



Defense Health Agency

Defense and Veterans Brain Injury Center

“The TBI Family” Podcast

“Art as Self-Care for Caregivers,” Episode 107, Transcript

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Host: Dr. Scott Livingston

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Maureen Norman: One minute I was there, the next minute I was over a cliff [laughter]. So I landed on a cliff edge. And then on my face. So see, so that did take some skill. Now we're really putting effort into this [laughter]. But I didn't stay there. I didn't linger long. I fell now again, rolling off that one. So a total of 30 feet. Landed on my face again. Okay? So you see what I mean? This is that simple stuff for beginning TBIs right. This is some effort going in here. [Pause] So another thing when you have TBI is you suddenly forget what you're talking about. So what was the last thing I said?

Audience member: You fell off a cliff.

Norman: I fell off a cliff. I fell off a cliff.

[music]

Okay. So about a year later, Walter Reed put my face back together again for me. And if you don't like what you see you can take it up with them [laughter].

[music]

Dr. Scott Livingston: Hello, and welcome to the TBI Family. A 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. In this episode, we're going to talk about using art as a way to deal with the challenges of caregiving. First, though, we wanted to remind you that March is Brain Injury Awareness Month. DVBIC dedicates this month to getting people to think ahead. To us, that means being safe by trying to prevent traumatic brain injuries through the use of protective equipment and common sense. It also means knowing the signs of a traumatic brain injury so that you can recognize it if you or a family member sustain an injury. And finally, we want people to think ahead by getting help if they need it. The sooner a TBI is diagnosed and a course of care put in place, the more likely it is that a TBI will have fewer, long-lasting consequences. You can help spread the word about traumatic brain injury during the month of March through your own social media accounts. Just go to dvbic.dcoe.mil and download DVBIC's hashtag card to share on your social media accounts.

Look, I really didn't know what a hashtag card was either until the social media team here explained it to me, so let me explain it to you. It's basically a piece of paper with the ThinkAhead logo on it that allows you to write a personal message about brain injury that you can share with your followers and friends. Take a picture of yourself, or maybe a family member, holding that sign, and share it on your social media accounts with the hashtags think ahead and BIA month. We can't wait to see your pictures. Now, let's talk about caregiving and art. To get started, we're going to bring in our producer, Terry Welch. So, Terry, how did art become one of the ways caregivers are

helping alleviate the burdens of caregiving?

Terry Welch: The arts and war have always had a very strong connection. Everything from Homer's Iliad, to the Hindu Bhagavad Gita, to our national anthem are basically responses to war in one way or another. But it wasn't until the 1940s that the concept of art therapy came into being. There are a lot of discussions about what art could do for people who are struggling with communicating difficult feelings. The act of making the art has been shown to have therapeutic value, and the art itself becomes a way of looking at what the person is dealing with. I spoke with--

Bill O'Brien: Yeah, my name is Bill O'Brien, and I'm the senior advisor for innovation to the chairman of the National Endowment for the Arts.

Welch: He said that in the early 2000s, the art community saw that art could be a way to help people deal with the difficulties of the wars in Afghanistan and Iraq.

O'Brien: As we had experienced as a nation this war carrying on, I think we all started to recognize that there's a real toll that was being taxed on a small number of the population, really, that was carrying out these wars, that included both service members and veterans and family members, and that there were some psychological health issues that were really intriguing to us because they seemed to be, in some ways, calling for meaning-making and some of the creative arts therapy kinds of things that we'd been looking into as a means to really respond to an urgent issue.

Livingston: So once the NEA decided that art could actually be helpful, what were the first steps that they actually took?

Welch: Well, there may have been art therapists working with individuals in some capacity since the wars began. But the first organized effort was the creation of a program called Operation Homecoming.

O'Brien: We would send some of the best writers that we know of in the country, who are interested in giving back to the military, to aircraft carriers in theater over in the Middle East, on bases, to provide some support on the craft of writing. The idea, I guess, back then was to create a platform for the wartime experience to be shared.

