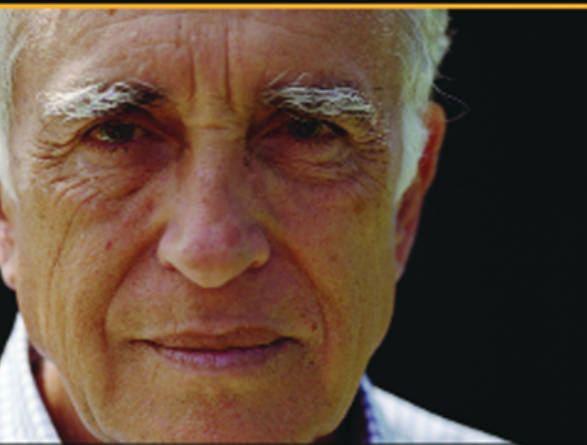




My husband was hit by a drunk driver.



I fell off a ladder cleaning the gutters.



My ex-boyfriend beat me up.



I sustained a blast injury in Iraq.

LIVING WITH BRAIN INJURY:

A guide for and about adults with moderate to severe brain injury.

2006 Edition



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Brain Injury Association of America

Founded in 1980, the Brain Injury Association of America (BIAA) is the nation's leading organization serving and representing individuals, families, and professionals touched by a life-altering, often devastating, traumatic brain injury. BIAA's mission is to create a better future through brain injury prevention, research, education, and advocacy. Reflecting its commitment to grassroots support for persons with brain injury and their families and friends, the Association has a network of more than 40 chartered State Affiliates.

By disseminating information and resources, participating in legislative advocacy, facilitating prevention awareness, hosting educational programs, and encouraging research, the Brain Injury Association of America and its State Affiliates work to reach the millions of people living with the "silent epidemic" of brain injury.

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Disclaimer

The Brain Injury Association of America does not endorse or recommend any methods, treatment, or programs that may be referenced in this publication. The Brain Injury Association of America disclaims any liability arising from use of information in this booklet. The Association recommends that individuals with brain injury and their families use this guide as a resource and adapt the information to their specific needs. BIAA recommends that persons with brain injury, their family members, and other caregivers consult professionals to determine the best options to meet their individual needs.

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Introduction

The Brain Injury Association of America developed *Living with Brain Injury: A Guide for and about Adults with Moderate to Severe Brain Injury* to provide basic information for patients and their families, caregivers, professionals, friends, and associates. The term *brain injury* is used throughout this publication for both acquired brain injury and traumatic brain injury. *Traumatic brain injuries* are specifically those caused by external physical force.

This guide includes what you need to know to understand the condition of a person with a brain injury, the professionals who will treat him or her, and the tests and treatments he or she will undergo. It addresses brain injury's definitions, causes, and consequences, and summarizes some of the rehabilitative and community service and support options available to people with brain injury and their families.

The first figure of the guide, *Stages of Care*, summarizes standard approaches from diagnosis through rehabilitation, explaining what to expect at each stage.

Chapter 1 describes the structure of the brain and explains how different types of injuries affect it.

Chapter 2 describes the initial (or acute) phase of care, the one that takes place in the emergency room and in the hospital immediately afterward. It includes a glossary of terms that health professionals might use as they treat the patient. It also describes the different types of diagnostic tests and medical treatment those professionals may use.

Chapter 3 outlines the rehabilitation stages of care. It identifies the health professionals who may be on a rehabilitation team, explains how they predict the outcome of brain injury (including a special section on the steps involved in neuropsychological assessment), and describes what a *care plan* entails.

Chapter 4 relates physical, emotional, and behavioral changes and difficulties a brain-injured person may experience and suggests ways family members and caregivers can help with the patient's recovery.

Chapter 5 sets out the different kinds of treatments, education, residences, and support services available in the community for the patient and his or her caregivers. It also defines medical and legal terms frequently used in arranging for care. Finally, this chapter describes the various avenues of financial and medical assistance available from the Federal government. A special section addresses the decision whether or not to reenter the workplace.

Appendix 1 provides detailed information on relationships between the brain and behavior. Appendix 2 discusses acquired brain injury. Appendix 3 lists terminology used to describe disorders of consciousness. Reference material used to create this guide and sources for further study are listed in Appendix 4.

Stage of Care

This chart depicts the types of care a brain-injured person may receive at each stage of his or her recovery and where that care may be provided. Individuals with a brain injury do not always progress in a linear fashion from trauma care to community. Individuals may be admitted, discharged and re-admitted at any point during the continuum of care.

Phase of Care	Location	Examples of Care	Where Discussed
Critical Care	Hospital emergency room	Early, sometimes intensive medical intervention to stabilize patient and prevent complications	Chapter 2
Acute Care	Hospital	Medical care to achieve the best outcomes Diagnostic tests Development of a care plan	Chapter 2
Acute Rehabilitation	Hospital	Highly intensive skilled rehabilitation to improve function (3+ hours of care/day for an average of 3–5 weeks) Goals may include bowel and bladder control, communication skills, maximizing movement, and basic self-care skills in hygiene, orientation, and learning.	Chapter 2
Subacute Rehab	Hospital or skilled nursing facility	Medical stability Complex nursing care Rehab services (1–3 hours/day for an average of 2–3 months)	Chapter 3
Post-Acute Rehab	Residential facility, day treatment program, or home	Home/community integration; increased daily activities Several weeks to several months	Chapter 3
Specialized Rehab	Neurobehavioral unit. Highly structured, usually in a hospital	Specialized rehabilitation unit to help people control behaviors and impulses	Chapter 3
Continuing Support	Family and community	Education in physical and psychological changes and how families can help Programs, agencies, and support services that assist patients and their families	Chapters 4 and 5

Chapter 1: About the Brain and Brain Injury

The Brain

The brain controls all functions of the body, including walking, talking, and eating. It controls functions that occur naturally, such as breathing and blood circulation, as well as the senses of sight, smell, and touch. Finally, the brain performs complex, higher-level functions, such as thinking, learning, reading, and remembering.

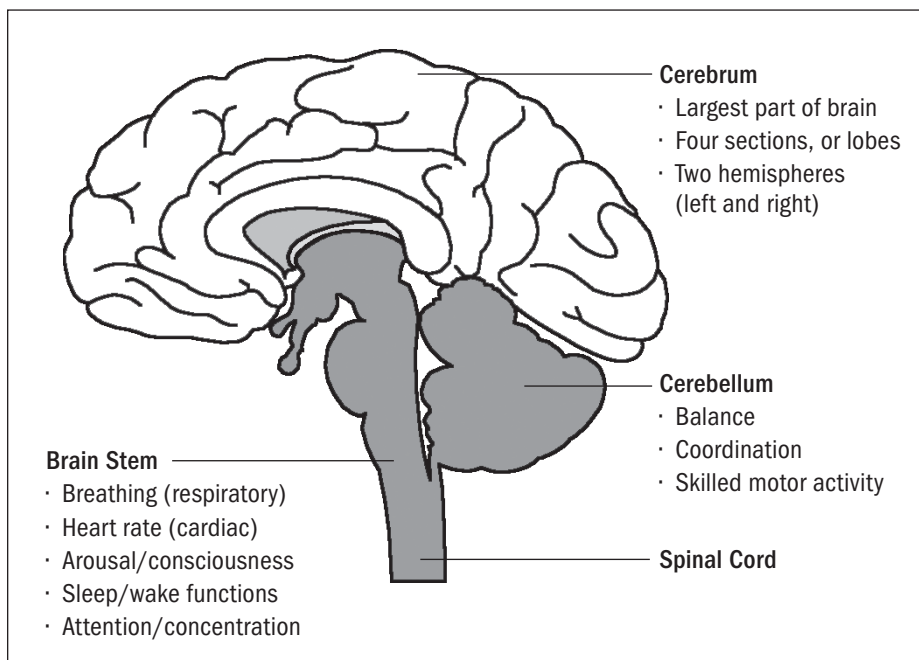
Regions of the Brain: As shown in the diagram below, the brain has three main regions: the *cerebellum*, the *brain stem*, and the *cerebrum*. All three regions work together, yet each has its own special functions. Most brain injuries affect several areas of the brain.

Brain Stem: The brain stem, about the size of the little finger, sits at the base of the brain and is an extension of the spinal cord. The brain stem has two main functions: control of basic life processes (such as breathing and heart rate) and arousal and consciousness (that is, alerting the thinking part of the brain). As a result, damage to the brain stem may reduce arousal and alertness and impair breathing, heart rate, and sense of touch. Twelve *cranial nerves* based in the brain stem run through the rest of the brain.

Cerebellum: The cerebellum, about the size of two large plums, lies under the lower back of the skull. It has a right and a left side and handles two main functions: maintaining balance and coordinating movement. Damage to the cerebellum may therefore cause difficulties in coordination and balance (for walking and standing).

