

## Living with TBI – from the University of Washington

This program is sponsored by the Washington State Department of Social & Health Services/Aging & Disability Services Administration.  
University of Washington Traumatic Brain Injury Model System.

**Video Link:** <http://www.brainline.org/content/multimedia.php?id=957>

### [Music]

**Anita:** Having a head injury, it ended my life the way it was before.

**Zsche:** There are times when I thought it was just so absurd, so unfair, that... you know I had some real moments of despair.

**Allen:** The thing that I missed the is having... the capabilities and the ability that I used to have.

**Brian:** I was just in shock. Why am I here? Why am I speaking funny? Where am I?

**Voiceover:** Anita, Zsche, Allen and Brian have had traumatic brain injuries or TBI. Almost a quarter of a million Americans are hospitalized every year with brain injuries. TBI can alter an individual's physical abilities. Even more devastating are the potential personality changes and loss of cognitive skills.

**Dr. Kathleen Bell:** People may have paralysis, they may have problems with speaking and understanding language. They may have problems with double vision... they may have... difficulty with moving about. The most common problems that people have and this stretches mild to more severe brain injuries, are problems with thinking and problems with... managing behavior or emotions.

Even or people who have relatively brain injuries, they often have a more difficult time with thinking. They may think slower... takes them longer to process information. They may have problems with their memory.

**Anita:** Since I had a head injury, it doesn't take very much pressure to make my mind go blank. You know you just... it just sort of shorts out and you can't think. And so I have to do a lot of things to... sort of organize, the way information comes in and control how much comes in so I don't get overwhelmed by too much at once.

If I'm able to do that, then gradually I'm able... I've been able to return to the kind of work I used to do which is real important to me.

### [Music]

**Female Speaker:** You know like all the people who are...

**Voiceover:** Four years a car accident Anita Kay with broken bones in her pelvis and lower back.

**Anita:** Being physically strong and athletic was part of my identity. The day before the accident I ran around Discovery Park for example, so it was hard to go in one day from someone who does that to... someone who can't even standup.

**Voiceover:** Anita regained much of her physical abilities through rehabilitation therapy and a lot of determined work. But she had a brain injury as well and that has been the longest part of Anita's recovery.

**Anita:** I had no idea going in how long it would take and I think it's really important for people to be realistic or to know they're in for a long haul. About nine months after my wreck, I had neuro-psych evaluation and the neuro-psychologist said that with the kind of head injury I had, it could take four and a half years for it to be better.

And I got very angry when I heard that. I thought he was a quack, I thought he didn't know what he was talking about and I was in complete denial and I completely pushed that information away.

**Voiceover:** Anita was a health policy system analyst who worked with a lot of data. Immediately after the accident, she couldn't read and she couldn't do math.

**Dr. Myron Goldberg:** In traumatic brain injury oftentimes there is damage to the neurons and those neurons carry out our vital functions of... of thinking, of emotions and all our physical behaviors. When there's damage to certain of our neurons... there's inefficiency in how the brain processes information.

**Anita:** When I'm working on a problem in data analysis, in the past I could track mentally, the steps in the process. Now I have... it's difficult for me to do that, so I've had to change ways I do my work. I open up like on a computer, I open up a separate window and I write notes about each step that I go through... even for some relatively simple processes because... I can't trust myself to, you know, get a line of thought going again and hold it after I've been interrupted or follow it all the way through if it's real complex.

**Voiceover:** Learning to make adjustments and preparing to go back to work are part of rehabilitation.

**Dr. Kathleen Bell:** There are people called vocational rehabilitation counselors who can help, sit people down and workout what are they good at, what kind of work or productive activity is out there that they might be able to take their old skills and learn some new things and apply them to a new kind of work or a new kind of volunteer activity so that they can have productivity in their life and feel accomplished.

**Voiceover:** Answering those questions is the first step. Next is fitting an individual's new abilities into the workplace.

**Dr. Robert Fraser:** Sometimes they're very, very marketable and then also some things that have to be worked around or... in certain cases, we're going to have to get resources and assistive technology and other kinds of things to help you work around your barriers. But the job's going to have been done additionally by procedurally or we may have to modify the workstation or we may have to use a certain type of computer program to help you do the work better.

**Anita:** They helped me work toward those goals and they had to adjust the therapies that would help me to... develop abilities that would get me back to what I want. And those things for me again were to be able to go back to work, doing something like my former work, to be able to go back outside and enjoy athletics again. And so that... that helped a lot.

