BRAIN INJURY: A LIFELONG JOURNEY

A Call for Brain Injury to be Recognized, Treated, and Covered as a Chronic Health Condition

Every year, at least 2.8 million Americans sustain a traumatic brain injury. While many of these injuries are fairly mild and cause only temporary neurological impairment, there are currently more than 5 million people living with a permanent brain injury-related disability – that's one in 60 Americans.

The chronic, long-term effects of brain injury are wide-ranging, and can include fatigue, sensitivity to noise and light, memory loss, mobility problems, chronic migraines, trouble with focus and executive functioning, depression, anxiety, and susceptibility to conditions such as Alzheimer's disease, stroke, Parkinson's disease, and chronic traumatic encephalopathy (CTE).

Brain injury is viewed by many in the healthcare system as well as the general public as a one-time event with effects that become stable, rather than the beginning of a process of recurring or persistent effects that continue to change. Unfortunately, the idea that brain injury can permanently change a person – their capabilities, their personality, their ability to work and socialize as they once did – is not something understood by people who have not experienced it.

There is also a lack of understanding about the long-term effects and chronic nature of brain injury, particularly among those living with invisible disabilities. But designating brain injury as a chronic condition that can require lifelong management of symptoms would go a long way toward correcting misconceptions about a condition that impacts millions of Americans.

> The pieces of me are still in there, but I use them differently. I had to go through the mourning process for a long time, and to realize that this different Carole is not a cracked version of who I used to be. She is a worthy person in her own light.
>
> **Carole Starr**
> *Brain Injury Survivor*

This Brain Injury Awareness Month, the Brain Injury Association of America is calling for the Centers for Disease Control and Prevention and the Centers for Medicare and Medicaid Services to designate brain injury as a chronic condition, and that brain injury should be recognized, treated, and covered as such. In addition to the impact on public awareness and understanding about this condition, formal designation of brain injury as a chronic health condition would increase the priority for funding brain injury research, allow for additional public health resources to be focused on lifelong effects of brain injury, and would incentivize health insurance providers, particularly in Medicare and Medicaid plans, to provide additional benefits and other supports as they do for other chronic health conditions.

Designation and the Impact on Public Health and Health Insurance

There is a common misconception, both among the general public as well as within the greater medical community, that brain injury is a solitary, one-time event, much like a broken bone. This misconception poses problems for patients who live with chronic symptoms as a result of their brain injury and are seeking treatment for those symptoms.

"It leads to a prejudice against patients that have continued symptoms, which leads to a misinterpretation of those symptoms to being either malingering, fabricated, some sort of psychiatric disorder, or some sort of secondary process that is completely unrelated to the primary traumatic brain injury at large," said Gregory O'Shanick, MD, President and Medical Director for the Center for Neurorehabilitation Services and the Brain Injury Association of America's national medical director-emeritus. "That leads to misdiagnosis, mistreatment, and increased morbidity, mortality, and excess medical cost. And in some situations, leads to suicide, because patients despair and give up."

Brain injury is often a silent epidemic or invisible injury. Many people are undiagnosed or misdiagnosed, and don't know they have a brain injury, or don't think they have a brain injury, which makes things even more difficult.

Wendy Waldman
NeuroResource Facilitator

There are a significant number of people who survive their brain injury, only to develop problems later on, explained Brent Masel, MD, BIAA's national medical director.

"Brain injury is often a silent epidemic or invisible injury," said Wendy Waldman, BSW, CBIST, NeuroResource Facilitator at the Indiana NeuroResource Facilitation Program. "Many people are undiagnosed or misdiagnosed, and don't know they have a brain injury, or don't think they have a brain injury, which makes things even more difficult."

Formal recognition by the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) has the potential to provide several advantages for brain injury survivors, including the allocation of additional public health resources to focus on the lifelong effects of TBI as well as health insurance plans, primarily Medicare and Medicaid, providing additional benefits and other supports as they do for other chronic health conditions.

