

TBI SURVIVOR

Dr. Claudia Osborn

Interview by **Kimberly Paetzold**, Editor



A graduate of Vassar College and Michigan State University College of Osteopathic Medicine, Claudia Osborn was a physician of internal medicine with an office and hospital practice in Detroit, Michigan. In addition to being a physician, she also instructed interns and residents. That life ended abruptly one summer evening in 1988, when a young driver struck her bicycle and she sustained a traumatic brain injury. Nine months later, she entered a rehabilitation program that lasted eighteen months. At its conclusion, she began writing, at first as a form of therapy, but it soon became a cause in itself borne of a need to “be understood by others.” In 1998, Claudia’s story was published in her book titled *Over My Head*. Even with the assistance of her mother, who organized her notes and journals and edited her manuscript, the book took seven years to complete.

Currently, Dr. Osborn is an Associate Clinical Professor of Internal Medicine at Michigan State University (MSU) College of Osteopathic Medicine. She has been an advisor on TBI education and prevention to the Centers for Disease Control (CDC) in Atlanta, and currently advises the National Institute of Child Health & Human Development (NICHD), the Institute of Medicine (IOM) in Washington DC, and the Michigan Department of Community Health. When her schedule permits, she teaches first year medical students at MSU College of Osteopathic Medicine, but most of her professional time is spent lecturing throughout North America on traumatic brain injury rehabilitation. In the spring of 2001, *Psychology Today* honored her for her contribution to mental health. Dr. Osborn is a Fellow of the American College of Osteopathic Internists.

Thank you, Dr. Osborn, for taking the time to interview with Rainbow Visions. Based on your personal experience, what is the most common misperception about brain injury?

That it can be fixed – like a broken leg. It’s on the wish list of every TBI survivor that deficits caused by his or her injury can be corrected. Since those with brain injury lack awareness, such misperception can be especially troublesome if it keeps them from working on their shortfalls.

There is help for brain injury survivors, and rehabilitation is a key step. We have a long way to go in informing the public about rehabilitation and how critical it is to continued recovery and growth.

Being a doctor, was it easier or harder for you to accept the consequences of a TBI?

One would expect that knowing the possibilities and consequences of an injury would make it harder, but for a long time I didn’t know I was injured. When I did comprehend the extent and the implication of my deficits, it was very difficult for me to accept the consequences of my injury. I gave a dozen years of my life preparing for a profession I loved. I didn’t know what else I could do that would be as meaningful or satisfying to me. The greatest hurdle was accepting that the “me” I had always known was gone and learning to find an identity and purpose I could admire for the new person I had become.

You write at one point in your book that you would do anything to prevent a “flood.” What does that mean?

Most simply put, it means you are drowning in confusion and emotions that you can’t sort through. It is a tumultuous experience in which you cannot figure out

what you must do next even with a simple problem. A flood may be brought on by a variety of things – including something as undemanding as being asked a multi-part question or given two things to do at once.

I still flood, but I use strategies to make it less vexing. For instance, when a flood is about to wash over me, I have an all-too-familiar physical reaction that is difficult to describe. One feature is a tightening of my chest. When this happens, I try to change the focus of my attention rather than trying to solve a problem I no longer understand. I try to detach myself and remain calm. If I am successful, I may be able to ease myself back into working on an answer. If not, I set the problem aside and leave the situation entirely.

Another issue you learned to cope with was adynamic behavior. What type of strategies did you incorporate to overcome this deficit?

You can’t master adynamia just by learning strategies. I am still adynamic – seventeen years later – but I’m able to handle it more effectively. Adynamia is essentially a loss of drive, a behavioral problem caused by damage to the frontal lobe of the brain. My mind would prefer not to initiate and stay blank, so I need every possible stimulus I can employ – my service dog, an alarm system, a coach – to move through a decision making process. The more that goes on around me, although distracting, the more it keeps me tuned in. In contrast, someone more disinhibited (lack of control, impulsive behavior) would benefit from decreased stimulation.

How important is a structured rehabilitation program to individuals with brain injury? What is the most important thing it offers?

A structured program is essential. You cannot teach someone how to have a memory, but one can be taught strategies that allow tasks to be performed by a different means. When you park your car at

the mall, you likely depend upon memory to find it again. I record the location. My method takes longer, but is more reliable than yours. Beyond learning compensatory strategies and coping techniques, a good rehabilitation program helps the individual come to terms with losses and to understand the new person one has become.

My rehabilitation program helped me understand the implications of my deficits, introduced me to the concept of strategies, and helped me lay a foundation upon which I could later build a new life. However, one must understand that rehabilitation does not “cure” brain injury, but it does give you the tools to help yourself. I will never be able to give up the strategies that enable me to function. Many years later, I still need a coach / assistant to work with me several times a week. My trusted coaches and my strategies allow me to function well and to do things often taken for granted. As a result, I have been able to grow and build a new life.

During your rehabilitation, you learned to use strategies and props to compensate for cognitive difficulties and memory loss. What is your most effective strategy?

There isn't just one. The most effective technique for me is to use a combination of strategies and props. This means using my journal, a day-timer, a computer, alarms and recorders every day. The most important thing I do is use them and customize them from time to time as my needs change. Continual practice is essential. It would be foolish arrogance to think I could function well without them.

