



Defense and Veterans Brain Injury Center “The TBI Family” Podcast
“Advocating For Your Loved Ones / What Doctors Want You To Know”
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Host: Dr. Scott Livingston

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Steve Springer: we involve them in the care of the patient from day one. They're physically with them here in therapy, whether it's physical therapy, occupational therapy, in the physician's office, the whole nine yards. We make sure they're involved. So again, they really provide that, again, real-life safety for the patient when they're not with us. But also, the patient gets maximum effect from everything we do. When we work in tandem with that family member care provider. [music]

Dr. Scott Livingston: 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. I'm your host, Dr. Scott Livingston. Communication between a service member or veterans caregiver and their health care provider is an important element of their recovery. Caregivers can experience frustrations when it comes to communicating with providers. And providers rely on clear communication to best provide for veterans and service members. The TBI family's Myron Goodman--

Myron Goodman: Hello.

Livingston: --and Sidney Hinds--

Sidney Hinds: Hey, there.

Livingston: --recently spoke with both providers and caregivers to better understand how they can work together to provide for their patients and loved ones. So the two of you went out to speak with providers and family caregivers about the ways they interact on behalf of service members and veterans?

Goodman: Yes. I spoke with Sharon Grassi and Jessica Rodriguez, who are a mother and a spouse respectively, to veterans.

Hinds: And I had the opportunity to speak with Dr. Medha Shah, who is an attending physician at the Washington DC VA Medical Center. And with Steve Springer, a nurse practitioner at Walter Reed National Military Medical Center.

Livingston: Myron, what did caregivers have to say about their role?

Goodman: Well, Sharon and Jessica both spoke about the transitions necessary to become a full-time caregiver.

Jessica Rodriguez: To me, becoming an advocate means supporting or speaking on behalf of my loved one. Helping request services for them. Helping them find adequate care. Finding competent specialists that have a background in that type of injury that he has, which is blast exposure. Really trying to work with those health care team members and getting them to communicate together. And really just being a voice for him. That's the biggest role as an advocate.

Sharon Grassi: Becoming an advocate for me really meant understanding what the person that I'm advocating for needs. And that is a huge education [inaudible] what do they want me to do? What does my son need from me? What is he expecting? And then when I think of that term of defining my role for him, then I could really reach into the different diagnosis that he has and try to understand them better. Because it was really difficult for me, not coming from a medical background, to advocate for someone outside of my own experience, my own norm. So I think sometimes it's easier to advocate for someone else than to advocate for yourself, so that part I can get. But really understanding and making sure that I was doing what he wanted and that I understood the breadth and the depth of his diagnosis so that then I could communicate appropriately with those providers to get what he needed in a timely fashion or in an appropriate fashion.

Goodman: So you can see that Sharon and Jessica have had to overcome a lot of challenges in this transition.

Hinds: The providers I spoke to were very conscious of these challenges. Steve Springer emphasized that caregivers are vital in helping the provider deliver optimum care.

Springer: They're what we call a care extender for us. They work in tandem with what we do. We're only with the patient a few hours a day. These people are with them 24/7. They fill a real-time life safety role for the patient. Has the patient taken his medications or are there things that we don't see when we're with the patient that have come up medically? Or are there psychiatric issues or traumatic brain injury issues that we may not be aware of which are impacting the patient's behavior? And also, their overall recovery.

Livingston: So from my experience, this rings true, that providers do rely on caregivers to be there even when they can't be.

Hinds: That's right. And in that same vein, Dr. Shah emphasized that the caregiver may see things that the provider does not.

Medha Shah: You may be someone who's able to understand them much better. And so, you become their voice in that way. And that's from a medical perspective. But from a non-medical perspective, I'm really thinking about the overall biopsychosocial factors in your home and how that environment has changed and what some of the things that you're seeing in your house is just basic stuff that looks different from where you'd like it to be.

Goodman: The caregivers can be the eyes and the ears of the provider but they obviously can't do it on their own.

Hinds: That's absolutely right. Steve Springer made a point of explaining the resources available to caregivers.

