

## Strategies For Surviving DVD

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Video Link: <http://www.brainline.org/content/multimedia.php?id=2132>

### [Music]

**Anita Kay:** Welcome to training for caregivers on Traumatic Brain Injury. Whether your family member or friend who takes care of a loved one or a professional caregiver, what you are about to learn can help make your job easier and more rewarding.

This course is designed for you to take at your own pace. At several points, you will be instructed to pause the DVD and read a lesson or module in the training manual. This manual presents facts about the brain and how its injury can affect thinking, behavior, and overall health. The manual will not make you a medical expert, but knowing some basic facts about brain injury can help you understand the person you are working with better including why they may think or act as they do and this can be very useful in figuring out effective ways to help the person you are caring for, as well as yourself.

After reading each module, you will start the DVD again to see the faces of some real TBI survivors and their caregivers, who have volunteered to share their experience with you. Besides giving you examples of the facts, you are learning from the manual, these real life experts will show you how to be a truly great caregiver.

Injuries to the brain are very complex. They affect the whole person, body, mind, and spirit. As a survivor of a brain injury myself, I can tell you that recovery may take a long time. Providing care for a TBI survivor will sometimes challenge your abilities to the limit, but as you are about to see it also can be very interesting and rewarding. So let's get started.

### [Music]

In this first module, we will start with some basic definitions you need to be familiar with, then we will review some facts about who is most likely to get a brain injury and how injuries often occur. You will also learn some common ways brain injuries are diagnosed and measured and what those terms you may hear, like the Glasgow Coma Scale or Rancho Los Amigos scale really mean and don't mean. Please pause the DVD and read module one now and when you are finished click the start button to go on with the DVD.

### [Music]

**Ed:** I used to drive semi truck and 15 December of 2000, I was delivering in California and I was walking next to my rig and a 17-year-old kid hit me with his car and from the tire skid marks, they figure he was doing about 70 miles per hour, so that pretty much retired me from everything.

**Sheri:** It has been a life-changing situation. One that most people don't understand the depth of, because it is not just one part of your life that changes, it is pretty much every part of the aspects that you were thinking were normal are now not normal anymore.

### [Music]

**Todd:** It happened in 1995 in Miami, Florida and it has been obviously years, 12 or 13 years since the accident happened.

**Carole:** And the boat went up over the embankment of the canal and flipped forward with the backend throwing the people out from the back and everybody got thrown out, there were four people in the boat and landed on very rocky shore and there was no access by roads for emergency vehicles, so it was a helicopter rescue, so it took a little while. There were four people, one died instantly in the accident and the other two had relatively minor injuries. And then Todd was in a coma for four months and on life support the whole time.

**[Music]**

**Aniko:** Well my traumatic brain injury happened on 10-15-02, so in October it will be 5 years ago. When I was being so stupid, because I was with an ex-boyfriend at the time and we got involved with too much drinking and then he shot heroin, crashed me into a telephone pole that came down on me, causing a fractured skull.

**Jay:** Aniko [assumed spelling] was one of my patients at that time and she had stitches and was wearing helmet and I encouraged her and she was, she could barely stand up at that time, she was wheelchair bound.

**[Music]**

**Otis:** I was hanging out with a few of my buddies and we ended up getting some alcohol, going over and saying we were going to have a fun time. We were out cruising around and we ended up, everyone ended up falling asleep and I was a little intoxicated and I tried driving home and I live about 18 miles out of town and probably about 3 miles away from my house, I must have fell asleep and I ended up, I was on the straightway and it ended up, I was probably going about 90 or 80 and they said I went out of control and wrecked.

**Anna:** At first, the EMS people didn't know that it was Otis, because he had such facial trauma. They thought it was another kid. The only reason my mom really knew when they were loading him up in the ambulance was he had a tattoo right here that has a CS and he knew it was him.

**[Music]**

**Lupe:** I was in a car accident, head on collision. I don't recall the accident at all. I most of what happened, I only know because I was told later, but I passed out, a medical reason, they did all kinds of tests and never did find out what caused it, but I passed out while I was driving and went into the other lane.

**[Music]**

**Adrien:** I was involved in a concussion, while participating in football. I remember things as at the beginning of the game, we were running pre-game warm-ups and we were split off into three different groups, the wide receivers, the running backs and the linemen and I am a linemen and we were down running routes out of the backfield catching passes. Well the wide receivers were running towards us, the same way as we were running at them and my coach threw like a very long deep route and I was running down the field, was running a full sprint, well I didn't notice that a teammate of mine was running at me at full sprint.