Cerebrum: The cerebrum is the largest part of the brain. It has two regions (or halves), left and right. The left side generally receives messages from and controls the movement of the right side of the body; the right side does the same for the left side of the body. The *dominant side*, which is usually on the left (for right-handed people), controls speech, understanding, reading, writing, arithmetic, and other language functions. The *non-dominant side*, usually the right (for right-handed people), processes nonverbal information, including spatial orientation, relationships of objects to each other, and recognition of shapes, forms, and faces. The cerebrum hemispheres are further divided into four sections, or *lobes*—*parietal*, *frontal*, *temporal*, and *occipital*.

Please refer to Appendix 1 for more information about the relationships of the brain to behavior.



What Is a Brain Injury?

There are two main categories of brain injury: traumatic and acquired.

Traumatic Brain Injury

A *traumatic brain injury* (TBI) is the result of a physical shock: a blow, jolt, or impalement. Not all blows or jolts to the head result in TBI. The severity of such an injury may range from mild¹ (a brief change in mental status or consciousness) to severe (an extended period of unconsciousness or loss of memory [amnesia]) after the injury. A TBI can result in short- or long-term problems with a person's ability to function.

Statistics on Traumatic Brain Injury in the United States

- At least 5.3 million Americans currently live with disabilities resulting from a TBI.
- More than 1.4 million Americans experience a TBI every year.
- Each year, 1.1 million individuals are treated and released from an emergency department following a TBI.
- More than 50,000 people die every year as a result of TBI.
- The risk of TBI is highest among adolescents, young adults, and persons older than 75 years.
- Blasts are a leading cause of TBI for active duty military personnel in war zones.

Acquired Brain Injury

Acquired brain injury is a general term that refers to any injury to the brain after birth. Such events may include infections or lack of oxygen to the brain, a blood clot or a stroke, and/or a TBI. The term does not refer to congenital brain injuries or those that occur during birth.. For a discussion of acquired brain injury, see Appendix 2.

1 For information about mild brain injury and concussion, visit <http://www.cdc.gov/ncipc/tbi>. This is a link to a booklet entitled Facts about Concussion and Brain Injury and Where to Get Help, which may be downloaded or ordered at no cost from the Centers for Disease Control and Prevention in Atlanta, Georgia.

Chapter 2: In the Hospital: Acute Care

Critical Care	Hospital emergency room	Early, sometimes intensive medical intervention to stabilize patient and prevent complications
Acute Care	Hospital	Medical care to achieve the best outcomes Diagnostic tests Development of a care plan
Acute Rehabilitation	Hospital	Highly intensive skilled rehabilitation to improve function (3+ hours of care/day for an average of 3–5 weeks) Goals may include bowel and bladder control, communication skills, maximizing movement, and basic self-care skills in hygiene, orientation, and learning.

Types of Traumatic Brain Injury

- Primary Injury
- Secondary Injury
- The Treatment Team
 - Types of Diagnostic Tests
 - Types of Medical Treatment

At the time of the Traumatic Brain Injury:

Primary Injury

Health professionals actually talk about two types of injury when the brain is harmed. *Primary injury* refers to what happens to the brain and skull at the moment of impact. The effect of this impact is related to unique structure of the skull and brain.

The bone of the skull is very hard, while the brain is very soft. When a traumatic injury occurs, such as a car crash or a fall, the impact may cause the skull to move very quickly. The brain moves at a different speed because it weighs less than the skull; as a result the brain may hit the bone of the skull, causing bruising and bleeding. Sometimes, the impact can be so severe that the brain bounces back and forth inside the skull, causing very severe bruising and bleeding.

Here are some other words health professionals may use when they talk about what may happen at the primary TBI:

- **Axonal Stretching:** The stretching and tearing of certain brain tissues that can happen as a result of an impact. The *axons*, part of the brain's nerve cells, may die and cause swelling in the brain. The swelling causes more injury (see below).
- **Contusion:** *Contusion* is a medical term for bruising. A traumatic brain

injury can result in bruising anywhere in the brain, but often most of the bruising is on the underside of the frontal and temporal lobes since the bones underlying these parts of the brain are irregular and rough.

- **Coup-Contra Coup:** The word *coup* means “blow,” and *coup-contra coup* refers to a two-part blow. Upon impact, bruising and contusion can occur not only at the site of the blow to the head (coup) but also at the site directly opposite it (contra coup), as the brain slams into the skull.
- **Skull Fracture:** A skull fracture occurs when bones of the skull are broken or cracked. Skull fractures may be simple or compound. Compound fractures (where bone breaks through the skin or surrounding soft tissue) could see loose bone fragments enter the brain or place pressure on it.

Secondary Injury

Secondary injury occurs in the brain and throughout the body after the primary brain injury has happened. Such injuries may include the following:

- **Anoxia:** A lack of oxygen to the brain. Brain cells, like all cells in the body, need a constant supply of oxygen to stay alive. When blood flow to the brain is reduced, the brain no longer receives its supply of fresh oxygen and brain cells die or are severely damaged.
- **Brain Swelling:** The brain, like any other part of the body, swells after severe trauma. Because the brain is encased in the hard, unexpandable skull, however, brain swelling can have more serious effects than swelling in, say, an arm or a leg. In fact swelling is a major cause of damage to the brain after injury. Direct pressure can harm brain cells, or pressure may impair blood flow, cutting off oxygen. If the swelling is extensive it can squeeze the brain stem, disrupting normal life functions and leading to death.
- **Hematoma:** A pool of blood that forms in the body. If the blood vessels in the brain are broken by the impact of a blow to the skull, they may leak, forming a hematoma. A hematoma can cause brain injury by directly damaging nerves or by causing increased pressure in the brain, which also squeezes nerves. The treatment for a hematoma is to surgically drain the blood.
- **Hypovolemic Shock:** A person who has had a TBI may lose a lot of blood, and that loss can result in damage to brain tissue.
- **Hydrocephalus:** The flow of fluid from the spinal cord and brain into the cavities, or ventricles, of the brain is sometimes blocked or disrupted after a brain injury. When this happens fluid can build up in the brain and cause increased pressure. This condition is called *hydrocephalus*, and it can be a serious secondary brain injury. Pressure can be relieved through a procedure that involves inserting a needle into the brain cavities, drawing off the fluid, and routing it through a tube into the abdominal cavity.
- **Increased Intracranial Pressure (ICP):** Because the brain is enclosed within the skull, the fluid formed from swelling or bleeding has nowhere to go. It builds up and causes increased pressure, further damaging brain tissue. The word *cranial* refers to the *cranium*, or skull.

- **Seizure Disorders:** In medical terms, a *seizure* is the sudden appearance of convulsions, a disturbance of the senses, or a loss of consciousness. Seizures are often caused by injuries in the temporal or frontal lobes that disrupt the electrical activity of the brain. They can occur immediately after, soon after, or much later after a brain injury. Seizure disorders are usually treated with anticonvulsant drugs.

Disorders of Consciousness: As they diagnose and treat a patient, health professionals may also discuss *disorders of consciousness*. One such disorder is a *coma*, when the patient lacks any purposeful response to his or her surroundings, although reflexive behaviors may still occur. Please refer to Appendix 3 for more detailed information about the terminology used to describe cognitive functioning, various coma states, and other disorders of consciousness.

The Treatment and Acute Rehabilitation Team

Many professionals and specialists are involved in acute care and rehabilitation. Key members of these teams are listed here. Following each entry on the list is a Web site for further information.

Emergency Physician: A doctor who initially diagnoses and stabilizes acutely injured patients, including those with TBI. (<http://www.aep.org>)

Neurologist: A specialist in disorders of the nervous system; may be involved in the diagnosis of brain injury and may continue to monitor recovery. (<http://www.aneuroa.org>)

Neuropsychiatrist: A specialist who concentrates on behaviors, personality changes, mood changes, memory changes, and changes in sleep/wake cycles related to brain injury; may diagnose, monitor, and prescribe medications for these problems. (<http://neuro.psychiatryonline.org>)

Neuropsychologist: A psychologist who specializes in brain-behavior relationships; usually administers a series of tests to evaluate a person's cognitive, emotional, intellectual, and academic/vocational skills. (<http://www.apa.org>)

Neurosurgeon: A specialist who performs surgery on the brain and has expertise in diseases of the central nervous system. (<http://www.aans.org>)

Occupational Therapist: Helps the individual regain the physical, perceptual, and cognitive skills required to perform activities of daily life. (<http://www.aota.org>)

Physiatrist: A specialist involved in rehabilitation; in hospitals and rehabilitation settings, often leads the rehabilitation team and coordinates its goals into a unified approach. (<http://www.aapmr.org>)

Physical Therapist: Focuses on improving the patient's motor functioning and movement. (<http://www.apta.org>)

Trauma Surgeon: A surgical specialist who diagnoses and manages the care of acutely injured patients; performs non-brain surgeries and other therapies aimed at limiting brain injury. (<http://www.aans.org>)

Types of Diagnostic Tests

Doctors use a number of tests to learn more about a brain injury and its effect on the body, and to create a treatment plan. Some of the most common of these diagnostic tests include:

Angiogram: An examination of the blood vessels in the brain.

