Volume Two - Third Edition

Understanding Orain Lnjury

Neurologic Rehabilitation

An Educational Guide for Family & Friends

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Introduction

The human brain is a miraculous and complex organ. It integrates both internal (bodily) and external (environmental) information that allows individuals to think, to feel, and to physically and socially act, react, and interact with each other as individuals or as groups. The brain governs everything from driving a car and anticipating activities of the day, to feeling happy or sad, and managing relationships with friends, family, and employers or business partners. It also regulates vital bodily functions such as heart rate, blood pressure, and respiration.

Injury to the brain may significantly change the course of an individual's life, as well as the lives of those close to them. In many cases, neurologic rehabilitation helps a person achieve the most independent level of functioning following a brain injury. The process of rehabilitation can be slow and full of uncertainties, questions, and frustration. For many, it involves adjusting to a new way of life. For all survivors and their families, a brain injury means facing new challenges.

The purpose of this book is to help the reader understand the nature of brain injury, its consequences, and the social, cognitive and physical barriers facing those recovering from such an injury. This book will help to explain the rehabilitation process including what may be expected from patients recovering from brain injury, and how family members can help during the healing process. This book will also explain the different types of rehabilitation programs available and allow families to discover the benefits of being informed consumers. Family members may share the book's information with those who are unable to read it for themselves.

Health care professionals and the media use a variety of terms to describe injury to the brain. This book reflects many different terms in both conversation and literature used for describing an injury of the brain. Some of the most common terms are brain injury, traumatic brain injury, head trauma, head injury, and neurologic injury. Many terms are also used to describe people who have sustained brain injuries. Survivors, patients, and persons with neurologic impairments are a few of the most frequently used. All of these references are used throughout this book.

The first half of the book includes a description of the usual physical, behavioral and cognitive consequences of a brain injury; and a discussion of the neurologic rehabilitation process including aspects of patient assessment, the development of rehabilitation goals, various approaches to treatment and a discussion of community reentry issues such as vocational retraining and supervised living.

The second half of the book includes information regarding common adjustment issues, frequently asked questions; as well as a section on available community resources and supportive services for survivors and their families.

The reader will hear excerpts from a young man who describes his struggle to put his life back together after a brain injury turned his world upside down. His experiences will help to demonstrate the many emotions and problems encountered by survivors.

While reading and learning about brain injury rehabilitation, questions may arise. Readers may wish to use the blank note pages in the back of the booklet to record thoughts and questions that may later be discussed with health care professionals. Above all, this guide was prepared to provide survivors, families and friends with the knowledge, support, and resources necessary to help face the many challenges ahead.

A Survivor's Story - Ramael Slater

"I was living an exciting life. I was on my way to becoming a successful young man. An actor extraordinaire, an artist, and a perfect grade point average, colleges were looking for me! There wasn't anything I couldn't do. I felt like I was on top of the world. Then one night I fell off. While driving home, my mother and I were struck by a criminal trying to escape from the police in a stolen truck. He hit our car at 113 miles per hour. In one fatal instant, everything I was, and probably could have been, was lost.

It wasn't until a month later, when I woke from my coma, that I found out what happened. My mother died a week after the accident. I felt like I didn't have any purpose in life anymore. Why did my mother die and I live? With a brain injury, there wasn't much I could do but feel pitiful and miserable about myself. I didn't like myself. I just took up space. I was depressed and wished I was dead."

PART I

Understanding the Consequences of Brain Injury

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THE CONSEQUENCES

Many physical, intellectual and behavioral changes can occur after a brain injury. Some of these changes are temporary; others can be long-lasting or permanent. Each individual's potential for recovery is different, and complete recovery to an individual's pre-injury level of functional independence may not be a realistic expectation. The location and severity of the brain injury, the amount of time that has elapsed since the injury and an individual's psychological reaction to the injury can all influence the degree of recovery. Pre-injury personality, learning style, and the nature of an individual's relationships with family and friends can also affect the recovery process.

Because so many factors influence the recovery process following a brain injury, it is difficult to accurately predict which symptoms will occur and how long they will last. What is well known is that the recovery process is gradual and requires patience on the part of family and friends.

The following section describes many of the symptoms a person may experience following a brain injury. After reading it, one will better understand the various physical, cognitive and behavioral changes that can occur following a brain injury. Consider that all of these changes do not necessarily occur in all survivors, but any of these changes may occur to some degree.

Physical Consequences _____

It may be easier to understand the physical impairments that may result from a brain injury rather than the behavioral or cognitive consequences since physical impairments are more easily seen. Just by observation, one may get a general sense of physical limitations and thereby develop certain expectations.

Some of the physical consequences that may occur after a brain injury include impaired coordination and slowness of movement, paralysis, weakness on one or both sides of the body, seizures, sensory problems, problems with vision or perception, and difficulties with speaking or swallowing. Other physical problems may include fatigue, pain, ringing in the ears, headaches, changes in sleeping patterns, as well as loss of hearing, sense of smell, and/or taste. The following section will discuss some of the physical symptoms that may occur following a brain injury.

Loss of Motor Control

Individuals with neurologic impairment may experience weakness of one arm or leg, or weakness of both the arm and leg on one side of the body. This is called hemiparesis. Some patients may be unable to move both legs and both arms. This type of paralysis is referred to as quadriplegia. Poor balance, decreased endurance, slowness of movement, loss of the ability to plan movements of arms, legs, and other body parts, and poor coordination can also occur. Survivors may also experience spasticity or abnormal tone and stiffness in the muscles. Even though their limbs still function, survivors may be unable to properly control their body movements. There may also be problems relating to involuntary movement disorders such as uncontrollable tremors. The nature of motor control disorders varies with the parts of the brain that are injured. In general, most motor control disorders improve to some degree with medical or physical interventions.

Seizures

Following a brain injury, a person may experience seizures. Seizures can occur immediately after the injury or may develop days, weeks, months or even years later. A burst of abnormal electrical activity in the brain causes these seizures. Seizures may be due to reversible or irreversible changes involving the surface of the brain. For example, a reversible factor may include a temporary extreme rise in intracranial pressure, while an irreversible change may include the formation of scar tissue which permanently alters function in a part of the brain.

Various types of seizures can occur. The most common type is a major motor or generalized seizure. With this type of seizure the person's entire body stiffens and then begins to shake involuntarily and is accompanied by an altered state of awareness. A person having a generalized seizure may breathe irregularly, and lose bowel and bladder control. Individuals who have this type of seizure often regain complete awareness on their own after a few minutes, feel confused, and complain of soreness. In some cases, the person may need emergency medical treatment to stop the seizure.

