



Defense and Veterans Brain Injury Center
“The TBI Family” Podcast
“Veterans Affairs Respite Program and a ‘Battle Buddy’ Caregiver”
Episode 103, Transcript
TRT: 21:52 min
Host: Dr. Samantha Finstad

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Susan Barnes: I'm Susan Barnes. I live in the Silver Spring area and I'm retired.

Producer: How long have you been coming to spas, or this spa specifically?

I've been coming to Maisie's forever.

Maisie Dunbar: Hi. I'm Maisie Dunbar. Part of being a caregiver, sometimes you're so caught up in caring for your loved one, you forget and neglect yourself. So you must find the time to take care of yourself.

Producer: How important is it to take time out of your day for yourself?

Barnes: Oh, it's essential. Absolutely essential. And I have been in the position of being a caretaker for a couple members of my family so I know you're just always thinking about the other person and never ever thinking about yourself. You don't realize exactly how much of yourself you are giving. It's not until you stop and you do something for yourself that you realize, "Hey, I really did need this." And it rejuvenates you. And in turn you can then give more to the person that you're caring for.

[theme music]

Samantha Finstad: Hi, and welcome to the TBI family a bi-weekly 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 Dr. Samantha Finstad. In this episode, we discuss a program that helps caregivers get some time to themselves while ensuring their care recipient is still being cared for. We'll also talk to Danny O'Neel who, like 25% of quote family caregivers, isn't related to the veteran he takes care of. Before we get to those stories, though, we want to take a few minutes here at the top of the podcast and ask for your help in two ways.

First, when we started this podcast, we were told that a lot of caregivers feel like no one knows what they're going through. So we see this podcast as not only a way for us to pass information along to caregivers of people who've sustained a TBI, but also for caregivers to talk to each other and share their stories to let others know they're not alone. We understand that these stories are private and can sometimes be difficult to tell. So if you prefer, we can use a different name and even alter your voice. Now, if you're interested in talking to us and sharing your story, please send us an e-mail at info@DVBIC.org or by messaging us through the Facebook page, which if you haven't done it yet, you should like to us to follow. You can also send us your questions, suggestions, or comments by e-mail or on Facebook just like our listener Jock did who wanted us to hurry up with making our transcripts available. By the way, you'll be able to find those transcripts shortly on our website: dvbic.dcoe.mil

The other way you can help us get the word out is by subscribing to and reviewing the podcasts on iTunes or the app you use to listen to us. Doing so helps the podcast rise in app searches which, in turn, helps other people who could use the podcast find it more easily. We think we're doing good stuff here and because of that, we'd like to

make sure that anyone who needs this information can find it. But that's enough of that. Let's get on with the rest of the podcast. When taking care of someone else, you don't want to minimize taking care of yourself. And making time for yourself can be hard. But it's critical. Whether it's a few minutes to run errands, get a cup of coffee with a friend, or enjoy a relaxing spa break like our friends at the top of the podcast, or maybe even a weekend visit to family or friends, getting a break can make it easier to take on your toughest challenges. For caregivers of service members and veterans who have sustained a TBI, that break can be the thing that prevents burn out and allows caregivers to continue to functioning at their peak. In some cases, it could even be the key from preventing a care recipient from being institutionalized. The Department of Veterans' Affairs can help caregivers get that break they surely need. We spoke with Dana Cooper...

Dana Cooper: I'm a registered nurse by background, and currently I'm the director of home and community based care programs here in the Department of Veterans Affairs in central office DC.

Finstad: ...who told us about the VA's respite program for caregivers.

Cooper: The respite program in the Department of Veterans Affairs is a program that provides respite which is just a temporary relief for caregivers to have a break from their care giving responsibilities for veterans that they're caring for 24 hours a day. We provide that care either in an institutional setting such-as our community living centers or community nursing home settings or we can also provide that care in their home in an adult day care center or a setting of their choice. Our preferred setting is whatever the veteran wants, so we can provide that a lot of times in their home. Veterans can receive up to 30 days of respite care in a calendar year. If they need more care than that, then we often can do that for them just depending on what their needs are and what the caregivers needs are.

So a lot of times respite is seen as a babysitting service, and it's really not a babysitting service. It's a service that is provided to give the caregiver some time away. And the service is a service for the veteran, so we want to make that care plan specific to the veteran, so it's not, it's not a babysitting service. So we can have something for the veteran to do so if it's going and taking the veteran to a movie or if it's taking the veteran and doing something with the veteran that is of interest to the veteran, then that's what we want to do. So it's a service for the veteran that allows the caregiver to do something for themselves and really give them the opportunity to have a break from each other. Because, believe it or not, the veteran gets tired of the caregiver, too. And so we need to have that break in service that's a respite, for not only the caregiver, but for the veteran, and that they each have an opportunity, so that they can come back together, and that the care that's being provided, from the caregiver to the veteran, and the veteran is happier, too. It's not a service that's frowned upon. It's not a matter of saying that the caregiver's weak. It's a service that gives both people a break.

Producer: So who qualifies for the program?