CT/CAT (computerized axial tomography): A special type of x-ray that measures the density of the brain (or other internal organs) and generates an image.

EEG (electroencephalogram): A measurement of the brain's electrical activity, as produced by its nerve cells. An EEG can check for seizures or decreased activity in the brain.

EKG (electrocardiogram): An assessment of the function and electrical activity of the heart.

ICP Monitor: A device to measure pressure inside the brain. The test involves placing a narrow tube through a small hole in the skull (see Secondary Injury, page xx).

MRI (magnetic resonance imaging): A tool that uses radio waves and a strong magnetic field to produce an image of the brain (or another organ).

Neuroimaging: Tests to create pictures of the brain's activity during various tasks. These studies may include SPECT (single photon emission computerized tomography) and PET (position emission tomography),

X-Ray: A picture to reveal whether a skull is fractured or other bones are broken.

Types of Medical Treatment

Each person with a brain injury must have an individual treatment plan that includes steps to stabilize his or her condition and prevent any further brain damage (arising from, for example, more bleeding, swelling, increased intracranial pressure, or blood clotting).

Listed here are some of the medications and other treatments that a doctor or surgeon may prescribe during the period immediately after a brain injury. The first two apply to the period during which the patient is hospitalized.

Fluid Restriction: Fluid a patient drinks may be absorbed by the brain, causing it to swell. Ask the primary nurse before giving fluids.

Positioning: Usually the head of the bed is slightly raised to prevent buildup of fluid and pressure in the brain. Ask the nurse before you adjust the bed position.

Medications: A physician may prescribe...

- ...antibiotics to prevent and treat infections.
- ...anticonvulsants to control seizures.
- ...antispasticity agents to decrease muscle tone and prevent seizures.
- ...antidepressants to reduce feelings of depression and improve mood.
- ...antianxiety agents to reduce anxiety.
- ...psychostimulants to increase alertness.

Neurosurgery: Major advances have been made in brain surgery in recent years. You are most likely to hear about one of the following four procedures:

- **Craniotomy:** The skull, or cranium, is opened to relieve increased pressure caused by fractured bone, a blood clot, or swelling.
- **Burring:** The surgeon makes a small opening in the skull to remove blood clots.
- **Bone Flap Removal.** The surgeon removes a piece of the skull to relieve pressure caused by swollen brain tissue.
- **Ventricular Drainage:** The surgeon inserts a catheter (tube) leading from the brain into the abdomen to drain spinal and brain fluid (see Hydrocephalus, page xx).

Chapter 3: **After the Hospital: Post-Acute and Specialized Rehabilitation**

Subacute Rehab	Hospital or skilled nursing facility	Medical stability Complex nursing care Rehab services (1–3 hours/day for an average of 2–3 months)
Post-Acute Rehab	Residential facility, day treatment program, or home	Home/community integration; increased daily activities Several weeks to several months
Specialized Rehab	Neurobehavioral unit. Specialized rehabilitation unit to help people control behaviors and impulses	Highly structured, usually in a hospital

- Predicting the Outcomes of Brain Injury
- The Rehabilitation Team
- The Neuropsychological Assessment and the Care Plan

Predicting the Outcomes of Brain Injury

How well a patient will do following a brain injury depends on three general factors: the individual’s health before the injury, the nature of the injury, and the post-injury course of recovery. Each of these factors is described below. No two people are alike, and no two brain injuries are exactly alike. Each person’s injury and recovery are different. In fact, it is usually difficult to predict for a given person how long recovery will take or what the long-term consequences of a brain injury will be. In general, however, doctors have observed better recovery when less severe injuries are sustained by healthy people.

Pre-Injury Factors

- **General Health:** An individual who was in poor health before a brain injury is likely to have a worse outcome than someone who was in good health.
- **Prior History of Brain Injury:** Any injury to the brain has both temporary and long-term effects. A previous brain injury, even a minor one, may hamper recovery from later injuries.

Injury Factors

- **Severity of Injury:** Generally, the more severe the brain injury, the more likely the patient will have long-term problems.
- **Extent and Location of the Injury.**
- **Complicating Medical Factors:** Damage to other regions of the body, bleeding, seizures, fluid in the brain, infections, and other conditions can worsen

the initial brain injury.

- **Anoxic Injury:** Injuries that deprive the brain of oxygen for more than four or five minutes are more likely to have serious consequences.
- **Access to Acute Care:** The sooner a person receives medical treatment after a brain injury, the better his or her long-term outlook.
- **Length of Coma:** A longer period of coma is generally an indication of a more severe injury, and may itself lead to a greater risk of long-term problems.

Post-Injury Factors

- **Recovery Time:** Initial recovery from a brain injury is often rapid. Full recovery, however, continues at a slower rate for the rest of the injured person's life.
- **Continuum of Care:** Most rehabilitation professionals agree that individuals with severe brain injury require ongoing treatment and long-term support. Rarely can someone with a brain injury return directly to work or school. A period of intervention is usually needed. A patient who receives the treatment and support he or she needs is likely to have a better recovery than one who does not.
- **Psychosocial Issues:** Rehabilitation and recovery often take a long time. Self-motivation, coping style, support, and encouragement from family, friends, and others are critically important. People with good support networks and coping styles are likely to manage their recoveries better than others.

The Rehabilitation Team

Note that some members of the *treatment* team described in Chapter 2 continue to care for the patient during the rehabilitation phase.

Occupational Therapist: Helps the individual regain the physical, perceptual, and cognitive skills required to perform activities of daily life. (<http://www.aota.org>)

Physiatrist: A specialist involved in rehabilitation; in hospitals and rehabilitation settings, often leads the rehabilitation team and coordinates its goals into a unified approach. (<http://www.aapmr.org>)

Physical Therapist: Focuses on improving the patient's motor function and movement. (<http://www.apta.org>)

Rehabilitation Nurse: Monitors, coordinates, and delivers nursing interventions; involved in planning, implementing, and evaluating the individual's plan of care. Responsibilities vary depending on the stage of recovery. (<http://rehabnurse.org>)

Social Worker/Case Manager: Links the patient, the family, and the team members; may provide education, resources, emotional support, and discharge options; may negotiate between facility and financial resource. Responsibilities vary in different settings. (<http://www.naswdc.org>)

Speech-Language Pathologist: Evaluates and treats problems with communication, swallowing, and, in some settings, cognitive problems such as memory, higher-level reasoning, and problem solving. (<http://www.asha.org>)

Vocational Rehabilitation Counselor: Evaluates the individual's past vocational or educational performance and current vocational skills with the goal of helping him or her resume appropriate and realistic employment. (<http://www.Nrca-net.org>)

The Neuropsychological Assessment and the Care Plan

To guide treatment, the rehabilitation team will usually recommend a *neuropsychological assessment*. This assessment should be administered by a neuropsychologist. It identifies strengths and weaknesses in a person's thinking skills, whether there is evidence of loss of abilities, and whether these losses will hinder reintegration into the community. It suggests ways to improve strengths while working around areas of weakness, and may touch on the following areas:

- sensory perceptual and motor functions
- verbal language skills
- attention
- memory
- speed in processing information
- executive functions (for example, concept formation, problem solving, planning and organization, flexibility in thinking)
- general intellectual skills
- academic skills
- personal adjustment and emotional functioning

Using the neuropsychological assessment and other methods of evaluation, the rehabilitation team will develop a *care plan*. Such a plan will describe the treatment methods and goals, frequency of therapies, and medications to be used. It will also outline the plan to discharge the person with a brain injury to his or her home or community. The discharge plan will include recommendations, follow-up appointments, and points of contact for the patient and his or her family.

Chapter 4: **Challenges and Changes**

Continuing Support	Family and community	Education in physical and psychological changes and how families can help Programs, agencies, and support services that assist patients and their families
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- Changes in Thinking
 - Speech and Language Difficulties
 - Behavioral and Psychosocial Changes
 - Changes in Physical, Motor, or Sensory Abilities
 - Early Recovery and How You Can Help

Changes in Thinking

Brain injuries often result in thinking and learning problems, also known as *cognitive* problems. Cognitive problems may include difficulty concentrating, remembering new information, solving problems, and processing information quickly. The more serious the injury, the more serious the problems are likely to be. Improvement generally occurs over the course of days, weeks, months, and even years. Some individuals may have difficulties throughout their lives.

An individual with brain injury may do very well physically and seem able to communicate information. He or she may seem normal. Yet at the same time such a person may have serious difficulty with memory, problem solving, concentration, or structuring his or her day. Such individuals may need to live in a supervised setting or may need someone to help them organize their day-to-day lives.