The CDC spends a good deal of resources on public as well as provider education, noted John D. Corrigan, PhD, the Brain Injury Association of America's national research director and professor in the department of physical medicine and rehabilitation at The Ohio State University, explaining that designating brain injury as a chronic health condition would provide the opportunity to educate health professionals not immersed in the world of brain injury about the importance of a history of brain injury as a factor in a person's health, similar to how a primary care provider would consider whether a patient was prone to high cholesterol. In that instance, Dr. Corrigan explained, "You would give them advice and tell them what they could be doing to minimize that chronic condition and optimize their overall health."

Flora Hammond, MD, Nila Covalt Professor and Chair of Physical Medicine and Rehabilitation, Indiana University School of Medicine, and Chief of Medical Affairs at the Rehabilitation Hospital of Indiana, believes the designation would provide infrastructure and resources for providers as well as the community to be more proactive and intentional in how people are helped after brain injury, with the potential for improved outcomes as well as a more appropriate alignment of resources for people living with brain injury.

"It would provide focus that goes beyond the short term," Dr. Hammond said. "Presently, there is such a focus on how someone is doing in the first weeks to months after injury, over time people forget about the potential effects of injury to recover and prevent worsening. Thinking of it as a chronic condition would have more focus on the long-term."

Dr. O'Shanick noted that emphasizing care in the acute period has helped to bolster survival rates for patients with traumatic brain injury. "When I started doing this in the 1980s, the mortality rate for TBI was 50-80 percent. Now, you have individuals surviving that would never have survived before, because of the acute care," he pointed out. However, he added, "If we are going to save people, we have got to have equal amounts of funds at the back end, and it's got to be used in a wise manner." He noted that case management services need to be improved so someone can oversee and manage a survivor's care in the long-term.

A critical period for many individuals with brain injury is the period after they leave acute care. "The way that healthcare is structured, there is a lot of emphasis on treatment in the hospital – but what happens after that? Are they being supported with therapy? What are their residential options? When we talk about recognizing, treating, and covering brain injury as a chronic condition, I think that last piece of it is making sure there are resources there – insurance resources, nonprofit resources – to continue providing support once they leave the acute care setting," said Page Melton Ivie, Chair of the BIAA Board of Directors.

"There is a lot of support in the hospital, but once you walk out the door, you're on your own. We need to make sure we are continuing to support survivors and their families, because they are going to have a lot of questions going forward."

She speaks from experience. Her husband, Robert, suffered an anoxic brain injury 21 years ago and now requires full-time support. After Robert spent 10 days recovering in a hospital, she was told that it was time for him to return home. The prospect of that was terrifying – Robert did not remember who she was and was still profoundly injured. "I scrambled to find the next option, which was a rehab hospital, and from there he moved to a residential setting. We were lucky we had resources," she recalled.

Dr. Hammond pointed out that most people living with brain injury do not have a brain injury specialist treating them – and if they do, it generally is not happening in the long term. "Many people are left with no follow-up after acute care," she explained.

The CDC also provides education and resources for surveillance when a health condition is considered a chronic condition. While CDC directs a lot of resources to surveillance of chronic health conditions, almost none of that is being spent on brain injury, Dr. Corrigan noted. As a result, estimates of brain injury prevalence in the U.S. are outdated. "CDC's prevalence estimate was done more than 25 years ago and is based on the flawed assumption that only those who have immediate and persistent disability at one year post-injury should be considered a prevalent case," he said. "Everybody else is considered as not being affected by their brain injury." Overall prevalence of people who have had a brain injury and are still experiencing effects is likely closer to 11 to 12 percent.

Dr. Corrigan added that, in addition to the public health resources allocated to the study and surveillance of chronic health conditions, there are benefits related to health insurance and benefits that come with the designation of a chronic health condition. "There are insurance benefits that provide access to additional services," he explained, citing as an example Medicare Advantage Plans that are customized for persons with chronic diseases. These plans, he said, called C-SNPs, provide additional services tailored to the issues faced by someone with a chronic condition.