**Patricia:** All I had seen as I go down to the field was my son laying down on the ground and he was having a seizure and he had bubbles, saliva and bubbles coming out of his mouth and his eyes were very wide open. He wouldn't close them. He wasn't doing anything.

**Adrien:** As soon as I was just getting to the ground, I closed my eyes, opened my eyes, I am laying down in the bed. I have no idea where I am at. I have tubes in my nose helping me breath, an IV in my arm, no idea what was going on and I started to freak out and my mom was right there next to my bed and she is what is wrong, what is wrong. And I said I was just playing football. She said no, no, no and I said yeah, I was just playing football. And she said no that was two weeks ago.

**[Music]**

**Erik:** 16 years ago June, I was hit by a truck and hit and run and that is what happened, happened.

**Rosmarie:** The accident happened on June 12, 91, it was 16 years ago, this last week and it was a motor vehicle accident, in which he was a passenger and somebody without a license had turned into them and we never heard from them anymore. Ike was on complete life support for almost a month, but we were told every single day to turn it off, he wouldn't be here the next day, but we were stubborn and just hung in there and of course there was damage to the brain everywhere.

**[Music]**

**Bev:** I was in a car accident back in 1966, so it was like 40 years ago. It happened to be the day after Thanksgiving in Kenai Alaska. I was in a coma for four and a half months and I woke up the week of Easter in 67 in San Antonio, Texas.

**Jim:** She was basically injured on the right side, but her left side was involved too. She sort of hit the brain, the tractor-trailer hit the vehicle, hit one side and then it bounced over to the other side, so she was really affected.

**[Music]**

**Stephanie:** My brain injury was 18 years ago. I had my 18th birthday on June 20th and one would think 18 years having an injury, you know with that, one would think you would be over the injury in 18 years, but traumatic brain injury isn't an injury per se. It is a life change.

**[Music]**

**Anita Kay:** In this next module, you will learn how the brain is actually made up of several parts, which have different functions. The kinds of problems a person has will be related to which parts of the brain have been injured and what kind of injury it is. Now don't worry, this doesn't mean after completing this module that you will be expected to know all the medical details about the person you are caring for, but again some scientific knowledge, combined of what you know about the person from your own experience can make you better at solving problems that arise and in coming up with care strategies that will most benefit the unique individual that you care for.

Please pause the DVD and read module 2 now. When you are finished, click the Start button to go on with the DVD.

**[Music]**

As you continue to learn about the brain, keep in mind its amazing ability to heal or rewire itself over time. Researchers refer to this self-healing and relearning ability as plasticity. As a caregiver, you can support the brain's natural abilities by providing interesting activities, while also making sure goals and challenges are not too far beyond the person's abilities. Here are the experts again to show you how.

**Sheri:** Every day, from the time he got up to when he went to bed, I would try to work with him on different parts of his life and we had playing cards that were colored different colors, so that we could work on his eyesight. We had memory games just that we bought at the Value Village that were kid's games, so we could work on him with the short term memory and we would try and watch games on TV, so we could learn, his speed of processing, get that back up to a normal speed.

**Ed:** This boy she trained the heck out of me. I mean there were times that I was going why are you doing this all the time, because it was bugging me, but it was because she wanted me to get better. And I know had she not persisted the way she was, I wouldn't be like I am now.

**Sheri:** Let them try and do a lot of things on their own, before you jump in and try to help them, because they have to learn how to talk on their own. They have to learn how to do their own functioning and if you are one of those people that wants to move them out of the way, because you can do it faster, try to refrain from that, which is kind of the way I was before too, but I learned that okay, he doesn't stack the dishwasher the same way that I do, but he is doing it.

**Otis:** One of my good friends made a DVD about our senior vacation, our graduating class, we went on a vacation down to San Diego and she made a DVD had all the pictures and a big old slide show. It helped me out to remember a lot about what I did and how I went down there and enjoyed myself with my graduating class.

**Aniko:** Walking has been the most rewarding, because at first, my doctor said oh I am so sorry honey, you are paralyzed and you are never going to walk again. Not true, now I can walk just fine.

**Jay:** So, I helped her with the help of parallel bars, helped her to stand up and be able to take a step forward and always encouraged her that every day you walk a little bit and you can improve.