Welch: Operation Homecoming actually led to the creation of a very well-received book that features stories from service members and their families. The team at the National Endowment for the Arts realized there was a real need for the arts here, so they began working with the DOD to include art therapy in the mix of treatments for the invisible wounds of war, both TBI and PTSD.

So the NEA created a new program called Creative Forces aimed at helping service members. And they reached out as the National Intrepid Center of Excellence, which we call NICoE, obviously, stood up at Walter Reed National Military Medical Center.

O'Brien: Very early in our conversations with them, we recognized, as did the military medical folks that we were talking with, that this is a really complex and wicked problem in terms of the signature wounds or the invisible wounds. They're spiritual and existential in nature. And that really leads you to, I think, an understanding that putting the arts at the core of that process helps to make visible some of these invisible wounds. There's mask-making, songwriting, creative writing and therapeutic writing and all of these efforts in and of themselves do have, we feel, some sort of healing quality, and we're really trying to drive the hardcore medical research forward to understand what are those benefits and how do we measure them and how are they best leveraged. But I think the other thing in a team approach of integrative medicine like they have at the NICoE trying to address these invisible wounds, the output -- the art, the mask, the poem, the song -- ends up becoming a communications tool that improves the ability for everybody who's working on these problems with them to perform better.

Livingston: Were there other arts programs besides Creative Forces and NiCoE?

Welch: Definitely, a lot of existing arts programs began including opportunities for service members. For example, Susan Bethel is the Director of The Art League in Alexandria, Virginia. She recently told the NEAs podcast Artworks about how they created the IMPART program.

Susan Bethel: The Art League is a visual arts nonprofit. We have a mission to nurture the artist. We do that through a school that enrolls 6,000 students. We have an art gallery that has a membership of 1,000 people and we have community outreach programs. One of them being the IMPART Program. The IMPART Program started as an impulse. I was having a conversation with someone who had come to one of our openings. And she was explaining how much her art classes and her participation in art shows meant to her during her cancer treatments. It was about five years ago. And I kept on coming across, as we all did, reports about returning injured military personnel. And in this area of the country, we certainly see Walter Reed and Fort Belvoir. And they're sort of iconic discussion points. So just started having a conversation with some of the other artists here at the Art League. And so I thought, "Well, we can do that. We can try that." We're naturally set up to be a home for that kind of program. And Blair seemed the person to kick us off. And I have to say that it's succeeded beyond our wildest expectations. It's really been an extraordinary process.

Welch: Other programs were created from whole cloth with veterans in mind. Sam Pressler was a student at the College of William & Mary and was researching veteran treatment for a paper when he said he was stunned by the disconnect between what service members and their families were going through and how little most civilians knew about their experiences. As someone who had lost a close relative to suicide, he had seen how humor had helped him and his family in a dark time, so he founded the Armed Services Arts Partnership or ASAP.

Sam Pressler: When we have disconnects, we tend to use humor because humor and laughter are one of the more universal languages. As a very naive 21-year-old college student, I thought stand-up comedy class for veterans is the answer to those problems [laughter].

Welch: Naive or not, the program has grown quite a bit since it launched at the William and Mary Center for Veteran's Engagement.

Pressler: Down there we started with a small writing group, a music program, and a stand-up comedy class for veterans. We've been fortunate now to expand from Hampton Roads to Washington D.C. where we offer classes in stand-up comedy, improv, creating writing, and storytelling. All of our programs are intro level classes. They are about seven to ten weeks in length. We're not explicitly art therapy, we're much more art education focused, so in those programs we focus on skill building, fostering a place for expression, and allowing veterans and their families to have a place to connect with one another and build camaraderie. But then providing a platform and a stage so that you could have your story told to an audience of people who oftentimes are civilians and may not have heard of these authentic stories. And so we use that platform to provide access, engagement, ideally an educational platform for people in the community. So better support, better into military families.