On the Medicaid side, Dr. Corrigan said, the benefits are potentially enormous. An overwhelming majority of Medicaid patients are on managed care plans, which are regulated by the states via contractual obligations. "People with chronic health conditions always receive additional attention in those contracts. Managed care providers have to make commitments to give people with chronic conditions more service," he said. Often, that service is case management, but can also include other supports that help to keep someone living in the community and not in a nursing facility.

> I am fighting for brain injury to be recognized as a chronic condition, because it would help so many people on the front end of their injury, instead of waiting for years and trying to figure out if they are having problems related to the injury. Having that recognized, examined, and treated early on could make a dramatic difference in quality of life for so many survivors.
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> **Page Melton Ivie**
> *Caregiver & Chair of BIAA's Board of Directors*

Other Chronic Health Conditions

The Centers for Disease Control and Prevention (CDC) defines chronic diseases as conditions that last one year or more and require ongoing medical attention or limit activities of daily living, or both. Per its website, the CDC recognizes seven chronic health conditions:

- Arthritis
- Cancer
- Diabetes/Prediabetes
- Epilepsy
- Heart Disease
- Stroke
- Lupus

Through its National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), there are eight divisions that study chronic diseases and their causes/risk factors:

- Division of Cancer Prevention
- Division of Diabetes Translation
- Division for Heart Disease and Stroke Prevention
- Division of Oral Health
- Division of Population Health
- Office on Smoking and Health
- Division of Nutrition, Physical Activity, and Obesity
- Division of Reproductive Health

> The misconception that brain injury is a solitary event leads to a prejudice against patients that have continued symptoms.
>
> **Dr. Gregory O'Shanick**
> *National Medical*
> *Director-Emeritus, BIAA*

CDC also conducts surveillance of chronic diseases in an effort to better understands the extent of health risk behaviors, preventive care practices, and the burden of chronic diseases; monitor the progress of prevention efforts; and help public health professionals and policy makers make timely and effective decisions. These surveillance systems include:

- Behavioral Risk Factor Surveillance System
- Chronic Kidney Disease Surveillance System
- Health-Related Quality of Life
- National Assisted Reproductive Technology Surveillance System
- National Adult Tobacco Survey
- National Health Interview Survey
- National Health and Nutrition Examination Survey
- United States Cancer Statistics
- National Youth Tobacco Survey
- Pregnancy Mortality Surveillance System
- Pregnancy Risk Assessment Monitoring System
- US Diabetes Surveillance System
- Water Fluoridation Reporting System
- Youth Risk Behavior Surveillance System

The Centers for Medicare and Medicaid Services, meanwhile, recognizes 21 chronic conditions:

- Alcohol Abuse
- Alzheimer's Disease and Related Dementia
- Arthritis (Osteoarthritis and Rheumatoid)
- Asthma
- Atrial Fibrillation
- Autism Spectrum Disorders
- Cancer (Breast, Colorectal, Lung, Prostate)
- Chronic Kidney Disease
- Chronic Obstructive Pulmonary Disease
- Depression
- Diabetes
- Drug Abuse/Substance Abuse
- Heart Failure
- Hepatitis (Chronic Viral B & C)
- HIV/AIDS
- Hyperlipidemia
- Hypertension
- Ischemic Heart Disease
- Osteoporosis
- Schizophrenia and Other Psychotic Disorders
- Stroke

Researching Brain Injury and its Chronic Effects

While many of the Americans who sustain a brain injury will go on to recover and return to business as usual, there are many others that will continue to live with lingering effects for years – potentially, the rest of their lives. Survivors report symptoms like cognitive fatigue, migraines and headaches, emotional dysregulation, impairments to their vision, difficulty with initiation or sequencing, loss of sensation or sense of smell, sleep disorders, processing disorders, and mental health issues such as depression, anxiety, and obsessive-compulsive behaviors. Beyond these anecdotal experiences, there have been an abundance of studies published in medical journals recognizing the chronic nature of brain injury:

