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SPEAK UP: Care Should Be a Right, Not a Privilege

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Care Should Be a Right, Not a Privilege

What my experience with “mild” traumatic brain injury taught me.

BY PAGE WALKER BUCK, PH.D.

I was almost killed in a car accident in May 2008, exactly 24 hours after getting my Ph.D.

A 17 year old who had borrowed his friend's car pulled out in front of a school bus, which swerved to miss him—and hit us. My 11-year-old daughter and I were taken in separate helicopters to local trauma centers, where our acute injuries were treated. I had several broken vertebrae and ribs, and a head wound. I also sustained a traumatic brain injury (TBI) and suffered from cognitive impairment, dizziness, vertigo, balance problems, double vision, and migraines.

At the time, though, I didn't know I had a TBI. Not one doctor or nurse—or any of the discharge papers—mentioned the words “brain” or “injury.” No one made a recommendation to watch for signs of a brain injury or suggested following up with a neurologist. They considered me lucky: my Glasgow Coma Scale score (the standard measure of consciousness) was perfect, my CT and MRI scans were fine, and I was able to discuss the risks and benefits of back surgery. I had no identifiable markers for brain injury—except, of course, for the fact that I had been hit in the head by a bus.

Only after the pain of my broken bones dissipated several months later did I begin to realize how *not* okay I really was. I couldn't remember the names of dear friends, the floors and walls seemed to be constantly moving, and I couldn't make it through the day without becoming speechless from exhaustion.

I started to research my symptoms online. Before long I was convinced that I had a TBI. I wanted to get an official diagnosis and start a rehabilitation program, but I couldn't find a single neurologist who would take a new patient on short notice.

I cried myself to sleep night after night. I was as sad, frustrated, angry, and hopeless as I had ever felt in my life. Late one night I remembered that one of my professors from graduate school had a husband who was

a neurologist, so I contacted her. Making this call was no small feat: I hate asking people for help, and I worried news would spread. How would my academic colleagues regard a newcomer with a brain injury?

Getting in to see a neurologist was the first of many hurdles. I had to continually fight with my insurance company to cover each of my treatments: a neuro-psychological evaluation, vestibular rehabilitation for balance, vision therapy for the double vision, and cognitive therapy for the fact that twice I almost started a house fire after forgetting that I was cooking something.

Trained as a social worker, I was lucky enough to have the resources and persistence to demand—and receive—incredible care. My rehab team saw me through months of physical and cognitive therapy and one of the most difficult emotional experiences of my life.

After several months of rehabilitation I was able to start my job. I am happily enjoying a very full life. I don't have the

same coordination or quickness of wit; I don't even have energy to stay up late to watch the *Academy Awards*—but I am here, and for that I'm incredibly grateful.

Unfortunately, most people in my situation are not able to access expert care for TBI. Many struggle with symptoms without a diagnosis and go on to experience long-term cognitive, physical, emotional, and social consequences, including the loss of work and even family.

Traumatic brain injury—including the “mild” form known as concussion—is a major public health concern. Once believed to be a virtual rite of passage in childhood and sports, concussions require careful diagnosis, management, and follow-up. Care for traumatic brain injury should not be a privilege but a right. NN



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