

Beyond The Invisible

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Video Link: <http://www.brainline.org/content/multimedia.php?id=2544>

[SOUND EFFECTS]

Tracy: I took it for granted at first being able to do everything and then after the injury it got cut in half. Nothing came easy; you had to take your time doing it.

Brian: It's hard. It's tough that you remember like your whole life and then you can't remember certain best moments of your life. There are things like your children's birth and that's hard.

Angie: We were told at that point he was not going to live. He was going to be a vegetable and how we were going to sit down and talk about donating his organs. It was horrible. It was a really horrible experience for us as parents; and I wish I could say I want to erase that time but it's just something that will be with us forever.

Michelle: He went through angry. Like, "Why aren't I 100% and why did this happen to me? Why did that person look through his scope and pick me? Why can't I have the life I had?"

Eddie: And then right there is my old glory which I salute the land of the free, because of the brave, because of men like me.

Narrator: Over the last two centuries, the consequences of warfare to the American soldier have been well documented. However, in recent years, advances in body armor, combat armor and modern weaponry have quietly created a new challenge for society--a medical condition that has flown silently under the radar; something that in many cases can be invisible to the human eye but carries with it huge consequences. Over the next few minutes you'll meet Tracy, Eddie and Brian--three veterans of Operation Iraqi freedom who were injured during deployment. In all three cases these men returned home with the signature injury of these wars--a traumatic brain injury. What you are about to hear are some of the struggles they and thousands of other service members and veterans have had to endure on their journey back home.

[MUSIC]

Steven Flanagan, MD: I'm often asked what is a traumatic brain injury. And a traumatic brain injury occurs when there is some external force applied to the head or to the brain

that causes it to be injured. You need to realize that the brain has the consistency of formed Jell-O in the natural state; and as the brain moves within the skull it can be injured. There can be bruising, there can be stretching of the nerve cells and it results in various problems. Problems with motor activity, using your arms or your legs, or it could be more commonly associated with problems with thinking, with memory, not being able to pay attention or concentrate like you were able to before.

Tracy: It got so I couldn't remember a lot. I could hear people talking but I couldn't understand what they were saying. It was like all coming in as garble. And when I got back to the VA they told me that it was part of the brain injury; and I get lost a lot. It's starting to get better but if somebody is talking too fast or something it's all garble and I've got to keep asking them what they said.

Narrator: Reports vary about the exact number of U.S. service members serving in Iraq and Afghanistan who return home with some form of traumatic brain injury. All agree, however that the numbers are significant. Many of these injuries will be the result of an explosion or blast and won't be identified until well after their return.

Marry Hibbard, PhD: CDC, Center for Disease Control, estimates that 25% of all individuals who have brain injuries remain undiagnosed. That's a huge number when we're talking about the frequency of brain injury. Particularly in the military, we have to assume everybody who's been through the war is at high risk of having had a brain injury. And so these individuals may or may not have been properly diagnosed either at the time of the IED explosion or the multiple IED explosions that they've experienced; and it's only when they go home and try to pick up the structure of their former life without the high regimentation of the military life that they begin to fall apart.

Michelle: He didn't know he was a soldier, yet he could look at a picture and he knew the people in them, he'd recognize them but he might not have necessarily known their name and he couldn't understand why they were in uniforms in the desert. He knew his birth date but he didn't know how old he was. Like I'd ask him, "How old are you?" and he'd just cry but he knew his birth date, he knew I was from Canada but he did not remember memories from things that we did when we were dating. He knew we had two kids, he knew they were a boy and a girl, but he couldn't remember specific memories of things that we did with them. He'd look at pictures and he would just get frustrated or I'd have videos on a laptop and he would slam it shut and he didn't want to look at it because he couldn't remember things. Then they started just coming in all different blocks that were from all different timeframes just coming at him all at once but not in chunks of time. It wasn't when he was 5 then 6 then 7; it could be when he was 15 then 5 then army and it just started coming at all erratic timeframes.

Narrator: Memory loss especially short term loss along with the inability to stay organized, are two common symptoms associated with a TBI. One of the ways that the VA is helping veterans combat these effects is with the PDA or personal digital assistant.

Tracy: This is set for today; at 1:15 I've got an appointment with Kendra. She's my--I don't know if you call it a masseuse or what--I go for a massage. I go every two weeks; she puts my ribs back into place because they pop out; 2:00 I've got meds; 6:30 I've got a VFW meeting; 7:00 I've got meds.