**Dr. Robert Fraser:** I think support groups are helpful also, hopefully it's a support group that really has a focus about optimizing community adaptation, but you know if you back from your peers, sometimes that's... easier to accept from another person with a brain injury then even... even loved ones.

**Voiceover:** Anita continues to recover, continues to define the way she lives now.

**Anita:** Recently I after weather, it's like big wind storms. I've been watching an osprey nest, there's a tall pole along Marine Drive, there's an osprey nest up there. So I've been watching you know a situation where roofs have blown off, trees have fallen over... all of this destruction, but that nest is still up there.

And that's what I do now, it's like... I went to look around me every day and find things that are an inspiration to keep going...

**Voiceover:** Traumatic brain injury happens when force is applied to the skull.

**Dr. Kathleen Bell:** What happens is that the force is transmitted through the skull and the brain, which is a very soft material, kind of on the order of cottage cheese, gets this force applied to it and not surprisingly, deforms, has bleeding, has swelling and that ends up either destroying or at least partially damaging the neurons that make up the brain.

**Dr. Mary Pepping:** It's ironic, it's a fragile item, it's this three pound substance with you know nice tough skin-like covering, I love the Latin term for that, as someone with a tough Italian mother I like the notion of *durra mater* or tough mother, that's what protects it. And cerebral spinal fluid protects it. The skull is very thick, it protects it. There's really a tremendous amount of protection but there are also a lot of things that can go wrong in a severe traumatic brain injury.

**Voiceover:** The frontal lobes and temporal lobes are most vulnerable in any type of brain injury. Damage to those lobes affects a person's executive functions including analyzing information, problem solving, decision making and much more.

**Dr. Mary Pepping:** The temporal lobes overlie two very important, deep structures within the brain, the hippocampus that's really important for memory and the amygdale that's very important for rage reactions. So people with temporal injury are often or can be quite irritable.

**Dr. Kathleen Bell:** People may do things very impulsive or may do impulsive things that they would not ordinarily do. They may not be able to... manage outbursts of anger because that sieve that usually helps them to react more appropriately may not be working very well. So they may say or do something that they later regret.

### [Music]

**Voiceover:** Three years ago Brian Morseberg was injured in a fight. He was in a coma for three months, when he woke up, he found he could barely communicate.

**Brian:** When I first came out of the coma, my speech was atrocious. You think it is hard to understand me now? You should have heard me when I first got out.

**Voiceover:** Through rehabilitation therapy, Brian has improved his speech. Because of his brain injury, he's learning a new way to live.

**Brian:** Before my injury, I was always negative, and always looking at why life wasn't easier. And after the injury, I don't ask, I tell myself, "Make it easier! Work harder!"

**Voiceover:** A former high school dropout, Brian recently earned his diploma.

**Brian:** I graduated in 1995, and they held my diploma for that long.

**Voiceover:** Brian's parents help him with his rehabilitation.

**Brian:** My dad works with me on some of the physical aspects of my recovery. And my mom, she works mostly with my mental and emotional comeback.

**Voiceover:** And his son makes him feel like a very special dad.

**Brian:** It makes me feel like Superman. When I go visit him, I take my manual chair, and get on the floor to play with him. He then turns in the chair and gets in it, and says "Hi, hi!" And then when I'm sitting in the chair, he runs around behind me and tries to push, and it's so funny.

**Voiceover:** For Brain traumatic brain injury led to a life philosophy he hadn't experienced before.

**Brian:** I may sound different, look different, but I still matter. In my opinion, self comes from here, and here, even though this is not all the same, this is constant.

**Voiceover:** There are three main injuries, contusion, axonal injury and bleeding.

**Dr. Kathleen Bell:** The first one is contusion to the brain which is essentially a bruising of the brain matter where there's some bleeding inside the actual body of the brain. Then there is a diffuse axonal injury, in the brain the neurons actually have very long stalks that travel through various parts of the brain. And if the brain is twisted, if there is any kind of torque placed on these very delicate fibers can twist and they can break. And that means that you can get damage that's wide-spread across a large portion of the brain, from this twisting motion. And the third kind of injury that you can see with the brain is a large collection of blood, which can happen if a blood vessel is injured in the brain or if the lining of the brain is torn so that you can have large collections such as subdural hematomas or sub-arachnoid hemorrhages.

