Joanne Anderson-West: So we adopted him a part of our family. On Thanksgiving, we all hold hands, and we pray. And we thank God for one thing. As we go around, we tell each other what we’re grateful for. When we got to him, he said he was grateful for having a home, and it brought a tear to everybody’s eye. So by the time everybody got here, he was happy, and he was so grateful that he had family. He has family. So Christmas time, it’d be the same way. Everybody will gather here, and when I soak my turkey breasts, I soak it in milk and [egg?], and you soak it overnight. And you stick it in the bag, stick in the-- nice and juicy. My guy's going to love it.

Terry Welch: Are you sure you're comfortable sharing your recipe with people on a podcast?

[Music]

Forget everything I said [laughter].

[Theme music]

Samantha Finstad: Hello and welcome to the TBI family, a bi-weekly podcast for caregivers of service members and veterans who've experienced traumatic brain injury. This is program is produced by the Defense and Veterans Brain Injury Center, otherwise known as DVBIC. Hi, I'm Dr. Samantha Finstad, your host.

In this episode, we're going to talk about cognitive rehabilitation, which can help people who've sustained a TBI deal with cognitive deficits as the result of their injury. But first, family caregivers often struggle under the burden of caring for veterans with more severe types of brain injury. Sometimes, keeping the care recipient it at home, just isn't feasible, which can lead to caregivers having to turn to nursing home care for their loved one. Our producer, Terry Welch, looked into an alternative to nursing home care, offered by the Department of Veterans Affairs. And he's here to tell us about it. Hi Terry.

Welch: Hello.

Finstad: So can you tell us about how you found out about this program?

Welch: The program is called the Medical Foster Care Program, and I first heard about it at a family caregiver conference here in DC. In the last episode, you may remember I spoke to this woman about the caregiver respite program.

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

Welch: It turned out she also oversees another program called the Medical Foster Home Program. So I asked her to explain it to me.

Cooper: Our Medical Foster Home Program is a program that is a alternative to nursing home care. It allows veterans
who meet the level of care need, for a nursing home placement, to stay in their community with the caregivers who are willing to open up their home and care for veterans in their own homes and provide the care that is needed, so that these veterans, who otherwise would be at an institution, are able to stay in a community.

**Welch:** Those caregivers, with the backup of a team of local medical professionals, provide 24-hour assistance to veterans under their charge.

**Finstad:** So what about some other things, like food, transportation even things like leisure activities?

**Welch:** Cooking, bathing, travel to and from appointments, all of that is part of what the caregiver does.

**Finstad:** So depending on the severity of the brain injury, that could be a lot of care.

**Welch:** It definitely can be, but Dana said they’re very careful about making sure the caregiver is up to the task.

**Cooper:** We individualize the care plan for that veteran. And we ensure that the caregiver has been given the proper education, in order to care for the specific needs of that veteran.

**Finstad:** But still, that does still sound like a lot of work.

**Welch:** The veterans do pay a room and board fee, depending on the level of care required. But the difference between those fees and the cost of a nursing home, is huge. And there are VA programs to help cover those costs, if needed. But you’re right. It’s a lot of work, and Dana said it takes kind of a special person to do it.

**Cooper:** They are people with very big hearts. Most of the people that tend to come into this type of caregiving, are people who have been in some kind of caregiving role in the past. We have a lot of retired or former healthcare workers, nursing assistants, nurses, social workers, or the like. Sometimes it’s just someone who has been in a caregiving role in the past, either cared for a loved one and now has that skill. And sometimes it’s just somebody who just wants to be a stay-at-home parent. So we have a whole variety of different types of people. But usually it's someone who wants to be able to give back to our veterans.

**Finstad:** Wow, that sounds like really an amazing program. I’d love to meet one of the people that does that. But you did. You talked to one, right?

