

# Understanding BRAIN INJURY

What you should  
know about  
brain injury  
and recovery

Produced by Shepherd Center and KPKinteractive in collaboration with the American Trauma Society, the Brain Injury Association of America and the Christopher & Dana Reeve Foundation



Shepherd Center

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# Brain Injury: Basic Facts

More than five million people in the United States live with the after-effects of brain injury. About 2.87 million people sustain new brain injuries each year.

Brain injury, also called *acquired brain injury*, is any damage to the brain affecting a person physically, emotionally or behaviorally. Brain injuries can happen at birth, or later, from an illness or a trauma, and are called either traumatic or non-traumatic, depending on the specific cause.

## CAUSES

### Traumatic Brain Injury (TBI)

Motor vehicle accidents	Violence or gunshot wound
Falls	Military attack or bomb blast

TBIs do not always include an open head wound, skull fracture or even a loss of consciousness.

### Non-Traumatic Brain Injury (NTBI)      Involves no external force or action

Stroke (leading cause)	Other illness such as cancer
Lack of oxygen	Brain infections or inflammation
Tumors	Other infections

### Level of Severity used to describe both TBIs and NTBIs:

- Mild, moderate or severe
- Level is primarily determined by the length of loss of consciousness, as well as time in post-traumatic amnesia
- Does not describe the expected outcomes in the patient's life

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### **Physical symptoms of brain injury include:**

- headaches
- seizures
- trouble speaking and swallowing
- lack of bowel and bladder control
- motor impairment  
(trouble moving body normally)
- difficulty coordinating balance
- vision problems
- changes in sensory perception
- changes in sleep patterns
- changes in sexual function

### **Changes in Cognition, Behavior and Personality:**

- personality changes
- confusion
- trouble communicating
- memory impairments
- depression
- mood swings
- disorientation
- acting inappropriately
- difficulty forming sentences or choosing vocabulary
- difficulty with reason, focus and logic
- poor concentration
- limited attention span
- difficulty remembering conversations/forgetfulness

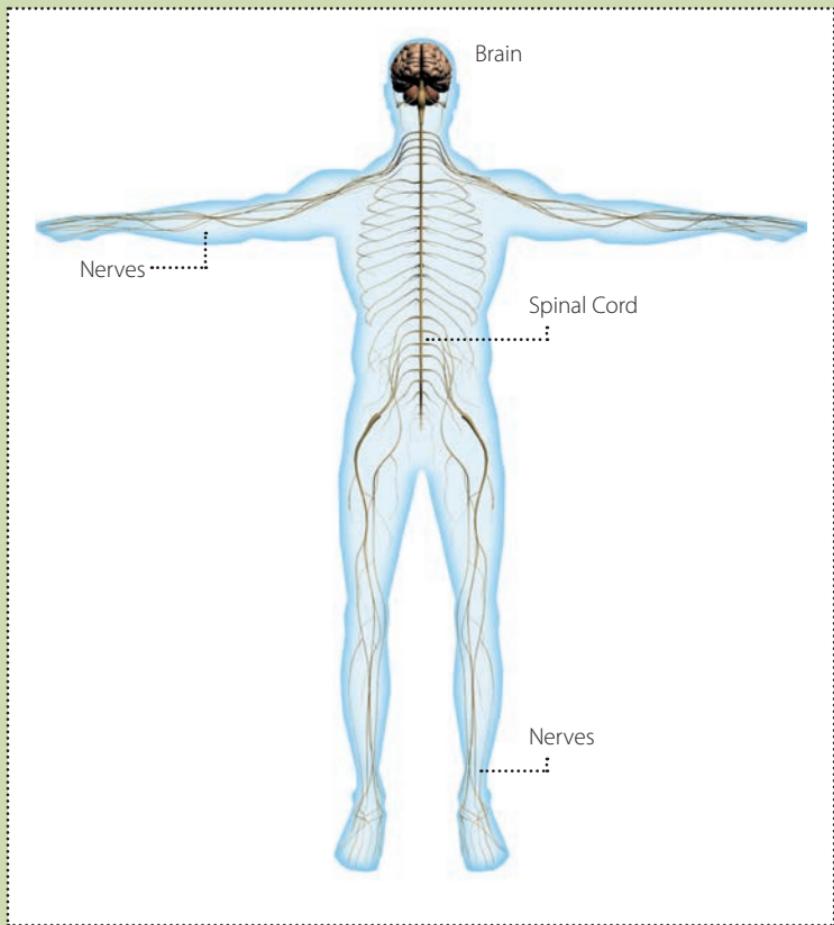
To adapt to these changes, it will help you and your loved one if you develop coping skills and find and use supportive resources (see resources section, page 16).