Welch: So the voice you heard at the beginning of the podcast before the theme music was Maureen Norman, who was a participant in the comedy classes. She's an army veteran who sustained three TBI's and was skeptical about signing up.

Norman: I didn't know what to expect. And then when I thought I understood what it was I didn't like it, but then once I kept going-- it's taken me all the way to the White House. What's not to like?

Livingston: Did she say the White House?

Welch: She did. Participants in ASAP have not only performed at open mic nights but performed for President Obama at the White House. In fact, that clip was from her White House set.

Livingston: Terry, do we know what the effectiveness of creative arts therapy is in treating these service members and veterans? Has any research been done in this area?

Welch: So there has been some research, and a lot of it has, actually, found positive results. I spoke with Dr. Elizabeth Warson, she is a former professor at George Washington University and now she's in private practice out in Colorado. She said that there's a lot of research that still needs to be done on this, but it's kind of a hard area to research. For example, at the NICoE where art therapy is part of a larger program, how can you tease out exactly what the effect was of the art therapy as opposed to all of the other interventions that are taking place there? And she said that makes it really difficult to figure those sorts of things out.

Elizabeth Warson: The one NIH study that was conducted on mindfulness and art therapy was breast cancer survivors. When you look at it in great detail, it was done at Thomas Jefferson University, I think it was back in 2008 it was curriculum based so it was really challenging to figure out what was working. Was it the mindfulness? Was it the art therapy? So it was a really challenging study just looking at it in terms of replicating, but it was a landmark study because it was the first-- I believe it was the first NIH study in our field.

Welch: Now, I will say it's worth noting here that a lot of these programs we're talking about are not what you'd actually call art therapy. Art therapy is conducted in a clinical setting to achieve medical goals that doesn't mean there isn't a value to making art, though. Here is the NEA's Bill O'Brien again.

O'Brien: You can use your experience and your unique worldview and make something of it and when you make something of it, you have then a product that allows you to speak to the world and the world to understand you better. In a clinical setting that has a really useful output so that your doctor and your psychiatrist and your speech therapist all have this as a communication enabler. Out in the community, it serves a different purpose. It allows all of us to come into a deeper sense of what the wartime experience is, and I think we all need to know what that is and I think, by and large, we're all very interested in it.

Welch: And Susan Bethel echoed his sentiments.

Bethel: The IMPART program was never intended to be art therapy and is not an art therapy program. It's been something that's evolved, and we've been humbled by the idea that it can produce therapeutic results. We're not tracking that, and we're not setting ourselves up to preach that we provide that kind of therapy. We're just glad that in terms of the statements about those who participate in the program that they've found some resolutions in terms of their therapy goals. And I think that's great. I think that's something that Walter Reed and Fort Belvoir are looking into through the Intrepid Center. And that's, we have a connection with the Intrepid Center, and that's where we have a lot of referrals that come to the program. Art is a healing part of our world. And I think that's what they've discovered with this.

Livingston: Can these programs help caregivers? They seem to be aimed mostly at service members and veterans.

Welch: They do seem that way. And in part, because they were initially created for that reason. But they're expanding because they see the need to help family members and caregivers.

O'Brien: So we're starting now to really have an expanded focus that includes family resilience in both clinical and community settings. And we have a dedicated creative arts therapist at Fort Belvoir, one of our Creative Forces sites who is helping us to understand, think about how we can tailor some of the things that we've been doing for service members and veterans, and provide those same kinds of opportunities for family members.

Welch: And some of the programs have just evolved naturally as they realize caregivers could use this help as well. For example, there was a program created by the Writer's Guild.