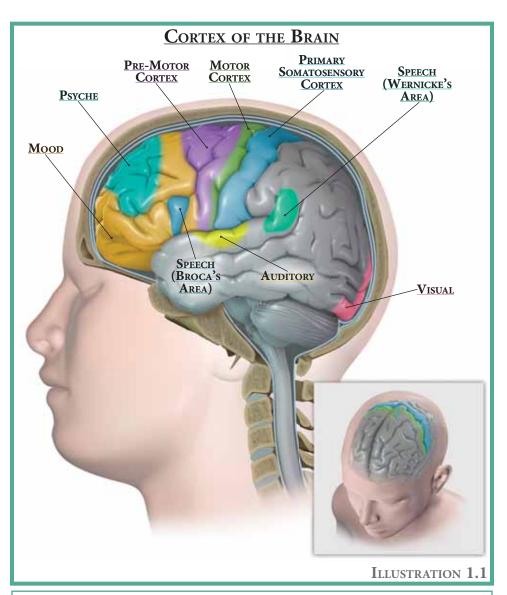
Other types of seizures include focal motor and partial complex seizures. A person having a focal motor seizure can experience odd twitching or jerking movements that may involve the face or limbs on one side of the body. Usually, this type of seizure is brief, and the person remains alert. In a partial complex seizure there is also odd twitching or jerking movements but in addition there is a lapse of concentration and awareness. Often the patient and people close by are not even aware that a seizure has occurred.

Epilepsy is a term that refers to a problem of recurrent seizures. In some cases post-traumatic epilepsy occurs following a brain injury. There are medications known as anticonvulsants available to help prevent and control post-traumatic epilepsy.

Sensory Problems

Following traumatic brain injury, a person's senses – sight, sound, touch, taste, and smell – can be lost or damaged. Changes to the sensory system may involve an increase or decrease in sensitivity or a total loss of any of the senses.

Some people who have sustained a brain injury may become more sensitive to touch, such that even a light gentle touch to a part of the body may evoke a feeling of pain. Others may lose sensation to parts of the body to the extent that portions of the body become numb. Individuals with visual impairment may be unable to see people or objects located on one side of their visual field, experience double vision, or have problems with depth

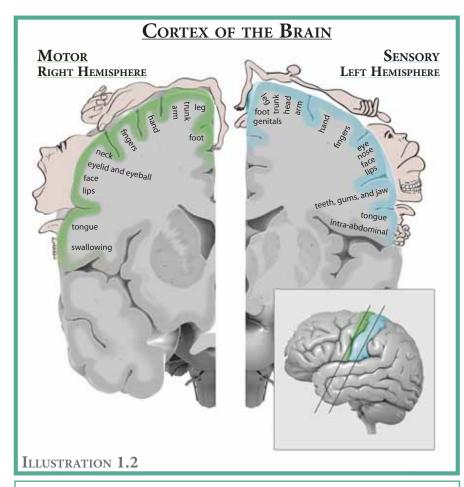


This illustration shows the different sections of the brain and outlines the areas of sensory and motor function, which can be found in the parietal and frontal lobes.

perception. After a brain injury, some individuals may not be able to see or hear as clearly. Loss of smell or taste is also possible. In some cases an individual may lose entirely the sense of hearing in one of their ears. Sense of position might be lost, and these individuals may have difficulty perceiving where their arms and legs are in relation to their bodies and to the space around them.

Impaired Alertness & Fatigue

Fatigue is common in the early stages after brain injury. After an injury, the body needs time to rest, recover, and rebuild its strength. For some individuals, just staying awake, alert, and attentive is an accomplishment. A person who is inattentive and drowsy is sometimes accused of being unmotivated. However, the person may not lack motivation; he or she may sincerely be tired. After a traumatic brain injury the "activating" centers of the brain that normally function to keep an individual awake may become impaired. In some cases these individuals may require medications intended to enhance daytime alertness so they may be more awake to participate in their rehabilitation therapies. Rehabilitation schedules should include adequate rest periods. The decreased alertness and mental fatigue will gradually lessen as an individual recovers.



This cross-section details the areas of the sensory and motor cortex which are responsible for many functional abilities.

Language Disorders

The muscles in the mouth and throat may not function correctly when an injury to the brain damages a cranial nerve – one of the main nerves that controls the muscles in the face. One disorder that may result as a consequence of brain injury is dysarthria. A person with this condition may have difficulty pronouncing words because the oral muscles needed to produce speech are weak or have reduced coordination. Dysarthria is characterized by slurred or slowed speech and, at times, an inability to vocalize. Another disorder, dysphagia, makes the survivor unable to chew and swallow efficiently. A disorder known as aphasia occurs when brain injury results in the inability

of the individual to properly formulate words or sentences and/or to comprehend written or spoken language.

Regulatory Disturbances

After a brain injury, a change in the normal sleep cycle may occur. In the beginning, the night and day sleeping pattern may be reversed. The individual may not be able to sleep through the night and may instead need several shorter rest periods throughout the day. Medications may be helpful in restoring a normal sleep cycle. Changes may also occur in the ability to regulate body temperature as well as other aspects of homeostasis such as blood pressure or heart rate. In some cases there may be excessive retention or loss of body fluids. Signs of excessive fluid retention may include generalized swelling and a low blood sodium level. Fluid retention may result from an excessive secretion of a brain chemical known as an antidiuretic. Reduced secretion of this same chemical may result in excessive loss of fluids, resulting in dehydration. Some individuals with a brain injury may suffer the loss of fluids due to excessive sweating. Many experience a temporary loss of bowel and bladder control due to difficulties with cognition or mental alertness. In some cases, bladder or bowel problems may be due to other causes and may be treatable.

Cognitive Consequences _____

When rehabilitation professionals talk about cognitive abilities, they are referring to how a person thinks and processes information. Memory, attention, organization, planning, and perception are several of the intellectual functions that make up a person's cognitive abilities. Some or all of these functions can be disrupted following a brain injury.

Attention & Concentration

Going about our lives, most are unaware of the ability to pay attention and focus on one task while blocking out all distractions. Sustaining attention requires the mind to block out or inhibit both internal and external distractions. This very complex process is easily disrupted by neurologic damage.