**Welch:** I did. I drove up to a neighborhood suburb in the north part of Baltimore called Parkville.

[sounds of car stopping, getting out]

**Welch:** Hello.

**Nicole Trimble:** Hey, how are you?

**Welch:** It’s this real pretty little neighborhood, these well-maintained, older brick homes. And I met Joann Anderson-West. She calls her home Hawkins House Assisted Living, after her mother, whom Joann took care of, before her death as a result of breast cancer.

**Anderson-West:** I began to take care of her during her last couple years of her life. And prior to taking care of her, the way life works, I had volunteered for GBMC.

**Welch:** What’s GBMC?

**Anderson-West:** Greater Baltimore Medical Center. I took a volunteer class to take care of the people with cancer. I would relieve the family. So that was my beginning of taking care of people. So by taking care of relieving the families and then my mother developing breast cancer, I began to take care of her. So that's when a desire began, of me helping and taking care of others.

**Finstad:** So Joann already had experience doing this, like Dana mentioned.

**Welch:** Yeah, but she doesn't just see this as something she does because she learned how to do it. More than once, she called it her ministry. She sees taking care of others as a duty she's called to perform she showed me around her
house, and the whole thing's been set up to make the care recipient's lives really comfortable. Because the two men who live with her have some trouble walking there are these handles in the bathrooms by the side of the toilet, and helping them get out of the shower. There's one of those automated chairs that helps take them upstairs.

Anderson-West: All right. Now watch it now, so you won't be one of my patients [laughter]. All right. We call this the [inaudible]. This is the gliding chair, goes up and down for the residents. A remote or the arms can take you back and forth.

Welch: Each of the men who lives there has a private room with this view under the tree-lined street of the neighborhood. It's a nice set-up. My grandmother was in a nursing home and my wife has worked in nursing homes, and there are some very nice ones, but I'm not sure any of them could feel like a home in the way that Joanne's home does.

[To Anderson-West] This is what?

Anderson-West: This is the dining room, this is where we gather around three meals a day, plus our snack, but--

Voice of a resident from another room: Terrific food.

Anderson-West: Oh. Very good food. Thank you very much [laughter]. But I try to make it as homely as possible. I want to give them the feeling that this is home and it's not-- I don't like the word facility. I don't like that word facility. They need to be in a place--

Can you tell me a little bit about how this would work with family members that are visiting or extended family? How does a place like this fit into the family life?

Welch: It's kind of up to the person who runs the home about visiting hours and things like that, so I believe that that's a lot more flexible than a nursing home.

Finstad: So you visited one of these places, but did you get any sense of what this program would be like on a larger scale or if this really is a unique place?

Welch: Well, according to Dana, about 5,000 veterans are receiving their care at one of these medical foster homes. And while I was at Hawkins House I went out on the porch and chatted with this woman named Nicole Trimble. She's a social worker who's the coordinator for Maryland's Medical Foster Care Program. I asked her if this was a unique situation here, kind of a model home others of its kind couldn't live up to. She said Joanne's definitely special, but not unique in that regard, if you know what I mean.

Trimble: You know I'll come from a visit and I often have that feeling like best day ever. Like this was a good day. A lot of these gentlemen, for one reason or another, might not have homes or families, and you kind of get that all in one when you come into the Medical Foster Home Program. Excuse me, I don't know [laughter] why I'm being so emotional. This really gives veterans the opportunity to remain in the community, to remain vital, and to not have to be placed in an institution. And not only do they get good care but they also get a family. Not just the caregiver or the caregiver's family, but the veterans that live together. They become a family. They look out for one another. So I feel privileged to work in this program.

Finstad: Did you have a chance to talk to any of the residents? To me, how the residents feel about the program is really the real question I want to hear answered.

Welch: I talked to a guy named Ralph Stepney. He's a Vietnam-era veteran who, he said, kind of lost his bearings after his wife died. So he doesn't have a traumatic brain injury. A lot of these folks are in there for all kinds of reasons, but pretty much everything we're saying can apply for someone who has a traumatic brain injury too. But Ralph, he lost everything; and he also suffered a stroke that would make living on his own difficult. He was homeless before he reached out to the VA for help, where he met Nicole.