Also, be sure to share details about your loved one with the medical team so they can get a sense of his or her general intellect, rapport with people, and the things he or she liked to do before the injury/diagnosis. This information will be useful during the hospital stay and later rehabilitation process to help re-establish the person's life.

# Anatomy of the Brain: The Basics

The brain and spinal cord work together as the main parts of our central nervous system, which dictates our movements, activities, thoughts and feelings with the information received from our nerve cells, mind and environment.

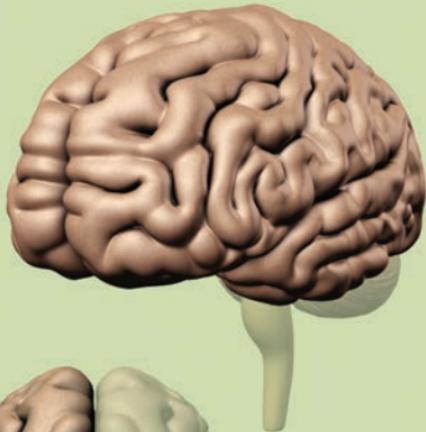
## Central Nervous System



More **Brain Anatomy** on Next Page

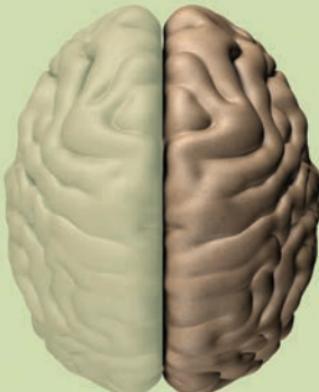
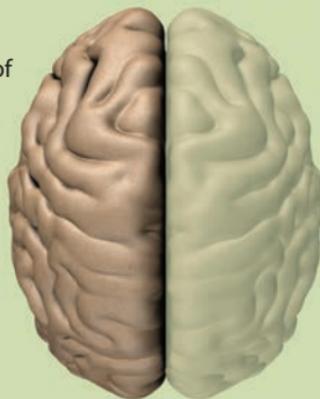
### Hemispheres/Cerebrum –

The brain is divided into two halves working together to command feelings, thoughts and behaviors.



#### Left hemisphere controls:

- Movement and sensation of the right side of the body
- Language: speaking, reading and writing



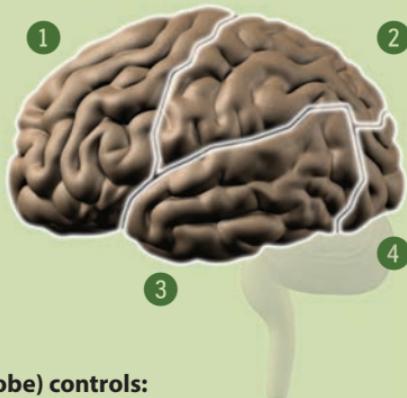
#### Right hemisphere controls:

- Movement and sensation of the left side of the body
- Spatial awareness (especially of the left side of the individual and the world)
- Non-verbal aspects of communication

**Lobes** – Each hemisphere is further broken down into smaller sections called lobes.

**① Frontal lobe is responsible for:**

- Main movement of extremities, trunk and eyes
- Judgment
- Behavior control
- Voluntary movements
- Directing attention
- Concentration
- Motivation
- Control of emotions and behavior
- Expressive aspects of language



**② Parietal lobe (behind the frontal lobe) controls:**

- Sensation
- Sense of space

**③ Temporal lobe (sits along the side of frontal and parietal lobes):**

- Memory
- Understanding language
- Plays an important role in emotions
- Complex visual processing

**④ Occipital lobe:**

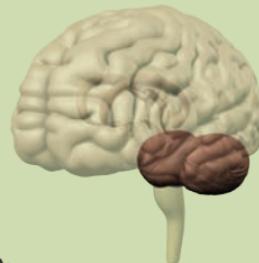
- Most vision processing; interprets what we see

