



**Defense and Veterans Brain Injury Center “The TBI Family” Podcast**  
“VA Program of Comprehensive Assistance and Talking to Kids About TBI”  
Episode 109, Transcript  
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Host: Dr. Scott Livingston

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**Meg Kabat:** I really would want caregivers to know that we have heard them and we hear their concerns. And their concerns are certainly my concerns. And that we're taking it very seriously. To the point where we have made a significant change in the way that the program is operating. And that we are really focused on or dedicated to making it right.

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**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. Back in April, National Public Radio reported some Veterans Affairs medical centers were dropping caregivers from the VA's Program of Comprehensive Assistance for Family Caregivers.

**Quil Lawrence:** [Audio courtesy of NPR] Which meant VA paid Alicia a stipend of nearly \$2,000 per month. But I got in touch with Alicia Graham because of something I'd been hearing for over a year: Caregivers claiming they'd been dropped from the program without cause.

**Livingston:** Caregivers reported that they had received little warning or explanation and felt blindsided by this change in their status. Which in some cases meant that they might lose their stipends that they'd been previously receiving. Less than two weeks later, Steve Young, the VA's deputy undersecretary for health for operations and management, issued a memorandum to the VA which suspended those revocations indefinitely as the VA underwent a quote, "internal review to evaluate consistency in revocations from the program and standardize communication with veterans and caregivers," unquote. Our producer, Terry Welch, spoke with Meg Kabat, director of the VA Caregiver Support Program, about the Program of Comprehensive Assistance, the confusion surrounding it, and the way forward.

**Terry Welch:** Just to start off, why don't you tell me a little bit about the creation of the stipend?

**Kabat:** Sure. So I think there's a couple bits of important background information before we even get to the stipend program. Back in 2007, there was actually a law passed that allowed VA to provide funding to some sites across the country, VA medical centers across the country, to take a look at family caregiving in general. And to try out some different ways of supporting family caregivers. So as those pilot sites were rolling up, there was a lot of push in Congress, and really across the country, to figure out new and different ways to support family caregivers. There were really two different programs. And the first program is the Program of Comprehensive Assistance for Family Caregivers, which is the stipend program, as many call it. And that program is specially targeted at the unique needs of caregivers of veterans, who were injured in the line of duty on or after September 11, 2001. So it provides, really, additional services and supports beyond what VA is authorized and allowed to provide to family caregivers of any veteran who requires some assistance. And the things that make it so unique, so comprehensive, [is] the stipend that's paid directly to the family caregiver. That stipend is based on the level of assistance that's required by the veteran, in terms of how much assistance they require for personal care services. I think it's important to note that as this legislation was being passed, there was a lot of discussion about that stipend being to pay caregivers to provide

services. It's really not that. It's really meant as recognition for the work and the support that these family caregivers have provided to veterans and continue to provide to veterans. They often had to give up their own careers, their own jobs, their own health insurance, and health insurance is actually another key component of that program.

**Welch:** How many people receive the stipend now and how many people—is it what was expected when this was launched?

**Kabat:** So the program currently serves about 3,000 veterans and their family caregiver, that dyad. And no, that number is significantly higher than was originally estimated by VA. And I think that's for several different reasons. One is that really in collaborating with the White House at the time and Congress and Veteran Service Organizations VA was given the authority to really expand who would be eligible for that program and to really look at the unique needs of veterans who have a mental health issue or a cognitive issue. So they may be able to complete some of their activities of daily living such as bathing and dressing independently but they require assistance, they require reminders around things like those activities of daily living. But also to keep them safe in their environment at home. And to really function at home and in the community, they require the assistance of someone else.

**Welch:** There was an NPR report in April, April 5th, I believe, that talked about some caregivers losing their stipend. What was the response inside the VA to that report?