Ralph Stepney: And he sent me to Miss Joanne down here Baltimore Parkille. I fell in love with this house and Miss Joanne-- between Miss Joanne and Miss Nichole, they really brought me a long way; and I'm grateful to the VA. Miss Joanne, she's almost like family. She's family, because she treats me like family. She's a very excellent cook. She has a
beautiful home; and I'm very, very comfortable here and I enjoy life again.

**Finstad:** Wow.

**Welch:** Yeah, we were both kind of teary-eyed by the end of that. I'd be remiss if I didn't point out how much he talked about the food, which is another thing that separates the medical foster home program from institutional living.

**Stepney:** Great northern beans and ham. That's that's my favorite dish, great northern beans and ham

**Unidentified voice:** That sounds nice.

**Stepney:** Oh yes, yeah [laughter]. Like I said, she's a very excellent cook, you can see that I done put on weight since I've been here, I'm trying to lose but it's hard to do here [laughter].

**Finstad:** That's what makes life worth living to many people, is good food. So what else is there to say about this program?

**Welch:** I guess just that families who are interested in taking advantage of the program should contact their local VA to see if it's even available for them, it's not yet at every medical center but Dana Cooper said they're working on it. Also, Joanne had a message she wanted to send anyone who's even thinking about becoming a medical foster home program caregiver.

**Anderson-West:** There is a need, there is a great need to become a medical foster home-- I call myself mom, even though those guys are old enough to be my father or brother but I am very proud to be a part of this program. I think that our veterans deserve it, I think there’s a lot more veterans out there that need to be taken care of, and I would pray that someone out there would have the heart to want to bring them into their home, and to treat them like their own brother or sister or father. [music]

**Finstad:** The Medical Foster Home Program medical teams we should mention are part of the VAs Home Based Primary Care Program which can send medical teams to veterans homes to provide care. We'll put a link to both programs web pages in the description of this podcast.

[music]

**Finstad:** Cognition is another word for some of the basic work the brain does, the gathering and processing of information. Now, being able to pay attention, understand, remember, and deciding what to do with that information are just some of the things that fall under the umbrella term cognition. When someone sustains a TBI, all of these types of mental work can be affected. However, the brain can be remarkably resilient and there is hope for those that suffer from cognitive deficits following a TBI. The TBI Family's Dr. Deborah Bailin spoke with two experts on cognitive rehabilitation which is a type of therapy that's intended to help people recover or compensate for problems with cognition.

**Deborah Bailin:** Thank you joining us on TBI Family today. My name is Deborah Bailin. I'm a medical writer and science communicator at DVBIC. And I'm here today with Inbal Eshel and Linda Pacon who are going to talk with us today about cognitive rehabilitation otherwise known as cog rehab. And so Inbal and Linda, can you first say a little bit about who you are and what you do?

**Inbal Eshel:** Sure. So my name is Inbal Eshel and I am a speech language pathologist. I have worked with both civilian and military traumatic brain injury patients and families for over a decade, most recently at Walter Reed where I was the lead TBI speech pathologist for about five years. I've been here at DVBIC headquarters for a bit over a year, now and loving it, and I'm currently spearheading the process of revising DVBIC's cognitive rehabilitation clinical recommendation for service members and veterans with mild and moderate traumatic brain injury.

**Bailin:** Thank you. Linda?

**Linda Picon:** Good morning. Thank you. My name is Linda Picon. I am also a speech pathologist by background. I am the VA liaison to the Defense and Veterans Brain Injury Center. So I am a VA employee working in collaboration on
clinical research and education activities between the Department of Defense and the Department of Veterans Affairs. 2017 will mark my 25th anniversary working with veterans and service members with traumatic brain injury and their families, and I have worked at the Tampa VA for 22 years, and now in Washington DC at DVBIC for the last 2 and a half.