Springer: The civic support, the biggest ones, obviously, you got The Red Cross, the USO, Fisher House. There are a variety of other nonprofits that are out there that provide local support. There are several we use here. They're really good for the nonspecific things that are not covered by the military itself. Good example, you have a wife that has a newborn. They need a baby stroller. They didn't bring it with them. That's when you would call one of these support groups and say, "Look, I need a stroller and two boxes of diapers." And literally within the hour, usually, you'd have double what you asked for in the office. But again, making sure this information gets to that [inaudible][warrior?] and that family member is key. A lot of times, early into their hospitalization, myself and other people will do a lot of that coordination for them. As they progress further down the road, we'd ask them, again, especially for our traumatic brain injury folks to assume that role of asking for the support. One, we want them to establish a relationship. And two, we want to see how they can actually handle activities of daily living. Are they going to be able to reintegrate back into society successfully? Because sometimes, you can do too much for people. You need to carry them to a certain point and then start putting a little bit expectation back on them so they make sure they have those life skills back on place and they can function-- it's life safety. Obviously, the big one is, can you remember-- look at the red light before you cross the street. Folks which are impaired or have brain injury may not think that. Or did you remember to put the milk in the refrigerator after you shopped? There's a lot of things that we really start expecting them to do which may not even be on most people's radar. But we really want to make sure they can handle that. The multitasking, the everyday activities. For somebody, it's not 100% functional. Just getting up and figuring out what clothes to wear and do your medications in the morning can really be a challenge.

Hinds: Steve also spoke to the various people a caregiver might have to interact with to have their veteran or service member.

Springer: I'm going to the physician-in-charge, which for us, is physical medicine doctor. They direct all the care for our amputees. Under them, some of the key players. Of course, we do collaborate with Traumatic Brain Injury, Psych Support. Also, to include Orthopedics, Physical Therapy, Occupational Therapy, Prosthetics, and of course, the nursing support staff which is myself. I'm one of two care coordinators. Physicians dictate the care. We all collaborate with each other. The patients shouldn't have to ask for that to happen. That should happen automatically, and it should be explained to them again, "You're going to see Physical Therapy for three weeks for this care. Do you know why you're going? What are your questions? What are your concerns? What goals do you expect us to meet for you at the end of that care?" It may seem simple, but a lot of people are intimidated by healthcare in general. They are really reluctant to talk and ask the questions they need to. That's important. They are receiving the care. We're working for them. They need to let us know what their expectations are, and of course, that's back to that open communication again. We recommend things because, again, we do tend to be the experts in our field, but we want to collaborate with the patient to make sure we're meeting their goals, too, at the same time.

Livingston: That can be a lot for a caregiver to take in, especially if they're new to the role.

Goodman: It can be a very stressful time. Sharon was caught off-guard the first time she reconnected with her son, post-deployment.

Grassi: With my son, he was still active duty military, and he seemed to be putting the needs of others over his own needs. He was even neglecting his own needs, and he was having a problem really processing things that he needed to do for himself. At the time, I was connecting it to PTSD. I was connecting it to a lot of pressure coming out of deployment, and I really didn't understand what was going on. Today, I understand what was happening to him was TBI. At the time, he had still not had a TBO evaluation. The only thing that I had as a diagnosis was PTSD. So he worked himself, basically, into a corner helping others and ended up putting himself in a military brig, which is just a difficult position and a really bad place for someone who is dealing with PTSD and TBI. It exacerbated what was going on with him, and at the time-- well, and the day after, he ended up in the military brig, he attempted suicide. So my minimal attempts to, "Hey, step in. This is the mom. What's going on?" became pretty much me barging in, flying to Hawaii, and saying, "This is enough? We're done. There are some problems. There are some medical problems, and we are going to deal with them." And so, even from that day, even though there wasn't a place for me in the military to speak that way - and they didn't take very kindly to it on a number of occasions - that wasn't what I really cared about anymore. It was, "This is going down a wrong path. I don't care if he did or did not do what he ended up in the brig for. You will take care of him. You will identify whether any of this took a part in getting him to this point, and we will take care of him." So really, the day after suicide was a very big turning point for me.

Goodman: Once they realized they had issues that needed addressing, they were thrown into the role of advocating for their loved ones. Both of them came away with advice other caregivers can use.

Rodriguez: Look into brain-injury-related resources in your state. Make sure that you write them down. What they can do and what they cannot help you with. Really start developing a support network for yourself to help your loved one that has brain injury. Some of the best ways to do that is through researching. Learn as much as you can about the type of injury that your loved one has. And that could be researching it online. It could be finding a specialist that just deals with that type of injury. And they could be out of state, the country. But it's not impossible to connect with those people. But you have to find them and you have to find the one-- those people that are going to be significant, important with the type of injuries that are unique to your loved one. I can't stress that enough because that's where I fell short for a while was trusting that a neurologist could take on that-- my loved one's injuries, and know everything about that type of injury including the best treatment modality. When there are so many others out there that could be better suited for the injury. And if you see things that aren't really going with that diagnosis that your loved one has. And fitting with that diagnosis whatever the symptomatology the doctor tells you it's behind that diagnosis. If you're seeing the thing that is different don't be afraid to raise your voice. Don't be afraid to point out those things that aren't matching. And really stepping up and saying, "We need further testing. Why is this

happening?" Don't be afraid to ask questions. Don't be afraid to ask what that specialist has for their experience and their background with that certain type of injury of your loved one.