O'Brien: The Writer's Guild is basically the guild for all of the professional writers who write movies, Broadway

plays, TV shows. So it's the best writers in the country. Writer's Guild East is the office that's in New York City, so they have a lot of playwrights, but also a lot of television and movie folks as well. And they have a foundation where they want to give back to altruistic causes. And close to 10 years ago, they started focusing on giving back to the military, and their first impulse was pretty natural, let's work with people who've been wounded. And their whole notion was that they didn't want to pretend to be therapists, but they thought that there was something healthy about this, and they wanted to come in and help provide people with the ability to put their stories down. And they worked with different types of populations. I think they worked with some amputee populations, and they went into hospital settings in various part of the country. And somehow, they just kind of-- as they got to know these people and their families, the thing that they came in to us for funding for -- and it was an interesting narrative for me to hear -- is that as they got to know what was happening with these people and with their families, they started to be really intrigued by the issues related to caregivers. So they focused the program specifically on caregivers, where they partnered, I think, with the Wounded Warrior Project, and they would help identify these people who were isolated, whether it's a spouse or a parent, or whoever was taking the brunt of the caregiving role.

Livingston: Are caregivers taking part in any of these programs that we've been discussing?

Welch: Some of these programs are lacking family members and caregiver participants now or at least as many as they'd like. Some of that might just be because of who chooses to take part. Sam, for example, said his organization is actively seeking family members and caregivers.

Pressler: Service doesn't just impact the person who's directly serving or in combat. It also impacts the family, the mother or husband who is back home taking care of the kids and doing that alone. It impacts the kid who has to deal with a father or mother not around for a long period of time for -- or dealing with the trauma that may come home. So we really believe that it's important to give a space for everyone who's involved in that unit, and now more recently we've added caregivers beyond just the immediate military family members because they're also a part of that, and we think it's important to convey to provide an opportunity for this engagement for all those involved in the veteran military experience and then give them a platform to convey those experiences.

Welch: And some caregivers are taking part.

Pressler: We did a veterans open mic at Dog Tag Bakery which we do every month, and in December 2016, one of the storytellers was a woman who -- she was a caregiver and she told this incredibly compelling story about her experience as a caregiver, and I think people -- I mean, me in particular, but other people in the room were able to walk away with a better understanding of that, and it's definitely as the Elizabeth Dole Foundation has done the Hidden Heroes piece, I think it is something that even beyond the military family member is very much hidden from the broader society.

Welch: That caregiver he was talking about is named Betsy Eves. Now Betsy works as the programs coordinator for the Yellow Ribbon Funds Caregiver Program. But her experience points to one of the many reasons caregivers might not be taking advantage of arts programs. Her husband suffered from service connected conditions including TBI that ended his military career. When the military sent them to the Fort Belvoir Warrior Transition Unit she had a revelation.

Betsy Eves: It wasn't until I started meeting other spouses in the same situation that I realized that there is a title to what I was doing and it was called caregiving. As soon as I figured that out, I kind of jumped into the caregiver community here with both feet. And immersed myself in as much of it as I possibly could.

Livingston: That seems to be a common thread. People aren't realizing they're caregivers. And because of that, not realizing that there are programs and resources available to them.

Welch: Yep. That's an ongoing problem. And Betsy said it was one of the reasons she wanted to tell her story.

Eves: I was kind of really excited to share it with the general public. And to have the platform that ASAP provides me to do so. Being on that stage, a dog tag with ASAP allowed me to, in a safe space, talk about the hard stuff, talk about the things that you don't talk about when it comes to being a caregiver. And so I was able to share those hard things. And then I was also able to share the good, joyful moments as well. And the happy moments when therapy is going well. And so there wasn't a dry eye in the room at the end.

Welch: And that's another part of what makes these programs valuable. It makes caregiving visible. For example, that Writer's Guild program opened the eyes of many of its participants.

O'Brien: They were able to come to New York and say things like, "I thought I was so isolated, and I thought I was the only one going through this." And it is so meaningful for me to see that other people who are dealing with this are feeling the same way.

Welch: One of the people who took part in the program was Melissa Comeau.