**Kabat:** Certainly, this is something that at the program-office level and even in many other levels VA has been talking about and really taking a look at for quite some time. As I said because of collaboration early on when the initial regulations were written, VA was really able to offer this particular program to a large group of veterans, much larger than had initially been intended. So there are some unintended things that happened then. And certainly one of the things that has happened is we know that veterans, when they are engaged in treatments around especially mental health issues, but also with cognitive issues, actually can make progress, can actually learn different coping skills, can be taught to use a smartphone for example and set their own reminders, and those kinds of things, and become increasingly independent. And because the Program of Comprehensive Assistance is really focused on the functioning level of the veteran it is very different than, for example, the compensation and pension program where veterans are being assessed and rated in a very different kind of way. So certainly the initial response was certainly not one of surprise or concern. And we do in the caregiver support program office seek to hear from caregivers on a regular basis, have close working relationships with many Veteran Service Organizations and other nonprofit organizations focused on caring for veterans and their families. So we knew there was a lot of concern about this particular aspect of the program and really I think the word revocation is a legal word and is sometimes confusing and so if we try to use plain language and think about this in a more of a health care term we're really talking about being discharged from a program. And so we're taking an opportunity—I think it was very wise more on the part of the secretary to take a strategic pause around discharging individuals from the program so that we can really take some time and really look at the process and make some changes in things like our communication to the veteran and caregiver, make sure that we're being consistent across sites and also really working towards providing more and more really specific guidance and clear language to both veterans, caregivers but also to our staff out in the field to make sure that everyone is using the same language and is being clear about who is eligible, who's not eligible and really working collaboratively to get that veteran to their highest level of independence.

**Welch:** So tell me a little bit more about the memo that was put out. It was like, basically, a week and a half later, two weeks later, that the memo came out that said “hey we're going to put this hold on a little bit.” Tell me a little bit more about that.

**Kabat:** Sure. Sure so, the secretary made the decision to suspend the revocations, or the discharges for a period of time. And to really allow us to take a look at the whole process. And think through strategically about how we can make sure that we're communicating clearly to veterans and caregivers. And also our clinicians in the field. And that the message we're sending about this program is clear and consistent. And that, if veterans do have the potential to make gains in their level of independence, that we really embrace that. And we encourage the caregivers and the veterans. Obviously, we know that they embrace that. Veterans and their families want those veterans to be as independent as they can be. I do think that part of what has happened over time is that the evaluation process has gotten much clearer, it's been more refined. I have really welcomed this strategic pause and we're getting a lot of

things done. And we look forward to really making some improvements in the program.

**Welch:** Yeah, it seems that, in a way, this would be something you'd almost celebrate. Look, my veteran is getting back to being able to do this so I can go back to work and all these things can happen. But obviously, with the money factor, it probably causes some trouble there too.

**Kabat:** Absolutely. It's a very complex issue. And I think part of it is about timing. And that because these kinds of things weren't really taken into account when the regulations were first written there is, although caregivers receive an additional 90 days of both health care coverage as well as those stipend payments, that may not be enough, and that's one of the things we really need to take a look at and think through. Should there be a more gradual step down process? And to make sure that caregivers and veterans really know, from the moment they apply to the program, that this is a program that may not be something that they will be involved in moving forward if they're able to make gains in their level of functioning.

**Welch:** So, there's this strategic pause right now. Do you have a timeline when you see that pause ending at this point?

**Kabat:** So, we don't have an exact timeline by any stretch because I think both our secretary and our acting undersecretary want to make sure that we get this right. And so, there are a couple of milestones certainly that we want to hit. One is we are rewriting the letters that get sent out to family members, to family caregivers, and to veterans upon discharge from the program. We want to make sure those letters are right, that they're accurate, that they provide all the information they're supposed to provide, and that really they are helpful. So that's one marker that we're working on. We also are in the process of taking a look at about 300 records, to doing an audit per se, if you want to call it that, to see what we find out from there. And that audit is really going to lead us to make a decision about what to do moving forward in terms of some other—in terms of any family caregiver and veteran who've been discharged previously. So, we have a couple of things. We're also working on publishing a policy. VA has policies that we call directives that go through a lot of concurrence and are reviewed and make sure we get them right. And then they are publicly available. And this is true for most of VA's policies. So, we're very close in having a directive published about this particular program and that would also be an important milestone in the process of making sure that we're being transparent and really working in the best interest of family caregivers and veterans.

**Welch:** One of the articles that I read, people were surprised about all the other programs that were still available to them. What kind of programs would want to highlight to those folks?