Cooper: Any veteran who is enrolled in health care with the VA is entitled to care. It's part of their basic medical benefits package. Unfortunately, for us, it's one of our most underutilized services. And we try to promote this service, because we realize our caregivers are essential to being able to keep veterans at home, because we want to prevent institutional care for them. So last year alone, we served just under 17,000 unique veterans and their caregivers. And we realized that service is something that we need to promote and do more of.

Producer: There was someone talking about a way that is either in place or is going to be in place to be able to pay people who are Battle Buddies or people from your community or church to help out. Is this part of that same program?

Cooper: Yes, it absolutely is. Our Veteran-Directed Home and Community Based Program is available at some facilities already. Our goal is to have that at every single facility. Right now it's available at about 63 different medical centers and our goal is to roll that out over the next three years to every single VA medical center. And what that allows is veterans to actually purchase their own care, through either caregivers of their family, churches, or communities, including Battle Buddies or the like that they're most comfortable in providing their care. And that type of care works really well, especially for respite. Our goal is to individualize that respite to the caregiver needs, so we're not just giving them someone who just doesn't meet their needs. So if we have a

younger veteran, for instance, our TVI veterans who really need somebody to go running with them, for instance, you know. We try to match a caregiver, sometimes they're Battle Buddies, that can actually go out and do things that are active with them as opposed to just providing them somebody who's just going to sit and watch them, for instance. So we try to individualize each veteran's care plan to their actual needs.

Producer: How important would say respite is to the family caregiver and their mental health?

Cooper: Oh, my goodness. In caring for someone, to do that non-stop is burdensome. To care for a veteran and your children and someone else and never get a break, it will drive you crazy. And so, people need a break. They need to be able to take care of themselves. They need to be able to take care of their own health. And if you're not healthy, then you're not healthy enough to be a caregiver. And once you lose the ability to care giver, and then that leads to the long-term effects, such-as needing a long-term care placement option. And we don't want our veterans in an institution. The respite is so important, even if it's just two hours a couple days, a couple days a week, or a couple times a month to go get your hair done or go get lunch with some friends. It's just enough to get away so that you can have some time from your care giving responsibilities and just take a break.

Producer: What's the one thing that you want them to take away from this discussion?

Cooper: The one thing I would really encourage people is, it's okay to ask for help. It's okay to say you need a break. It's okay to say, "I'm a caregiver," to acknowledge that you're a caregiver and to say, "I need a break." A lot of times people don't even acknowledge that they're a caregiver, because you just assume that's your responsibility. And it's okay to say, "I've had enough and that I need to walk away." And it doesn't mean you're any less of a caregiver because you do that. In fact, it's taking responsibility for your own mental health and your own self-being, because everybody needs that time. So I encourage people to ask for that help, because it's available. And it's available as much as you need, especially for our post 9/11, our TBI, and our spinal cord injury patients. Those are the ones that are really difficult to manage, and if we don't take care of our caregivers, then we're doing our veterans a disservice. So I really want them to be able to acknowledge that it's okay to ask for help, because it's available. And that's the program's there for.

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Finstad: If you're interested in taking part in the VA Caregiver Respite Program, contact your VA social worker or case manager who can begin the process. You can also find out more information about the respite program at VA.gov. We'll put a link to the respite program's page in the description of this episode. By the way, if your veteran doesn't have a case manager or social worker, we'd like to remind you what Dr. Joel Scholten, the National Director of Physical Medication and Rehabilitation of the Veterans Health Administration told us in our first podcast.

Joel Scholten: A good case manager is worth their weight in gold. They're trained to kind of interact with families and start to recognize when there can be evidence of increased stress on either the individual or the family and the caregiver. And so they can, by being aware of that, they can also start to intervene and kind of pull the team together to make sure that there's adequate support not only for that individual but for the caregiver, as well.

Finstad: So you should make sure to contact your local VA to get that extra help.

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Finstad: The continued push by government agencies and nonprofits to find new ways to assist military family caregivers has led to both innovative programs and a newfound understanding of the role of the caregiver in the full medical landscape of our nation's wounded warriors. One group that hasn't quite seen the same amount of recognition are those caregivers who are not, in the genetic sense, family. Yet according to a 2014 study by the RAND Corporation and the Elizabeth Dole Foundation, almost a quarter of the nation's 5.5 million military caregivers are actually friend caregivers, neighbors, friends, or former battle buddies who volunteer their time to help service members deal with their injuries or the transition from the military to civilian life. One of those people is Danny O'Neal. On September 11th, 2001, the then 19-year-old O'Neal was working in Livermore, California on a road construction crew. After hearing about the attack on the World Trade Center, he quit his job

that day and enlisted in the United States Army. After leaving the service in 2008, having sustained his own TBI that continues to actually affect his memory, O'Neel began taking on caregiving roles with some of his fellow veterans. On a recent call, he told us why he decided to do it.

Danny O'Neel: Because of the last decade and a half of war, I have accumulated a huge base of friends who have had significant and serious injuries and mental health issues coming back some more, so that led me to realizing that my job wasn't, my duty wasn't done just because I put down my weapon and took off my armor. I still had a whole lot of work ahead of me.