Following a brain injury, a person may have a hard time paying attention to a specific task or thought and may instead jump randomly from thought to thought. The person may be unable to focus on a task without being distracted; even slight distractions can cause confusion. In severe cases, a person's attention span may last only a few seconds. Because attention and concentration are needed before learning can occur, improving these functions is a crucial part of rehabilitation.

Confusion

When patients begin to regain awareness after a brain injury, they are likely to be very disoriented and confused. They may not know the day, week, or year. They may not know where they are or what happened. They may not even recognize family or friends. As survivors begin to react to this disorientation, as well as to other cognitive problems, they may repeatedly ask many simple and searching questions. As they struggle to cope with these difficulties, frustration and more confusion may result. To offset and reduce confusion, individuals may occasionally develop their own explanation of events. This is sometimes referred to as "confabulation." These explanations may not be correct, but often contain bits of reality.

Impaired Planning Ability

The ability to plan, initiate, direct, and monitor one's activities is often referred to as executive functioning. Planning involves many cognitive skills, including memory, learning, judgment, attention, and organization. Because brain injury can affect any of these cognitive areas, a person's ability to plan can also be impaired.

"For the first few months, I tried to hide my real feelings. I always made jokes and tried to look happy. I even tried to feel happy, but that was the hardest thing to pull off. I wanted to believe that my mother was still alive but just hiding somewhere. So, day after day, I kept thinking she would come back. When she didn't I felt worse and worse."

Symptoms of planning impairment are varied. A person with impaired executive functioning may attempt to solve problems in a disorganized manner, have difficulty keeping steps in order when performing tasks, or get stuck on a thought or a particular activity and be unable to stop. Many of these individuals may not know when they perform a task correctly or incorrectly. Others may be unable to understand abstract thoughts and may only be able to interpret information literally.

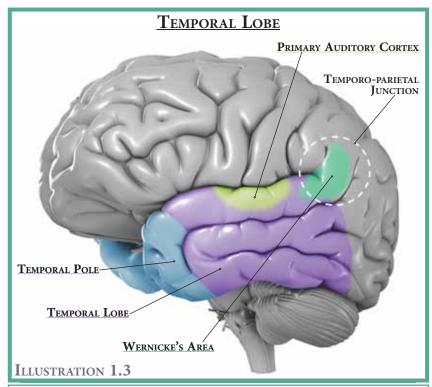
Impaired executive functioning can be long-lasting and devastating to the TBI survivor and his or her family and friends. Severe executive functioning deficits coupled with neurobehavioral deficits often lead to legal entanglement, or inappropriate and costly psychiatric treatment. Without external supports this may result in a vicious cycle, within which no progress can be made until the cycle is broken, and the individual receives appropriate intervention for the neurologic deficit.

Memory Impairment

Memory impairment constitutes a major barrier to learning following a brain injury. This type of impairment results in various abnormalities related to the brain's ability to receive, store, and retrieve pieces of information. In a person with memory impairment, any or all of those components can be affected. Short-term memory (the recall of recent information) is more susceptible to loss than is long-term memory (the recall of past information

collected over many years).

Amnesia is one common type of specific memory loss that may occur after a brain injury. Amnesia can affect a person's ability to learn new information, because it impairs the ability to form new memories for as long as it lasts. Having amnesia can be compared to losing a piece of a jigsaw puzzle; the person with amnesia can only remember some of the events that occurred in the past and cannot put together a complete picture of recent events. A person who is unable to remember events that occurred during a period of time preceding their injury has retrograde amnesia; while someone who is



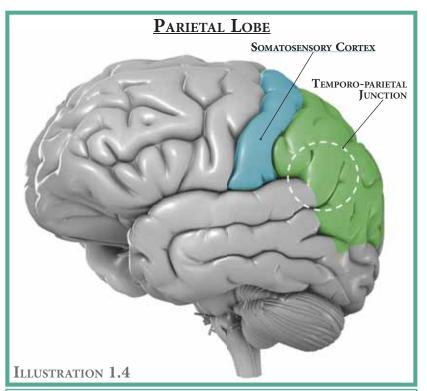
The temporal lobes are portions of the brain primarily related to memory functions and behavioral controls.

unable to recall certain events that have occurred since their injury has anterograde amnesia. Amnesia almost always involves a loss of memory of the details of the traumatic event and is usually permanent.

Memory impairments can be frustrating for everyone involved. For survivors, it can delay recognition of their progress, which, in turn, can cause feelings of stagnation and discouragement. Since memory enables individuals to successfully function from day to day, a main goal of rehabilitation is the improvement of memory function. Techniques to overcome or compensate for memory deficits can bridge all stages of recovery. In many cases, use of adaptive strategies, such as memory notebooks and day timers, can help survivors remember their schedules and other important pieces of information.

Impaired Communication Skills

The ability to communicate is perhaps the most essential element in all human relationships. It involves more than just the power of speech. It requires the understanding of language and the ability to formulate and express thoughts. One or all of these areas can be affected following a brain injury. Individuals who have impairments involving the power of speech may slur their words, speak too slowly, or speak with improper rhythm and pitch. They may also lose the ability to read and write. Some survivors may experience aphasia, a language problem that involves difficulties with comprehension or the expression of spoken or written words. Survivors who have difficulty understanding the spoken or written word may have receptive (fluent) aphasia. Those who have difficulty verbally expressing thoughts, naming objects, or remembering words may have expressive (nonfluent)



The parietal lobe processes the sensations of touch, pressure, temperature, and pain. It helps you to reach, grasp, and know the position of things around you.

aphasia. Some individuals may have components of both expressive and receptive aphasias.

Being unable to communicate can be very frustrating for a person recovering from a brain injury. Patience and continual work to re-establish a functional method of communicating is of vital importance.

Impaired Abstraction & Judgment

Following a brain injury, a person's ability to think abstractly may be impaired. This person may not be able to take a specific object or task and apply or generalize it to another similar

object or situation. Such behavior is referred to as being "stimulus bound" or "concrete" because the person's brain only recognizes and reacts to actual objects in the present environment. These individuals having an impaired ability for abstract reasoning will be unable to interpret common proverbs (such as "a bird in the hand is worth two in the bush" or "don't count your chickens before they hatch"...). In this instance, a friend may say "hit the road," to tell a person with a brain injury that they are leaving. However, the survivor may think the

person is going to actually try to hit the road with a foot or hand because he or she only understands the expression in a literal fashion.