Steven Flanagan, MD: Often times people who have a traumatic brain injury will look perfectly okay to family members or to health care professionals with regards to their ability to use their arms and their legs but there is a problem with their cognition. They're going to be complaining of difficulty paying attention, irritability, mood changes.

Michelle: To me, it's just almost like a child. A person can be one way one day and they could be a different way the next. A person can be angry in the morning and be happy in the afternoon.

Allan M. Landes, PhD: One of the less well understood or less recognized changes are that traumatic brain injuries can often cause problems with judgment, reasoning or emotional functioning so that they can sometimes be misunderstood as psychiatric or personality changes.

Angie: So there are a lot of behavior issues--things that shocked us really because my son in his day would never be in my home and start cursing and calling me names. He wasn't the type of person to do that; and he would go through stages where every other word would be a curse word. He would say things that were inappropriate so those are challenges and at some point they would be upsetting to us because we didn't know how to handle them. And being with that and understanding how he was to a certain extent because we don't fully understand it naturally but understanding that redirection was the key for Eddie. What I mean by redirection is if he should say a curse word, we would redirect that and say, "Hey how about substituting that word for something else?" Or, like it was explained earlier, if he would hit the bedrail with his arm because he was frustrated, we would redirect him and say "Hey take that right hand and work the fingers. You need to work those fingers so they get working again." So we found that redirection was the key with Eddie and as long as we do that he's good to go.

Steven Flanagan, MD: Other people complain of just being all of a sudden being very fatigued doing things that didn't fatigue them before; so these are very common symptoms and these are things that health care professionals and the VA and elsewhere need to really pay attention to; and when they see somebody with those symptoms link them if they can to some event that happened before like a blast injury, altered mental status at the time of that blast injury so linking an event, a traumatic event to those symptoms are

what healthcare professionals need to do, particularly in the VA where we know so many folks are coming back from these conflicts with traumatic brain injury.

Narrator: In the case of Eddie Ryan, his case extends beyond memory and behavioral issues to include rehabilitation therapy for the acute problems he has with motor skills.

John Veracka: My role is primarily to keep Eddie's muscles from, like I said, from getting contractures, keeping them stretched out, keeping his muscles elastic so they can move so if the brain does heal he has the ability to have function so he's not so bound up. Also to help strengthen the good parts that are still functional and help him rebuild the pathways from the brain to muscles; because Eddie has feeling throughout his body the only thing he's lacking are the motor skills.

Narrator: Even before Eddie began receiving therapy the Ryan's found themselves in a situation that many veterans and their families are faced with today. A lack of resources about where to turn to for help immediately following the injury.

Angie: We didn't know where to go; we didn't know where to turn to. It's like you have a son who has a brain injury and there you are and so what do you do? You're in hospital after hospital, you're going from agency to agency, finally get home and now you're home and who do you call? Unless someone would come up to my husband and I and say, "Hey there's this agency, there's this organization, there's this association that can help with TBI or with whatever, we would never know what was available to us." But especially TBI's because there's a lot of that going on to have that access to know hey I can call the Brain Injury Association and they can come and they can give me some resources that I can use to help. So I'd like to see that happen because we didn't have that so we were scrambling around looking for help anywhere we could get it. So that would be something I'd like to see.

Narrator: The Ryan's soon discovered that locating resources meant confronting the harsh reality of finding service providers who were trained to work with individuals with a TBI.

Angie: We do live in the mountains but should that make a difference? Should it be a reason why we can't get home health care or therapies to your home? I think not. These young men and women go to serve our country and they come back and they don't have health care? It's sad that we have to constantly battle for help for our son; and I know that these are the families that are going through the same exact thing. Some of the aides that have come to our home were not properly trained in TBI and that was difficult; because I knew a lot of the issues that he had and that was easy for me to do, it was easy for me to train a lot of the aides to help in those areas, but when you're dealing with a TBI I firmly believe that the people that are coming to the home should have some experience with that; because it becomes difficult for that person and frustrating as well because some of

them are afraid of what is there and so a lot of times they end up leaving. And that becomes hard for us because then we're left with no help at all. The only reason we've done what we've done is because we are desperately in need of help. If you're just here and you're not understanding the injury then you can't help the family to become a unit anymore, and that's what we were looking for. We were looking for someone trained in TBI to come in keeping Eddie safe, alert and going while we became that family unit again.

Eddie: My family is my heart, my soul, my food, my well-being. I love you mom.

Angie: I love you too Eddie.

Eddie: I love you dad.

Chris: I love you too.