- A 2022 study published in **Lancet Neurology** found that TBI has the highest incidence of all common neurological disorders and is increasingly documented not only as an acute condition, but also as a chronic disease with long-term consequences, including an increased risk of late-onset neurodegeneration.
- A 2021 article published in the **Journal of Neurotrauma** stated that a small but meaningful subset of TBI patients experience symptoms that persist for months or years after injury and significantly impact quality of life for the person and their family.
- Also published in **Lancet Neurology** was a 2017 study that found that TBI can have lifelong and dynamic health effects on health and well-being and that, for many patients, TBI "should be conceptualized as a chronic health condition." It also acknowledged that functional outcomes after TBI can show improvement or deterioration for up to two decades post-injury, with rates of all-cause mortality remaining elevated for many years.
- A 2016 study in **Critical Care** found that TBI may cause persistent, sometimes lifelong consequences, with a high proportion of patients diagnosed with severe TBI requiring prolonged rehabilitation and suffering from long-term physical, cognitive and psychological disorders. This study also found that chronic effects have also been identified in a proportion of cases initially designated as "mild" or "moderate."
- A 2010 paper published in the **Journal of Neurotrauma**, co-authored by BIAA's National Medical Director Brent Masel, MD, states that TBI is a chronic disease process that fits the World Health Organization definition as having one or more of the following characteristics: it is permanent, caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, and/or may require a long period of observation, supervision, or care.

There have also been studies published in various medical journals and other outlets outlining the specific chronic effects and disease risks among TBI patients:

- A 2024 study published in the **Journal of Head Trauma Rehabilitation** found that chronic pain affects approximately 60 percent of people living with TBI, even up to 30 years post-injury.
- **Movement Disorders**, the official journal of the International Parkinson and Movement Disorder Society, published an article in 2013 that found that head trauma has been implicated in the cause or development of Parkinson's disease.
- A 2013 study in **Neurology** concluded that TBI may be an independent risk factor for ischemic stroke. Stroke is considered a chronic condition both by the CDC and CMS.
- A 2003 study published in the **Journal of Neurology, Neurosurgery and Psychiatry** supported an association between a history of previous head injury and the risk of developing Alzheimer's disease.
- In the CDC's **"The Management of Traumatic Brain Injury in Children Executive Summary"** Report to Congress, the department found that an injury of any severity to the developing brain can disrupt a child's developmental trajectory, and that as a result of TBI children can experience changes in their health, thinking, and behavior that affect learning, self-regulation, and social participation, "all of which are important in becoming productive adults." The report also noted that some post-TBI health problems such as changes in behavior and cognition, emerge over time and are associated with significant financial and social challenges in adulthood.

In its Knowledge Translation Center, **TBI Model Systems** has published fact sheets for TBI survivors outlining some of the long-term health effects of brain injury, including:

- About half of all people with TBI are affected by depression within the first year after injury, and nearly two-thirds are affected within seven years after injury. The rate of depression is much lower in the general population, affected fewer than one person in 10 over a one-year period.
- Irritability and anger are more common in people with TBI than they are in people without TBI, with some research showing that up to 75 percent of people with TBI have irritability and up to 50 percent of people with TBI have problems with anger.
- As many as 70 percent of TBI survivors report mental fatigue.
- Over 30 percent of people with moderate to severe TBI report having headaches which continue long after injury. The percentage of people with mild TBI who report having headaches is even larger.

Bolstering Brain Injury Research

One of the myriad benefits of designating brain injury as a chronic condition is the potential for more funding for research efforts that study brain injury and its chronic and dynamic nature. While there are a few projects that are dedicated to studying brain injury outcomes, such as the TBI Model Systems and TRACK-TBI, this research is tremendously underfunded.