In “Over My Head” you write about the presentation you gave when finishing your initial rehabilitation. In that presentation, you listed personal goals as follows: “We are striving to gain function and competence in every area of our life, be it cognitive, behavioral, or personal. In order to do so, we need to meet three overlapping and interdependent objectives:



Micah
Claudia's
SERVICE DOG



He appears to be nothing more than an adorable eight-pound bundle of fluffy white fur, but Micah is a highly trained assistant known as a service dog. Many of us assume service dogs are limited to seeing eye or leader dogs that guide the blind. However, dogs may be trained to assist the deaf, those confined to wheel chairs or hospital beds, or with

neurological problems such as seizure disorders, Parkinson's Disease and brain injury. Like many working dogs, Micah wears a uniform – a tiny red vest with the words “Service Dog” stitched in gold to make it easier for people to recognize that he is a working dog, not a pet.

Like all service animals, he has a long list of attributes: Intelligent, loyal, watchful, obedient, and silent while working (unless he needs to alert Claudia.). Because she does not need Micah, who is an eight-year-old Maltese, to lift, carry or physically move her, his tiny size is immaterial. His primary duty is to keep Claudia attentive and focused, providing many cues for her that she would otherwise receive from her alarm and recorder. However, Micah is more consistent than mechanical devices that must be activated by Claudia, and he allows Claudia to expend less energy to accomplish a wide range of tasks

As Claudia travels frequently to lecture and sleeps while awaiting flights, it is Micah who wakes her up and makes sure she boards the plane. He takes her for a two-mile walk each day no matter what city they are visiting, and returns to the hotel room without getting lost. He can return her to any location – her car, a meeting place, or her seat in a restaurant or conference hall. He reminds her to take her medications and keeps her from straying away when she is with a friend in a crowded mall. This isn't magic. Utilizing his special canine abilities, he has been carefully trained to do these tasks.

Micah is, by Federal law, allowed to accompany Claudia to any public place. The Americans with Disabilities Act (ADA) provides all disabled persons the legal right to take their service dog into every place open to the general public including restaurants, malls, airplanes, post offices, beaches, and hotels.

When in these working situations, Micah wears his uniform and carries documentation of his status. Of course, it is Claudia who carries Micah's service dog papers. At eight pounds, he is a bit small to carry his own. □

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(1) Awareness – must identify and understand deficits,

(2) Compensation – develop strategies to compensate, and

(3) Acceptance – some things about us can not be restored.”

When did you find that you came to the acceptance stage?

My acceptance was a very slow process. I achieved it about the time my family could say, “You know, it’s actually possible to live again with Claudia.” I had increased my language skills and my errors were not so frequent that I had to be bailed out of everything. The biggest gain was arriving at that emotional place where I was willing and able to look forward to new dreams and new goals and willing to spend time working hard at the small steps. Acceptance comes when you stop thinking about what might have been, when you stop wasting your days looking back at the person you were before the accident. You have to appreciate that you still have the gift of life. It is a common tragedy, and not just in brain injury, that when faced with tremendous grief or loss, we spend our time looking back instead of moving forward. To answer your question, I came to accept my situation sometime between my second and fifth years post-injury.

There is a lot of information out there for families trying to cope with a loved one with a TBI. Do you have any advice for TBI individuals on coping with their families and relationships?

Oh yes! It’s terribly important that TBI survivors insist that their loved ones be educated! Families and friends have their own kind of denial. TBI usually dramatically impacts lives – economically and socially. There are abrupt changes in relationships; survivors are unaware of some of these radical changes. Meanwhile, families and friends have this whole continuity of memory as if the person they loved has died. Families often become

lonely for a person that no longer exists.

Support groups, such as those provided by many rehabilitation facilities and the BIA (Brain Injury Association) can provide families both an education and a place where they can express their anger and concerns. My family tried so hard to protect me. Their response into inquiries regarding my recovery was always, “Claudia’s doing great. Everything is fine. We’re so lucky.” Meanwhile they were ready to strangle me. Just as there wasn’t any way to talk about the negative issues, there wasn’t any way to talk about the successes. When I finally learned something after 600 repetitions, my family had no one to tell. Who would understand their saying, “Wow! Claudia took her shoes off before her shower today!”

It takes great effort to work through family dynamics. You have to make the brain injury the focus, not the survivor, so the survivor feels in control. That’s particularly important for those of us who are already adults. I was a physician and not used to anyone telling me what to do, and I didn’t tolerate condescension well. To combat this, friends and family created one-word responses to issues. For example, when I repeatedly asked the same question, instead of getting angry or saying, “Ask me again and I’ll throttle you,” they would raise their hand and show as many fingers as I had asked questions. When cued that way, I understood I was creating a frustration and it was time to leave the topic alone for a while. We had a word for when they wanted me to be quiet, another for times when I was disinhibited, yet another when we had company and I needed to engage. I chose the prompt and I gave them permission to use it. That gave me a sense of control. That is much more effective than nagging. It was not unlike my alarm, recorder or service dog; only this was a coach giving me a signal. It addressed my deficit, without attacking me. We were working as a team to address the brain injury instead of fighting each other. I

still need some of these cues.

Family members try to protect us when we don’t know what we’re doing. They don’t want us to fail, so they fill in all our needs. The problem with that is the survivor never improves. Those with brain injury have awareness problems and if you always fill in the blanks, the survivor hasn’t a clue that he or she can’t cope alone. If a family always compensates, the individual with brain injury will not stretch or use compensating strategies necessary for independence. I believe it’s imperative that coping strategies be used. Yes, we will fail often, but letting us fail teaches us to effectively use the strategies necessary to succeed. For example, let me burn dinner every night until I figure out a way not to – but don’t let me burn down the house. With that approach, research shows that a majority of TBI survivors have the ability to grow and change every year of their lives. That’s terribly important! And it has been true for me.

Though the survivor may not be able to explain this to family members, it’s absolutely necessary that families and loved ones learn it. ♦