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**Cerebellum (underneath lobes):**

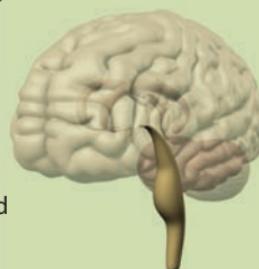
Most important for regulation of voluntary movement – posture, balance and coordination

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**Brainstem (connects the brain to the spinal cord):**

- Controls automatic functions like breathing, blood pressure and arousal
- If even partially damaged, can cause coma or minimally conscious state
- Critical connections between the brain's hemispheres, the cerebellum and the spinal cord



# Scales, Tests and Diagnostic Measures

## Rancho Los Amigos Levels of Cognitive Functioning Scale –

**Revised:** Often used to explain behavioral, cognitive and emotional changes that take place during healing

Level 1	<b>No Response: Total Assistance</b> – Patient appears to be in a deep sleep and does not respond to voices, sounds, light or touch.
Level 2	<b>Generalized Response: Total Assistance</b> – Patient reacts inconsistently and non-purposefully to stimuli; first reaction may be to deep pain; may open eyes, but will not seem to focus on anything in particular.
Level 3	<b>Localized Response: Total Assistance</b> – Patient responses are purposeful, but inconsistent and are directly related to the type of stimulus presented, such as turning head toward a sound or focusing on a presented object; may follow simple commands in an inconsistent and delayed manner.
Level 4	<b>Confused, Agitated: Maximal Assistance</b> – Patient is in a heightened state of activity; severely confused, disoriented and unaware of present events. Reacts to own inner confusion, fear or disorientation. Behavior is frequently bizarre and inappropriate to the immediate environment. Excitable behavior may be abusive or aggressive.
Level 5	<b>Confused, Inappropriate Non-Agitated: Maximal Assistance</b> – Patient appears alert; responds to simple commands. Follows tasks for two to three minutes, but easily distracted by environment; frustrated; verbally inappropriate; does not learn new information.

Level 6	<p><b>Confused, Appropriate: Moderate Assistance</b> – Patient follows simple directions consistently; needs cueing; can relearn old skills, such as activities of daily living, but memory problems interfere with new learning; some awareness of self and others.</p>
Level 7	<p><b>Automatic, Appropriate: Minimal Assistance for Daily Living Skills</b> – If physically able, patient goes through daily routine automatically, but may have robot-like behavior and minimal confusion; shallow recall of activities; poor insight into condition; initiates tasks, but needs structure; poor judgment, problem-solving and planning skills.</p>
Level 8	<p><b>Purposeful, Appropriate: Stand-By Assistance</b> – Patient is alert, oriented; recalls and integrates past and recent events; learns new activities and can continue without supervision; independent in home and living skills; capable of driving; deficits in stress tolerance, judgment; abstract reasoning persists; may function at reduced social level.</p>
Level 9	<p><b>Purposeful, Appropriate: Stand-By Assistance on Request</b> – Patient independently shifts back and forth between tasks and completes them accurately for at least two consecutive hours; aware of and acknowledges impairments when they interfere with task completion; requires standby assistance to anticipate a problem before it occurs; depression may continue; patient may be easily irritable and have a low frustration tolerance.</p>
Level 10	<p><b>Purposeful, Appropriate: Modified Independent</b> – Patient is able to handle multiple tasks simultaneously in all environments but may require periodic breaks. Irritability and low frustration tolerance may persist when feeling sick, fatigued and/or under emotional distress.</p>

## Glasgow Coma Score (GCS) – Scored between 3 and 15\*

The Glasgow Coma Score test measures the initial responses or lack of responses your loved one may have to determine the level of their brain injury.