Common changes in cognitive abilities or difficulties after a brain injury may include the following:

- lack of awareness of one's limitations
- confusion about time, where one is, and who one is (a health professional may say that such an individual is "disoriented to time, place, and person")
- inability to focus on one thing, activity or person
- lack of initiative

A person with a brain injury may have impairments in his or her ability to:

- recall or store recent information (short-term memory)
- learn new information
- evaluate what is important or significant
- distinguish between what is safe and what is dangerous

It may also be difficult for such a person to:

- recall pre-injury events (remote memory)
- maintain attention or concentrate for a long period of time

- plan, organize, and make decisions
- perform basic arithmetic
- arrange things in correct order (sequencing)
- understand abstractions
- understand cause and effect

Problems that commonly affect ability people with brain injuries include:

- **Cognitive Impairments:** These may affect a person’s ability to do normal daily activities, such as attending to personal hygiene, dressing, eating, working, homemaking, learning, and managing money. An individual who has experienced a moderate-to-severe brain injury typically requires at least some initial supervision, guidance, and direction in order to start, follow through, and complete tasks safely.
- **Memory Problems:** Problems with memory (recent or long past) can be the most lasting and disabling results of a brain injury. Memory loss makes it difficult for the individual to respond appropriately to daily situations, and can significantly affect his or her ability to live independently.
- **Executive Functioning (term used by professionals to describe planning and organization skills):** Executive functioning can be likened to what a business executive does to keep an organization running smoothly: organizing, planning, creating, evaluating, and, perhaps most important, starting new projects. Our ability to engage meaningfully in tasks, evaluate what we are able to do, and to congratulate ourselves on what we have accomplished is part of being able to understand ourselves.

Because of impaired executive functioning, an individual with a brain injury may not respond in the same way others do. For example, if the individual confronts a problem on the job or at home, he or she may react by yelling or throwing something. The person may interpret the problem inaccurately and then use poor judgment in arriving at possible solutions. Or he or she may fail to recognize that a problem even exists.

- **Lack of Insight:** After a brain injury, the person may be unable to see his or her cognitive, emotional, or behavioral difficulties, and may have limited awareness of their impact on his or her life.
- **Lack of Initiation:** An individual with a brain injury may have difficulty engaging in meaningful activity unless prompted. For example, such a person may not pursue relationships, begin to work, or perform simple hygiene. Lack of initiation is one of the most common disabilities to follow a severe brain injury, and is often inaccurately labeled as laziness, faking, or malin-gering.
- **Concrete Thinking:** Concrete thinking is taking things at face value—look-ing only at the surface appearance of things, without understanding what might lie below. It is the opposite of abstract thinking, and may characterize a person with a brain injury. Such a person may have little or no ability to generalize or apply information from one situation to another. As a result, the individual may not understand the purpose of certain therapeutic exer-cises and may even resist therapy.

Speech and Language Difficulties

Speech and language problems are common following a brain injury, particularly a severe injury. Specific problems may include:

- reduced understanding of spoken or written words
- impaired expression of thoughts and ideas
- difficulties with reading, writing, finding the right word (“retrieving”), or naming things
- difficulty speaking (speech may be too fast or too slow, slurred, or in other ways hard to understand)
- repetitive speech or thought processes

Health professionals separate communication difficulties into two major types. A person with brain injury may have problems understanding spoken or written language: these are called *receptive* skills. Or a person may have problems speaking or writing: these are called *expressive* skills.

A person may have trouble speaking if his or her facial or oral muscles are weak and uncoordinated as a result of a brain injury. A listener may have difficulty understanding him or her because of slurred words, halting speech, or a monotone voice. Likewise, the individual the brain injury may be frustrated when he or she cannot understand or be understood.

A speech/language pathologist may be able to help a person with a brain injury overcome these communication problems, improving his or her interpersonal relationships and ability to return to work.

Behavioral and Psychosocial Changes

A person with a brain injury may exhibit unusual behavioral changes: He or she may become easily frustrated and have difficulty controlling verbal and physical aggression; may become short-tempered and lash out inappropriately; or may withdraw and avoid activities. Individuals with brain injuries and their families often say that such behaviors are the most challenging barrier to recovery, even years after the injury.

A person with a brain injury may also have difficulty establishing or maintaining an intimate or sexual relationship. Such a person may have no interest in sexual activity, or want to engage in sexual activity but have trouble with intimacy. He or she may become self-absorbed, focused on his or her own needs, and unable to be a giving partner.

Other common behavioral changes following a brain injury include:

- wide emotional swings
- increased impulsivity
- hurting oneself (head banging, picking, biting oneself)
- increased physical activity, hyperactivity, or insomnia
- excessive drowsiness during the day
- immature and self-centered behavior

- decreased sensitivity to others
- difficulties with self-management and self-regulation
- sadness or depressed mood, with or without suicidal or self-destructive thoughts
- increased anxiety

These dramatic changes in ability to relate to others can have devastating effects on people with brain injuries, their partners, and their families. Individual or couples therapy is often needed to address these issues, as is education and structured guidance.

Changes in Physical, Motor, and Sensory Abilities

A brain injury can affect a person’s physical, sensory, and motor abilities. These effects vary depending on the severity, type, and location of the brain injury. Changes that could occur include:

Physical Changes

- changes in weight, body temperature, appetite
- headache or other pain
- seizures

Motor Changes

- loss of bowel or bladder control (incontinence)
- coordination and balance problems
- inability to coordinate muscle movements
- weakness in any or all limbs
- too much or too little muscle tone
- decreased endurance, more easily fatigued
- choking or swallowing problems
- decreased gag reflex
- difficulty speaking clearly and fully

Sensory Changes

Sight

- weakness of eye muscles, double vision
- blurred vision
- impaired depth perception
- increased light sensitivity

Hearing

- loss of hearing or deafness
- ringing in one or both ears (tinnitus)
- increased sensitivity to sound

Smell

- loss or decreased sense of smell (anosmia)
- perception of smells without a source

Taste

- loss or decreased sense of taste

Touch

- increased sensitivity to touch
- impaired or reduced sense of touch

Early Recovery and How You Can Help*

By Denise Stelpflug, MS, CCC-SLP

Family, caregivers, and friends of a person with a brain injury are important members of the treatment and rehabilitation team. They know the individual's emotional and physical needs and can participate in the recovery process.

They can help with recovery by being mindful of the recovering person's:

- Atmosphere/environment
- Communication skills
- Cognitive and behavioral skills

Atmosphere/Environment

The right environment can enhance recovery. Some suggestions are:

- Promote an enriching (not overwhelming) atmosphere.
- Provide a consistent schedule, (same times for morning routine, etc).
- Arrange living quarters for easy access to areas used daily, (e.g., bed, dresser, closet, and bathroom). Keep regularly used items within easy reach.
- Make sure living quarters allow for safe and easy mobility. Keep pathways clear of obstructions and remove throw rugs (or insert non-stop backing so they don't slip).
- Keep lights neither too light nor too dark, especially in hallways and stairways.
- Display familiar pictures of family, friends, and pets.
- Use familiar blankets, bedspread, furniture, and so on.
- Vary audio stimulation with TV, radio, short stories, conversation—but provide only one at a time.
- Vary visual stimulation by looking outside, examining pictures or reading materials, playing games.
- Go outside and get a breath of fresh air.
- Allow only one or two people in the room at a time. Too many people can be overwhelming.

- Speak with minimal or no background noise. Other sounds (such as water running, the TV or radio, background conversation, airplanes, a dog barking) can be very distracting.
- Speak of familiar names and places; talk of shared interests and experiences.
- Converse when the individual is awake and alert, not tired.
- Encourage attempts at communication. Compliment successes.

If a person has had *too much stimulation*, he or she may become...

- ...suddenly fatigued, and his or her alertness/attention may decrease.
- ...sleepy, and close his or her eyes.
- ...agitated or combative.
- ...upset, confused, and/or tearful.
- ...frightened, and escape the situation altogether.

Learn what makes a person frustrated or overwhelmed, and recognize the signs that it is happening. When it does, remove the individual from the situation or minimize distractions in the environment.

Communication Skills

Communication is the exchange of information. It involves speaking, listening, reading, writing, and gesturing. Communication may be made easier by following these suggestions:

When speaking:

- Communicate in a calm, relaxed manner. Avoid talking too loudly, too softly, or as if speaking to a child. Talk at the person's age level.
- Talk in close proximity, in the same room.
- Speak slowly. Say one sentence, and then pause. Avoid stringing lots of sentences together. If needed, use pauses within sentences.
- Be aware of how much information the person can process. Sometimes a two-to-four-word sentence is all he or she can process at one time.
- Use visual aids (such as objects or pictures) when speaking. You can write down the message in addition to saying it if this seems to help.
- Emphasize the words that carry most meaning.
- Ask simple questions: 'Where is __?' or ask questions with yes or no answers.
- Give simple directions: 'Point to __', 'Show me __'.
- Ask positive questions: 'Do you want __?' instead of 'Don't you want __?'
- Ask questions providing simple choices: 'Would you like __ or __?'
- Use gestures and facial expressions to accompany messages. Body language tells a lot!
- Use traditional and appropriate greetings to start and end conversations.