Melissa Comeau: So my husband, when he was in the hospital, was reached out to by Wounded Warrior Project. And then Wounded Warrior Project reached out to me as his family member. And just in my interactions with them, they asked me sort of what I was interested in -- then I wasn't really interested in bike riding or Odyssey Groups, but I always listed writing as my hobby. So I was invited to go to a wonderful writer's workshop with the Writers Guild Initiative in New York City, which was cosponsored by Wounded Warrior Project. So they flew me out there and put me up at a very nice hotel, and I went to work with the Writers Guild every day for a long weekend.

Welch: Melissa, who's now the Director at the Military and Veteran Caregiver Network, said the program didn't simply help her deal with being a caregiver but made her trust her own voice.

Comeau: I can still remember the most validating moment of my entire writing life is very timidly I shared one of the poems that I had written and Mr. Weller leaned back and just sort of said, "Did you really write that just now?" And I was like, "Yes." He said, "That is very, very good." And the validation that came from that moment was really inspiring and really made me think about my writing in a different way.

Welch: In fact, Melissa received even more validation when her poetry was published as the book *Sleeping With The War*.

Comeau: To be honest, I was terrified to share my poetry. Ultimately, it's very personal and a very intimate look at my life with my husband and his rehab and recovery. So, I researched publishers that I felt were interested in the veteran's perspective to be honest and I thought, maybe if I could market it as this is a veteran's experience by proxy, like a family member or caregiver experience and in my search I found the War Writers' Campaign and they're a non-profit publisher. They work closely with Iraq and Afghanistan Veterans of America and that sort of nonprofit, that need to share, the sort of idea that your stories are healing and sharing your story helps others not feel alone, that really was in sync with what I felt I had written.

Welch: Now, Melissa knows that publishing or even sharing one's work might not be the goal for every caregiver who takes up an art program, but that doesn't mean that they shouldn't consider art as a way of relieving stress.

Comeau: I would honestly say that my self-care practice is writing. I found it's affordable, all I need is a piece of paper and a pen or my phone and it's a really nice way for me to write out negative emotions, or write things I'm grateful for or appreciate, and just sort of express my view or my perception of my reality in a way that helps me stay focused and calm. It's always been a great stress reliever for me. My family knows that if I'm sitting in bed writing that that's my me time. And I could be writing about them. I could be writing about the [circus?]. I could be writing really about anything. But that connection with me with my pen and paper is a self-care practice. I mean, it's very therapeutic for me.

Livingston: Many caregivers may find participation in an arts therapy type of program to be frivolous and find it hard to work that into their already busy schedule.

Welch: I think you're probably right. But Bill O'Brien said that the self-care aspect of art can not only be beneficial to the caregiver but to the care recipient as well.

O'Brien: Focus on self is important because the job they're doing is tremendously important. The responsibility that they're left with on a day-to-day basis to help address the aftermath of war is enormously important. When you are in a position -- I can only imagine, but I can certainly appreciate that if you're in a position where you feel that there's a tremendous amount of physical, psychological, economic stress that's involved with this kind of responsibility, you have to provide an opportunity for your own self-care to be a part of the picture. Just to be able to get -- I mean, that's the thing where it can become selfless [laughter]. It's kind of a weird Catch-22. But if you don't take care of yourself, you're just going to make it harder on yourself and then you're less at your full capacity.

Welch: And it bears repeating. Telling the caregiver story is important because military caregivers are, whether they see it this way or not, providing a service to the country by, as Lincoln said, caring for those who've borne the battle. Everyone I spoke to made the same point. Caregivers have a story that deserves to be told and they're the best ones to tell it through whichever medium they choose.