**Voiceover:** Those injuries maybe mild, moderate or severe.

**Female Speaker (nurse):** So I'm going to do a kitchen evaluation today to look at your safety in the kitchen.

**Dr. Myron Goldberg:** In a mild brain injury typically the person has not lost consciousness or lost consciousness only for a very, very brief period of time. The prospects for recovery relatively rapidly are quite good. And within several weeks... a good number of people have recovered, you know, entirely.

The majority of people will recover with a mild brain injury... within several months to a year. When we get up into the moderate and severe injuries, the difficulties become accordingly much... much more significant.

**Voiceover:** Severe traumatic brain injuries are usually caused by a high speed impact, followed by 24 hours or more of unconsciousness. The first stage of treatment is to get the person stabilized medically.

**Dr. Myron Goldberg:** There is a host of things that need to be treated emergently, that save the person's life. Once that person becomes medically stable, the second phase of treatment may... may start and... that is in rehabilitation.

**Dr. Mary Pepping:** Maybe a message of hope for everybody who's trying to get back on their feet, whether from mild, moderate or severe, that the appropriate treatment can really make an important difference in how people cope and to not give up on... on getting that treatment.

**[Music]**

**Arlene:** How many is...

**Allen:** Nine biscuits.

**Arlene:** Nine biscuits okay, so...

**Voiceover:** The success of treatment depends a great deal on the individual and of course on the nature of the injury. Another important factor is support from friends and family.

**Dr. Mary Pepping:** Coping with this kind of injury is one of the toughest things any person could ever be asked to do because they're really coping with an alteration in such basic components of who they are as a person, that it creates a huge challenge to their identity as a human being and their sense of meaning and value. It can challenge all of their roles within a family and in a community and in a workplace.

**Allen:** Place on a surface generally sprinkled with Bisquick.

**Arlene:** Okay, so I've got the board over there for you.

**Voiceover:** It's been four years since Allen House crashed his motorcycle. His helmet saved his life but it didn't entirely prevent brain injury.

**Allen:** Short term memory comes and goes and when it goes, something else fills it up and then it goes and it's hard to recall... what was there before. And she has been very good in keeping me on track to do different things... She... uses the computer to print out a list from our calendar that today is Tuesday and at 10 o'clock you... walk the pups. At 11 o'clock and on, when we eat lunch and take a rest and... so that gives me an idea of what... what her expectations are or what's on the schedule for the day. And... sometimes I stick pretty close to that and sometimes I don't.

**Voiceover:** Allen always remembers that he loves his wife Arlene and they both love their pets. The strong bond they share has made it possible to work through the changes in Alan and in their relationship.

**Allen:** I was depressed because of the accident and how it affected me and... I... didn't want to be a burden. I know that I made her feel bad a lot and... I found that the worst thing that I could do was say that I wish I was dead because she didn't like that. But it was a real thought that crossed my mind because... I didn't feel good about myself at all.

**Arlene:** He certainly has gotten better... but it's been you know, it hasn't been all sweetness and light, it's been tough. But I think that for me personally, it's been... a journey that... you know I certainly didn't ask for but we've done it together.

**Dr. Mary Pepping:** It's one of the most daunting things to say to someone you know, you've had all these injuries, physical and cognitive and behavioral and now you get to try to tackle the toughest set of symptoms you've ever had with a compromise in your intellect or your memory or your attention or your endurance or your speed. But we still want you to try to get it fixed and we want you to take a productive place back in society and not be overwhelmed by what's happened to you.

**Dr. Kathleen Bell:** People may seem... to have problems with get up and go. They... have difficulty with initiating activities... so that they look lazy and it's not that they're lazy, it's that the brain is not giving them that impetus to do what needs to be done. They can tell you what they have to do, but getting to do it is a whole other story.

**Arlene:** While you're doing that, I'm going to... see if the soup is cooking.

**Allen:** Okay.

**Voiceover:** As Allen relearns the tasks of everyday living, there can be frustrating moments.

**Allen:** I think I usually cope by you know banging my head against it or getting into it more to see if I can figure it out and sometimes I can and... sometimes I think well I guess I'll... try that later or...

**Arlene:** Well sometimes you just walk away from it. We do a time out and you just kind of... walk away from it for awhile.

**Allen:** And sometimes I get tired of walking.

**Arlene:** Yeah. But I can sure tell him, I'll come in and distract him.

**Dr. Myron Goldberg:** For the family member, my main message to them in the course of the recovery is... patience, is patience. Recovery from traumatic brain injury takes time and takes treatment, but oftentimes, time.