"I don't know of any funding programs by the National Institutes of Health or the Centers for Disease Control and Prevention that are dedicated solely to TBI," pointed out John Corrigan, PhD, national research director for the Brain Injury Association of America. "If you look at cancer, at Alzheimer's disease, and many chronic diseases, they have large portfolios."

But the incidence of traumatic brain injury is much higher than Alzheimer's, and is higher than cancer, yet traumatic brain injury research gets a fraction of the resources and attention, Dr. Corrigan noted. "I think the prospect that, when healthcare realizes that this indeed is a chronic condition and they want to know why, what's behind the dynamic-ness, what's behind the higher levels of excess mortality, we would start getting funding programs looking for the answers. But until the problem is recognized, the questions won't be asked."

Flora Hammond, MD, pointed out that while both the Veterans Administration (VA) and National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) have been looking at brain injury and its long-term effects, the topic of brain injury as a chronic condition is vastly underfunded and underrecognized by funding agencies.

Greater funding would allow for more elaborate longitudinal studies, Dr. Corrigan pointed out. And while there are longitudinal studies occurring – such as the TBI Model Systems – they tend to be loss leaders for the funded programs. "There are so many people we follow over time but the funding stays the same," Dr. Corrigan said. "We are constantly talking about ways we have to cut the data we are collecting." As a result, they do not have data about treatment received, medications taken, or the genetics of the people studied. "Just think about what that one program could do if it was fully funded."

He added that many of the questions being addressed by programs like the TBI Model Systems are derived from relationships that investigators have with survivors, family members, and clinicians – for instance, the high incidence of chronic pain in people who have had moderate and severe TBI. "Does the current chronic pain treatment work the same for them as it does for people without brain injury? We don't know. We have the money to describe it, but not to investigate it," Dr. Corrigan said.

Areas of Interest

We asked brain injury professionals and survivors what they would like to see receive more funding and attention in brain injury research:

"Mental health and brain injury, substance abuse and brain injury, and services that are specific to that. Because that's very rare, to see a focus on mental health or substance abuse and a dual diagnosis. Brain injury doesn't discriminate, but certain populations are more at risk to brain injury, and oftentimes those populations are at a lower socioeconomic status, or in the criminal justice world, a domestic violence situation, a mental health situation, and they may not have the funds that can open doors for them. Social determinants of health have a big part in this." – Wendy Waldman

"Medication. It's hard to do trials with medications, so seeing more effort in terms of what we can give people that will make them better." – Dr. Brent Masel

> I would like to see more of a focus on social determinants of health. Besides the injury itself, there are so many more influencers that affect it, like education, healthcare quality, and a social or community context. I would like to see more funding toward those other components and influencers that are really going to affect recovery.
>
> **Dr. Kelli Talley**
> *Brain Injury Survivor*

"We need research to be able to better understand people's outcome trajectories and what their needs are, and then we need to be able to better stratify who needs what after injury, determine who needs what resources and what the role of social determinants of health are, the environmental aspects, what are the medical comorbidities we need to be monitoring for, and how." – Dr. Flora Hammond

"The TBI Act needs to be funded again. It is a vital investment in collecting data about the prevalence of brain injury, and it's necessary to supporting growth and awareness of TBI." – Angela Marie Tucker

"The long-term effects of how brain injury affects individuals, and more toward the social impact it has. On relationships, on the way that living with TBI affects those day-to-day activities and the way you're able to interact with the world. There's a lot of emphasis on the medical side, which is great, but I would like to see research and resource toward other social and emotional impacts of TBI." – Cazoshay Marie

"I would like to see more research on the effects of a person with lived experience who was able to advocate and tell their story – how much it builds up their self-esteem and self-worth or improves their outlook on life." – Kelly Lang

Survivor and Caregiver Perspectives

The Brain Injury Association of America spoke with several individuals living with chronic effects of brain injury, as well as their loved ones who provide care, support, and advocacy, about their experiences and thoughts on what a formal designation would mean to them and their families.