Another really good thing for me was looking for medical journals. And one was The Journal of Head Trauma and Rehab. It's a very good journal that has lots of research that's up to date, and newer research, and how rehab modalities and treatment modalities for TBI injuries. But it's really raising your voice and asking those questions. And not being concerned with if you made a wall because you're going to whatever it is, financial, it could be with the insurance saying they're not going to cover anything. Don't be afraid to appeal. Don't be afraid if you have to do more than one appeal. I'm in that process right now. And when I first had to do an appeal and I came back denied, I felt defeated. But it wasn't defeated because I know what's fueling me is that he needs the right treatment. He needs acknowledgment of his injury. And he needs the right treatment to get better or to get to his optimal level of function. And that's not going to happen with me sitting here and feeling defeated. It's only going to happen with action. And it's going to happen with me raising my voice for my loved one. And that's the same for others who need to push their case. Whoever it is you're fighting for that may be a daunting task. And you're one person. But start developing that support team with the Brain Injury Association of America. They have advocates across the country that can help you fight for your case. They have brain injury lawyers that can help you with those appeal processes. This is newer knowledge for me that I wish I had 10 years ago to give to somebody. So if you need to push the healthcare case for your loved one. Don't be afraid to step in and be that voice.

Goodman: But Sharon and Jessica realize the importance of being a tireless advocate.

Sharon: In the VA Hospital, there is not a lot of connecting the dots. You have to have an advocate. Well, throwing a guy with PTSD and TBI and physical injuries into a military brig there is even less connecting of the dots. And it became a huge push reaching into every advocate that I could. I called every organization, every Senator, congressman, anybody that I possibly could to reach out and say, "My son needs care." I wasn't saying, "My son needs to get out of the brig." I was saying, "My son needs care. You need to help me get care for him. You need to make sure that he's evaluated." And what's kind of odd about this interview is a captain from the DVBC called me back. He reaching into the hierarchy of the brig. He reached out and she called me back and she was like, "I am so sorry. This is very difficult. This is a problem. We do need to do it." Shortly after that, one of his providers in the brig put in the notes that he needed to get an evaluation. I would like to think that she is one of the reasons that he got to Balboa Hospital, finally got an evaluation and we began the long push for getting him care, getting diagnosis, getting evaluations which coincided with him going to Ft. Sill and then to Walter Reed, and then we really began to understand what was going on. And I was able to finally become his advocate as he came out of the military officially. Prior to, I was just a bully mom [laughter] but afterwards, I was officially a caregiver and an advocate.

Livingston: It sounds like what caregivers really want is clear and open communication with providers.

Hinds: And that's very interesting to hear because the providers I spoke with echoed a lot of the points Sharon and Jessica made regarding open communication and regarding finding a support network.

Springer: A key point for any caregiver is know they are supported by a full team. We're there for them whatever they need. Make sure they get to whoever person, specialty they talk to and also too there's another second part of that in addition to the medical team approach is we look at every aspect of their care. Early on we weren't doing real good with the traumatic brain injury aspect. We were missing things and saying, "Oh, this was to be expected." And how you treat a person is important especially in regards to traumatic brain injury because you really can't, again, hit them with a lot of detailed information, present them and expect them to recall it. You have to interact with them a lot differently. Feed them bits and pieces of information. Sequentially make sure that they're understanding it and again, that's back to the caregiver. That's really where it's really key for them to understand what's up so they can remind the patient. Say, "Okay, look. Do you know you have an appointment at 2:00 today? Did you remember that/ Did you write it down?" That kind of thing. And again for a caregiver, they really need to be aware of the burnout factor. They need to take care of themselves and make sure they know what systems are out there to support them. Again early on we focused so much on the patient, we overlooked the impact it had on the caregiver, the family, the friend. Whoever it was, significant other that was helping that patient and there was burnout. There was significant burnout which impacted how well we could take care of the patient. When you burn out the caregiver, you've got a problem and it's easy to do. He's so focused on the patient it's easy to fall into that trap. So again, they need to be

aware of that, self-aware what's going on. Need to talk with the other family members here, the other caregivers [inaudible], find out what things worked, what problems they might have had because them getting advice from that group of people is also really key and critical because they're living it right now, they've been down that road. And they always cover things too, which tend to be a little more outside of the medical field, but, which are still really important to that patient and that family member to make their stay here productive. We want to eliminate as much stress as we can, make sure they know what's out there, they're a lot of different support systems, there's groups out there, the army, the marines, the air force, they all have their own support systems, and there are hospital support systems too, which is all there, but a lot of times, people don't know to ask for that, that's our responsibility and they also get that information from those other family members and caregivers that have been here a long time.