- Be careful with humor and irony. A person with a brain injury may not be able to detect changes in your tone of voice and may interpret messages literally (e.g., “I’ll be back in a minute,” means just that).

When listening:

- Pick a quiet place to talk, with minimal background noise.
- Determine the general topic of conversation and give your undivided attention.
- Allow time for the individual to respond. Responding to a question may take time.
- Allow the individual to retrieve a word, yet make sure he or she doesn’t get frustrated. Successful communication should be rewarding.
- Establish preferences:

Does the speaker want you to guess what he or she is saying? Finish the sentence?

Does he or she want you to interpret for guests? Order food in a restaurant?

- Determine the strategies to use if you have a communication breakdown. If you cannot understand the individual, try some of the following:
- Agree on a signal when you don’t understand.
- Tell the speaker which part of conversation is not understood.
- Ask the speaker to repeat the misunderstood words.
- Repeat part of the sentence that you understood.
- Ask the speaker to say it in a different way, use alternative words, or describe it.
- Ask him or her to write the word or words; point to a picture, word, or object; or gesture.

Behavioral Issues

- Be prepared for off-topic, inaccurate use of language, and even some swearing. Such responses are common for individuals with recent or severe brain injuries. Accept this without amusement, anger, or emotion. Help the person by providing the appropriate words.
- Reward or praise appropriate behavior and language.
- If the same behaviors, words, or sentences are repeated several times, direct the person to another activity.
- A person with a brain injury may have trouble controlling his or her emotions. He or she may laugh or cry easily. Suggest another activity until emotions are calmed or more controlled.
- Be aware that a person with a brain injury may only be able to concentrate for a few minutes. Provide breaks.
- Help the person orient himself or herself by posting a calendar, a daily schedule, and a sign describing where he or she is.

In general, DO NOT:

- Put the individual on display or force him or her to speak. This makes communication more difficult.
- Assume that a person's inability to express him or herself means that he or she has lost intelligence or knowledge.
- Make fun of inaccurate or mispronounced words. The individual is already trying very hard to communicate.
- Talk for the individual unless it is necessary.
- Laugh when the situation is not funny. Laugh with the individual when it is appropriate.
- Scold or join untrue statements. For example, the individual may feel he or she is in jail. Say "You may think you are in jail, but you are in the hospital right now."
- Treat the person like a baby.
- Accuse the individual of being careless if he or she spills a drink, drops something, or becomes incontinent. Most likely he or she is not doing these things on purpose.
- Overload the individual with false positives, like "You'll get better in no time."
- Tease the individual if he or she cannot perform a task, even if you saw him or her perform the task previously. He or she is most likely trying hard, but inconsistent performance is common.
- Argue. Arguments are emotional and take a lot of energy. Discuss issues; accept and agree on differences.

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Chapter 5: **Community Living: Finding Resources**

Continuing Support	Family and community	Education in physical and psychological changes and how families can help Programs, agencies, and support services that assist patients and their families
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- Community Outpatient Programs
- Residential Options and Support Services
- Terms to Know
- Finding Resources in Your Community
- Entering or Reentering the Workplace

Community Outpatient Programs

Outpatient refers to any program where the patient does not stay the night. Such programs may include:

- **Day Treatment:** These short-term, intensive programs are designed to improve skills needed for daily life, address psychological and behavioral problems, and prepare a person to return to the community and to work. A person in day treatment usually participates in two to four types of therapy, three to five times a week.
- **Education:** The role of education depends on a person's age. Students under age 22 who have not graduated from high school may be eligible for special education services. Community colleges, four-year colleges and universities, and trade or vocational schools often have disability-support specialists who can help a person with brain injury get access to the right accommodations and services.
- **Home Therapy:** Patients may receive physical, occupational, and speech therapy in their homes.
- **Vocational Rehabilitation:** These training services and supports aim to help individuals go back to work at the highest possible level. **Daily Living and Recreation Programs:** These programs help people with brain injuries develop basic functional skills, meet their basic needs, and have fun. Individuals attend during the day and return home in the evening.
- **Respite Care:** The primary caregiver of a person with disabilities needs relief from time to time. In those instances a respite worker can take care of the injured person for a few hours to a few days.
- **Support Groups:** Support groups are established by families of persons with brain injury or by individuals with brain injuries themselves. Members discuss and learn to cope with common problems.
- **Clubhouse:** A place for people to rebuild their lives. Participants are called members, not patients, and the focus is on their strengths, not their injuries.

They engage in clerical, data-input, or meal-preparation tasks, or in reaching out to their fellow members. Members may also receive help in securing housing, advancing their educations, learning self-care, and securing government benefits.

- **Supported Employment:** Supported employment services range from occasional reminders from a coworker to a job coach who helps a person with disabilities learn job skills and routines. Such services are often essential for people with brain injury who want to find and maintain employment. The more costly supported employment services, such as job coaching, are usually required only until the person with brain injury learns the job routine. The job coach can then gradually withdraw in favor of natural supports, such as a written list of reminders.

Residential Options and Support Services

- **Previous Residence:** Many people can return home following a brain injury. Some can live independently, while others may live with their family and receive home health support.
- **Independent Living Centers:** Such centers offer a variety of services to help people with disabilities retain their independence, including peer support, information and resources, advocacy, and skills training. People with disabilities can be both employees and volunteers at these centers.
- **Adult Family Homes:** A place where three to four unrelated adults live and receive care. Each person can receive up to seven hours of nursing care and services a week.
- **Community-Based Residential Facilities:** Facilities where unrelated adults live and receive care, treatment, and support services up to 24 hours a day. They can include group homes, adult family or foster homes, and supported or supervised living.
- **Family Support Services:** Services designed to help a family stay together and cope when a family member has a disability, including special classes, home nursing care, family counseling, crisis support, and respite care.
- **Home Health Care:** A program or an organization that sends health aides, part-time and intermittent skilled nursing care, and other therapeutic services to patients' homes.
- **Intermediate Care Facility (ICF):** An institution that provides a bed, meals, and skilled nursing care for people who have disabilities but do not need the level of care offered in a hospital. Medicaid coverage for people living in ICFs is similar to that for people living in skilled nursing facilities. ICFs must meet state standards in order to receive payments from Medicaid and Medicare.
- **Long-Term Care:** A range of services provided for extended periods of time at home, in the community, or in a skilled nursing facility, including health care and social supports for people with long-term disabilities.
- **Residential Care Apartment Complexes (Assisted Living Facilities):** A place where adults reside in independent apartments, each with an individual, lockable entrance, a kitchen, a bathroom, and sleeping and living areas.

Such facilities provide up to 28 hours a week of support services, including personal and nursing services.

- **Skilled Nursing Facility (Nursing Home):** A residential facility that provides 24-hour services, including room and board, for people with mental or physical disabilities. Nursing facilities are suitable for individuals who require more than seven hours a week of nursing care.

Terms to Know

Advance Directive

A document people create to explain what type of health care they would and would not accept if they were to become seriously ill. A directive goes into effect when the individual can no longer think clearly or tell people what health care he or she wants. Advance directives often indicate medications to which the person is allergic, treatments the person does not want, and treatments that have been effective in the past.

Advocate

An individual or agency chosen to serve the best interests of a person with a brain injury.

- An advocate can help deal with legal or ethical issues and may pursue funding or services on behalf of the injured person.
- Every person disabled by a brain injury has the right to seek the assistance of an advocate.
- Legal representation and advocacy services may be obtained from protection and advocacy agencies. Such agencies guard against abuse and neglect, advocate for the basic rights of individuals in institutions, and oversee governmental agencies that provide housing, treatment, and education.

Client Rights

A guarantee, expressed in writing, of the basic rights of people in treatment programs. Staff members must adhere to these rights in their facilities. A violation of these rights could be considered unlawful and serve as grounds for a lawsuit.

Client rights include:

- personal rights (for example, the right to be treated with dignity and respect and to live in a safe and clean environment)
- treatment rights (for example, the right to receive prompt and adequate treatment in the least restrictive manner)
- communication and privacy rights (for example, the right to have visitors, to use the telephone, and to have privacy)
- medical record privacy rights

Licensure and Credentials

Rehabilitation and community facilities are licensed by their states and accredited by such organizations as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or the Commission on Accreditation of Rehabilitation Facilities (CARF). The Rehabilitation Accreditation Commission sets national standards for rehabilitation and community facilities.