Bailin: Great. Thank you. So before we get to cognitive rehabilitation, we should first say a little about cognitive deficits. Linda, can you explain what cognitive deficits are and what caregivers need to know about them?

Picon: Sure. So cognitive deficits— I think that sometimes people refer to them as difficulties with thinking skills is the best way to describe that. Cognitive deficits can range widely depending on the severity of injury most of the time, so people with mild traumatic brain injury may have difficulties with attention and concentration, memory, problem-solving. But those with more severe types of traumatic brain injury, while they will also have those same problems, they will tend to have those problems typically in a very severe presentation as well, to the point that they may have actually confusion and disorientation and behavioral difficulties that may be associated with cognitive difficulties.

Bailin: And from a clinical perspective, how do you diagnose someone as having cognitive deficits when they come in for treatment?

Eshel: So that’s a really good question. We use typically a combination of things like a motivational interview, where we try to really dig into the patient’s perception of their difficulties, so asking a lot of questions about daily functional challenges. So some self-report. You could also use self-report measures, so actual scales that are designed for the patient to self-report on their symptoms to things like actual standardized assessments, where we may use a set of tools that have been standardized and [normed?] for this particular population. So we may also use things like functional assessments, which are where we take the person that we’re working with or the patient out of the therapy room to try to get a really good sense of where things are breaking down, in a more realistic or real life setting. So there’s a whole range of different ways that we might explore somebody’s cognitive deficits. We may, of course, also interview family members and their caregivers to make sure that we’re getting a very well rounded understanding of where the person is and how they’re presenting to us.

Bailin: So we’ve been talking about cognitive deficits and what they are, and why don’t we go ahead and move on to cog rehab? So what exactly is that? So people have these issues with memory and getting through daily living. So what do we do to rehabilitate them? Tell us a little about that.

Picon: Cognitive rehabilitation is actually a number of different things. There’s not one particular task that is defined as cognitive rehabilitation. Cognitive rehabilitation can take the form of restorative therapies, where we’re trying to actually improve a function back to original level. However, there’s also cognitive rehabilitation that is compensatory in nature. Meaning, that we may not be able to improve your basic cognitive ability but we can improve the way you do things so that you can compensate, for lack of a better word, for a limitation.

Eshel: I would just say that the really great thing and this really ties into what Linda was saying, is that we can tailor cognitive rehabilitation to really meet the specific needs, the specific functional needs, of every patient. So, there is no cookie-cutter, one-size-fits-all, cognitive rehabilitation. That does not exist. What does exist is the process through which a therapist and a patient and family and caregiver work together to address the most critical functional needs of that patient, and so if that happens to be in the area of memory, then we tackle and we figure out if there are restorative or compensatory approaches that will really help with that particular set of functional challenges. So it’s really about tailoring your approach to whatever the specific day-to-day needs are of that person, of that individual.

Bailin: Can you give us an example of what you’ve been describing?

Eshel: Sure, absolutely. So let’s say that we have a patient who comes in and they say, "My memory sucks." Right, actually, probably, most speech pathologists have heard something like that. Let’s say the patient says, "I can't remember my keys, I can't remember my phone, I can't remember when my appointments are supposed to be, and I can't remember what my doctors tell me after our appointments are over." So what we would do in therapy is we
would start by saying, "Okay, let's prioritize. For you, for this particular patient, what is the most critical thing that you want to tackle first?" Now let's say they say, "It's just really my appointments and my calendar, because I feel really badly that I can't seem to get to my appointments. I don't remember when they are, I don't know." So we say, "Okay. Well, what strategies are you already using?" because often times, folks will have already tried to initiate some type of strategy use. So let's say this particular patient says, "Well, I have it on my calendar, my paper calendar, but it's at home. I don't carry it with me." So, again, cognitive rehab might really be about brainstorming. Okay, so if you don't bring your paper calendar with you, what about your smartphone? Do you carry your smartphone with you? And let's say they do, so then it's really about, "Okay, well how do we maximize that tool - it could be a smartphone, it could be anything else - to really support you in what you want to do?" So it might be something like setting up calendar reminders, and it might be something like making sure that every time you get a paper schedule of all your appointments, the first thing you do is you sit down and you make it a routine. The first thing you do is you sit down and you enter all of those appointments into your calendar right away. So there are very, very concrete ways that we try to strategically tackle whatever that functional complaint might be, and again, it's going to look different for different patients.

