



Defense and Veterans Brain Injury Center “The TBI Family” Podcast
“Pathway of Care / The Caregiver Journey Map”
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Chris Lawrence: My staff sergeant that was next to me wasn't as severely physically injured. He got a pretty bad concussion, and it was so bad that they medevaced him. People in the command made fun of him because there was nothing bleeding, nothing broken, no visible, obvious injuries, but he couldn't walk, and he had a hard time talking and all this stuff. Well, he had what they called a TBI. Now, he's a first sergeant. He's freaking still in Marine Corps, kicking butt, taking names. He's doing amazing things with his career because he was able to get that help immediately. [music]

Scott Livingston: Hello. And welcome to The TBI family, the podcast for caregivers of service members and veterans who've experienced traumatic brain injuries. This program is produced by the Defense and Veterans Brain Injury Center, otherwise known as DVBIC. And I'm your host, Dr. Scott Livingston. At the beginning of this podcast, you heard from Chris Lawrence, a former Marine sergeant who sustained a traumatic brain injury from an IED blast in Iraq, talking about how one member of his unit dealt with a traumatic brain injury quickly. Chris is one of the TBI champions who, as part of DVBIC's A Head for the Future campaign, tell their stories to try to get others to seek help and to let them know that they're not alone. As Chris implies, service members haven't always had their brain injuries recognized early.

Bradley Lee: I came home, about two weeks after I got hit.

Jennifer Lee: So, he came home mid-tour from Afghanistan, and I started noticing changes when he went down to my mom's pasture, and he was target practicing, and he got really kind of scared. He let me know that when he was down there, he realized he didn't know how he got there or what he was doing. And that is what initially really concerned me.

Bradley Lee: I had a lot of headaches that came on and then just blank periods.

Jennifer Lee: So when Brad was actually on his way back, I decided to email sergeant major and ask him to please have Brad checked out ... for my own peace of mind, for his health and safety.

Bradley Lee: I don't remember thinking that I needed to get help. When I got back into Afghanistan and tried to get my weapon back, they told me I needed to talk to my sergeant major. And he made me go see the doctors in Bagram.

Jennifer Lee: So I would say that his command sergeant major did the right thing. He got him the help and the evaluation that he needed.

Livingston: That's Army Sgt. Bradley Lee and his wife, Jennifer, who have also volunteered to tell their story which begins ... well, where? Where did the recovery and caregiving journey start? At the time of the injury? When it was first recognized? What if, as in the case of former Marine Capt. Wally Blair and his wife Jasmin, even after a traumatic brain injury is recognized it's not taken seriously?

Jasmin Blair: I started looking up the symptoms because I noticed a lot of different things after he came back from his incident in 2007 and started noticing just a lot of different issues coming up. And as time went on, they just continued to get worse. At the beginning, we didn't think it was anything really of a concern, but then as time went on it just came to a point to where it was just almost like it came to blows.

Wally Blair: My wife Jasmin recognized most of the symptoms that we never really put one and one together, and the—as we call it, the Marine officer guilt—I was perfectly fine as long as I stayed engaged just self-medicate through. I'll be all right, even to include the sleep disorders that I had over the past... close to 10 years now. Just pushed through it but she used a primary proponent. And I guess, listening to it from Jamie, just reinforcing the fact that, okay, maybe I should just get looked at. I came back from Fallujah and went to Al Asad, where I followed up with my primary care doc who just, "Yeah see now, you got your bell rung." Typical thing. Sleep disorders, headache, everything that followed.

Livingston: As you can tell, many service members who have experienced traumatic brain injuries also experienced different treatment. Caregivers have also had dissimilar experiences, some receiving support and help quickly and some feeling as if they are on their own. However, there are two teams working to help ensure that service members who sustain brain injuries—and their caregivers—have paths they and their providers can turn to, a sign that says, "You are here" in the recovery or caregiver journey. The TBI Family's Terry Welch brings us the story.