Competency or Capacity

Only a court can rule whether or not a person is able to make informed choices about his or her living situation, finances, or health care. The judge's ruling concerning an individual's competence is based on evidence presented during a hearing. People whom the judge deems unable to make informed choices are called "incompetent" or "incapacitated."

Consumer-Directed Services

A method of funding and delivering health care and community supports that allows people to choose what services they want, who will provide them, and where they will be provided. Used by a private health insurance company, the term usually means that an individual may seek services from a doctor not in the insurance plan or network by paying an additional fee.

Guardian or Conservator

A person or an agency authorized by a court to make decisions for another person. If a judge has clear proof that someone cannot make decisions because of a disability, that judge can ask a guardian to make them for that individual.

Power of Attorney

A legal document authorizing one person or agent to manage all or parts of another's personal or financial affairs.

- Decisions about whether to give up some or all rights, who receives the power of attorney, and when or for how long the power is granted are made *by the individual with a disability, not by a court.*
- The individual with a brain injury decides when a power of attorney is needed. Because power of attorney can be taken away or canceled by the individual, power of attorney is not recommended for persons whose competency is being determined.

A *durable* power of attorney is one that persists even when the person who granted it is no longer mentally or physically able to make decisions. It is often used to give a person or agency the power to make medical decisions for someone with disabilities, using that person's money to pay his or her expenses. Nursing homes or service providers are often given durable power of attorney to handle money and other decisions for the people with disabilities they serve.

Finding Resources in Your Community

- Contact your local Brain Injury Association affiliate (1-800-444-6443) or go to <http://www.biausa.org>. BIA affiliates may have information on residential placement, financial help, support groups, day programs, recreational programs, and vocational programs.
- Call your local Human Services Department or the equivalent. Ask for the intake department. Ask about the availability and eligibility requirements of community programs, waivers, and financial supports.
- Ask the rehabilitation social worker or discharge planner working with your family for resources in your area.
- Contact your local Independent Living Center to ask about resources, peer

support groups, advocacy information, and skills training.

- Check to see if you have a resource number (such as 211) in your state or region. If so, call for local resources.

In addition to local and state programs, these sources of information can help determine whether any of the following national programs are appropriate for you:

Medicaid or Medical Assistance

A joint federal and state program that provides health care for people with very limited incomes and resources. Medicaid is often the only health insurance plan for people with disabilities and limited incomes. Federal regulation stipulates that all states must provide coverage for certain basic health care needs, such as care in an institution. States can also provide voluntary services, such as long-term community-based care.

Every state has made different choices about what voluntary services to provide. Every state also has different rules about who qualifies for Medicaid and how much support an individual can receive. In many states, people who qualify for supplemental security income (SSI) automatically qualify for Medicaid. However, an individual does not need to qualify for SSI in order to receive Medicaid benefits.

For information about your state's Medicaid program, go to:
<http://www.cms.hhs.gov/medicaid>.

Medicaid Home- and Community-Based Services Waiver (1915c(b) waiver)

Generally, when Medicaid covers a service, it must cover the service on an equal basis for everyone in the state with similar needs. A waiver allows a state to ignore this rule and some others. It may allow a state to fund services in the community for a limited group of people who would normally have to receive them in an institution. For example, a state could cover a service only for people with certain disabilities, limit coverage to certain cities or regions, limit coverage to 10 people even if 50 people needed it, limit the amount of money it spent on any one person, or waive income rules to make more people eligible.

For information on your state's Medicaid waivers, go to: <http://www.cms.hhs.gov/medicaid/waivers> or <http://www.hcbs.org>.

Medicaid Buy-In

A program that allows working people with disabilities and high medical expenses to buy Medicaid coverage even if they earn too much to qualify under ordinary rules. A person is not required to be receiving supplemental security income (SSI) in order to be eligible for a Medicaid buy-in program. Not all states allow a Medicaid buy-in, and each state sets its own eligibility rules.

For information on whether your state offers a buy-in, go to: http://www.cms.hhs.gov/TWWIA/07_BuyIn.asp.

Medicare

Medicare is the national health insurance program covering all Social Security recipients either over 65 years of age or permanently disabled. Medicare is not a welfare program. Medicare is administered by the federal government and should not be confused with Medicaid, which is administered by the state government.

Medicare benefits are the same for beneficiaries in all states. Coverage is similar to that provided by private insurance companies. Medicare pays a portion of the cost of medical care and usually charges a co-payment or deductible. Part of the program's cost is met with payroll taxes on employers and employees. Another part is met with monthly payments from people receiving Medicare, as well as the state and federal governments.

More information on Medicare is available at: <http://www.cms.hhs.gov/medicare> or <http://www.medicare.gov>.

Representative Payee

A person or agency allowed to accept Social Security payments for another. If a person's disability makes him or her unable to manage Social Security benefits, a judge can appoint a representative payee. Children under 18 must receive their benefits through a representative payee. A representative payee must make decisions in the best interest of the person with the disability. Representative payees also must make sure the person has enough food, clothing, shelter, medical care, and personal comfort items. Representative payees can spend Social Security money only on supports for the person with the disability, and must keep records of how the money is spent.

Supplemental Security Income (SSI)

A federal program that provides money to people with low incomes at least 65 years old or with severe disabilities. The funds help pay for food, clothing, and shelter.

For more information, go to:

<http://www.ssa.gov/notices/supplemental-security-income>.

Social Security Disability Income (SSDI)

A federal program for people who have worked for several years and who become severely disabled and unable to return to work for at least a year. To qualify, a person must have almost no resources or savings. The program gives the person, or family members who rely on that person's income, money for basic food, clothing, and shelter. The money is provided until the person dies or is able to return to work.

For more information, go to: <http://www.ssa.gov/disability>.

Ticket to Work and Work Force Investment Act

A federal law passed in 1999 to help people receiving Social Security disability benefits get the supports they need to return to work. For example, the law gives states the option to allow people with disabilities to buy Medicaid coverage even if after they return to work they make too much money to qualify for under normal rules. The law also helps people receiving SSDI get free job training and placement from approved employment agencies.

For more information about the Ticket to Work program, go to:

http://www.ssa.gov/work/Ticket/ticket_info.html.

Entering or Re-entering the Work Place After Brain Injury* by Carolyn Rocchio

Returning to work or finding that first job after school can be very challenging for individuals with brain injuries. Having a job is not only important for economic stability, being employed increases self-worth and fulfillment. Russian artist Marc Chagall wrote, “Work isn’t to make money; you work to justify life.”

People with brain injuries face great challenges to regaining their places in society. Not only must they cope with the loss of the person they were before the injury (and the impact of that loss on their self-esteem), but they must also adjust to a new and changing personality with limitations poorly understood by those around them. This alone is enough to create depression and lack of motivation to get out and keep trying. Nevertheless, everyone needs a reason to get out of bed and contribute to society.

Challenges to reentering the workforce

Beyond depression and a sense of loss, people who have suffered a brain injury have difficulty reentering the workforce for a variety of reasons. To begin with the general public—employers included—has little understanding about how traumatic injury harms the brain, particularly when a person looks the same. As a result, both employee and employer may have unreasonably high expectations. Brain injury can impair memory, alertness, attention, problem-solving skills, organization skills, judgment, visual perception, and language processing, all of which are used in the workplace. Before an injury, employer and employee could take these important capabilities for granted: the employee could easily accommodate distractions, new job responsibilities, and disruptions. But following a brain injury even the smallest interruption can make it hard for a person to return to a task. It may even be impossible for some to continue without the assistance of a job coach.

Of these various impairments, problems with thinking and learning (cognitive deficits) are by far the most persistent and troublesome consequences of brain injury. Without rehabilitation to develop ways to compensate for deficits, many people with brain injuries will find returning to their previous job out of the question and preparing for new employment equally challenging. Further, cognitive deficits often get worse as a person tires, and in the workplace people are normally expected to put in an eight-hour day. Even a person who wishes to work part-time may be unable to compete in the employment market if he or she cannot find a job that provides rest periods.

Another challenge comes from employers’ normal expectation that coworkers “get along” with one another. Many individuals with brain injury have lifelong problems with interpersonal skills, and difficulty relating to coworkers acceptably. Emotional instability and mood swings create a hardship for coworkers, particularly ones who knew the employee before the injury and are puzzled about the changes. Inappropriate behavior, particularly inappropriate sexual behavior, can be a real problem. In general, employers cannot tolerate decreased social judgment.

Individuals with motor impairment may experience less difficulty in seeking employment due to the public’s better understanding of physical disabilities. Again, though, employer and employee may both overlook cognitive deficits, resulting in overly high expectations.

Overcoming challenges and going to work

Despite these challenges, most people *can* work after a brain injury. But it takes time and effort to find a niche where a person can feel needed and proud of a job well done.