**Bailin:** So it really sounds like a big part of cog rehab involves communication and collaboration, and I would think that that would mean caregivers play a role in communicating and collaborating with the person they're caring for. Can you comment on that a little?

**Picon:** Cognitive rehabilitation is best when it's therapist directed. Therapist driven. It's really a collaboration between that patient, the therapist, and the situation. That does not mean that things do not occur also at home. Kind of homework assignments, and that you have to carry over these tasks that you are working on in therapy in your home environment and with your caregiver. But it's really that therapist-patient relationship that makes the cognitive rehabilitation work because it's something that it's a plan. It's a relationship. It's that alliance that we're all going to work in this together, and the caregiver is certainly a significant part of that relationship in mostly helping that patient carry out those assignments and those activities. If you take the example that Inbal gave when someone gets appointments and they, part of their routine, then needs to be learning how to make, to put those appointments in their calendar, in their phone calendar. Well, when you're talking about someone who has memory problems, it's sort of the catch-22. You have a memory problem, but we're asking you to remember to put your appointments in the calendar so that you don't forget. You see where that's sort of, it doesn't fall into place unless there's a caregiver, a support, a family member, someone there to support that person through that process where this becomes second nature, so that you can actually take what's learned in therapy and bring it over to the family, the home, and the functional environment.

**Eshel:** The therapist and the patient spend what, maybe 50 minutes, an hour together, maybe once or a couple times a week. And all the rest of their time is spent with caregivers, with colleagues, with family members and so, and friends. And so I think we have to really keep that in mind, that the time that we spend doing official cognitive rehabilitation in a therapy session is extremely limited. And so we rely on caregiver kind of support and family and friend support of this individual to really make all of these strategies that we kind of try to learn together to make them carry over. And I think it's a critical role, the role of the caregiver.

**Bailin:** What is the long-term prognosis for somebody whose undergoing cognitive rehabilitation? I'd imagine that it's probably different depending on whether you have mild TBI or a moderate or severe or penetrating injury. Tell us about what the prognosis is.

**Picon:** The bottom line is it's very difficult to say in a nutshell what is the prognosis for everyone. There are a number of different factors. Often times, people who have very severe problems will have problems for a long time, but that's not always the case. Severity of injury does not always dictate how well someone is going to do over time.

**Eshel:** One factor that seems to really assist in the long-term outcomes and in the prognosis of patients dealing with traumatic brain injury is things like family support. And family support, especially in this context, when we're thinking about caregivers is critical. And especially for folks who have sustained more severe injuries, that tends to be a huge factor in somebody's ultimate kind of trajectory and where they end up in positive way. So I just wanted to add that note that things like family support are really critical, especially when you're dealing with the more severe injuries.
Finstad: So this is normally the part of the podcast where we play some music and tell you where to get some more information about the things we just talked about and move on. We'll get to that. But after the interview was over, the discussion about different methods of cognitive rehabilitation continued. And Inbal said:

Eshel: I did do community outings for five years on a weekly basis [laughter] with my folks at National Rehab, literally every Wednesday, that was our outing day. So I did that quite a lot [laughter].

Producer: So what kind of community outings would you do?

Eshel: We did community outings all over the place. We went to the grocery store [inaudible]. Oh, yeah.

Finstad: So, in order to demonstrate, one kind of cognitive rehabilitation, as well as how distracting multiple stimuli can be even when doing something as routine as grocery shopping, we went down to Inbal's office and asked her to take us on such a sample community outing to the local grocery store.

Eshel: All right. We'll be back.

Finstad: Even before we reached the elevator, she was telling us how these community outings would usually go.