**Patricia:** Working with motor skills, what exactly are the need, most of the need was to force him to use his left side, his left hand, so what that is, it was not only a reminder, but instead of just reminding him, I know to use the other one, it is like teaching when they were young. It is like look what you can do with this hand and try this, how about you hey stop here, put this hand here and reach with your left hand.

**Adrien:** Everything I did was a learning experience. It could be the simplest thing as playing a game of cards, you know, memorizing the short term of letters or words or playing just little individual games help me, because it not only worked my brain and my thought process and all that stuff, it also helped me with my hand and other disabilities that I had at that time.

**Jim:** Well we encourage things, sometimes that you will want us to do stuff and we will say well maybe you might try that, you know, so we try to do that, try to do as much as possible.

**Lupe:** Don't do everything for them, let them see what they can do and if they are saying let me do it, maybe be there and watch, but don't always just be there to do everything for them. That isn't going to help. I think with any kind of healing you need a little bit of a push and that would be robbing the person of that they actually need.

**Jay:** I know that you need to have a rehabilitation phase and let residents do as much as they can, because then they want to be independent. Of course, that is still there, but what I am trying to say if someone is trying to do something and getting frustrated, need help. You cannot comb your hair with one hand. You cannot do your ponytail with the one hand, so you would rather go out there and help someone, so when you know physically if someone is not able to do something, then you better go out there and help someone, because otherwise then someone is going to get frustrated or angry or can

lose, you know, can lead to more problems.

**Adrien:** That is the biggest thing that my mom did when I was there is she listened. If I had a problem, if I had something, I would explain it to her, she would then go back, think about it and then come back to me with something of how to fix it or how to improve that. I felt that she listened very well. She didn't, even though I was at a big handicap and I wore a blue helmet 24/7 because of my injury, you know, she was there, very willing to give any advice that she could or help me out in any way possible. She sat there and she listened to me, you know, she wasn't trying to tell me right from wrong or how to do this or how to do that. She told me what was needed to be done or how to go about things and then I went out and did it.

**Rosmarie:** Well now the short term memory is a real problem and there was sometimes when temper was a little problem and it still is sometimes now when somebody makes him feel like he is mentally retarded, like he is dumb, doesn't know any better. And he does, he just doesn't know how to express it.

**Lupe:** Lots of post-it notes and just for my husband and my sister to remind me constantly, because I would forget, so they would just remind me constantly. I had so many appointments that I actually needed a secretary to keep me where I needed to be. Just people reminding me and in a nice way, because as I progressed in getting better, if they would have reminded me as much as they did in the beginning, it would have been an insult. So it is really something to tread very delicately on because a person doesn't want to feel like, they don't want to feel like they are crazy and that is exactly what they feel like, like they are crazy.

**Sheri:** Brain injury people, they have to get to point C by going through maybe 5 points, not just you and I would go through A, B and C. they have to go through a whole bunch of points before they get to D and if you interrupt them in the middle of it, like before they got to C, they would have to start all the way at the beginning again and go through every part of it, before they would come to the final conclusion.

**Jay:** Sometimes goals are based on what a resident wants to do, so sometimes you talk to them, have a good communication and then, and then see whether you have time to, they have time to fit in with their schedule to do any kind of activity, because you don't want to rush somebody into something which they don't want to do, because then it can result more fatigue and then tiredness, so you don't want to overload a patient with things, you know. So you would rather concentrate on activity, which they are already doing and then have a good communication, so that you can help them with other things they want to do.

**Ed:** If you work at it hard enough, you will get control of it and I kept telling her I am going to beat this thing, I am going to beat it, I am going to beat it, I am going to beat it, the head injury, but there are times when I start thinking maybe I am not.

**Sheri:** And it is harder for him, because he doesn't remember the rehab. He doesn't remember the stages he has gone through, but as the caregiver being there before the accident, during the accident and after the accident, I can see the progression since that time in six and a half years and it is remarkable to think of how far she has come and all the determination that he has had to do it.

**Adrien:** Probably the most she did, not the most, but the most that helped me was her emotional support, because I was very, I was very emotionally disturbed, not disturbed, but saddened when I got back because there were a lot of things that I was unable to do. My friends were off doing this, doing that, but I couldn't do it, because of where I was at in my instance. So she provided a lot of emotional health, emotional strength, keeping me up on my two feet, you know hey one day is another step towards success.

**Lupe:** I was grieving everything that my life was and I was grieving not knowing that I was going to be when I was finished healing or how long it was going to take to heal, how much of me that I was I would have back and how much I could still relearn.