First, family involvement is critical, especially to understanding how the injury has affected a person's cognition and behavior. It is particularly important that the individual with a brain injury and his or her family confer with a neuropsychologist to understand fully what abilities have been preserved, and how deficits may limit choices in the future. Many rehabilitation facilities (particularly transitional or community reentry programs) help people with brains assess their employment choices and either prepare to reenter the workforce or, in the case of graduating students, plan for their first jobs.

For students, under the Individuals with Disabilities Education Act (IDEA), starting at age 14 youngsters with disabilities in public schools should have a transition plan under development, readying them for life after graduation. For some this may mean higher education, while for others the focus may be on preparing to enter the workforce.

For older people, the Rehabilitation Act provides for Vocational Rehabilitation (VR) services in every state. Although the names vary from place to place, the services offered are the same:

- training (trade education, technical or business school, college, or on-the-job training)
- physical aids (such as hearing aids, braces, or medical services)
- assistive technology (computers or other devices and accommodations to a disability)
- tools or equipment to perform your job
- transportation
- job-placement assistance (leads, help with filling out applications, and interviewing practice)

To be eligible for VR services, a person must have a disability that impedes employment, and VR intervention should offer a reasonable chance for successful reentry into the workforce.

When a person with a brain injury seeks assistance from VR, he or she should take a family member or friend to help with the process of intake interviews, appointments for evaluations, and the development of the Individual Written Rehabilitation Plan (IWRP), which outlines goals mutually agreed upon by the counselors and the client with a disability. This is particularly important because if a client fails to keep appointments or keep up his or her responsibilities, VR will terminate the case.

Some people are concerned about a loss of Social Security benefits if they return to work. Social Security does offer a plan, however, under which an individual can work for a period of nine consecutive months (a trial period) without loss of benefits. Arrangements can also be made to continue Medicare coverage even

when Social Security disability benefits are terminated (see *Ticket to Work*, p. XX).

Ultimately, for some entering or returning to the workforce may not be an option. However, even when people cannot return to employment many families have creatively developed cottage industries, incorporated individuals into family businesses, or arranged for satisfying volunteer opportunities. Goodwill Industries, Easter Seals, Catholic Community Charities, Jewish Family Services, and many sheltered workshops throughout the country offer opportunities for individuals with disabilities to use their skills in a productive manner. The most important thing is to give each individual the chance to be a productive member of society

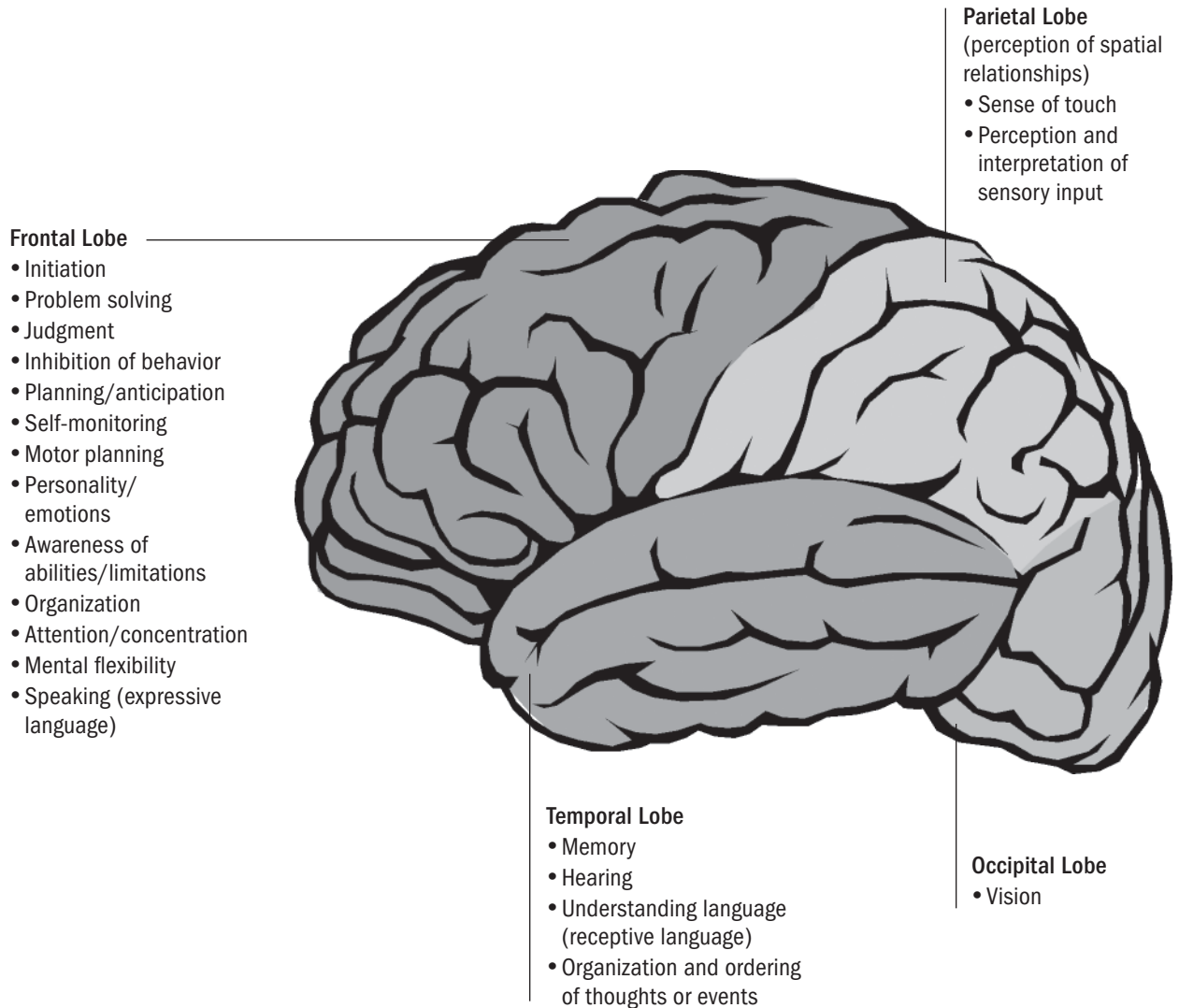
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For more information, call the Brain Injury Association of America's National Brain Injury Information Center at 1-800-444-6443 or visit www.biausa.org



Appendix 1: **Brain-to-Behavior Relationships**

Each lobe of the brain controls different functions or behaviors, as shown in the diagram that follows.



Appendix 2: **Acquired Brain Injury**

Although a person with an acquired brain injury (ABI) differs in many ways from a person with TBI, many professionals agree that treatments that work for a person with TBI can also often help individuals who experience an ABI.

Persons with acquired brain injury or their families may hear the following diagnoses from health professionals:

Stroke or Cerebral Vascular Accident (CVA): A stroke or CVA is a disruption of blood flow in the brain. It may be caused by a TBI. Other causes of CVA are aneurysms (weakening of the blood vessels, causing a pouch-like effect), arteriovenous malformations (veins appear to connect to arteries), and intracerebral hemorrhage (bleeding within the brain, often caused by severe high blood pressure, or *hypertension*). Doctors often grade the severity of a CVA on a scale from I (mild, transient) to V (resulting in a coma).

Anoxic Injury: Damage to the brain due to lack of oxygen or reduced flow of oxygen. This type of injury can occur from trauma as well as other events such as heart failure, near drowning, or electrocution, which can alter oxygen flow to the brain.

Encephalopathy: *Encephalopathy* is a general term used to describe brain injury. It includes damage to the brain caused by infections (for example, meningitis and encephalitis), tumors, and metabolic disorders (that is, chemical changes to the brain).

Brain disorders that get worse over time, such as Alzheimer's or Parkinson's disease, are usually not considered acquired brain injuries.

Appendix 3: Terminology Used to Describe Disorders of Consciousness

- Coma
- Vegetative State
- Minimally Conscious State
- Evaluating Disorders of Consciousness

Coma

A *coma* is a brain state that can occur in response to head trauma or as the result of a sudden or longstanding medical condition. Coma lasts no more than 2 to 4 weeks.

A person in a coma lacks any purposeful response to his or her surroundings, although reflexive behaviors may still occur. The person cannot be aroused. Medical tests such as electroencephalograms (EEGs) reveal that the patient has no sleep/wake cycles. The eyes remain closed, even when painful stimulation is applied.

Vegetative State

A *vegetative state* (VS) is a condition that sometimes follows emergence from coma. An individual in a VS shows no behavioral evidence of self and no awareness of the environment. As a person emerges from coma into a VS, however, his or her eyes open, either on their own or in response to stimulation. Around the same time the vegetative functions of the body (for example, breathing and heart rate) begin to work on their own again. A VS may be temporary or permanent.

Minimally Conscious State

A *minimally conscious state* (MCS) is a condition in which the person shows minimal but definite behavioral evidence of self-awareness or awareness of the environment. MCS is usually a temporary condition, but it may become permanent.