Eshel: Okay. So, essentially, before we go on any outing, it's at least an hour or two, a couple hours of prep time, depending on the complexity of the outing that we're planning for. And as I mentioned earlier, a key thing that we're going to determine in the planning phase is what are our goals another thing that we used to do all the time when we did community outings at National Rehab was figure out a role for each individual who was going on the outing. So, for example, somebody might be keeping track of the time, and that's really, really important. That's actually an incredibly important skill in general, is to be able to stay on a schedule. So, for example, making sure that we leave ourselves enough time to get there when we want to, but even more critically, figuring out what time we need to pack up and start to get ready to come back, so that we, again, get back to where we need to be on time.

I think just like in real life, a lot of times things don't quite go as you planned. And I think that's actually part of the beauty of going out into the community, because it is really so much more like real life and you can't plan for everything. So a lot of what we do on outings is really focus on being flexible in the moment, when things happen that you're not anticipating, and solving problems, again, that you never knew were around the corner. For example, one that we ended up tackling quite regularly was taking public transportation. When you're taking public transportation and you might be in a wheelchair, and the metros might be closed or the escalators not working. There's a tremendous amount of problem solving that goes into just navigating everyday challenges. So I need to get some candy for the office, so let's see. So what we might first do is encourage our patients to just kind of an environmental scan. So where we're standing right here, we might try to get oriented to what's around us. So for example, the first thing that we might do is we might say, "All right. Where's the directory?" And have everybody kind of look around, figure out where the store directory is in case we need to use that to help guide us to where we need to go. But then we might also just kind of look around and see which aisle we might be standing in front of. Right now, we actually happen to be in front of the seasonal items aisle and I see--

[Christmas music playing]

Producer: And seasonal music.

Eshel: --and seasonal music. And there's a whole lot of candy over there. So let's go over, let's go head over there. So for some folks with maybe more severe injuries, just getting to this aisle and getting to this point might really be a very big success. For others who have milder injuries, it might be really about finding the exact, specific brand that they really, really were interested in. For, again, for the folks with more severe injuries that might have difficulty scanning their environment and might have some neglect, then you might actually have to encourage that person to start all the way at the top left-hand corner and then systematically work their way across the entire top row before moving down the next one, and the next one, and the next one.. So it really just depends on the types of severities of difficulties that folks are having with what types of strategies we might use.

Now that we've gotten all the items that we need in our basket, we have to make some decisions, right? About
whether we do self-checkout or whether we try to pick a lane and have a cashier help us out a little bit. Typically, I would say that, especially for the folks with the more severe injuries, we should definitely go with the traditional cashier route, because there just tends to be a little bit more support for that.

So we had a successful shopping experience. We did kind of had a goal, we knew what we needed, we had a plan, we used the environment, we used resources. Sometimes we need to ask for help, right? We all need to ask for help sometimes, so that’s another strategy we can really encourage folks to be flexible and to be able to ask other employees of the store for help. We kind of reviewed what we had purchased. We had kind of gotten everything that we needed. And so, yeah. We managed our time, again, these are all really important that you can consider when you’re out in the community, and I think we did-- we think we did a good job. Yeah, job well done.

[music]

So now we’d like to tell you that DVBIC has some excellent resources on cognitive rehabilitation on our website, dvbic.dcoe.mil. We’re also in the process of creating a new tool for providers on the topic of cog rehab, and if you’re really interested in listening to more about the issue right now, you can click on the link in this episode’s description, to a webinar that we presented on the subject that’s really aimed at medical providers but we think there’s plenty of information for caregivers to take away from it.

[music]

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

In the next episode, we’ll talk about how substance use can make traumatic brain injury symptoms worse, prevent full recovery, and increase the risk for repeated TBI.

[music]

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 Department of Veterans Affairs, to Ralph Stepney, to Nicole Trimble, and especially to Joanne Anderson-West for inviting us into her home, and thanks to you for listening. We’ll see you in two weeks.

[music]