**Jim:** Well we have always tried to encourage her and to you know have a positive outlook on things, but we have and in general, although as we said, it is sort of a daily thing, it isn't like we are going to do that today, we didn't do it yesterday, but it is just constantly if we see her down or not feeling good and particularly her mother, she knows the words to say. She knows how to sort of get her back on track.

**Stephanie:** By helping the other person you care for be around others like them, talking to them, as a person, as a patient and participating in their therapies with them. For example, taking a walk around the block with them or sitting down with them and having a conversation with them and not saying all the negative things they hear down from other people. That will really help both the person you care for and them with your relationship, even if it is a work relationship. You can still benefit from the things that they have persevered through.

**Rosmarie:** Every time we had a step of improvement, because [inaudible] wanted the next step and you know we really worked hard, but what I want to say is it is possible that doctors make mistakes too and don't know everything and a person can wake up, so we have to have lots and lots of patience and don't give up immediately. That is what I would say.

**Aniko:** I think I would have to tell them just be patient and take your time, because it may take awhile but eventually a person will work it out and be good. Yes, they will get there.

**Jim:** Well I think the thing is it is patience that is the, if something isn't working or isn't working right, the best thing that I can come up with is just stop what you are doing and sort of back off, maybe take another run at it later.

**Aniko:** On a scale of 1 to 10, I would definitely say 11, yes, it is that important.

**[Music]**

**Anita Kay:** As I mentioned before, a brain injury affects the whole person, not just what is inside her head. The brain is the main control center for most aspects of our physical and psychological being. In this module, we will explain what this means in more detail, then learn some ways to help another person adjust to changes in physical and mental abilities following a brain injury. Please pause the DVD and read module 3 now, when you are finished click the Start button to go on with the DVD.

**[Music]**

Previously, you were introduced to our volunteer experts, now some of them will talk about how important it will be to help a survivor finding something they are able to do and that they absolutely love. For some survivors, this means getting back an ability they had before the brain injury. For others, it can be finding new activities or friends to match the person they have become.

**[Music]**

**Todd:** Well in essence, art was the start of a brand new life for me. It is just a way to live your life with yourself. Either you talk about other people or you just do it, you know. I just feel that now each person is a specific person, an artist and they all revolve around your mental ideas about society and other people, there was other people, some other people reflect off me. I could go on for days talking about this and there has [inaudible] that art can be considered.

**[Music]**

**[Silence]**

**Bev:** My what a lovely day, I am in the shade under one of my trees. I am watching a couple of bumblebees. I will look high into the deep blue sky, where I will see a plane go by, say what a beautiful day. Would you like to come out to play? Everything is going my way, my, what a lovely day.

**[Music]**

**Otis:** My dad talked me how to really basically drive again and all that and teached me to go out and how to mechanic and my hand and eye coordination a little bit better. My mom does it for my reading, writing and all that and tells me just because I got in that car wreck doesn't make me a handicap or make me, I have a brain injury doesn't make me have a handicap. I can still do anything any other person, a normal person could do.

**Lupe:** I mean like for me going back to school, I am sure my husband had some real concerns about that, but he knows me and he knows how I am and that was real important, not just because I was going to learn anything, because I didn't, but because I needed to be, have a piece of my life back to give me hope and I needed to get back from where I fell off the track and at least try to do whatever I can do, to just try.

**Ed:** Well, I had a CDL, a Commercial Driver's License and I was driving the biggest trucks on the road and well now we are, I am not the major, bread earner for the household. I don't make the high income I used to make. And I mean I have enough problems remembering to shave first thing in the morning, unless I want to grow a beard or so my psychiatrist said I needed my own vehicle and it costs a lot of money to renew the commercial driver's license, especially the one I had with all the endorsements and so we are on a fixed income, my wife said it was costing too much. I said well I will give up my commercial driver's license, if you give me the pick-up truck as my vehicle and so she did. So now, the pick-up truck is my personal vehicle, so I have made it my civilian semi-truck. I have lights and horns and I may be overdoing it too, but it is my personal vehicle now and I look forward to it every time I can get behind the wheel and go driving. I even took the horns out and mounted air horns into it.

**[Music]**

**Rosmarie:** Well soccer really came down to I was afraid of him playing soccer again, even so some people didn't know him from before and he was a very good soccer player, so were his brothers, played against the Canadians and German teams here, but I was always afraid of the secondary brain injuries, so we really waited for a long time and then when he finally started and this was four years ago, he started as assistant coach, but since he wanted to win and the team didn't win, he said if I play too we will win, which they did.

