



## **SURVIVOR PROFILE:** **Learning about the Personal Side of Brain Injury Recovery with Model and Lifestyle Expert Kay Stephens**

*International model, mother, author, student, and businesswoman Kay Stephens had a concussion in the fall of 2003 while in New York. She was told the effects would fade in a few weeks, but they didn't. She tried to hide her symptoms from friends for a long time, thinking she was going crazy. Things started looking up once she decided to take control by finding out what had been happening to her since her injury. Fourteen years and hundreds of medical appointments later, she still looks for ways to cope with changes in her personality and health. She recently chatted with BIAAZ Executive Director Carrie Collins-Fadell to discuss her new normal.*

**Q** Can you tell us a little about yourself?

**A** I am a former fashion model with PULSE Modeling Agency in Kingston, Jamaica, as well as the International Marco Rasala Models in London, England. I did print, runway, and commercial work, and was mostly active in the 1980s and 1990s. Additionally, I have a background in public relations, which has allowed me to work

for corporate, quasi-government, non-profit, retail, and consumer-related brands. After modeling, I pursued three small business ventures in my hometown of Kingston, Jamaica: the first dealt with public relations, publicity promotions, and production services; the second was a school that offered grooming, modeling, fashion, and makeup styling courses; and the third involved makeup artistry and a line of makeup products.

I am the mother of one daughter, LiLi Stephens-Henry, who completed a theater degree with Howard University and attended a semester at the British American Drama Academy (BADA) for classical theater training. She is currently living in Los Angeles pursuing an acting career.

My friends say I am fiercely loyal, never daunted by a challenge, and will not take no for an answer.

In 1994, I produced a scarf handbook: SCARVES- A Caribbean World of Difference to your Wardrobe, which sold twenty-thousand copies in the Caribbean. In 2001, I returned to college for my English Language Arts degree in order to become a teacher. In my second-to-last semester, I was diagnosed with benign paroxysmal positional vertigo (BPPV).

**Q What was the nature of your injury?**

**A** It was a very windy day in November 2003, and one of the buildings I had class in at the Queens College campus was undergoing repairs. It was surrounded by makeshift fencing, with metal poles held down by sandbags. I was struck in the head with an estimated 60 lb. metal pole as the fencing surrounding the building came down at the same time I was entering the building for my class.

I suffered a concussion with short-term memory deficits, but was told that the problems would correct themselves within a few weeks. I also incurred cervical injuries of herniated and bulging discs, cervical lordosis, (secondary to muscle spasms), a broken right clavicle, torn tendons, and a rotator cuff tear of my right shoulder, caused by its apparent attempt to break my fall. My vision problems involved saccadic deficiency,

fusional vergence dysfunction, low hyperopia, presbyopia, headaches, diplopia, and photophobia. I also suffered hyperacusis (a hearing disorder), benign paroxysmal positional vertigo (BPPV), urinary urgency, nocturia, detrusor instability, hip and right shoulder bursitis, and pelvic injuries. In addition, I experienced a condition called anosmia, a lost sense of smell, for three years before it returned in December 2007.

After years of struggling and thinking I was going crazy, in 2008, I started to take control of finding out what was wrong with me. I took a neuropsychological exam, which revealed a “mild” traumatic brain injury, short-term memory problems, attention deficits, and emotional deregulation. The Brain SPECT scan showed various areas of my brain had very low oxygen flow. With this knowledge, I could focus on these injuries one-at-a-time. This has resulted in close to 1,500 medical appointments for rehabilitation therapies and surgery, as well as psychotherapy for depression.

**Q Your diagnosis reminds us that “mild” traumatic brain injury can be anything but mild when you are the one living with it. What was your recovery process like?**

**A** The past 14 years have been long, challenging, and overwhelming. My life, or living as I knew it, stopped. My Type A personality was placed on early retirement.

I spent the better part of six months in 2009 at Mt. Sinai Hospital in their brain injury program called Phase II. The program is a comprehensive, empirically-validated day program that focuses on the treatment of executive dysfunction, specifically in the areas of problem solving, anticipation,



planning, and effective execution of all purposeful behavior. Additionally, the program focuses on attention training, which remediates various aspects of attention and concentration.

