing with alcohol or drug abuse in a family where someone has a brain injury?

**Dr. Nathan Zasler:** Again I think... complex question, it's a problem of some significance among survivors of brain injury, in part I think because of coping difficulties that they may encounter and they turn to substance abuse as a way of dealing with their inability to cope. Depression also increases the risk for substance abuse.

And all too often we have people who had substance abuse issues before their injury that continue or are aggravated or you have a... a period where they stopped and then resume after their injury because of the reasons that I mentioned. This is an area that there isn't a lot of good research on, but at least the experience among the programs that have tried to deal with this on an international basis, I think really is a multi-pronged approach that incorporates behavioral interventions with medical interventions.

I think that providing support and an AA type of... program, again traditionally I don't think works very well in people with significant cognitive behavioral impairments, but a program that's modeled on that, that also takes into consideration the types of impairments we see in people with brain injury is important.

And now there are also a number of pharmacological agents that can be used to suppress desire for things like alcohol and certain types of drugs, not all, but certain types of drugs.

**Doris McMillon:** Okay, thank you so much. Let's take our next question, please go ahead.

**Audience Member 2:** How can caregivers support themselves and their loved ones financially when they can no longer work?

**Doris McMillon:** Sarah, would you take that?

**Sarah Wade:** I don't know that there is a good answer to that question. Sometimes someone can't work. If you're fortunate you can return to a part-time job if you have an employer who is willing to be cooperative with your situation. In my situation I've, at times worked out of the house, but unfortunately that's... that's a challenge that I... I have no good answer for. I think for someone like me to return to work, I would need better and more appropriate supports for my husband. So those are things that I think we as caregivers need to keep fighting for.

**Doris McMillon:** Carolyn, do you have any suggestions?

**Carolyn Rocchio:** No, I agree totally with Sarah that... that is a major problem, wives have to give up jobs to stay home, mothers do as well.

**Doris McMillon:** Dr. Zasler.

**Dr. Nathan Zasler:** Can I comment on that briefly?

**Doris McMillon:** Sure.

**Dr. Nathan Zasler:** I mean I think the discussion is sort of assuming that people are going to be cared for at home and I think although that works for some people, it doesn't work for everybody, whether that's an issue of financial ability to do that or the psychological family makeup and the amount of support that individuals get.

For some families it's not possible to care for an injured person or over the long haul.

**Doris McMillon:** Okay. Let's take our next question, please go ahead.

**Audience Member 3:** How do caregivers know when their loved one is ready to move back out into the real world and figure out how to balance dependence and independence?

**Doris McMillon:** Carolyn, would you take that?

**Carolyn Rocchio:** I've done a lot of re-evaluations for my son... to kind of keep me abreast of what kind of progress he's making. When you're with somebody day in and day out, you don't always see their progress. A lot of evaluations that have helped me know, you know when he's ready.

In the situation we're in, my son has no option of working out in the competitive job market and fortunately when he was in rehab in California, he was trained to do a job.

He (unint.) packaging machine which we replicated in our business so that he... we knew when he came from California, he was ready to start working in our little business. And he's done so for 14... well, since 1986.

**Doris McMillon:** Let's take our next question.

**Audience Member 4:** Do you have suggestions for explaining brain injury to a child whose parent has been injured?

**Doris McMillon:** Dr. Zasler.

**Dr. Nathan Zasler:** It's a tough question, again I think it depends on the age of the child certainly, so it needs to be developmentally appropriate explanations, but I would go by the KISS principle if you know

that principle and keep it as simple as possible and basic. Again, I think the whole issue of explaining that this is still your parent, they still love you, you still love them.

But they may appear different or behave different is important and also the whole issue, which we talked about earlier, of maintaining hope, I think is important particularly in children... not just adults, so that they don't feel... as oftentimes everybody does, a loss of control of what's going on in their life, in their environment.

**Doris McMillon:** Carolyn would you add to that please?

**Carolyn Rocchio:** Yeah, there's some nice literature that's been prepared... particularly to deal with small children and the Brain Injury Association of America on their web site, has some listings of little booklets that are very appropriate, particularly for young children, that helps explain it.

**Doris McMillon:** Thank you, our next question please.

**Audience Member 5:** Yes, how do caregivers know whether or not they're doing the right things, is there any research out there to help us make decisions?

**Doris McMillon:** Carolyn.

**Carolyn Rocchio:** Oh I don't know that there is a good answer for that... it's pretty much try it, if it works, you go for it. But you also need all that input. I've been fortunate with excellent input from the professionals that I've dealt with, pretty much have a plan for where we're going.

And I constantly have my son re-evaluated on a periodic basis just... nothing extensive, but I want to know as he does improve or in the case where he may lose some ground, what we need to do to fill that gap.

**Doris McMillon:** Alright, let's take our next question please.

**Audience Member 6:** What resources are out there for advocating for personal and legal rights for someone with TBI?

**Doris McMillon:** Carolyn?

**Carolyn Rocchio:** Well we have the Americans With Disabilities Act, every state has a protection and advocacy agency, there are legal ways that you can get some assistance, getting to it, finding it and I would strongly suggest if you have questions along that nature, get in touch with your state brain injury association for some direction.

**Doris McMillon:** Alright thank you and that was our last question. I want to thank our audience for their questions and in closing what I'd like to do is get a final thought from each of our panelists and Carolyn, I'll start with you.

**Carolyn Rocchio:** I just, you know, enjoy the moment. I... we... we just love the good times... we try not to be too critical of things that go wrong. Nobody's perfect... you take it a day at a time and you know... humor, please use humor, it's gotten through... gotten us through a lot of bad places in the road.

**Doris McMillon:** Good, Dr. Zasler.

**Dr. Nathan Zasler:** Well in summary I think I would reiterate what I said about the need to maintain

motivation. And I also think faith is important, whether that's religious faith or just maintaining faith. And I know that doesn't sound very medical so coming from a doctor it may seem a bit foreign. But I do think those are important, I also think educating one's self is empowering as Carolyn has said and other people have said and empowerment decreases one's sense of loss of control which is often a big issue for families, particularly in the early phase of dealing with this.

So I would... again encourage the people to acquire knowledge which will help facilitate not only their own adjustment to their loved one's injury, but also hopefully facilitate their loved one's care.

**Doris McMillon:** And finally, Sarah.

**Sarah Wade:** I think particularly with the population that I'm in, people that are service members or veterans, I think it's important that... to realize that you don't have to feel trapped, if the resources you need aren't there we have elected officials in Washington that have the power to change those things.

Still to this day for instance, the benefits in the VA, the benefit side of the house in what they call special monthly compensation, attended pay, those sort of things, still do not recognize brain injury as a qualification, it's nowhere listed in the federal code.

And these are things that need to be addressed and you know, if... if you have a need, step up to the plate and tell your Congressman.

**Doris McMillon:** Okay, alright, thank you so much. I do want to Dr. Zasler and Carolyn Rocchio and Sarah Wade for sharing their advice and experiences with us. And thanks as well to our studio audience. I'm Doris McMillon, thank you for watching us on Brainline.org.

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