Terry Welch: Let's deal with first things first. The people we spoke to at the beginning of this podcast mostly suggested they had experienced differences with the initial recognition of a traumatic brain injury. So that, when the injury had occurred, they had sometimes carried on without stopping to receive treatment. This issue has been somewhat mitigated. A DoD policy implemented in 2010 now requires all service members who were involved in a potentially concussive event, like a vehicle rollover or being within a certain distance from a blast or etc., to be assessed for a concussion, whether they're reporting symptoms or not. A recent study conducted by DVBC found that this incident-based reporting regulation, among other administrative policy changes, probably led to the identification of twice as many concussions, which, as Tracey Lattimore, director of the Army Traumatic Brain Injury Program and member of the DoD's TBI Advisory Committee (or TAC) says, is a big part of getting service members on the right path toward recovery.

Tracey Lattimore: The TAC has a number of efforts that it's trying to achieve. First thing we're trying to do is we're trying to improve outcomes and maximize outcomes. And we collectively think the best way to do that is through early identification and treatment.

Welch: But, once a service member was getting treatment, he or she might have received different treatment based on their service. The Army, Navy, and Air Force medical systems all operated slightly differently with different training and structures. It was for this reason the Department of Defense decided to create the TBI Pathway of Care.

Lattimore: The concept of the Pathway of Care was to identify one overarching health policy-based algorithm that enables patients and health care providers alike to understand how they're going to move through the system. So that plays out: a patient who is injured, whether in combat or here in a training accident, in a garrison environment, or after hours in a car accident, they should know when they— what the expectation is, how quickly they're going to move through the system, what the expectation for recovery is. If they don't get better after a certain point, when do they move on to the next level of care? The patient needs to know that for their own expectation management so they can drive their own care.

Welch: In the past, almost all of the attention in treatment algorithms, like the Pathway of Care, was understandably focused on providers, making sure that best treatment practices were being put in place, but with little regard for helping patients understand where they stood at any point in the process. The TBI Pathway of Care is different.

Lattimore: This is kind of a health policy-based algorithm that allows patients and providers to understand the larger system of how a patient's going to recover. So the provider will still use this medical algorithm, but the patient will know, "I'm going to get better at this point or I should expect to have a referral to a higher level of care?"

Welch: Of course, as is often said here at DVBC, once you've seen one concussion, you've seen one concussion.

Lattimore: Every patient looks a little bit different. And so we're not trying to force patients to conform to a system that's not working for them. What our focus is is to expand the initial assessment to capture all of the clinical trajectories that we're seeing on a regular basis now, identify what those are, and then promote standardization within that clinical trajectory. And you may have more than one aspect of the concussive injury that's affecting you.

Welch: So the goal of the pathway of care is to provide individualized treatment along a general path so patients and providers know when it's time to move to the next step.

Lattimore: If I, as a primary care provider, can evaluate these different areas, I'm going to be able to develop or consult to develop an individualized rehabilitation plan that ideally will set you on a path to quicker recovery. And then you take that individualized rehabilitation plan, and you fit it into this overarching pathway of care. And now you have complementary individualized rehabilitation in a more standardized system.

Welch: So while we've been talking about the pathway of care, if you'll excuse the mixing of metaphors for a moment, imagine a pyramid. On the wide bottom layer of that pyramid, you'd find most people who sustain a concussion. They recover fully within days or weeks and have no lingering symptoms. On the next level up, you find people who, after a designated period of time, haven't recovered fully and are then referred to a specialized clinic. Above them, in a smaller layer of the pyramid still, you find those who need to go to an Intrepid Spirit Center or polytrauma center for even more specialized and intensive treatment. The pathway of care is designed to let service members and their providers know when it's time to step up to the next level.

Of course, while the TBI pathway of care helps illuminate that recovery journey, service members and veterans are usually not alone on that trip. Caregivers are often taking their own parallel and unique journeys. That's why the Elizabeth Dole Foundation partnered with the Department of Veterans Affairs and Phillips to create a new "Caregiver Journey Map." Laurel Rodewald, the foundation's director of programs, said one of the main goals of the "Caregiver Journey Map" was to give caregivers a sense of the journey ahead as well as the path they've already tread.