Livingston: What sorts of strategies can caregivers use?

Hinds: Dr. Shaw recommended that caregivers make their own list of priorities, and then make sure that those priorities are addressed over the course of meetings that they have with healthcare providers. She also brought up the potential usefulness of Telehealth options.

Shaw: I hope that if they are not aware of it that Telehealth, and secure messaging, and some of the other technology that we have now can connect patients and the patients care unit with their clinician even if their clinician is not close by, it's really remarkable and I have been able to get so much information that I otherwise can't get, and not exactly real time, but sometimes real time. I can see a patient's home. A caregiver doesn't have to tell me what's wrong and hope that I'm envisioning things correctly. She can walk me around his or her environment and say, this is what it looks like and this is what's happening. And it's really, I don't know, it's pretty fantastic.

Goodman: So it sounds like providers can benefit from open communication as well?

Hinds: Absolutely. Steve Springer emphasized that caregivers should feel encouraged to voice any and all concerns that they have.

Springer: We always encourage open line of communication with any provider on any subject that patient or family member has a question about. We are constantly asking, interacting with them. I know personally, I make it a point to talk with as many as my patients every day as I can, the office door is always open, I always return all call and email within at least eight hours, if not one business day. That's just a personal standard I set. And I want to have a good work relationship with all of the patients, their family member, and the other providers on the team. I can honestly say in all my 15 years here, I've never had a negative interaction with another healthcare provider on the amputee care team. It is always about the patient, the family member providing the best care we can. And again, it's the responsibility of the patient and the caregiver to let us know what's going on, they have to talk to us constantly. If something we're doing is not working, let us know, we'll change it. We're working for them, we want to make sure we give them the best result as possible in regards to medical care, and we really want them to talk to us. And again, the family is the key. That caregiver is in with that patient during all aspects of their care except the operating room and if we could do that, we'd do that too. But realistically, we really want to go ahead and make sure that they understand that they are the center of what we do. We are patient care driven. We want to make sure that they understand that and we want to collaborate with them to give them the best outcome that's possible with what we do.

Livingston: So providers really do want caregivers to be vocal about what they need and about what their service member and veteran needs as well.

Hinds: Exactly. The more these support networks interact, the better the outcome for the patient.

Goodman: Better for the patient and the caregiver.

Livingston: Gentlemen, this has been very eliminating. Thank you both.

Goodman: Dr. Livingston, before we close, Jessica and Sharon had a great networking opportunity when they connected with us on the podcast. We'd really like for you to listen to that.

Grassi: Yeah.

Rodriguez: Thank you.

Grassi: Thank you so much. And it was really good talking to Jessica. You guys have helped in the little interim. We're going to have to find some time to connect.

Goodman: It sounded like you guys had a little connection there. I mean, it was cool.

Grassi: I know.

It was cool.

Grassi: I know. Well, you know there's so many moms on the groups that you really-- you get a little bit, and I'm new, I haven't been on that long. I'm a new [inaudible]. So I'm just starting to learn who everybody is. So it's just really, really nice to make those connections and then to start making housekeeper friendships. They're going to be [inaudible] [crosstalk] [laughter].

Rodriguez: Yeah. You too. So we're going to have to do the friend request thing, and get on the phone together, and maybe get our guys to talk to each other as well.

Grassi: I know. I know. [music]

Livingston: For more information on advocating for your service member or veteran and resources available to caregivers, check out the family caregiver curriculum at dvbic.dcoe.mil. That's D-V-B-I-C dot D-C-O-E dot M-I-L. [music]

The TBI Family is produced and edited by Sydney Heines and is hosted by me, Dr. Scott Livingston. It's a product of the Defense and Veterans Brain Injury Center led by acting director Kathy Helmick and the defense health agency's research and development directorate commanded by Rear Admiral Mary Riggs. Thanks this week, to Mark Oswell and Steve Springer from the Walter Reed National Military Medical Center, Sarah Cox and Medha Shah of the Washington, DC VA Medical Center, and Taylor Leaming of the Elizabeth Dole Foundation, who helped coordinate the interviews with Sharon Grassy and Jessica Rodriguez. Thank you for listening. [music]

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