## COMMUNICATING

### **About Brain Injury**

## Anyone can have a brain injury at any time.

Some people recover quickly, while others experience lasting effects. Brain injuries don't just affect the person with the injury—they also impact family, friends, and caregivers.

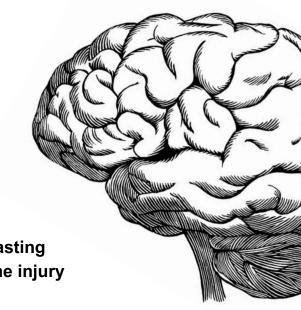
Brain injuries can be complex. This makes them hard to understand for those affected, as well as for doctors, therapists, and researchers trying to provide care and support.

It's important that we communicate clearly and consistently about brain injury. The words we use matter. They can affect whether someone qualifies for services, how professionals plan treatment, and how people understand brain injuries. And, more important, it affects how persons with brain injury experience their injury. The words we choose also shape public attitudes and expectations about life after a brain injury.

To improve communication, we worked with healthcare providers, researchers, and people with brain injuries to create this quidance.

This joint statement was created by a group of brain injury advocates, individuals with lived experience, and professionals representing the following organizations:

- ACRM Brain Injury Interdisciplinary
  Special Interest Group (BI-ISIG)
- Brain Injury Association of America
  (BIAA)
- BIAA Brain Injury Advisory Council,
  a lived experience council of BIAA
- National Association of State Head
  Injury Administrators (NASHIA)
- North American Brain Injury
  Society (NABIS)
- PINK Concussions
- The former US Brain Injury
  Alliance
- TBI Model Systems



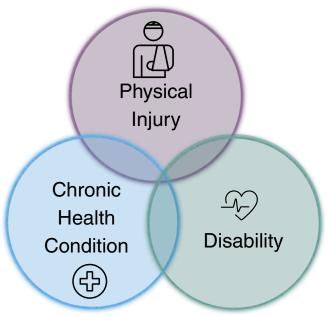
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#### **BRAIN INJURY IS A PHYSICAL INJURY**

A brain injury is a change in how the brain works. It can happen in two main ways:

**External force:** A blow or jolt to the head, like from a fall, an accident, or being hit by something that results in being dazed, confused or losing consciousness. This is called a **traumatic brain injury (TBI)**.

Internal cause: A problem inside the body, like a stroke, tumor, infection, or lack of oxygen. These are called non-traumatic brain injuries.



Injury to the brain, chronic conditions, and disability interact but are not the same.

Together, traumatic and non-traumatic causes are called **acquired brain injury (ABI)**. We will refer to these as "brain injury" in the remainder of this document.

Brain injury is a medical condition. Healthcare professionals may diagnose it using tests like brain scans (CT or MRI), bloodwork, or clinical exams. This often happens in a hospital right after the injury, but sometimes it's diagnosed much later.

Injuries have traditionally been described as mild, moderate, or severe, but these labels don't predict a person's outcomes.



Two people with the same injury severity can have very different experiences. Over time, how a person's life is affected depends on many factors beyond the injury itself, including medical care, rehabilitation, personal circumstances, and social supports.

# BRAIN INJURY AS A LONG-TERM HEALTH CONDITION

Some people recover quickly from a brain injury and have no lasting effects. But for others, the effects can last for months, years, or a lifetime.

Brain injury can affect many parts of a person's health and daily life. These effects may stay the same over time, get better, or get worse.

Sometimes, symptoms seem to go away but come back later—especially during times of illness, stress, or fatigue. Brain injury is dynamic and can change over time.

For these reasons brain injury is considered a **chronic condition**.

## BRAIN INJURY AND DISABILITY

Brain injury can lead to disability, but not always. While being a chronic condition means the effects of an injury can last a long time; having a disability means a person has difficulty with daily activities or life roles (like work or relationships) because of their injury.