O'Brien: When you address some of these really complex human condition issues in a mask that was on the cover of National Geographic or in a song that moves people in an open mic. That crystallization of what that experience is no longer looks like illness or damage. It's actually a skill. It's a craft. You Are My Sunshine, the lyrics are about, "I'm going to go jump in a river and drown." This stuff isn't all just happy and light. But we want to engage with those because it helps us understand who we are when we're feeling good and when we're feeling bad. So I really do like that sense of how art making that explores these complex existential or metaphysical issues that anybody can experience. I mean, Hank Williams is speaking for all of us and he has no PhD [laughter] from Yale. But he does a pretty good job of it for me and for a lot of people. And I think these folks who are coming through these programs are gifted in that same way. And when they're making art in some ways, that explores and communicates what this experience is. It's meaningful, it's useful, it's important, and it's crafty. It doesn't feel like damage as much as it is insight.

Pressler: The expression, it reverberates. It allows you to project your voice beyond a small room and influence other people and share your stories, have people connect with those stories, and also change people's perspectives about who you are as a person, as a veteran, as a military family member.

O'Brien: We're recognizing there are certain kinds of arts activities that are particularly suited for this kind of wellness pursuit and it might involve very hands-on types of things like blacksmithing, and glass blowing, and metal forging. It's a kind of thing that really just gets back to the question you said earlier that people don't feel like they're really positioned to be an artist. The truth is, I think everybody's an artist. Are you only talking about that thing that happens on a stage or are you talking about leather making and that kind of thing?

Norman: From the perspective as the person with the TBI, I'm not a caregiver, but there is an isolation that comes along with having a TBI, and I can imagine that comes along with being a caregiver for someone with a TBI. And if nothing else, getting out of the house, laughing, seeing some new faces, it can only be beneficial.

Comeau: And I do think it's really important that caregivers find a way to express themselves in a non-judgmental way. You certainly have the moral permission to share your story. You own your story. No matter how hard it is, no matter how dark it is, I certainly don't want to be known for my hard and dark stuff, but I feel that my sharing of some of the darkest, most intimate days of my life has opened doors and has helped caregivers realize that they're not alone. That's one of the most rewarding parts of this whole experience is I thought I was the only one. I've had caregivers come to me and say that especially with the night time issues that seem to plague some of our veterans. When the night comes, and it's dark and lonely, and you're the only other person that's witnessing this, and you're

half asleep yourself it's very hard to feel like anyone else in the world could ever understand that. And, certainly, having permission, and safety, and feeling that your voice matters can really help you connect with people that have been through something similar and reduce that isolation that so many caregivers feel.

Eves: I would say that you don't have to come to an open mic night to express yourself. I would say that's -- it's finally our turn to be okay with our journey through this. So the last 10 years, it's all been about the service member. It's all been about those guys coming back with amputated legs and major injuries, and now all the PTSD and the invisible wounds are coming out. But now, also, the wounds from the caregivers and the spouses are coming to the forefront, and it is our turn, now, to be recognized as having been a part of the war and the battle. And we need the support just as much as the service members do.

[music]

Livingston: We'd like to close this episode of the podcast with an example of some of that caregiver-created art. Melissa Comeau reads for us from her poem, "Sleeping With The War".

[music]

Comeau: Slow fear as the goblin tears the sheets. I wake up silent and cold. Shocking whispers of the dead. Steel cold wide open eyes screaming what they have seen. Sinking deep into the bed, he crawls over me with his heavy soul. Breath hot and filled with the terrible. Hands upon my shoulders like railway spikes. Our faces close. My heart dies with these memories that aren't mine. Swollen pain and terror has to escape. Captured by this man, kidnapped by this war, my screams can't fly laying here in my still blood.

[music]

Livingston: As always, if you have any questions about the podcast or about DVBIC products or programs, or if you're interested in telling us your story please feel free to email us at info@dvbic.org. That's info@dvbic.org.

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The TBI family is produced and edited by Terry Welch and is hosted by me, Dr. Scott Livingston. It is 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, of course, to Bill O'Brien, Sam Pressler, Betsey Eves, Marie Norman, and Melissa Comeau. Thanks to the NEA's Creative Forces Program, the Armed Services Arts Program, the Yellow Ribbon Fund, and Military and Veteran Caregiver Network. As always thank you for listening. We'll see you in two weeks.

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