In addition, survivors may be unable to exercise proper judgment. They may be unaware of their problems or may deny them. Without the ability to perceive and judge situations, these individuals may not fully comprehend the consequences of their actions. Impaired judgment, perception, and self-awareness can make decision-making difficult and can jeopardize an individual's safety. For instance, an individual having these difficulties may decide to go for a ride on the bus, but because of memory loss and confusion the person could end up at an unknown street corner with no idea of where to go next.

Finally, following a brain injury a person may have difficulty understanding the complexities of an issue and may have trouble telling the difference between subtle variations. For example, a survivor may think a family member who shows concern is actually displeased or angry. This occurs because the patient cannot tell the difference between constant attention and anger. Being unable to interpret the actions or intentions of others is also common.

Impaired Ability to Apply Newly Learned Skills

Individuals who have memory impairments will also have difficulties learning new information or skills. A person who has sustained a brain injury, may recall old, familiar skills to some degree, but new tasks may be forgotten soon after they are completed. Simple instructions may have to be repeated and a task practiced many times before it is learned. Once a task has been learned, a person having memory impairment may not be able to generalize or apply this knowledge to other tasks or to make it part of a daily routine. Thus, the need arises for family members and therapists to provide repeated instructions and other reminders or cues so that the individual may apply "new" skills and information appropriately from one situation to the next.

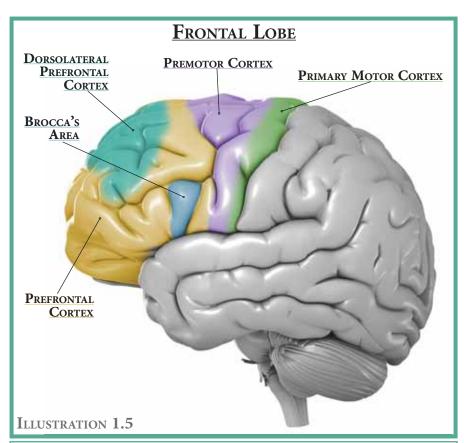
Lack of Initiation

Individuals with brain injuries can sometimes appear unmotivated, dull, or slow in movement, almost like robots. They may respond minimally to their environment, and yet rarely initiate any actions. This apathetic behavior is not caused by laziness. Apathy and poor initiation are common symptoms in individuals who have sustained injury to the brain's frontal lobes. This area of the brain helps in the control of a person's impulses, motivation and initiation.

A person with a frontal lobe injury may need prompting to start self-care activities, daily living tasks, and exercises. Encouraging these individuals to initiate conversation by using speech or gestures and by providing plenty of cues and encouragement will also help them to gradually compensate for this type of problem. An individual's initiation and motivation may gradually improve as the injured frontal lobes begin to heal.

Behavioral Consequences

Two characteristics that may be unique to human beings include the ability to understand and interpret one another's feelings, and the ability to exhibit self-control of emotions. For example, anger is an emotion adults often suppress in social situations. Interpreting and controlling emotions involves both frontal and temporal lobe



The frontal lobes are like a command headquarters. They are the part of the brain responsible for emotional control, inhibition of impulses, motivation, social abilities, expressive language, and voluntary movement.

brain functions. Just as people can experience cognitive deficits following a brain injury, they can experience emotional or behavioral ones as well.

Many behavioral symptoms can follow a brain injury such as anxiety, agitation, frustration, impulsiveness, repetitiveness, depression, regression (childishness) and disinhibition. Each person's symptoms are different and influenced by the extent and location of neurologic damage and the person's ability to cope with the injury and the problems it causes. Symptoms are also affected by conditions that existed before the injury (premorbid). For example, if a person had a history of moodiness, depression, or high-risk behaviors (such as a tendency toward alcohol or drug abuse),

these characteristics may become magnified following injury to the brain. As well, a personality disorder or psychiatric condition may become amplified in an individual following a brain injury.

Excessive Agitation

Excessive agitation and restlessness are common during certain stages of the recovery process. Connections exist between portions of the frontal and temporal lobes that normally allow individuals to monitor emotions so they behave properly in social situations. Injury to the frontal and temporal lobes may result in these or other inappropriate behaviors which may gradually resolve as an individual recovers.

Frustration may also contribute to agitation in brain injury survivors. Imagine waking up one morning in a world that doesn't make sense. The words and actions of others seem strange and unfamiliar. Remembering how to perform everyday tasks is difficult and actually performing them is nearly impossible.

This is probably how survivors of brain injury feel as they struggle to regain their functional and cognitive abilities. The sheer frustration of this struggle may cause the survivor to be verbally and physically aggressive toward others. Usually, this agitation and aggression is not meant to be a personal attack on anyone. Rather, it may be an individual's way to deal with various difficulties and demands with which the survivor feels unable to cope. Behavior, the way we act, is a "language" as well. Often, people will act in certain ways because they may be having difficulty communicating their needs or feelings.

When dealing with an agitated person, family members must try to remain calm, and they should try to create a calm, consistent, loving environment. Often it is recommended that families seek services from a psychologist for counseling to reduce stress common to families caring for relatives with neurobehavioral deficits, and to learn adaptive coping strategies.

Extreme Changes in Emotion

Extreme or rapid changes in emotion may occur in patients with neurologic impairments. Contentment and satisfaction can turn to tears and anger from one minute to the next. Related symptoms include mood swings, depression, anger, outbursts of rage, excessive laughing or crying, and swearing. Lack of ambition, lack of interest in the world, and change in personality may also occur.

Disinhibition & Impulsiveness

As previously mentioned, the frontal and temporal lobes of the brain contain regions that act as a mental "brake" that helps individuals to monitor their behavior and act in socially acceptable ways. After a brain injury, this

"brake" may no longer function properly. This may cause the survivor to act in a way that is uninhibited, impulsive, and out of character.

The inability to control impulses and emotions can result in lowered frustration tolerance, temper flare ups, cursing, and sometimes aggression. A disinhibited or impulsive individual may act upon socially inappropriate urges. Such patients also may exhibit social immaturity by making silly or inappropriate comments.

Disinhibited and impulsive behavior can be very frustrating and embarrassing for a family. Enormous patience may be required to handle these behaviors. Individuals exhibiting these symptoms should be given tips on how to control their behavior and should be praised when they remember to do so.

Self-Centeredness

After a brain injury, survivors often seem self-centered and demanding. They become intensely aware of their own feelings and needs, but they may be insensitive to the feelings of others. Family and friends should try to not withdraw from a person behaving this way. Instead, it is crucial to offer support and understanding. Psychotherapy directed toward developing insight, awareness, and coping strategies is helpful in assisting survivors in recovering social skills.