<b>Best Eye Response</b> (Scored 1 to 4)	<ol style="list-style-type: none"><li>1. No eye opening</li><li>2. Eye opening to pain</li><li>3. Eye opening to speech</li><li>4. Eyes open spontaneously</li></ol>
<b>Best Verbal Response</b> (Scored 1 to 5)	<ol style="list-style-type: none"><li>1. No verbal response</li><li>2. Incomprehensible sounds</li><li>3. Inappropriate words</li><li>4. Confused</li><li>5. Oriented</li></ol>
<b>Best Motor Response</b> (Scored 1 to 6)	<ol style="list-style-type: none"><li>1. No motor response</li><li>2. Abnormal extension to pain</li><li>3. Abnormal flexion to pain</li><li>4. Withdrawal from pain</li><li>5. Localizes to pain</li><li>6. Obeys commands</li></ol>
Total made up of three sectional scores	

\*Always look at a GCS broken down by components – not just the total. A GCS of 13 or higher correlates with a mild brain injury, 9 to 12 is a moderate injury, and 8 or less, a severe brain injury.

# Glossary of Terms You May Hear

**Anoxia (or hypoxia)** – Lack of oxygen; can be caused by heart attack, airway obstruction, near drowning, lightning strike or even electrical shock

**Axonal shearing** – When the brain's axons (main channels of communication) are stretched to the point of breaking, causing damaged brain cells to die

**Brain herniation** – Rising pressure inside parts of the brain causing parts to shift out of place

**Cerebral atrophy** – Loss in size of the brain tissue due to damage done to the nerves and other supporting cells

**Coma** – Deep state of unconsciousness. Patient cannot be aroused, does not respond to stimuli, and cannot make voluntary actions. It can be medically induced to give the brain time to heal.

**Coma Recovery Scale** – Measures hearing and vision, movement and communication, arousal, etc. to help determine the patient's long-term prognosis. It can also be used to gauge the recovery progress.

**CT Scan (Computerized Tomography)** – 3-D X-ray that gives doctors more detailed information about spinal cord or brain damage than X-rays

**Edema** – Swelling caused by increased uptake of water. Can lead to squeezing of the brain and subsequent loss of the flow of blood carrying critical sugar and oxygen

**Healthcare advocate** – A person who works directly for the patient or family for a fee, helping with paperwork, billing and management of post-trauma care

**Hematoma** – Pool of blood or bruise inside the skull caused by damaged blood vessels. It can increase pressure inside the brain.

**Hemorrhage** – Internal or external bleeding caused by damage to a blood vessel

**Intracranial pressure monitoring** – Monitoring of the pressure inside the skull

**Mild traumatic brain injury (TBI) (concussion)** – Patient may initially lose consciousness for 15 minutes or less; may experience memory loss about the trauma event; likely to feel dazed, disoriented or confused. Most traumatic brain injuries are initially rated as mild.

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**Minimally conscious state** – A condition of severely altered consciousness in which minimal, but definite, behavioral evidence of self or environmental awareness is demonstrated

**Moderate traumatic brain injuries (TBI)** – Patient may initially lose consciousness for 15 minutes to a few hours (defined as a GCS from 9 to 12); similar, but more significant symptoms than mild TBI

**MRI (Magnetic Resonance Imaging)** – Uses a strong magnetic field and radio waves to produce computer-generated images. It can help identify the degree and type of injury to the brain or spinal cord injury at a higher degree of sensitivity than a CT scan.

**Neuropsychological assessment** – Series of tests evaluating multiple aspects of the mind, including basic hand-eye coordination, higher-level thinking and cognitive skills necessary for everyday functioning

**Occupational therapist** – Skilled in helping individuals learn, or relearn, the day-to-day activities they need to achieve maximum independence

**Physiatrist** – Doctor specializing in physical medicine and rehabilitation

**Physical therapist** – Treats disabilities that result from motor and sensory impairments. Focuses on mobility: moving in the bed, transferring from one surface to another, moving a wheelchair or walking

**Recreational therapist** – Focuses on leisure skills, as well as access, resources, safety and adjustment in the community

**Rehabilitation nurse** – Performs hands-on care by utilizing nursing process and specialized training, as well as coordinating educational activities

**Unresponsive wakefulness, or vegetative state** – The patient demonstrates sleep/wake cycles and reflexive responses, but does not yet demonstrate purposeful behaviors.

**Severe traumatic brain injuries** – A patient may have a loss of consciousness for six hours or longer after injury (defined as a GCS of 8 or less). People remaining unconscious for a lengthy time may be in a coma, or a vegetative or minimally conscious state. A coma seldom lasts longer than several weeks. People who are unconscious for a longer period of time may be in a vegetative or minimally conscious state.