**Dr. Kathleen Bell:** Sometimes the families kind of take it on the chin because of all the frustration and the maybe anger or disappointment that people have, is sometimes directed at the people that they feel safest with which are their family members. And it's important for families I think to... to understand this, to... remember that... a family's job is to provide love and support and to help someone get professional help, but not to do it all by themselves. They... they can't carry the whole world on the shoulders, they have to get help.

**Arlene:** This is the timer, right there. Okay.

**Allen:** Does that say eight minutes?

**Arlene:** Yeah. Ask for help, ask your friends because if you're not taking care of yourself, you're not going to be able to take care of your survivor, your... your loved one.

**Dr. Kathleen Bell:** Recovery is possible and I think that's important for everybody to know that... as hard as it is... people get better... people get a lot better and life doesn't stop after a brain injury.

**Arlene:** Join a group when you're ready, you have to be ready to do that. Join a survivor group... or a support group rather to... to have other people to talk to. You have to talk to other people.

**Allen:** Be exposed to other people and to learn about their injury... and to be able to compare it to other people. I mean like... I think that's... been very helpful to me.

**[Music]**

**Dr. Kathleen Bell:** Traumatic brain injury is an injury that really affects the whole person. It affects everything they do because your brain is who you are.

**Zsche:** I just wanted to prove to myself and the world that I was still... that I still had something upstairs. So I read and... played chess and just did mental things to try to prove to myself that I could still do it.

**Voiceover:** Twenty years ago Zsche Nevar was a high school honor student in Eastern Washington.

**Zsche:** I was riding in a car with my friend and we were coming back from Mikesan (ph.) headed to



Anatche (ph.) and my friend bent down to get a tape, drifted into the oncoming lane and went off into the rough into the oncoming side, swerved back into the lane to hit the car, the oncoming car head-on.

**Voiceover:** He was airlifted to the trauma center in Seattle for surgery then taken to Seattle Children's Hospital for three months of rehabilitation.

**Zsche:** And that was occupational, speech, physical, all the therapies and... I was partially paralyzed, I think they call it hemi-paresis on the left side, so I had to learn how to use my left side again. I had to learn how to talk again, learn how to walk again... learn how to eat again. So it was a lot, you know, it was a lot to do.

**Voiceover:** Zsche returned to high school and graduated with his class. As a student it was discouraging to be intelligent but not always be able to demonstrate it.

**Zsche:** There was the typical symptoms of head injury like... executive function problems like organizing and keeping track of things and focusing, stuff like that. And I mean I would... intellectually know stuff, memory permitting, but... you know the actual... application of those skills was... was holding me back.

**Voiceover:** The physical affects of Zsche's brain injury are nearly invisible now. And that makes it harder for other people to understand his ongoing concerns.

**Zsche:** You know as you walk down the street nobody looks at you and says, oh he's head injured, no wonder he's on you know social security disability. You know why doesn't he have a job, you know, he seems fine to me. And that's part of the insidiousness of head injury is that... you know nobody can look at you and says, oh well you know, he's got a broken leg, there's no way he could be a construction person anymore. You know and it just... you don't really... nobody really knows... what... what are your problems are or what your problem is.

**Voiceover:** Zsche began studying philosophy to help him move on and accept his new life.

**Dr. Myron Goldberg:** If a person can learn the idea of accepting their difficulties, I think reduces down their emotional difficulties with the injury. At the same time, acceptance by no means mean... by no means means to... not to participate in activities that might, including treatment, that might improve their situation too.

**Zsche:** Really it's just making a new life for yourself, it may sound dumb, it may sound glib, but... you know you just find... you're not the same person so you got to find things that interest you now, not the things that interested you at another time or another person or... as another person or... you know, before.

**Dr. Kathleen Bell:** There's one person I can point out that I worked with some time ago who had a... was a fisherman and a fly fisherman. And his great delight before he had his brain injury was to tie flies and they were beautiful works of art. After he had his brain injury, he no longer had the use of one of his arms and it was... very difficult for him... to see what he was going to do in life because he could no longer work. There were many things he couldn't do and he couldn't tie flies. But one day I walked into my office and went into an examining room and the entire office was filled with canvases, beautiful oil paintings, all around the office. And he was smiling and sitting there and saying, look I love to paint. So he found a new outlet that was just... just wonderful... for his creativity and was a changed man.

**Voiceover:** With help there's more to life after a brain injury than simple survival. It's always a new beginning.

**Anita:** You just keep going moment-by-moment or day-by-day and you dare to think that what you used to think was impossible, it might be possible for you to do if you just keep going.

**[Music]**