Cazoshay Marie was walking back to her car after an event at the Downtown Phoenix Science Center in May 2017 when she was struck by a car driving 48 miles per hour. The accident left her with numerous injuries, many of which were obvious at the time, such as broken bones and a dislocated jaw. Others were not – including the traumatic brain injury that she said has completely changed the trajectory of her life.

"Prior to my brain injury, I was a wellness professional. I had my own business and held classes," Cazoshay shared.

Nearly seven years later, she still lives with lingering side effects from her TBI, including chronic migraines, difficulty with short term memory and concentration, and vestibular issues impacting her vision, which have affected her ability to do everyday activities like driving and cooking.

> I wasn't initially diagnosed with having a brain injury. I missed a lot of initial critical care and understanding of what was happening. I didn't understand that the things I was going through were normal. Everything just felt out of control."
>
> **Cazoshay Marie**
> *Brain Injury Survivor*

"There was a lot that I felt like I lost in a sense of my old self, but I also gained a newfound strength and determination to move forward, and to advocate for other people who are in my same position," she said, adding that it led her to become a speaker and disability advocate. "Although it changed my life's direction completely, it was not necessarily all negative."

Her story – one of long-lasting symptoms, journeys of acceptance, and a need to reevaluate one's life path – is not uncommon among brain injury survivors.

"There's not much that's familiar about my life since my injury," said Stacia Bissell, who sustained a brain injury after a bicycling accident in 2011.

At the time of her injury, Stacia was at a pivotal point in her teaching career, having taken on a new role in administration as the next step in her aspirations to run her own school. She was married with three children on the cusp of adulthood, had a robust social life, and was recovering well from back surgery two years prior. Her brain injury, and the lingering effects of it, changed everything.

"I was like this Wonder Woman-type of person, you know? A Type A go-getter, very ambitious," Stacia recalled. After her brain injury, she said it felt like "someone had moved the keys around on my keyboard, but they still expected me to type at the same rate."

Many TBI survivors who live with the chronic effects of brain injury speak about their lives in two stages – the person they were before their injury, and the person they are post-injury.

> In my experience, I have not met many people who know someone living with a brain injury, as prevalent as it is. Most folks that I know, I am the one that they know who has a brain injury. It's a lack of education, and a lack of awareness, that these misconceptions are so prevalent.
>
> **Angela Leigh Tucker**
> *Brain Injury Survivor*

"My life totally changed," shared Angela Leigh Tucker, who sustained a TBI following a crash with an 18-wheeler in 2008. "There was an acceptance journey that happened, once I was able to accept that Angela One died on July 31, 2008, and Angela Two was born on that same night."

That acceptance journey is not one that is quick, nor is it easy.

"I was 32 when it happened," shared Carole Starr, who sustained a TBI in a car crash in 1999. She was building a career as an educator, was an amateur violinist and singer, and figured she would be a wife and a mother one day. But her brain injury put her on a different path. "I had to mourn that for a long time," she said.

And unfortunately, the idea that brain injury can permanently change a person – their capabilities, their personality, their ability to work and socialize as they once did – is not something most people who don't have experience in life with brain injury can wrap their heads around.

"I think a common myth is that things are going to resolve, that you'll be able to do a lot of the things you used to do," said Dr. Kelli Talley, an assistant professor at Virginia Commonwealth University who sustained a severe TBI in a car crash in 1990.

It's especially common for those survivors whose lingering effects are invisible.

"She looks fine. She looks like an average, 25-year-old woman," Kelly Lang said of her daughter Olivia, who sustained a traumatic brain injury in a car crash at the age of 3. "People think she's much more capable, and then when she doesn't succeed, they're like, 'Well I don't understand what the problem is.'"

Olivia continues to live with several chronic effects of that TBI, including fatigue, processing issues, migraines, peripheral vision loss, and mental health struggles. Kelly, who was diagnosed with a brain injury from that same car crash as well, also lives with chronic effects including sleep disorders, difficulty multitasking, and fatigue.