**Shock** – Body response triggered by loss of blood to the brain, which can indirectly injure brain tissue

**Speech-language pathologist** – Works to prevent, assess, diagnose and treat speech, language, social and cognitive communication, and swallowing disorders

**Stroke** – An injury to the brain caused either by a lack of blood flow (ischemic stroke) or bleeding into the brain (hemorrhagic stroke). It is sometimes called a “brain attack.” Stroke effects depend on where in the brain the stroke occurs.

**Sympathetic storming** – Stress response such as agitation, fever, irregular vital signs and excessive sweating. It can occur anytime from 24 hours to months after the injury and is thought to be due to an overactivity of the “fight-or-flight” part of the nervous system. Also called paroxysmal sympathetic hyperactivity.

**Vocational therapist** – Helps people assess their job skills/readiness and return-to-work options

## Questions Families Should Ask Their Trauma Care Medical Team

Would you tell me more about my loved one's brain injury?

What are you doing right now? How will it help my loved one?

Can you tell me anything I might do that would be helpful?

Can you take me step-by-step through the basic care tasks you are performing (e.g., bathing, grooming and feeding) so I can possibly help with them, too?

When will I know my loved one is ready for the next step?

What is cognitive therapy, and how can it help my loved one?

What is the goal of rehabilitation therapy?

# Expected Emotions and Helpful Coping Tips

Emotional stages you will probably experience are: first, *denial* and *disbelief*; second, *sadness, anger* and *bargaining*; and third and most important, *acceptance*.

It's natural and important to grieve the loss of the way things were before the injury. It's also necessary to set new goals and find a way to move forward with your life.

As you begin to accept the consequences of what has happened, you can start to plan how to make the best of the challenge you're facing.

Your relationships with family and friends will be tested, and you may feel overwhelmed or try to go on like nothing has changed. Everyone copes with these feelings in different ways. With time and support, you'll begin to adjust to the challenge of brain injury and understand your "new normal." As you go through this process, be sure to:

- Empower yourself with as much knowledge as you can.
- Check out local and state support groups, and nationally recognized brain injury organizations, such as the Brain Injury Association of America, the American Trauma Society, American Heart Association, American Stroke Association and the Brain Trauma Foundation.
- Be wary of random internet surfing of topics related to brain injury.
- Rely on websites from reputable organizations that have consolidated information and offer helpful tools and checklists.

# Important Tips for the Days and Weeks After the Injury or Diagnosis

- Limit length of visits and the number of visitors at any given time.
- Allow yourself and your loved one time to rest between visits.
- Try to take turns at the trauma care center so you can get some rest.
- Have everyone who visits maintain a soft and calm tone of voice.
- Assume that your loved one can hear you and be thoughtful about everything that is said within earshot.
- Keep an open mind during every step of the process and never give up hope.
- Take advantage of all therapeutic opportunities and learn all that you can about the rehabilitation stage your loved one is currently experiencing.
- Talk about your feelings and concerns with supportive friends, family and spiritual leaders you trust.
- Meet with other people and families with both new and old injuries to share experiences, knowledge and resources.
- Take care of yourself in the best manner possible. This journey may be long, and you will need to be ready to care for your loved one when you take them home.
- Stay hopeful and positive throughout the recovery process.
- Don't let the highs get you too high or the lows get you too low. The ups and downs are inevitable in brain injury recovery.

# Steps to Negotiate the Insurance Maze

## OBTAIN

Obtain a copy of the full (not abbreviated or summarized) **EXPLANATION OF INSURANCE BENEFITS**. Read your policy carefully and thoroughly, including fine print, definitions, exclusions, etc., to learn the extent of covered services.

## CONTACT

Find out if you have been assigned a **CASE MANAGER** and contact that individual; if not, request that you be assigned to a case manager or benefits advisor. To be your loved one's best advocate, you should educate the case manager about his/her brain injury and particular needs to preserve the integrity of their body and health.

## DETERMINE

Determine the **REHABILITATION BENEFITS**. Inquire about the number of allowed days of coverage for inpatient acute and sub-acute rehabilitation, outpatient and home health rehabilitation; ask whether there is an annual maximum number of days and a lifetime maximum number of days.

## INQUIRE

Inquire about rehabilitation in a **BRAIN INJURY-ACCREDITED REHABILITATION FACILITY**, including both in-state and out-of-state facilities.