Steven Flanagan, MD: When I was in medical school many years ago we used to think the brain is how it is. It doesn't change, if it's injured that's it. You're basically out of luck; but now we know that the brain is plastic and what do I mean by that? I mean it can adapt to change. It's almost like a vast computer network. You can imagine a computer network not functioning well if some of those wires are clipped; and what the brain is trying to do is reconnect in a way to make things function again. It won't function typically as well as it did before the injury, but it's the brain's attempt to get better, to allow folks to do the things that are important for them to do.

Narrator: As the brain begins to heal, the reality of the situation starts to set in. This can often lead to overwhelming feelings of frustration, anger and depression as recovering individuals struggle with the issue of not allowing the brain injury to ultimately define who they are.

Michelle: I guess the best way to describe us dealing with it would be that it's been a rollercoaster ride and we're still all learning to cope with it; we're still coping with it, Brian's still coping with it. All of our family is because it affects them, his parents, my parents. It's had its ups and downs. He was really positive in the beginning, he was so determined to fight the injury and bounce back from it and he didn't really realize the impact it was going to have on his life and the speech and everything else. I don't think he realized how much work that needed and that it might not all come back because he was gaining such strides with the physical side of it so quickly; and when he realized that depression just set in so heavy. Our son went through a stage where you just didn't understand, was angry, his dad was gone for so long, I had to be with him at the hospital to take care of him. My children stayed with my sister because I just had to be there with him. He couldn't speak, he couldn't move, he didn't know if a nurse was going to be in the room as great as they were; but he was paranoid and scared and my son was angry and he didn't want to sit beside him at the table. That was really hard for Brian. My daughter kind

of turned into a little mother. She wanted to take care of everybody and make everyone happy.

Tracy: It's like living with some--say your parents like they're in their 80's. That's the best way I can describe it. It takes time for the brain to analyze what you're asking and you just move slower. Your brain don't function as fast as somebody that's normal.

Mary Hibbard, PhD: I think perhaps the biggest challenge as a rehabilitation clinician is dealing with the very painful discrepancy between who a person was before their brain injury and who they are now. Because you have a very distinct idea of who you are and what your abilities are; to wake up one day and to have a significant chunk of those challenged is a devastating thing. And so much of therapy is dealt with mourning real losses, maximizing abilities so you can compensate for the other weaker skills, and that ultimately then you can begin to function at a better level.

Leah Farnum: I think it's very common for our veterans, especially those with mild TBI, to deal with the frustrations of no longer being the person they were before and having that reality of being home and not only having to adjust to civilian life and no longer being in the military, but also having to readjust to this new self. So really going on a strength-based model, kind of focusing on what they have for resources, whether it be family or community support; in Tracy's case it was more community. He does have some family but no one that lives with him so really reaching out and connecting with folks, because otherwise there's no one who's going to call and check in with him. For the folks who do have family, giving them some guidance on what to expect and how to deal with that and who they can call to help also so that they don't get so frustrated.

Heidi Kinnally: The innate frustration that TBI patients feel I think is sometimes misinterpreted especially by the family or even the provider, it's taken personally. Some strategies you might use for that are maybe distraction or lowering lights, turning off the TV, giving yourself some breathing room. It's not easy to deal with that frustration but it's not something else that can be taken personally because sometimes the impulsiveness of a person with a TBI leads you in a direction so that you're almost feeding in or aggravating them more; so you kind of have to take a step back, look at the situation, lower all the stimulus in the area, so that the frustration maybe is lowered a little bit.

Allan M. Landes, PhD: Probably one of the biggest concerns or complaints that patients I work with have is the lack of understanding both in their immediate families and in the general community about brain injury. Particularly the general community because they're families are usually becoming aware. They're often misperceived as being crazy or crazy and lazy are the two that I hear the most coming off the cuff; patients who are being told that they are drunk or

intoxicated because they have an impaired gait or their speech is slurred, and in general the kind of stigma and fear that comes from people who don't understand what they're seeing and misinterpreted as something much more serious or much more threatening than it actually is.

Brian: It's embarrassing at first. I remember going to physical therapy once and over in Smyrna and they have the Starbucks there. Now I love Starbucks, I was waiting in line and I tripled ordered because my words and the people behind me I think they were around my age and they were whispering around me and they were like, "I think this guy is drunk and it's like 10:00." Usually I'm pretty snappy with comebacks and I was afraid to say anything and I said well why should I say anything. What am I going to say? Even now I can't say much. Even if I would have I sound a lot drunker than they thought I was. So if it wasn't for my friends and stuff when I got home, I would have been sitting at the house I guess.