Loss of Self-Esteem

Brain injury is a devastating trauma, and a survivor's reaction to it can be equally intense. When survivors realize that they no longer think or look the same, they may feel that they are not the same person they once were. Often, they believe they are less of a person. Among individuals with brain injuries, poor self-esteem is very common.

Survivors might feel that they will lose their families, their role in the family, their friends, or their careers. These feelings can cause depression and thoughts of suicide.

Families and friends should continually reassure the survivor that he or she is still important and loved while also highlighting the survivor's progress. Survivors should be praised and encouraged during the rehabilitation process. Psychotherapy and support groups may also assist in reducing problems with low self-esteem.

The Glasgow Coma Scale

Physicians and other health care professionals frequently use the Glasgow Coma Scale to evaluate the patient's level of awareness, which indirectly indicates the extent of a patient's brain injury. The scale rates three categories of patients' responses: eye opening, best verbal response, and best motor response. Levels of response indicate the degree of impairment to the nervous system or brain. The lowest score, 3, indicates no response from the patient, while the highest score, 15, indicates that the patient is alert and oriented to his or her surroundings. Physicians may use the scale in the emergency department and several times after admission in the intensive care unit to see how a person is progressing.

The Rancho Los Amigos Scale of Cognitive Functioning

GLASGOW COMA SCALE (recommended for age 4-adult)	
Eyes Score	
Open:	
Spontaneously 4	
To Verbal Command 3	
To Pain 2	
No Response 1	
Best Motor Response	
To Verbal Command:	
Obeys 6	
To Painful Stimulus:	
Localizes Pain 5	
Flexion-Withdrawal 4	
Flexion-Abnormal 3	
Extension 2	
No Response 1	
Best Verbal Response	
Oriented and Converses 5	
Disoriented and Converses 4	
Inappropriate Words 3	
Incomprehensible Sounds 2	
No Response 1	
GCS Total 3-15	

RANCHO LOS AMIGOS COGNITIVE SCALE

- Level I No response to pain, touch, sound, or sight.
- Level II Generalized reflex response to pain.
- Level III Localized response. Blinks to strong light, turns toward/away from sound, responds to physical discomfort, inconsistent response to commands.
- Level IV Confused/Agitated. Alert, very active, aggressive or bizarre behaviors, performs motor activities but behavior is non-purposeful, extremely short attention span.
- Level V Confused/Non-agitated. Gross attention to environment, highly distractible, requires continual redirection, difficulty learning new tasks, agitated by too much stimulation. May engage in social conversation but with inappropriate verbalizations.
- Level VI Confused/Appropriate. Inconsistent orientation to time and place, retention span/recent memory impaired, begins to recall past, consistently follows simple directions, goal-directed behavior with assistance.
- Level VII Automatic/Appropriate. Performs daily routine in a non-confused but automatic robot-like manner. Skills noticeably deteriorate in unfamiliar environment. Lacks realistic planning for own future.
- Level VIII Purposeful/Appropriate. Stand-by assistance.
- Level IX Purposeful/Appropriate. Stand-by assistance on request.
- Level X Purposeful/Appropriate. Modified independent.

The Rancho Los Amigos Scale of Cognitive Functioning is widely used to describe and communicate a brain injury patient's level of functioning and recovery. This scale helps give professionals an idea of how the patient is progressing over longer periods of time. Professionals at rehabilitation facilities often use "Rancho scores" to guide them in the development of treatment programs.

The scale is divided into eight stages that range from deep coma – no response to sound, light, or touch – to purposeful and appropriate behavior and cognitive functioning. As individuals improve after a brain injury, they may move from one level to the next, but they often demonstrate characteristics from more than one level at a time. Depending on the extent and type of injury, survivors may remain at any one level for an extended period.

PART II

The Rehabilitation Process

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GOALS OF REHABILITATION

Following a brain injury, an individual goes through a process of natural healing, which is called spontaneous recovery. This type of healing occurs most rapidly during the first six months after the injury, but it may continue for years. Spontaneous recovery can occur at any time and in any deficit area. Presently, there is no way to predict when spontaneous recovery will occur, and there is no way to make it happen faster.

The purpose of rehabilitation is to help accelerate the process of regaining functional abilities by presenting the individual with challenges that promote learning and improvement of skills. The goal of rehabilitation is to help the individual return to a life that is as independent and productive as possible while at the same time preventing complications or regression.

Although the goals may be the same for all people recovering from brain injuries, the pathways to get there can be very different. Each individual's rehabilitation program varies depending on the severity and type of injury, and on the survivor's individual needs. For example, a person with severe physical problems and moderate cognitive deficits might receive more physical therapy and less cognitive retraining each day. On the other hand someone with severe behavioral problems might receive specialized neurobehavioral retraining in all therapy areas until the behavioral problems improve.

A comprehensive rehabilitation program encourages survivors to reach their full potential. While the specific elements of each person's treatment plan may vary, most comprehensive rehabilitation programs try to achieve the same major goals, which are outlined on the following page.

Rehabilitation Goals:

Acute Rehabilitation

- Physical health and personal care skills
- Cognitive processing skills
- Language and communication skills
- Movement and mobility skills
- Social and behavior skills
- Environmental awareness and responsiveness

Post-Acute Rehabilitation

- Community living skills
- Vocational and work skills
- Academic and continuing education skills
- Social and behavioral skills
- Recreation and leisure skills
- Independent living skills

Generally, programs that treat brain injury survivors in the early or acute stages of rehabilitation focus on goals listed in the left column. As recovery ensues, programs offering continued rehabilitation services focus on the goals listed in the right column. However, some overlap occurs because most programs tailor treatment to the individual's level of functioning. Thus, survivors in either stage of rehabilitation may be working toward goals in both columns.

In summary, these comprehensive rehabilitation goals include the <u>prevention of secondary complications</u> (such as pneumonia or skin breakdown), <u>treatment to reduce neurological impairments</u> (such as strengthening activities to improve muscle strength), <u>compensatory strategies for residual disabilities</u> (such as the use of adaptive equipment to compensate for persistent muscle weakness or limb incoordination), and finally, <u>family or caretaker education</u>. While in a comprehensive rehabilitation program, patients learn to further develop basic skills and abilities that may have begun to return. In addition, they learn strategies to compensate for problems that may persist.