## VOICE

Contact your insurance representative for **ISSUES AND/OR CONCERNS** that relate to your health insurance and whenever you have been denied a service that you believe to be covered.

## DOCUMENT

Remember to always document/record **ALL CONVERSATIONS** with your insurance company: Include the date of the call, the reason for the call, the person with whom you spoke and the outcome of the call.

## EDUCATE

Educate your **INSURANCE REPRESENTATIVE** to be an advocate for your loved one's health care needs. Teach this person the risk factors for the secondary complications of brain injury, necessary measures to preserve the health and integrity of your body and importance of immediate access to insurance and health care professionals.

## CONTACT

If your injury occurred while on the job and you have qualified for **WORKERS' COMPENSATION**, talk to your Workers' Compensation case manager about what options for care are available to you following your trauma care treatment.

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*Adapted from What You Should Know About Health Insurance: Guidelines for Persons with Spinal Cord Injury (National Spinal Cord Injury Association)*

# Helpful Resources, and Credible Organizations and Websites

## American Heart Association

Works to build healthier lives, free of cardiovascular diseases and stroke  
[heart.org](http://heart.org) | 800-242-8721

## American Stroke Association

Works to build healthier lives, free of cardiovascular diseases and stroke  
[stroke.org](http://stroke.org) | 800-242-8721

## The American Trauma Society

Dedicated to the prevention of trauma and improvement of trauma care  
[amtrauma.org](http://amtrauma.org) | 800-556-7890

## Brain Injury Association of America

Dedicated to increasing access to quality health care and raising awareness and understanding of brain injury through advocacy, education and research  
[biausa.org](http://biausa.org) | 800-444-6443

## Brain Trauma Foundation

Dedicated to improving the outcome of traumatic brain injury (TBI) patients worldwide by developing best practices guidelines, conducting clinical research, and educating medical professionals and consumers  
[braintrauma.org](http://braintrauma.org)

## Disabled Sports USA

A network of community-based chapters offering sports rehabilitation programs to anyone with a permanent disability  
[disabledsportsusa.org](http://disabledsportsusa.org) | [info@dsusa.org](mailto:info@dsusa.org)

## Family Voices

Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities  
[familyvoices.org](http://familyvoices.org) | 888-835-5669

### **Help Hope Live**

Help Hope Live helps families address financial hardships arising from uninsured medical expenses related to catastrophic spinal cord or brain injury. Established in 1983 by medical professionals, Help Hope Live is a 501(c)(3) nonprofit organization that provides expert fundraising guidance to patients, families and communities nationwide, while offering fiscal accountability for funds raised.

[helphopelive.org](http://helphopelive.org) | 800-642-8399

### **Model Systems Knowledge Translation Center**

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the needs of individuals with traumatic brain injury, spinal cord injury and burn injury.

[msktc.org](http://msktc.org) | 202-403-5600

### **Office of Disability Employment Policy**

Federal government agency within the U.S. Department of Labor helping ensure that people with disabilities have equal employment opportunities

[dol.gov/odep](http://dol.gov/odep) | 202-693-7880

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If your loved one has a **dual diagnosis** of both brain and spinal cord injury, you may want to access these organizations:

### **Christopher & Dana Reeve Paralysis Resource Center**

Promoting the health and wellbeing of people living with spinal cord injury, mobility impairment and paralysis by providing comprehensive information, resources and referral services

[paralysis.org](http://paralysis.org) | 800-225-0292

### **United Spinal Association**

Leading the way in maximizing the quality of life and opportunities for people with spinal cord injuries and diseases since 1948

[unitedspinal.org](http://unitedspinal.org) | 718-803-3782

This booklet is a companion to the DVD **Understanding Brain Injury**. Together, these tools can help you understand and navigate this challenging time in your life.

## DVD Chapters

- 1** Introduction and About This Video
- 2** Brain Injury Basics and Anatomy of the Brain
- 3** Understanding Traumatic Brain Injury, its Causes, Effects and Classifications
- 4** Understanding Non-Traumatic Brain Injury and Stroke, its Causes, Effects and Classifications
- 5** Practical Advice for Coping with Brain Injury

Visit [BrainInjury101.org](http://BrainInjury101.org) to learn more about this video series.