**Kabat:** Sure. So, we really offer a lot of different services directly to caregivers, and I think there's sort of two different buckets here. There's the one bucket that has been available for quite some time, allowing all kinds of different services that allow veterans to stay in their homes. And these are things that are not necessarily available through commercial health insurance, through Medicare, and through employer health insurance, those kinds of things. So, things like equipment. Having the right kind of walker and wheelchair and grab bars, those kinds of things, as well as having your home adapted. So, a ramp installed, either a temporary ramp or a permanent ramp, doorways being widened for use of a wheelchair. Those kinds of things have long been available through VA, and so it's really important that if a veteran hasn't used VA services in the past, that they take a look at their eligibility and figure out whether or not they might be eligible to get some of those services that they may require as they age. And then what the Caregiver Support Program has been able to do is really offer a whole variety of different kinds of support programming to caregivers. So really helping caregivers understand the importance of their role, the significance of their role, and targeting in some specific areas that we have gotten feedback from caregivers about. Things like communication skills with either the veteran they're caring for sometimes, but more often with the treatment team that they're working with, how to be an advocate in a way that you get things done and also peer support, that's another area that we hear a lot about. Caregivers of veterans often feel as though they're the only one in a geographic area who's taking care of a veteran, and so we offer a variety of different kinds of both those training and education programs, as well as peer-support programs. So, I'll just give you a couple examples. We've partnered with National Council on Aging to provide a program called Building Better Caregivers, which is an online, six-week course. And each week, different content is provided through an online format about things like taking care of yourself, setting goals, dealing with difficult emotions, those kinds of things. And caregivers are grouped with about 20 other

caregivers. So, they get to know each other online. They can chat back and forth, send each other either public messages, or more private messages, set goals, and then hold each other accountable to those goals. And it's been a really wonderful way—many, many caregivers who've participated in the program, reached out to us and said, "We don't want this to end at the end of six weeks." So, we actually have added some additional services. And now, there's an online community that's available. And we have close to 1,000 caregivers participating in that online discussion boards and chat and things like that. The other set of programs we have that I don't—I, definitely want all the listeners to know about, is our Caregiver Support Line. So, we have a toll-free number staffed by social workers, who can really help caregivers figure out what kinds of VA services are available to help them in their role. And the social workers there, we not content with just answering those calls. So they, actually, have developed a whole series of phone-meeting seminars, whatever you want to call them. And we offer those about three times a month. And they're attended by 100 to 150 caregivers each time. They change the topic each month. And you'll have different experts and, sometimes, other caregivers, talk about a particular area. So, for example, during the holidays, it was, sort of, dealing with the holiday blues when you're a caregiver. It might be about asking your family for help or how to—things to, potentially, ask for help with from a long-distance relative. What are some things that, someone who's long-distance, can do to be supportive of you as a family caregiver, who's there day in and day out? And so, all of those calls are available to caregivers of any veteran of any era and who may or may not qualify for the Program of Comprehensive Assistance. So, these are just a couple of the different programs that we offer we really want to know about and encourage them to utilize.

**Welch:** In terms of the stipend issue, what would be the things that you would want caregivers to know about how the VA is taking on this issue?

**Kabat:** I think it's important to know that—I really would want caregivers to know that we have heard them and we hear their concerns. And their concerns are certainly my concerns and that we're taking it very seriously to the point where we have made a significant change in the way that the program is operating and that we are really focused on, or dedicated to making it right. And that the program is an important program. And because it was groundbreaking, there's no other—we can't take a look at another program and say, "Oh, well if we just did this because this other program has done this and it's made things work much more smoothly." We don't have that comparison. So we really rely on the feedback that we get from caregivers and veterans to course correct and to adjust so we get things right moving forward. I remain hopeful that we're going to come through this and come through this particular strategic pause and have the program be that much stronger and that much better and able to last a long time moving forward and continue to have the support of caregivers and veterans and Veteran Service Organizations.

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**Livingston:** The phone number for the VA's National Caregiver Support Line is 855-260-3274. You can get more information at the VA Caregiver Support Program's website, [caregiver.va.gov](http://caregiver.va.gov). If you're too busy to click on that site now, we'll put the link in the description of today's podcast. [music] For those of you dealing with issues related to a loved one's traumatic brain injury while also raising kids, explaining those issues to your children can often be difficult. So we wanted to give you some tips on how to do just that. But this story will be a little different. Here I'm going to switch seats for a second and hand the mic to our producer, Terry Welch.

**Welch:** Okay. So to get this started, sir, you know, you always introduce yourself at the start of this podcast as Scott Livingston, the host of this podcast. But that's not your full title. Give me your full title here at DVBIC.

**Livingston:** My job title is education director for Defense and Veterans Brain Injury Center.

**Welch:** So among other things, you're in charge of, besides this podcast, is creating things like the Family Caregiver Curriculum that we talked about in the first episode of the podcast. And we've also created some products that are extensions of the Family Caregiver Curriculum, I guess you'd say, that are directly for how to deal with certain issues around the house like talking to kids, finance issues, other issues like that. So we want to actually take the moment to talk to you about this, and we're also joined by Dr. Katie Stout who's the DVBIC director of clinical affairs. So we wanted to talk to you both about how to talk to kids about TBI in the family. So Dr. Livingston, what is one of the

most important things to know about how to talk to kids about TBI? How do we know what to tell them and when?