THE REHABILITATION PROCESS

The course of rehabilitation varies for each brain injury patient. For some, recovery occurs gradually and consistently. For others, recovery happens in spurts, with short periods of rapid improvement followed by longer "plateau" periods during which the person remains at the same functional level. In most instances, recovery may take months to years.

To prepare for the long rehabilitation journey, families should understand that progress is possible at any stage of rehabilitation. Developing realistic, short-term goals and keeping them in mind at all times can help reduce feelings of frustration and impatience.

This section reviews the rehabilitation stages survivors may experience. Also discussed are the types of programs available to help survivors recover functional independence.

The amount of time an individual spends in each stage of rehabilitation and in different treatment programs varies from person to person. For some survivors, a few months of rehabilitation may be sufficient. Others may need a year or more of treatment. With the exception of intensive care, most of the following program "types" offer short-term and long-term rehabilitative care.

Comprehensive Rehabilitation

In the emergency room medical professionals diagnose immediate problems and often perform life-saving procedures to stabilize the condition of the patients with brain trauma. Once out of critical danger, the patient is moved to an intensive care unit (ICU) for continued close observation and acute care. At this stage the challenge for medical professionals changes from sustaining and stabilizing life to preserving and restoring physical, cognitive, and psychological function.

It is in the ICU, once a patient's condition is stabilized, that certain rehabilitation interventions often begin. Rehabilitation interventions in the ICU may include passive range of motion exercises provided by physical and occupational therapists to maintain joint mobility, to maintain muscle tone, and to prevent joint contractures. Speech therapy interventions may include treatments for disorders involving speech, swallowing, and cognition. A patient is often transferred from the ICU to a step down unit, or a regular hospital floor where the rehabilitation process continues. Once the patient is transferred out of the ICU to the regular hospital floor, decision-making

responsibilities shift from a physician-based approach to a team approach involving the family in terms of making the choice of the next setting in the rehabilitation process. As the patient begins to need more intensive and active rehabilitation, options may include: the continuation of treatment in the acute care hospital's rehabilitation unit, treatment in free-standing rehabilitation hospitals, sub-acute care facilities, outpatient programs, or post-acute residential settings.

Once the patient is medically stable, the comprehensive rehabilitation process begins. Depending on a patient's condition, therapy may take place within the acute care hospital's rehabilitation unit or at an independent acute rehabilitation facility.

Because early therapeutic intervention is vital to long-term success, many comprehensive rehabilitation facilities also provide extensive services to meet the medical needs of individuals. Some facilities accept patients in a variety of conditions, such as those in coma, persons breathing with the aid of a ventilator, and those requiring a nasogastric or gastrostomy tube for feeding. These types of programs allow survivors to begin the rehabilitative process as early as possible.

Coma Intervention / Sensory Stimulation

A person in a coma is in a state of unresponsiveness to self or environment. As they awaken from this state, patients may go through various stages of arousal. They may appear to be in a deep sleep; they may move and respond to pain, or they may appear to be awake but remain unresponsive or are confused, agitated, or incoherent. These are all common behaviors for a person progressing from coma to a state of awareness. It is important to realize that individuals will not suddenly awaken from a coma and start talking. The process of arousal from coma is more gradual.

Patients still in coma can begin rehabilitation. Most rehabilitation professionals believe that coma intervention is an important element of the treatment process. Most programs encourage specialized sensory treatment that may help the coma patient become more responsive through stimulation of the five senses (smell, touch, taste, sight, and hearing). Various sensory stimuli, such as music, are introduced to the patient. The patient is then observed to see if he or she makes a meaningful response. Therapists and nurses involve the patient in a variety of stimulation and movement exercises. Frequent movement of arms and legs helps maintain muscle tone and helps

prevent muscle and bone deformities. The patient is also frequently repositioned to a sitting or upright position to prevent skin damage and decubitus ulcers (bed sores), and to reduce the chance of infections such as pneumonia.

Families and friends can be invaluable during the sensory stimulation process. No amount of physical stimulation from the health care staff can replace the familiar voice or the friendly touch of a family member or friend. Talking, hearing familiar voices, touching, playing favorite music, and stimulating other senses, such as smell, may help increase the patient's awareness of the environment and stimulate the emergence from coma.

Intensive Rehabilitation

As patients become more alert and aware of themselves and are able to interact within their environment, they can begin a more intensive rehabilitation program.

At this stage, survivors participate more actively in physical, occupational, and speech therapies, while continuing to receive medical and nursing care, as needed. The rehabilitation plan may combine educational, recreational, and psychological services based on each survivor's individual needs.

A neuropsychological assessment is often necessary to assist in the evaluation and treatment of cognitive and emotional disorders. Vocational and academic assessments may be conducted periodically throughout the rehabilitation process to determine the ability and readiness of an individual to return to work or school.

A therapeutic cognitive program incorporates exercises that include thinking skills, memory, concentration, and

"At first, I couldn't wait to get home. But before I could, I had to learn how to walk, talk, run, write, think, eat, drink, jump, dance, (and I still can't dance), dress and do many more things that we take for granted everyday. At times, I wanted to scream and pull my hair out. I couldn't work. I couldn't go to school. All I could do was therapy! For nine months, rehab was my life."

problem-solving into physical, occupational, speech, and psychological therapies. For example, if the team's goal is to increase the patient's attention span and improve concentration skills, a physical therapist may use simple game-type exercises and an occupational therapist may use cues, such as a wrist watch with an alarm to assist with treatment. Cognitive therapies may also involve cognitive activities groups, individualized activities (that may

include the use of computer games and programs), and recreational activities (such as community outings emphasizing skills such as money management).

If behavioral issues create problems, the survivor's rehabilitation plan will include behavior management goals. Much like cognitive retraining, behavioral strategies are tied into all areas of rehabilitation. A behavioral management plan may include components of psycho-social support groups and individualized therapies geared towards reinforcing positive behavior and the redirection of inappropriate behaviors.

During the early stages of recovery, persons who have sustained neurologic injury will be prone to both mental and physical fatigue. To prevent and manage fatigue, the daily rehabilitation schedule includes periods of rest and "quiet time."