**Erik:** I like the sports that is what I do, bowling, golf, soccer, I like soccer the best. Any sport, I do it.

**Otis:** I do have some friends that they go to college and they come back and we hang out, go fishing and all that, ice fishing in the winter and go camping, ride around in pick-ups, go hunting, everything we like to go out and do sports like softball and basketball quite a bit, which is hard for me now, my T7 fracture, it is hard for me to maneuver around as good as I used too.

**Stephanie:** Challenge has always been a motivating word for me, because prior to the accident, I had been a gymnast and a cross-country runner, so the word challenge to me means go for it. At the

hospital, the second doctor on hand said that I would probably never move again, okay. And those words running in my head when I woke from the coma, so as an ex-gymnast, I began to stretch as I could in the bed I was in. Anyway from then until rehabilitation stood in my wheelchair and they had told my parents based on my hospital reports, I would probably never walk again, maybe learn to mutter a little.

Well a month and a half later, I walked out of there saying goodbye. I coach gymnastics as a volunteer for a middle school in [inaudible]. I began coaching gymnastics in a grade school in Auburn February 25th I believe of 2003, I was coaching and I had lived out in the county I coached in, so I could receive a shuttle from the King County access bus, which is the public transportation for handicap people and on the shuttle was a man that would [inaudible] that I instantly connected with and at first I had no idea why, but then as he began to share with me that he was born with a brain injury and how he had lived the years of recovery all his life, we became the best of friends instantly and he is now my husband. We have been married for just over three years and as he cares for me and I care for him, it is so nice to be able to just be yourself and as I said earlier stop trying to impress everybody with your recovery.

**[Music]**

**Adrien:** I honestly believe what helped me was just the support I had around me. I had people that I didn't even know before coming up to me and say hey we have been thinking about you, my prayers are with you, if you need anything just ask and I believe that is honestly what helped me, because when I got back, it wasn't just a few people here and there, I mean the whole town of Sequim knew who I was. They knew what happened, everything, down to the little bit. I mean I got back the first night into Sequim and I walk through Safeway and I must have had 7 or 8 different people come up to me and ask me if I was Adrian and tell me we have been thinking about you, our prayers are with you, we are just glad to see that you are home now.

**Ed:** The way that I found out about the support group was I was having these temper tantrums that I was scaring my wife so bad and she found out about somebody from her work about this head injury, brain support group that met every week, so she came home and suggested I go to it. Well I was in denial, said I didn't need this, nothing is wrong with me, but she persisted and then she said will you just go to it once and if you don't like it, you don't have to go back. And so okay, I will go, so we went to the meeting and I sat down and I sort of listened to these people talk, because they first introduced themselves and what happened to themselves and then they would talk for five minutes or so about how their week went and everything and I started listening and I thought these people act and do the same way I am, so I kept going to these meetings and I went so long they made me the attendance taker.

**[Music]**

**Aniko:** We have a beautiful dog. She is one year old. She just had her birthday. Her name is Bailey. Now I do have a cell phone, of course, I do a lot of activities and my screen saver has Bailey immediately if I ever get lonely, Bailey is there. Yes, she is a beautiful doggie, one year old, Golden Retriever. She is so special.

**Jay:** I think her attitude has always been great, but sometimes she had like a moment, a time when she was at home and then sometimes she would watch TV and sometimes she didn't know what to do. She needed to do something, you know, so with getting the dog has helped to keep her more occupied, so feel being loved you know and now after they have known each other, they are very much good companionship. Bailey likes to follow her, even in the evening when she wants to say good night, Bailey wants to jump onto her bed and give her a kiss, so that makes her feel much better. Well if you are helping some resident achieve their goals, then they are so wonderful, because they are on their own and they are fulfilling their dreams and they are happy and then they don't bother you much, because



they are happy then you don't have to care much, because they are happy.

**[Music]**

**Anita Kay:** You saw how brain injury can change physical and mental abilities, because the brain is also the center of emotion and the complex processes that control behavior, changes will often show up in those areas as well. Emotional and behavioral control can present some of the greatest challenges to both the survivor and the caregiver. To complicate things even more, while some changes are due to organic injury, others might be psychological or emotional reactions to trauma and stress. In this module, you will learn a good overall method for helping someone learn to adjust their emotions and behavior, so they can get along with others and feel good about themselves. Finally, you will get tips on how to recognize and how to get help if posttraumatic stress disorder or PTSD is creating a challenge. In addition, you will learn what to do when issues related to aging, substance abuse or physical or mental disabilities get in the way of recovery.