**Livingston:** I think probably the most important thing is to realize that children aren't going to have the same understanding of a brain injury as a teenager or an adult. So putting it in terms that they can relate to, such as thinking of the brain as the control center for a spacecraft. When that control center is damaged, then the spacecraft isn't going to operate the same way it normally does. And it's the same with the brain. When the brain is damaged, it doesn't operate the same way it does, and sometimes it may not look or act anything like it did before the injury.

**Welch:** So, sir, give me some examples of at what ages people should address different sorts of topics.

**Livingston:** For younger children, around ages two or three, parents can communicate using simple words, creating simple books with pictures of family members and everyday objects and activities that the family takes part in. It could be things such as visits to the doctor's office, visits to their outpatient therapy, a nurse coming to their home. Offering the child dolls or play figures to recreate what happened, either when their parent was injured or what their parent's going through as far as their treatment. Picture books go a long way as well. There is a great book that the Defense and Veterans Brain Injury recommends, called *Big Boss Brain: Learning About Traumatic Brain Injuries*, written by Shannon Maxwell. And that's a great tool for parents to use for kids when they're at a loss for words to how to explain it. As children get a little bit older, you can rely on picture books like that, trying to familiarize your child with pictures of the brain and using, again, simple language explaining what typical brain functions are, bringing your child to doctor's appointments or therapy appointments to help them understand what the recovery process involves. As children get a little bit older, ages eight, nine, 10, and up from there, listening to what your child's thoughts are about what's happening, what happened to their parent, what's happening in their recovery, are they going to get back to normal, how they were before the injury. It gives them the opportunity to express their concerns and opinions but also allows you as a parent to give more than just a yes or no answer that you might give to a younger child. Depending on your child's age and level of development, the best thing you can do is to speak directly to them and using real life examples. Again, things that the child will relate to that are age appropriate. Even older children, adolescents, you can sit down and have a frank candid conversation with them about the TBI and provide a little bit higher level of information. Not too in-depth, that you're going over their head and they don't understand what you're talking about. It doesn't need to be clinical or technically precise information, but give them the facts. You can present them with information about the level of the injury, the parent's prognosis for recovery, treatments, expected outcomes. And I think the most important thing regardless of what age the child is, is to talk with the child, give them the chance to express their questions or concerns, fears, rather than talking at the child. You can present a whole bunch of information to them about TBI, but if you don't hear what their concerns and questions are, there's still going to be issues unresolved.

**Welch:** I can imagine that a lot of kids would want to kind of take part and help out the parent who's dealing with the TBI directly. So, are there ways, Dr. Stout, that kids could actually take part in the care, in the treatment of TBI?

**Dr. Katie Stout:** I think so. Piggyback on what Dr. Livingston said, yes they can, and it also depends on their age, also their level of development. Some kids incorporate a lot more knowledge early on and other kids cannot, so the parent really needs to take into account the child's level of understanding of the event, and also work with the patient's providers to make sure that a child coming to an appointment wouldn't be disruptive. In some instances, in rehab, the child is very helpful because they can take an active role in supporting that parent through their recovery. And some other office visits, with a neurologist, where it may not be as conducive for a child to come. There might be a lot of information that a spouse, a family member, needs to pay attention to and having a child there would be distracting. So, working with the providers and understanding the most appropriate time allows the child to feel involved and also limits their exposure to components that may be overwhelming for them.

**Livingston:** I think Katie made a good point about getting children involved in the recovery and often times the rehabilitation process. Depending on the child's age and stage of recovery sometimes they can be a hindrance to therapy sessions, and sometimes they can be very uplifting and offer positive reinforcement for the parent who is in rehabilitation at the time. But I think allowing the child to approach the parent recovering from TBI, based on where the child is, not forcing them into a role of, not necessarily being a caregiver, but assisting that recovery and caregiving process and younger children probably don't want any part of that at all. They just want to know what's

happened to mommy, daddy, my brother, sister and giving them very simple information is all they need. Really alleviating their fears at the youngest age. As they get older it really depends on the child. Some adolescents want no part in the caregiving role or assisting in the recovery because they feel guilty or they feel embarrassed, for a variety of reasons they don't want a hands-on approach to it. Whereas others will embrace that and say, "I want to get involved. I want to do as much as I can." So it's, again, listening to your kid. They'll tell you and you can pick up from them what they're willing to do to participate in that recovery process or potentially not at that given point in time, and then just give them space.