Brain Injury & Medication

Physicians may prescribe certain medications during the rehabilitation process dependent upon the patient's presentation and goals at that time. For example, persons with post-injury seizures may require medication to prevent seizures, which allows them to participate more regularly in therapies. Some medications are prescribed to control agitation, hostility, and hyperactivity, or to treat conditions ranging from aggressive or unstable behaviors to severe depression. Yet, other medications may be prescribed to increase arousal in drowsy lethargic patients who would be otherwise unable to participate in therapies. Please refer to the section on *Neuropharmacology* on page 38 for a brief synopsis of commonly prescribed medications for individuals having sustained traumatic brain injury.

Continued Rehabilitation & Training

During the intensive phase of rehabilitation, treatment focuses on regaining basic skills. Following this phase, individuals may need continued treatment and retraining to fine-tune skills, to address a specific area of functioning, or to refine social, interpersonal, vocational, and other higher-level skills needed for a successful return to the community. Depending on their specific needs, individuals may choose to receive services at an inpatient program or outpatient center.

Post-Acute Rehabilitation Programs

Often called post-acute or transitional, these programs provide continued rehabilitation in settings with structure and supervision while promoting independence and self-sufficiency. Individuals with brain injuries receive specialized training in areas such as vocational or academic rehabilitation, independent living skills, and behavior management. Clients at this level are usually past the need for daily medical care.

At post-acute facilities, individuals learn to care for themselves, manage household responsibilities, use community resources, and build social relationships. Many facilities offer expanded family counseling and psychological services to assist individuals and their families to make long-term adjustments.

Post-acute rehabilitation facilities provide physical, restorative, cognitive, and behavioral therapies in order to prepare individuals for the return to independent living, school, and work settings. Community integration programs may help individuals re-build their self-esteem though vocational and leisure skills training. Training may occur in traditional therapy sessions, in simulated work settings, and/or in real life community settings.

Day Treatment/Outpatient Services

After returning home, some patients need to continue therapy and retraining in specific skill areas. Day treatment programs offer hourly, half-day and full-day programs to address the needs of the individual. Many programs offer vocational and educational training as well as physical, occupational, and speech therapies. These programs may not be appropriate for all patients, since many survivors may benefit more from an inpatient facility. However, when outpatient services are appropriate, patients often enjoy returning home at the end of each day.

Group Home/Residential Living _____

Supportive living programs are available for survivors who have recovered physical independence, but whose families are unable to provide appropriate supervision and care at home. Specifically designed for individuals who are unable to live independently, these settings provide a safe, structured, and stimulating environment. Individuals can live comfortably in these settings and progress in therapies at their own pace. Days are usually organized for residents and often involve modified work experiences, exercise programs, daily living skills, and

leisure activities. These long-term settings may range from a home or a group of apartments to a campus-like environment. For most long-term programs, community involvement and interaction are key elements and facilitate the community integration process.

Specialized Rehabilitation Programs _____

Some rehabilitation settings offer treatment and rehabilitation for people with brain injuries who have very specialized needs. Individuals may enter a specialized treatment setting during the early, intensive phase of rehabilitation or transfer to such a program after completing the initial stages of treatment. Examples of some of these programs are listed below:

Behavior Management

Specialized facilities and programs are available for individuals with severe and moderate behavioral problems resulting from brain injury. These settings provide rehabilitation along with intensive behavior management and modification.

Pediatric Programs

Children and adolescents with neurologic injuries may receive rehabilitation in a treatment setting specifically designed for young people. Intensive rehabilitation is integrated into structured education programs. Children may take part in therapy sessions and activities in classroom settings that provide a comfortable environment for learning and social interaction. As children and adolescents progress, outside school systems may be incorporated into the treatment process.

Brain Injury with Other Conditions

Specialized rehabilitation is available for persons with neurologic injuries whose conditions are complicated by other injuries or medical conditions. Programs are available for patients with brain and associated spinal cord injuries as well as for individuals with brain injuries who have pre-existing mental and physical disorders. These are called "dual diagnosis" programs because they address two or more conditions through unified treatment. Some centers also incorporate drug and alcohol treatment with brain injury rehabilitation.

Respite

These programs offer short-term rehabilitation for individuals who need to brush up on techniques and coping strategies learned during inpatient care, "fine-tune" specific physical or cognitive skills, or address a problem that has surfaced since returning to the community. These programs also offer families a chance to take a break from the daily responsibility of caring for a person with a brain injury.

THE REHABILITATION TEAM

Comprehensive neurologic rehabilitation involves an interdisciplinary team of specialists. Each specialist concentrates on a specific area of treatment, but because rehabilitation is designed to address the person as a whole, many aspects of therapy overlap and the specialists often work together as a team.

Upon admission to a program, specialists evaluate the individual's condition and determine short and long-term goals. This initial assessment allows the team to develop an integrated, comprehensive treatment plan to meet the individual needs of the patient. Regular meetings, sometimes called staffings or team meetings, allow team members to share information, discuss progress, and outline future goals. The team may redefine goals if the patient progresses faster or slower than originally predicted.

Persons who have sustained a brain injury and their families should consider themselves a part of the team and treatment process. Family members can serve as motivators and historians, relaying past interests and aspects of the individual's personality.

In addition to other specialists, the treatment team may include the following:

Neurologist

A neurologist is a physician who specializes in the medical treatment of the entire nervous system, which includes the brain, spinal cord, nerves, and muscles. This specialist is frequently involved in the initial evaluation of the patient's neurologic status and may also direct the interdisciplinary rehabilitation team. Primary functions of the neurologist include: diagnosing the type of injury, recommending consultation with other physicians and health care professionals, and prescribing and monitoring neuro-active medications (such as those used in the control of seizure, behavioral disturbances, and impaired cognition).

Physiatrist

A physiatrist is a doctor of physical medicine and rehabilitation whose primary focus is the restoration of impaired function. Specializing in physical retraining, the physiatrist combines aspects of medical orthopedics and neurology. The rehabilitation team is sometimes headed by a physiatrist.

"I interact with others constantly; whether it's other clients or the staff who work here. All the therapists work together to help me. Sometimes I get help one-on-one. They are helping me go through all the stages of recovery in order to get back into a normal life."

Internist

Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. Although internists may act as primary care physicians, they are not family physicians, family practitioners, or general practitioners whose training is not solely concentrated on adults and may include surgery, obstetrics, and pediatrics. Internists are equipped to deal with whatever problem a patient presents with; no matter how common or rare, or how simple or complex. They are specially trained to solve puzzling diagnostic problems and can handle severe chronic illnesses and situations where several different illnesses may strike at the same time.