Please pause the DVD and read module 4 now. When you are finished, click the Start button to go on with the DVD.

**[Music]**

As you just learned in the manual, the emotional and behavioral consequences of a brain injury can present major challenges for the brain injury survivor and for you the caregiver. As you will hear next, one way to avoid some of these problems is to be trustworthy. Consider for a moment how you would feel if you were suddenly forced to depend on someone else for your basic needs and safety. You would probably want to know the other person will be there for you when promised, doing the things you need, also because many of us survivors cannot always trust our own memories or behaviors, we need to place trust in our caregivers to set boundaries and sometimes keep us from hurting ourselves or others. Listen as our experts discuss this very important issue of trust.

**Jay:** I think that trust it builds up with time with little things you do for someone.

**Aniko:** Well, I think you care so much, for example, I got a wonderful Christmas present [ Laughs ] And a beautiful card that went with it to prove it and I always feel great every day. I get a wonderful breakfast, wonderful lunch, super dinner, so happy.

**Jay:** I help her physically for example in the morning with her splint. Some of the things she can do herself, but I still have to watch her so she does not fall. And my responsibility is to see that she gets everything that she needs. And if she needs something from the store or something then I like to go and do it right away, rather than keep it pending, because I saw that with the traumatic brain injury patients, what happens is if they want to do something and they are not able to then that becomes a stress. So in order to reduce the stress, you offer them things, which they need and make them comfortable, so then their stress level stays down and low.

**Ed:** And crowds used to not bother me a bit and loud noises didn't bother me a bit, but now if I go into a grocery store or a Wal-Mart store or any store and it is really busy, I sort of freak out.

**Sheri:** And then in the beginning, we also had to have a safe place in the store, so if there was too much commotion or too many people or too much activity in a store, especially like a Wal-Mart. Those are huge with activity. We had a bench that we would know if we got separated or if he just had a time out, he would go to that bench and just wait there for me.

**Ed:** And we had a safe place to go to, so if we get separated in the store, I don't have to start running up

and down or walking, I can't run anymore, but walking up and down all the aisles looking for her or looking for the person I am with. I said okay, if we lose each other, this is our safe place, over by this bench. You know if you lose me, you go here. If I lose you, I will go here. And you know then when you are looking and go to that place and look, but and it works.

**Jay:** The traumatic, I think as I said earlier, it is good to be very compassionate and very caring and have a lot of patients. If a resident is angry, doesn't mean you have to be angry. You have to control yourself and find out the reason why he or she is angry.

**Sheri:** Because of the type of person he was before, with playing sports and being very active, it was very difficult for him to realize he wasn't going to be active anymore. He wasn't going to be able to do the sports or do the automotive things that he used to do and a lot of who he was, was gone and so I think that was when he started thinking about how mad he was that he was in this situation and that is when anger started surfacing and he didn't know how to control the anger or how to direct it or who to direct it too.

**Ed:** Oh I rant and rave and break things and scare everybody, especially the cats, my wife, myself and then I start, especially when I break something, I go well that was stupid. I have got to fix that too.

**Anna:** He has a really short temper toward my mom, even though he knows that is his rock. He turns to her for everything, even in his anger.

**Otis:** I used to just not care about a lot of other things, like someone would say something mean and I would be whatever, but now I have a really short temper now. If I don't like it, I will say something about it and I will blow up. I just have a really short fuse now. That kind of gets me mad, because I get mad at my mom or dad now and I don't like that anymore.

**Anna:** He wouldn't allow anyone else to help him. He always called on my mom when he couldn't walk and things like that, but he was kind of ornery to her, but now that he is healing and he is starting to remember how to treat people, she doesn't let him do that to her anymore. It is more, he is outgrowing that kind of orneriness toward my mother and he now talks to her and if he gets to frustrated and says time out, five minutes, you know. If it frustrates you, don't let it go beyond frustration, just stop what you are doing and go back to it.

**Jay:** Well, for anger management, like I said, you know the caregiver if the patient is showing anger then you need to, you don't need to argue with the patient, you know. You never argue with the patient. If somebody is getting anger for something, then you are in a situation that you would rather walk out of the room and then go back and approach her again later on and that would be the best way to manage someone's anger.