Laurel Rodewald: We want this to be something that contextualizes their journey and helps them see, you know, how far they've come, where they might be going, what are goals to shoot for, where they might find better resources along the way, and then also to help them understand that they're not alone, that feeling grief is part of the caregiver journey is absolutely normal. It's something that everybody faces at some point. And so the isolation, and grief, and all of the feelings that they might be feeling are okay, and they're normal. And so we want to validate that and provide the context for that.

Welch: The "Caregiver Journey Map," like the pathway of care, isn't just for caregivers themselves though. Whereas the pathway of care helps both patients and providers, the caregiver journey map is also designed to let those organizations that provide—or would seek to provide—services to caregivers know where and when they should offer help.

Rodewald: So being able to see – "Okay, I serve veterans when they're transitioning out of the military. At this point in the map, this is what the caregiver is experiencing as that veteran family transitions out. So can I provide x service at this point?" And then we hope that they will work with us to find those caregivers and to develop programming that provides meal support or transportation or whatever it is at that particular point in time so that they're providing the service when it's needed the most.

Welch: The process of creating the Caregiver Journey Map began with trying to get into the minds of two representative caregivers, and then, describe the paths they could take toward meaningful, effective, and healthy caregiving.

Rodewald: What we started with is a persona. And so, what this persona does is it aggregates the information about what a "typical" (and I use that with air quotes) what a typical military caregiver looks like. So we created two personas, Kelly and Patricia. Kelly is caring for her post-9/11 husband who suffers, I believe, from a traumatic brain injury, and they're a little bit younger. They have children. And so, what does her experience look like, knowing that she's going to be caring for her husband for the long term? And then Patricia is caring for her older Vietnam vet

father who has some physical disabilities, as well as some unrecognized PTSD. And so, what does that look like for her to be caring for someone from a different generation with a different relationship?

Welch: The “Caregiver Journey Map” then tries to represent those journeys using words and graphic, showing the path from the realization of being a caregiver forward.

Rodewald: We created sort of a flowchart that walks people through different points of the caregiver journey. And what I really like about this part is that there's forward momentum but it recognizes the fact that caregivers often feel like you're stuck in a cycle. And so, there are setbacks but there are also points where you can move forward in the diagnosis, and in the care for your care recipient, and it's meant to capture sort of the ebb and flow of the caregiver journey. So that is visually what it looks like. I think it will change a little bit so that it's a little bit, right now, it's very text-heavy and scientific, and we want it to be dynamic and people can really relate to it. So.

Welch: The map is still in the creation stage, and so, not ready yet to be shared with everyone. But the foundation will be taken to caregiver map on the road throughout the next year, seeking input from caregivers in cities around the country in order to fine tune and tweak the content and design. Laurel said the team working on the map understands the map has to be an honest depiction of what caregivers go through if it's going to be truly useful. So they want it to reflect the truth of the caregiver experience, recognizing the times when it can be hard, while giving caregivers goals for which they can aim.

Rodewald: It's a little bit idealistic but it's also, I think, it does capture the reality, but you're right, we don't want to be “It's going to be a downward spiral for your whole life.” That's not what you want to portray because I think that there is a lot of empowerment and goodness in being a military caregiver. I think there's a lot that makes that role absolutely phenomenal. I know the people that I work with on a day-to-day basis are incredibly inspiring, and so, you know, we want to reflect that part of the journey, as well.

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Livingston: If you'd like to learn more of our TBI champion stories, scroll down to the description of this podcast where you'll find links to the videos. You could also find the link down there to DVVIC's “Family Caregiver Curriculum,” a comprehensive guide to becoming a caregiver, finding resources and information on traumatic brain injury among other things. We will be releasing an updated version of the caregiver curriculum later this year. So remember to subscribe to this podcast so that we can let you know when it's available. Don't forget, if you find this podcast useful and think others might, please consider reviewing the podcast in iTunes or whatever app you use to listen. That makes the podcast easier to find for those who might need it.

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