**Welch:** We have talked in the past about things like how to deal with dizziness issues and how to create a TBI friendly home. So, how do we talk to kids about ways in which they can help alleviate problems that might exist around the home.

**Stout:** Again, you have to put in context the age of the child. With dizziness and balance issues, one of the things we previously talked about was making sure the home was safe. So removing trip and fall hazards, which would include toys. If your child's two or three and even four years old, the ability to always remember to pick up the toys is going to be a great burden for them. So balancing their ability to help mom or dad, who's recovering, and the level of expectation we place on them is really important. As they get older, they can certainly help more. And the level of expectation can go up. But I think the most important thing is, one, for the other adult family members to understand what barriers there are in the home to maintaining the safety of the person recovering. And then also what expectations we're placing on the child or children in the family. It's a big stressor for them when a parent or loved one is injured. And to put on top of that, their toy left on the floor could cause mommy or daddy to get hurt again, is a big burden to place on especially your younger children. So balancing your expectations of the child and the safety of the home is really important. That being said, one of the biggest things that I just mentioned is trip and fall hazards. So instead of expecting the child to always pick up all the toys, another strategy would be to develop a place that only was a toy area so the other parent or family member who's recovering wouldn't be around that area. Whether it be a playroom or a certain part of a living room that's kind of cordoned off to contain the toys as a strategy to prevent the trip and fall and alleviate the stressors on everybody in the house. And that's just one example of many that could be worked on with rehab providers and other case managers and nurses involved in the care of the patient.

**Welch:** So what sort of resources do we offer to families to help talk to kids and to deal with TBI in general?

**Livingston:** DVBIC has a variety of resources for parents to help explain traumatic brain injury and the recovery process. We have a series of booklets called the family needs product line that covers topics from very basic, how to talk to a child if their parent or other loved one as a TBI. Getting into specifics about moderate and severe traumatic brain injuries, because those often have much longer recovery periods and some long-term complications, problems associated with them. So the explanations need to be a little bit different for kids in those type of situations. Even talking to a child about returning to school if they've had a traumatic brain injury themselves, and they're trying to get back into sports and schoolwork and other activities. And all those resources are available on our DVBIC website under DVBIC resources for families and caregivers and are free of charge.

**Stout:** And the resources Dr. Livingston is mentioning are in the DVBIC family caregiver guide as well. That's also available on the web, and that content is currently in the process of being revised. So in the coming months, there will be updated content that continue to help support families and children with family members who've had brain injury.

**Welch:** What can parents do if kids really just aren't adjusting well, aren't coping with the issue?

**Livingston:** I think the issue's twofold. One, if we're talking about young children to pre-adolescents and much younger—again, giving them time to understand what's happening. Re-explaining it to them. Allowing them to voice their concerns or questions. Act out the injury that happened to their parent or loved one. Act out the recovery process. Just basically allowing them some time to process that information. With younger children, it's helpful to repeat some of that same information over again. They'll forget. What is a traumatic brain injury? Why is mommy or daddy acting this way? So being patient with them, being compassionate, repeating that information to allow them a chance to process that. It becomes more of a problem as you get into pre-teen and teenagers who may then start

withdrawing or really having difficulty coping. So as a parent, just being aware that your child is becoming withdrawn, is not engaging with you, the rest of the family, or the typical circle of friends, school activities, and seeking professional behavior health, if that's appropriate. I think at a minimum, having a conversation with their pediatrician or other health care provider, even if it doesn't go in the direction of them needing any type of professional care. But getting some advice from your family physician and pediatrician is very beneficial.

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**Livingston:** DVBIC's educational pamphlet, Talking With Children About TBI, can be ordered or downloaded on the DVBIC website, [dvbic.dcoe.mil](http://dvbic.dcoe.mil). It's only one of the many products and tools we have available for caregivers, service members, veterans, and providers. You should really check out the site.

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As always, if you have any questions about the podcast, or about DVBIC's products or programs, or are interested in telling your story, please feel free to email us at [info@dvbic.org](mailto:info@dvbic.org). On the next episode, we'll recap the first season of The TBI Family, talk about changes to DVBIC's family caregiver curriculum, and talk with some caregivers about what issues they'd like to hear more about.

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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 to the Department of Veterans Affairs Caregiver Support Program, to Quil Lawrence, and National Public Radio. And while I'm at it, thanks to the team here in DVBIC's Education Division, who creates products like the Talking With Children About TBI pamphlet. As always, thank you for listening.