Disability is not just about the injury itself—it depends on the world around the person. A person may experience more or less disability depending on the support they have from others, the places they go, or the tools and accommodations available to them. Because of this, disability is not a fixed state—it can change depending on the situation.



2

3

## THINGS TO CONSIDER WHEN TALKING ABOUT BRAIN INJURY

Calling brain injuries 'mild', 'moderate', or 'severe' is overly simplistic and can be misleading.

Traditionally injuries have been classified as mild, moderate, or severe based on early medical tests, but these labels do not predict how a person will recover or what their long-term needs will be. People with similar initial injuries can have very different recovery paths. Many factors influence recovery.

## Sometimes the effects of a brain injury are not recognized until later.

Some brain injuries are not diagnosed right away, and a person may not realize they are experiencing effects until they face new challenges, or a past injury is brought to their attention. Just because a brain injury was missed at first does not mean it is any less an issue. Brain injuries are missed for many reasons. Regardless of when a history of brain injury is identified, it is important to get the healthcare, rehabilitation, and support a person needs.

#### Outcomes after a brain injury are difficult to predict, especially in the first days to months following the injury.

While the initial severity is one factor, other elements—such as early treatment, rehabilitation, and personal circumstances—play a critical role. Long-term outcomes vary; some people maintain steady progress, while others experience ups and downs. Setting personal goals and making healthy lifestyle choices can help improve recovery.



Saying that brain injury is a chronic condition does not mean that people will experience symptoms all the time, or even ever again.

Some people may have long-term effects, while others may not. Symptoms can come and go, change over time, or appear later in life, especially with aging. It is better to be aware of this possibility than to be caught by surprise.

## Recognizing that brain injury is dynamic, not stable, means people can both improve and decline in their health and daily independence.



How symptoms change is partly influenced by what the person does to stay healthy. Recognizing this can encourage people with brain injuries to actively manage their health. Positive lifestyle choices—such as building meaningful relationships, managing stress, avoiding alcohol and drugs, staying physically active, getting good sleep, and eating a balanced diet—can help support brain health.

## Having a chronic condition does not mean a person will have a low quality of life.

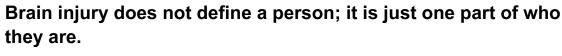


While managing a long-term condition can be challenging, many people adapt and lead fulfilling lives. Supportive relationships, effective coping strategies, and engaging in meaningful activities can improve well-being. It is important to focus on what enhances quality of life, not just the difficulties a person faces.



#### A person with a brain injury should be seen as a whole person.

Focusing only on specific symptoms or problems can lead to gaps in care. Whether or not all challenges are directly caused by the brain injury, it is important to take a broad approach to overall well-being.





Judging people based on their limitations can overlook their strengths and abilities. The way we talk about brain injury should be respectful, empowering, and recognize that every recovery is unique.



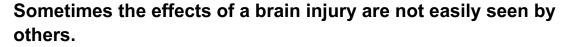
## People with brain injuries can and should be involved in decisions about their care, regardless of their level of functioning.

They may need support to communicate their needs and preferences, but their voice should always be included in decisions about their health and future.

10

## Support from family, friends, neighbors, and co-workers can have a big impact on how a person adjusts to life after brain injury.

Connecting with others who have experienced brain injury can provide additional understanding and encouragement.



11

This can lead to misunderstandings about the kind of help a person needs. In other cases, visible impairments may lead to stigma or unfair treatment. It is important to avoid making assumptions and to get to know each person as an individual.

## Making assumptions about the outcome of an injury—whether overly optimistic or overly pessimistic—can have harmful effects.

12

Assuming someone will fully recover just because their injury seemed less severe may cause them to miss out on needed support. Dismissing a person's struggles can make them feel unheard. On the other hand, assuming that a more severe injury means no hope for improvement can limit opportunities and take away a person's motivation to recover.

#### For further information and resources:

- BIAA
- MSKTC
- NASHIA
- PINK Concussions
- VA Polytrauma System