Finstad: We often that family members can be slow to identify themselves as caregivers, which means they miss out on some of the helps that's available to them. Do you think it's harder or easier to identify as a caregiver when you've chosen the title rather than it having been something that's thrust upon you to an extent?

Yeah. I never think of-- even now, it's hard for me to, I guess, identify as a caregiver only because I forget stuff. I have traumatic brain injury, too, so I'm not that helpful in some areas. In other areas, I am. And like you said, you mentioned the resources, those things I am good at, because I can point them in the right direction, say, "Hey. Listen. This is what's out there for us. And there's probably other ones that I don't know about, but this is a good start." And they listen to me, because I have the same experiences as them. So that's something that definitely helps me. When you get injured, you feel like you don't really want other people to help you because you have these injuries. You feel like you're still self-empowered, but you know that there's deficiencies. My buddy lost both of his legs. He's an adult but now his mom has been taking care of him for the last decade. So how does-- it's hard for him to be a man and still have his mom take care of him and make his lunch for him. He doesn't there's animosity sometimes or creates problems in that relationship. With me, it doesn't, because there's a brotherhood that we have that's-- I'm here to help and nothing more. I just want what's best for my brother, because they are family to me, even though I'm not a family member by blood, per se.

Finstad: What do you think people should know about friend caregivers, like yourself?

Well, there's a ton of us out there that aren't really recognized as doing a job or a task that's-- we really are saving the government money by helping, because a lot of these people would be in institutions or would be-- they would need other care.

Finstad: Have you experienced challenges as a friend caregiver that you don't think you'd have experienced as a family caregiver?

Yeah. So, okay. Well, for example, I had my soldier in Iraq. And recently, he was going through some significant issues. We had a lot of suicide in our unit, as of this last year. It's been decimated. Our company commander was on the cover of Army Times in January for committing suicide. So he's having issues. And he tried to talk to one of his providers, but he didn't really know how to get across what was kind of going on in his mind. And I think, he was ashamed about how he was feeling, because that's what happens. And all of a sudden, I got a call. Someone from his primary care physician. And essentially, she had asked me, "Was he having any issues?" And I said, "Well, obviously, because he came into my number because he didn't want to talk to you. And she said, "Well, I can't talk to you about his information." And I said, "Well, I have the information that you need. You know whatever you have written down in your notes that he's told you. But the information that he hasn't told you, is what I have." She couldn't talk to me about any of his information, and any time I've ever had to call a provider and say, "Hey, listen. I'm the battle buddy of so and so." And they laugh it off. I'm not a blood relative or a spouse. And for most of them, that's all that matters. But I can tell you their entire social security number. I can tell you where they were born. I can tell you their family members. I can tell you what their life is like and how they're struggling and what their coping mechanisms are. But they won't talk to me, which is fine, as long as I can help in some way. In the end, it should be a two-way street with communication. Because that's our biggest hurdle, is the communication between those who are helping the veterans and those who are providing services.

Finstad: What advice would you give others in your position?

You don't have to be a military combat veteran to be helping. If it's your neighbor who just happens to know that

you've been struggling, you need to know that there are resources out there who can provide support. There's going to be hurdles. But there's people out there, and groups, and blogs, and research that you can do to help make your life easier. And there are tons of people who are willing to help, even in the local community. I guarantee it. [music]

[music]

Finstad: Danny O'Neel is finishing up his final class for a degree in human services. He wants to continue to use his education to find new ways to get veterans the help they need. O'Neel is also a Dole Caregiver Fellow representing California. If you are a military caregiver in need of support, or you would like to learn more about the Elizabeth Dole Foundation's Hidden Heroes Campaign please go to hiddenheroes.org.

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We should add that DVBIC realized a few years ago that some veterans who've sustained a TBI might need a bit more help managing appointments, medicines, and such, so we began to allow identified caregivers, whether they were a family member or friend to become clients on their care recipient's behalf in our recovery support program. So if you're a caregiver of a service member or veteran who's sustained a TBI, you can find out more about the TBI recovery support program on the DVBIC website. dvbic.dcoe.mill.

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And that's our show. Again, if you have any questions about the podcast, about DVBIC products or programs or are interested in telling us your story, please feel free to e-mail us at info@dvbic.org. You can also find a link to that e-mail in the description of this podcast. Now on the next episode, we'll talk about cognitive rehabilitation which can help some folks who've experience a TBI overcome or lessen cognitive problems related to the injury.

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The TBI Family is produced and edited by Terry Welch and is hosted by me Dr. Samantha Finstad. It's a product of the Defense and Veterans Brain Injury Center commanded by army colonel Geoffrey Grammer and the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury commanded by navy captain Mike Colston. Thanks this week to the Hidden Heroes Campaign, the Department of Veterans Affairs, and the Elizabeth Dole Foundation's Laurel Rodewald for introducing us to Danny. We'd also like to give a special shout out to Kathleen Taylor and the public affairs team at our parent organization the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury for their support. Thanks as well to the BUMED visual information team at Walter Reed who helps us record, well, me. And thanks you to you for listening. We'll see you in two weeks.

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