**Ed:** Sometimes, I wonder, because I push her so hard to the limits so many times. As a matter of fact, I always wonder how she gets through it.

**Sheri:** But it is a difficult situation and it is very difficult considering it is your spouse and the person you never expected to have that with, so you are not only dealing with the brain injury, but you are also dealing with the shock of that happening and those two things together can be very powerful and it is another reason why it would be easy to walk away, but I didn't. And I am glad that I didn't, because he has worked through that a lot and now he is able to kind of control his anger a little bit more. Sometimes he removes himself from the situation or I remove myself if he is not leaving or he is not calming down, then I will go to another part of the house or if it is really bad then I will leave.

**Rosmarie:** I myself try to distract him with like a game, like you see standing on the table, Chinese

checkers is a really good thing that calms you down. You have to concentrate and at the same time, it is simple and that is a really good thing. I tried to bring up a different subject, you have to be very careful that you don't get angry yourself or it will carry on. Now I know this is hard for some people, especially like mothers, because you know how this is, you did this before, but now you can't and it makes the person feel like they are not as good as they should be so then the temper flares up more. It doesn't make it better, so you really have to put your own feelings kind of aside that is the ideal, kind of say okay, this is silly and I think again that is the lazy part, because if I make his temper worse, I have more to clean up.

**Sheri:**

I did find myself doing the same thing where when you would go to the store and he would throw a temper tantrum because he wanted to buy something and to make the temper tantrum stop, I would go ahead and give him whatever it was that he wanted at the store. Well that was reinforcing negative behavior and it took me awhile to realize what that was until actually I was in dog obedience school and learned about negative reinforcement for your animal and I started thinking that is true, because the more he was fuss, the more I would give into it.

**Jay:** With other caregivers, I would say they have to be passionate and caring. You have to treat residents as part of your family or even like friends. Be very close to them. Don't take advantage of their condition. That is why, be respectful but at the same time, be nice to them.

**Sheri:** Well the only thing that I can say is that you have to just keep working and you have to try and put yourself in their shoes. I have always tried to treat him with respect and dignity and I have tried to treat him the way that I would want to be treated if it was reversed.

**[Music]**

**Anita Kay:** We have reached the final module and you have learned a lot by now. Module 5 gives you a chance to tie it all together by learning about strategies that support overall well being and how to create and maintain a safe and supportive environment and we have saved one of the most important topics for last, how to take care of yourself, the care giver.

Please pause the DVD and read module 5 now. When you are finished, click the state button to go on with the DVD.

**[Music]**

This final segment with our experts is focused on your needs and well-being. They will now share with you some of the rewards and joys of their work and what they do when they need a break.

**Jim:** I think the whole thing, the time has been rewarding. We have made it 40 years, so that is an accomplishment. Some people they play golf. They have different hobbies. They work on cars and this is sort of not a hobby with us, but it is a vocation that we have invested in and we have made it this far.

**Jay:** My most rewarding experience was when I took care of her for a couple of months and then family called and told me, we see a great change in her. She is doing so well and her family told me, her dad told me, her physician told me and even her care manager, where she goes for day care, they called and told me that she is doing so wonderful, because she seems like a new person.

**Rosmarie:** Well certainly for me, it is from being told turn off the life support to see Alex playing sports after being told he would never walk, he will never talk and he will never eat and almost feeling like if you don't do what this person tells you, kind of [inaudible] if you don't turn this off, because there must be

something wrong with you and if you are stubborn enough and hang in there, a reward is seeing the person getting better you know.

**Sheri:** Some of the best things, when we have had conversations is I remember one time him saying that he wouldn't have gotten to the point he is now if I hadn't helped him while he was going through rehab.

**Carole:** You know it has been the gamut of really wonderful, wonderful feelings, like you know like you are happy you can do anything and make my son's life better to feeling exhausted and you know what am I going to do, I can't do this anymore, so huge gamut of feelings.

**Jay:** In the morning, there is a YMCA club here so at 9 in the morning, I am a member, I am in the pool, so one hour I am swimming in the water and I think it feels so great. [ Laughs ] So that is my stress reliever, when I come back at 10 o'clock after a swim, I feel so great. I am ready to take the challenge.

**Rosmarie:** When it gets really, really super tough, I do sometimes just stretch and say joy. You have to concentrate on the word. It doesn't have to be joy, it can be whatever. It can be just a number and stretch, because when you say it, you kind of have to concentrate on like what you are saying and you have to have a few minutes to kind of let go of things. It is almost kind of like maybe yoga.