In 2010, the missed skeletal and tendon injuries that created chronic pains for years and reduced usage of my right shoulder were treated with arthroscopy surgery. Unfortunately, during this time, I also learned that medications that may help one aspect of an injury may actually cause other illnesses, such as gastrointestinal problems. For five years, I battled acid reflux and GHERD, which developed into gastritis. At one point, I just wanted to die because I could not keep any food down. But help came in the form of a homeopathic nutritionist who advised me to “let food be my medicine and let my medicine be food.” After an intestinal cleanse and a more strictly regulated diet, I can say I cured my gastritis. Although I am not completely out of the woods, I can now keep food down and have gained back nine of the 20 lbs. I lost last year.

I am still doing physical therapy, and vision therapy/review has been reduced to once every six months. I get Botox injections for the headaches and cervical muscle spasms every three months, and those have been more successful in pain management than the trigger point injections. I feel like for the first time, I can actually return to some of my old activities, although in a more limited way. I call it “my new normal.” My memory has greatly improved and I utilize strategies taught in the Phase II program to manage emotions and remember important matters, such as bill payments. I still struggle with neuro-fatigue, which is now my greatest challenge.



**Q** **Your injury was in November of 2003. Many survivors report changes in friendships, family relationships, and even their taste in music. How has life changed for you since the accident?**

**A** I had always been the belle of the ball, the person who was always entertaining and welcoming others into my home. Then, almost overnight, I no longer wanted to speak to or see anyone. I became a coach potato. The constant medical appointments themselves provided plenty of human interaction. “F” bombs and arguments plagued me for a long while as I felt challenged and taken advantage of. Sadness derailed my once joyful demeanor and I couldn’t shake it. No praying, no singing of spiritual songs could help. There were times I felt suicidal, but my desire to succeed





against all odds was stronger than my will to fail.

I used to love romantic and epic films; now I love action flicks, the fast, shoot 'em-up kind. My daughter says it's because I don't have to think too much about the plot and storylines. Going out was a challenge so I stayed home. Restaurants and movies were too loud and made for painful and harrowing experiences. So too was shopping. Now, I've changed the way I do things by limiting the unpleasant experiences. In 2010, I called my closest friends together and told them my story. They listened. They cried. I cried. They are still learning what my limitations are and accepting that my physical company comes with some challenges and adjustments.

**Q You are very open that you have had about 1,500 medical and therapy appointments since your “mild” traumatic brain injury. What do you say to people who think you “look just fine?”**

**A** I used to be so offended by this statement. Then I had to understand that if you don't know, you just don't know. Through the campaign video, people are beginning to understand that looking fine has nothing to do with the challenges I have faced. Just as it took some years for people to understand post-traumatic stress disorder (PTSD), so too it will take the general public some time to truly understand the effects of a traumatic brain injury. With more public education, this can be done. One phase of the campaign is what not to say to someone with a brain injury.

**Q Recovery from a brain injury is a life-long journey. What would you say to other survivors who are**

**feeling frustrated and isolated from the changes caused by traumatic brain injury?**

**A** The first thing I believe is important is to find out what is wrong with you and then seek help. I couldn't have gotten to this place I'm at if I had not taken the time to heal and accept myself—yes, my disabled self—by learning to be okay with my limitations. It is okay. I reduce my expectations in what I can do and what I cannot do. As a Type A personality, I had to learn to not put so much on my plate. I am a glass half-full gal, not a glass half-empty. I want to spend the rest of my time doing happy things that bring joy. I believe that there are times when some relationships will have to end, but for the ones I keep or get to keep, I want to cherish them now, not later.

I say to those who are challenged by the dramatic changes a TBI has caused in your life to take it in stride. Focus on what you can do today. Review your options continuously to see what you can change or incorporate into your rehabilitation. Evaluate your situation and look for ways to make one change that will bring success. Share your feelings with someone who is objective; someone who will not judge you. That person might be a psychologist or spiritual leader. Have quiet times to reflect, cry, and smile on your week. Start each week with one goal in mind. Take the time to list all the things that you have achieved in your life. This record is great for reminding yourself that you are not a failure. Accept that you are entering a new phase in your life that will require you to make adjustments. Renew your first love—love of yourself—and love yourself some more. Trust that it will all be okay. That is my FRESH START approach!