Persons in a MCS, unlike those in a VS, may follow simple commands, utter single words or short phrases, express “yes/no” responses through speech or gesture (sometimes incorrectly), follow people or objects with their eyes, grasp and hold objects, or demonstrate appropriate emotional responses such as smiling or crying.

Some persons in MCS show only one or two of these behaviors, while others exhibit all of them. It may be difficult to distinguish persons in MCS from those in VS because these behaviors typically occur inconsistently. It is often necessary for professionals to evaluate the person more than once to detect behavioral signs of awareness.

Persons are not considered to be in a MCS if they are able to communicate consistently (at least “yes” and “no”) or can demonstrate the ability to use common objects, such as a cup or brush.

Evaluating Disorders of Consciousness

Rancho Los Amigos Levels of Cognitive Functioning

The Rancho Los Amigos Levels of Cognitive Functioning (RLAs) measure and track an individual's progress in the period immediately following a brain injury. They provide a basis for choosing one treatment or another.

The RLA scale designates eight levels of functioning, determined on the basis of behavioral observations. The lower the number, the worse the cognitive dysfunction. The goal of treatment is to help the patient move to a higher level on the scale.

I. No Response

The individual appears to be in a deep sleep and is unresponsive to any stimuli.

II. Generalized Response

The individual reacts inconsistently and non-purposefully to stimuli. Responses are limited in nature and are often the same, regardless of stimuli presented. Responses may include gross motor movements, vocalization, and physiologic changes. Response time is likely to be delayed. Deep pain evokes the earliest response.

III. Localized Response

The individual responds specifically but inconsistently to a direct stimulus. Responses are directly related to the type of stimulus presented. For example, an individual's head will turn toward a sound, or his or her eyes will focus on an object when presented. The individual may follow simple commands and may respond better to some people (for example, family and friends) than to others.

IV. Confused-Agitated

The individual is in a heightened state of activity, with a severely decreased ability to process information. Behavior is not related to the immediate environment. Hostility and attempts to climb out of bed or remove restraints are common. The individual requires maximum assistance to perform self-care. He or she may sit, reach, and walk, but will not necessarily perform these activities upon request

V. Confused-Inappropriate

The individual appears alert and responds to simple commands fairly consistently. Agitation that is out of proportion with, but directly related to, stimuli may be evident. Lack of external structure results in random or non-purposeful responses. Inappropriate verbalizations and high distractibility are common. Memory is severely impaired, but the individual may feed himself or herself with supervision, and requires only assistance for self-care activities.

VI. Confused-Appropriate

The individual shows goal-directed behavior but is dependent on external input for direction. Response to discomfort is appropriate. Responses are incorrect because of memory problems, but are appropriate to the situation. The individual follows simple commands consistently, and carry-over for re-learned activities is evident. Orientation is inconsistent, but awareness of self, family, and basic needs is increased.

VII. Automatic-Appropriate

The individual appears to act appropriately in the hospital and at home and goes through daily routine automatically, but is robotlike and has poor recall of activities performed. The individual has absent-to-minimal confusion and lacks insight. The individual frequently demonstrates poor judgment and problem-solving ability and expresses unrealistic future plans. With structure, the individual is able to initiate tasks or social and recreational activities.

VII. Purposeful-Appropriate

The individual is alert and oriented, able to recall and integrate past and recent events, and is aware of and responsive to the environment. Independence in the home and community has returned. Carryover for new learning is present, and the individual has no need for supervision once activities have been learned. Social, emotional, and cognitive abilities may be less than they were prior to injury.

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The Glasgow Coma Scale

The Glasgow Coma Scale (GCS) is used to assess level of consciousness during the first two weeks or so after an injury. The GCS is often used at the scene of an accident, in the emergency room, or in an acute care setting. It rates motor movement, eye opening, and verbal response.

Glasgow Coma Scale

<i>Best Motor Response (Arms and Legs)</i>	<i>Eye Opening</i>	<i>Best Verbal Response</i>
6 = follows commands 5 = localizes to pain 4 = withdrawal to pain 3 = decorticate* 2 = decerebrate* 1 = no response	4 = spontaneously 3 = to voice 2 = to pain 1 = no response	5 = oriented and converses 4 = disoriented and converses 3 = inappropriate words 2 = incomprehensible sounds 1 = no response
* A decorticate reflex is one that causes bending to the arms and straightening of the legs		
* A decerebrate reflex is one that that causes straightening of the arms and legs.		
GCS Scores range from a high of 15 to a low of 3. The higher the score, the lower the degree of impairment. Persons are considered to have experienced a mild brain injury when their score is 13 to 15. A score of 9 to 12 reflects a moderate brain injury. A score of 8 or less reflects a severe brain injury. Teasdale G, and Jennett B. Assessment of coma and impaired consciousness. Lancet. 1974 Jul 13; 2(7872): 81–84.		

Other Scales

The GCS is useful for monitoring progress during the week or so following an acute injury, but is not sensitive enough to detect subtle but important changes that commonly occur afterward. Other scales have been designed to detect subtle behavioral changes that may be important for establishing diagnosis and prognosis. Some of these scales are listed below.

Scale	Reference
Coma-Near Coma Scale	Rappaport M, Dougherty AM, and Kelting DL. Evaluation of coma and vegetative states. <i>Arch Phys Med Rehabil.</i> 1992; 73:628.
Coma Recovery Scale- Revised	Giacino JT, Kalmar K, and Whyte J. The JFK Coma Recovery Scale-Revised: Measurement characteristics and diagnostic utility. <i>Arch Phys Med Rehabil.</i> 2004; 85: 2020–2029.
Sensory Modality Assessment Rehabilitation Technique	Gill-Thwaites H, and Munday R. The Sensory Modality Assessment and Rehabilitation Technique (SMART). A valid and reliable assessment for vegetative and minimally conscious state patients. <i>Brain Injury.</i> 2004; 18:1255–1269
Wessex Head Injury Matrix	Horn S, Watson M, Wilson BA, and McLellan DL. The development of new techniques in the assessment and monitoring of recovery from severe head injury: a preliminary report and case history. <i>Brain Injury.</i> 1992; 6(4):321–325.
Western Neurosensory Stimulation Profile	Ansell BJ, and Keenan JE. The Western Neuro Sensory Stimulation Profile: A tool for assessing slow-to-recover head-injured patients. <i>Arch Phys Med Rehabil.</i> 1989; 70: 104.

References

The coma recovery explanations were derived from *The National Directory of Brain Injury Rehabilitation Services* (McLean, VA: Brain Injury Association of America, 2005). Also available as a CD-ROM.

J. Giacino and J. Whyte, “The vegetative and minimally conscious states: Current knowledge and remaining questions,” *Journal of Head Trauma Rehabilitation* 20, no. 1 (2005), 30–50.

Appendix 4: **References**

References for Chapter 1

The explanations of the normal brain, brain-behavior relationships, and definitions were adapted from Marilyn Lash et. al., *Training Manual for Certified Brain Injury Specialists (CBIS)*, 3rd ed. (McLean, VA: BIAA, 2004).

National statistics on brain injury are reprinted from the Centers for Disease Control and Prevention, “Facts about Traumatic Brain Injury” (CDC: Atlanta, GA, 2004), http://www.cdc.gov/ncipc/tbi/FactSheets/Facts_About_TBI.pdf.

The definition of traumatic brain injury is taken from the Defense and Veterans Brain Injury Center’s Fact Sheet (Washington, DC: U.S. Department of Defense, 2006), http://www.dvbic.org/pdfs/DVBIC_Fact_Sheet_2006.pdf.

References for Chapter 2 and 3

The medical definitions of brain injury and the information on types of diagnostic tests, the rehabilitation team, and predicting outcomes were adapted from Lash et. al., *Training Manual for Certified Brain Injury Specialists*.

The types of medical treatments were adapted from University of Iowa Hospitals & Clinics, “Acute Brain Injury: A Guide for Family and Friends,” July 2000, <http://www.uihealthcare.com/topics/medicaldepartments/neurosurgery/braininjury/index.html>.

Donald R. Hood, Bonnie Todis, and Ann Glang, *Preparing for Life after High School: The Next Steps* (McLean, VA: BIAA, 2006).

References for Chapter 4

The explanations of the functional changes after brain injury are adapted from Lash et. al., *Training Manual for Certified Brain Injury Specialists*.

References for Chapter 5

E. Prialx, *Legal and Medical Terms and Laws Important to People with Brain Injury* (McLean, VA: BIAA, 2006).

C. Rocchio, “Entering or re-entering the work place after brain injury,” *Family News and Views* 5, no. 4 (1998).

For more information on advocacy resources, contact the Oregon Brain Injury Resource Network at 800-544-5243 or tbi@wou.edu.



Brain Injury Association of America
National Brain Injury Information Center
1-800-444-6443
703-761-0750
www.biausa.org