**Anna:** Not one person can do this, it is a family effort or a group effort. It has to be not just one person, because it will burn out the one caregiver. It needs to be an entire family that steps in and helps the person with the brain injury, because of the frustration of the way they used to be and the way they are now. It just gives you, your life back even for a few hours to help you kind of regroup and have the patience with your loved one that had the brain injury.

**Carole:** Well, you know, you absolutely need to find something to take care of yourself and I do have those things. Sometimes when I leave here, I go immediately to a movie and that is one of the things that I found way back when he was in the hospital and when he was in the long term rehab program, sometimes being there that first year was very stressful, because he was really confused and really got agitated, sometimes didn't know where he was in the first I would say six months, he wasn't aware of where he was and there was some very interesting, I would say even looking back on that experiences with that, but anyway we got through it.

But I would feel so stressed when I left the hospital and I kept thinking what could I do to like you know just decompress and it was to stop and see a movie. I would go to a 10 o'clock movie at night, if I could find one and just sit there and forget about everything and I would feel much better when I left and I still do the same thing, because I found it works the best, by yourself, spur of the moment, you don't have to make plans with other people. I just go by myself.

**Sheri:** In the beginning, I couldn't really go out to far, because of the care that he needed, but now that he is able to do things on his own. If I leave something for him to eat and if I leave something for dinner, he is okay, so I can go out and do something a little bit more.

**Jim:** One other thing, we have met a lot of great people along the way, particularly in the support group. There are some really great people and I guess I have never met a survivor or caregiver that I didn't like. You know they are just great people.

**Rosmarie:** And I don't have to admit that I enjoy a lot of the sport activities that he goes to, because I help out with soccer and I have scored bowling and I am the carrier at cause. That is why I am kind of one-sided, but I get to walk a lot there and walking is another good thing, so walking and laughing.

**Jay:** Sometimes, I will do gardening and I will involve them and show them what I am doing or sometimes I am cutting the grass or doing some work outside, so sometimes I get them involved. They can look what I am doing, just like work around the house, some kind of activity, they like to watch.

**Rosmarie:** Now that Alex does belong to some groups, like on a Wednesday night I have two hours, almost two hours with another mother, sometimes we just complain. No, we talk about whatever comes to mind and if they happen to have, if we are very lucky, then they have a bar-b-q or a pot luck where they cook and we actually get to eat somewhere, wherever we want to and we can even shop around, one place together.

**Sheri:** So I think I am a lot different at my work, because like I said I work in a law enforcement place and I don't feel the stress from the job as much as some people do, because it is not going to bother me tomorrow. When I get into work the next day, there is going to be different cases to handle and different things to do and paperwork that I have to complete, but the major things, even what some people might think are major are no longer major to me, because major to me is my husband going to live and if he does, what kind of life is he going to have. That is major and is the most daily problems are just trivial and that has been the biggest change for me.

**Carole:** I maintain a lot of friendships and try to see my friends as much as I can. I started having an all girls night at my house about once every four months or so, because I had trouble seeing everybody, because I just didn't have the time, so everybody decided that they would bring food if I had it at my house. So we have a great time and we do this about every four or five months.

**Rosmarie:** You need to learn how to let go of things, like I said for me, housework, because I used to like it, like in the hospital, everything was very, very clean and I just okay. I am too tired now for planning this stuff. I am going to sit down and watch a TV show and also take shortcuts with cooking, you just kind of have to do that. You really have to do that, because you cannot tire yourself out so much, you won't be a help to someone else when you can't take care of yourself.

**[Music]**

**Anita Kay:** Congratulations, you have completed this caregiver course on traumatic brain injury. I hope you are excited about trying some of the ideas you learned today. Keep in mind that there is still a lot we don't know about the brain and new discoveries are being made every day. You might want to make a habit of looking for books, videos or news articles about TBI at your local library or on your computer, just to stay informed, especially when you are facing a problem and looking for a new approach.

You may also want to review the manual and DVD from time to time, especially when you run across new challenges or the person you are caring for begins a new phase of recovery. And remember while the knowledge and attitude of medical specialists and survivors obviously are important, it is you the caregivers who provide the daily support and foundation we need to rebuild our lives. On behalf of all survivors of brain injury, the stars of our film and I want to thank you for all you do for us each and every day.

**[Music]**

For more information, contact Washington State Aging and Disability Services Administration.

**[Music]**