Michelle: I wanted him to use his cane. He had a cane because sometimes his balance where he'd kind of weave and waddle a little bit and it sort of would let somebody know kind of watch out a little or there is something wrong with him. And he is always a person that is snappy with the comebacks and it's sad to see that he doesn't feel confident to stick up for himself and say something. I'd like him to have a shirt that just says I have a brain injury because I was fighting for your freedom.

Brian: As far as me with my--kind of like my anger and just kind of like my depression, just really- -I was really happy and I was like oh you know it happens if it's a war and blah, blah, blah, blah, blah. I had done the same thing. I mean still in my head I think that. Now I'm like well it was and it could happen to anybody but now I'm kind of pissed off. Now I'm kind of like, "Screw this, this sucks." And obviously it does suck. I feel bad for the people this happened to.

Narrator: As more and more traumatic brain injuries are being diagnosed, it's important to understand its overlap with post-traumatic stress disorder. A recent study reported that one in every five returning veterans from Iraq and Afghanistan suffer from PTSD. Often the PTSD is undiagnosed. Until a short time ago Brian was one of those undiagnosed. Now with the help of his local Vet center, he's beginning to cope with this challenge.

James M. Sheets: That center has helped these veterans cope with some of the readjustment issues of post traumatic stress disorder through counseling one on one, develop a therapeutic relationship with them, build up the trust, then together cognitively form some sort of therapeutic plan to recovery.

Brian: No one ever talked to me about PTSD or any of that stuff because everything was about my brain. And talking to them about that stuff really kind of set me straight because I was like why do I feel like this? And why is my family suffering? He's like well you realize

you actually up and had something many guys don't live through something like that. And after that you're going to go to a place to help you with that; PTSD is--I didn't think it was that big of a deal. A lot of guys just go you know it's just stress or whatever. I can deal with stress. The whole war is stressful.

Allan M. Landes, PhD: There is a substantial overlap between post traumatic stress disorder and traumatic brain injury; at least in terms of the symptoms people have and it's very difficult to discriminate which of those two disorders is causing the symptoms. Doing that's important because treating those two aspects of the patient is often taking very different approaches. What we find is that adding to that complication is that both of these disorders aggravate the other. The brain injury impairs a person's ability to regulate their mood and deal with their trauma, and the post traumatic stress causes significant emotional distress that keeps the brain overwhelmed and disorganized and makes it harder for them to recover.

Narrator: If we've learned anything, it's the traumatic brain injuries are by their very nature complex. However through hard work, determination and support, Tracy, Eddie and Brian have all made huge strides in their recoveries over the past two years. Tracy is taking up skiing using a bi-ski, planes to begin riding a road bike in the summer and is planning to enroll in a local community college later this year.

Tracy: If Nate would stop by the house today and didn't know much about the TBI, I'd just tell him, "I'm a little bit slower comprehending things. If you're asking me to go get something I might head towards the refrigerator to get you something and I would forget what I'm going for. So just bear with me that's all I can say.

Angie: Eddie's overall condition continues to improve and so do his dreams for the future.

Angie: So what's your ultimate goal?

Eddie: To run.

Chris: To run. You said that you want to run.

Angie: To be a DI.

Eddie: Oh that's what I was looking for.

Angie: You still want to go back and you've got to tell everybody what your dream is.

Eddie: My dream is to get back in the Marine Corp.

Narrator: And for Brian Wells he now spends his time enjoying his children playing basketball, snowboarding and taking college courses with the thought of one day becoming a recreational therapist for veterans who have sustained a brain injury.

Brian: I think guys that have a brain injury; it does kind of psych your head at first. You think this is it; I'm going to be this guy forever but if I looked back three years ago, I never would think this is going to be me; and I never would think that I'm going to be--I think the only problem that I can't do is drive and that's only because of my peripheral. That's the only thing I can't do. I know everything else that I can do. I didn't think that I'd have my family here with me. Because a lot of guys they get hurt and a lot of families leave them. Guys that get hurt they just don't realize that it's not the end of their lives. Family is the beginning; they have so many opportunities now.

Michelle: We have a blessing. He not only made it through but he's living a productive life; he has a gift to give to other people. He can give a lot of hope and encouragement to other people that were in my shoes and his shoes. Really I think he has an amazing gift to give people and I think everyday should be looked at as a gift.

Brian: If I can't be a soldier I want to be able to help a soldier or something like that.

Narrator: The three stories you've just seen illustrate the struggle that thousands of people with traumatic brain injuries face each and every day; as they learn to sort out the past and restructure the future. For more information on traumatic brain injuries please visit the Brain Injury Association of New York State website at the address on your screen.

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