Kelly and her daughter have faced this backlash and lack of understanding about the chronic and invisible effects of brain injury at school, at work, and even among some health care professionals. "I have had to explain, 'Look, she has a processing delay due to a brain injury. You yelling at her in a waiting room full of people is not going to help.' People have invisible disabilities you can't see, and you need to have more compassion."

Dr. Kara Beatty, a physician and TBI survivor of nearly 22 years, said she commonly hears from TBI patients that others don't understand that they are different now. "For a lot of my individuals, they're saying, 'I'm being forced to go back to work,' or 'My family does not understand why I cannot do these things.'" For her own part, Dr. Beatty received pushback in medical school when requesting accommodation for length and time on her medical licensing exam, despite her slower processing speed

> I hesitate to call it overcoming because I do not think that is what happened. I have limitations. I have just learned to deal with them, and to accept them, and to lean on my strengths more.
>
> **Dr. Kara Beatty**
> *Brain Injury Survivor*

as a result of her brain injury. “They were saying, ‘No, this happened too long ago. This happened 10 years ago, you should not need accommodations.’”

For some survivors, even attempting to explain the reasons for those changes – the chronic fatigue, the difficulties with memory and processing, the migraines – can exacerbate the misunderstanding.

“Language fails us. When I say, ‘I get really tired,’ or ‘I have trouble remembering things,’ people say, ‘Well, me too,’” Carole explained. “And it’s very isolating, when you can’t describe to people why you’re not the same anymore.”

Stacia commented that over the years she has developed strategies to help her cope with the lingering effects of her TBI, which include migraines, memory issues, fatigue, sensitivity to noise and light, tinnitus, speech problems, word retrieval issues, distractibility, difficulty sequencing, and anxiety.

“People don’t know that I’m using strategies for just about everything so I can keep up with conversations and my responsibilities, so I’m not overwhelmed by lights or crowds or noises,” she explained. “People don’t realize that my overplanning – I have to have a Plan A and a Plan B, and it’s tiring to make two plans for everything, but it’s necessary.”

Even for survivors who have returned to school or the workforce, who appear to have returned to “business as usual,” there can be difficulties. In fact, it’s something Dr. Talley noted she herself has struggled with.

“Particularly if you are successful – you make it through school, you go to graduate school, or you go into a job where maybe you’re doing something different, you still have these problems of trying to compare yourself to others,” she said. “I have had to say to myself so many times, ‘Kelly, they did not have a brain injury. They weren’t in the hospital for four months. They weren’t in a coma for two weeks.’”

Dr. Beatty agreed. “We compare ourselves to others, but then we’re also comparing ourselves to who we were, who we think we are supposed to be now,” she said.

There are dozens of misunderstandings and misconceptions about what brain injury is, and what it isn’t. But designating brain injury as a chronic condition would go a long way toward correcting those misconceptions about a condition that affects millions of Americans.

“It would do huge favors for anyone living with brain injury,” Stacia said. “Designating brain injury as a chronic condition would help people understand what brain injury is and what it isn’t. It would remove some stigma.”

Cazoshay agreed. “I think it would have a huge impact, because I think that it would be taken more seriously as a medical condition that affects people more than just in the short term. I think that it would provide people the opportunity to access more resources and education regarding what brain injury is, not just for people who have sustained brain injury, but also for individuals in the community at large.”

It would also help the public understand the importance of prevention, or what to do if they or their loved one sustains an injury.

> I think it’s just a common misconception that people have, that we’re functioning without actually working at functioning.
>
> **Stacia Bissell**
> *Brain Injury Survivor*

“People take their brains for granted, I think, and they do not know that protecting their brains should be as important as eating right to protect their heart or overall health,” Stacia said. “If there was extra effort being made about the value of protecting brains because of what could happen, just like what will happen if you don’t eat right because of your heart health, that would go a long way.”

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