Neuropsychologist/Clinical Psychologist

A neuropsychologist is a clinician who specializes in brain disorders involving impairments of an individual's emotional and cognitive functioning. Neuropsychologists study the interrelationship between the brain and how individuals think and act. A neuropsychologist often assesses an individual's cognition using psychometric tests and helps coordinate that aspect of the rehabilitation process for persons with brain injuries. Sessions with the patient and a psychologist or neuropsychologist may also include work to redevelop appropriate social skills and to redirect inappropriate behaviors. A psychologist may also help friends and families cope with the many emotional issues occurring after a brain injury.

Nursing Staff

The health care needs of people who have sustained brain injuries can be complex. The rehabilitation nursing staff helps to ensure a safe, supportive medical environment, 24 hours a day. During the early stages of rehabilitation, nurses monitor, evaluate, report on, and attend to the ongoing needs of the patient. They update physicians and therapists so that necessary changes can be made in medications or treatment regimens. They also work with patients and families daily to educate and reinforce specific interdisciplinary goals and carry out the treatment plans generated by the team. Rehabilitation nurses often assist the team in educating patient and their families on safety issues such as the prevention of falls, aspiration, and skin breakdown.

Respiratory Therapist (RT)/Pulmonary Therapist

A respiratory or pulmonary therapist specializes in the techniques and technology used to help a patient breathe and maintain open the airways. This therapist is usually involved in the early stages of treatment when a patient may have difficulty breathing. Among other duties, the respiratory therapist maintains the ventilator, assists the patient who is unable to cough up secretions from the throat and lungs, and helps to properly maintain the patient with an endotracheal tube.

Physical Therapist (PT)

A physical therapist functions in maintaining and improving the movement of joints and limbs and is skilled in evaluating and treating problems in these areas. Physical therapists try to restore the highest level of motor function possible. For some patients, this may be learning to walk again, for others it may be learning to maintain good posture while in a wheelchair. Evaluating and enhancing muscle tone, muscle strength, coordination, endurance, and general mobility are all responsibilities of the physical therapist. Individualized physical therapy programs often involve retraining of functional skills, such as the ability to transfer to and from a wheelchair or the ability to walk with a brace. The physical therapist determines whether a patient requires special adaptive equipment, such as a walker or splint, and evaluates and trains the patient's ability to use the equipment.

Occupational Therapist (OT)

An occupational therapist's role is to help individuals overcome the physical, cognitive, and perceptual problems that limit their ability to perform functional activities. The occupational therapist evaluates the survivor's ability to use upper limbs, perform fine motor skills, coordinate eye-hand movements, and use skills needed for self-care or activities of daily living (ADL's). The occupational therapist develops a treatment plan, which may include exercise and reeducation, to perform functional self-care tasks, such as bathing, dressing, and grooming; and cognitive tasks such as money management, cooking, and working with tools.

The occupational therapist may also provide special adaptive equipment to help in the performance of daily activities, in the improvement of the ability to function independently, and in the prevention of deformity of the hands and arms. Occupational therapists also evaluate and assist patients on therapeutic community integration outings.

Dietitian

Dietitian are members of the rehabilitation team who assist in the nutrition management of the patient. The dietitian evaluates a patient's nutritional needs and the administration of a proper diet. Because neurologic damage can cause a person's nutritional needs to change substantially, a special diet may be needed to help maintain proper nutrition to assist with healing. A special diet may also be prescribed for problems relating to weight loss or gain, swallowing and chewing disorders, or to aid in bowel and bladder functioning. The dietitian also serves as an educator, providing information on proper nutrition and good eating habits to help patients control their weight and maintain good health.

Speech and Language Pathologist

Language deficits are among the most common and long-lasting problems for persons with brain damage. The speech pathologist specializes in evaluating and treating a patient's problems of verbal expression and disorders involving verbal comprehension. Attention, writing, reading, and expression skills are also concerns of the speech language pathologist. They may provide instructions and exercises to improve comprehension and overall communication skills, and assist in the diagnosis and treatment of swallowing disorders and cognitive deficits. The direction of social interaction or conversational skills programs may occur during later stages of rehabilitation. An ear, nose, and throat specialist (otolaryngologist) may be consulted in some cases to assist with specific medical problems involving the process of swallowing or hearing.

Cognitive Therapist

The provision of re-training and compensatory strategies in cognitive areas such as memory, problem solving, abstract reasoning, insight, judgment, safety awareness, and executive functioning is a key aspect of any comprehensive neuro-rehabilitation program for individuals who have sustained a brain injury. The cognitive therapist works to heighten patients' awareness of cognitive deficits and help them with cognitive retraining and use of appropriate compensatory strategies. Many cognitive therapists have a background in education and apply methods of teaching to the specialty of neurologic rehabilitation. A comprehensive interdisciplinary cognitive rehabilitation program usually includes speech, occupational, and recreational therapists and the clinical psychologist. All members of the treatment team may participate in an individual's cognitive rehabilitation. In some settings, occupational therapists and speech therapists assume these responsibilities.

Cognitive therapy frequently involves various computer programs as adjunct training tools. Adapted with special devices, computers offer persons with limited motor control the chance to read, write, and take part in intellectual games.

Vocational Rehabilitation Specialist/Counselor

Vocational therapists help individuals develop the skills, aptitude, and confidence necessary to return to gainful employment. An initial evaluation of a survivor's interests, work skills, ability to follow instructions, attitude, and social skills allows the vocational specialist to determine the current level of vocational functioning. The vocational rehabilitation specialist then identifies performance areas needing improvement and develops a personalized treatment plan.

Vocational rehabilitation focuses on the enhancement of prevocational skills, such as endurance, concentration, and executive functions to help strengthen the basic skills needed to re-enter the working world. The previous employer, may be incorporated into the rehabilitation plan as a patient transitions back into the work environment. Together, the therapist, employer, and patient work toward a smooth transition back to the work environment. If vocational alternatives are required, the vocational specialist works with the survivor, family, and rehabilitation team to identify possible options.

Educational Therapist

The educational therapist is often a certified special education counselor or teacher with a college degree in education who assists in teaching the basic skills needed for the individual with a brain injury to return to school. Individuals who have sustained a brain injury may initially need a special educational environment.

The educational specialist evaluates a person's academic skills and develops an individualized program. This program may focus on such basics as reading, writing, and mathematics, as well as other areas of academics. Many treatment plans incorporate public or private schooling into the daily rehabilitation program.

Case Manager/Social Worker

A case manager or social worker often acts as a team leader to coordinate the goals of the patient, family, interdisciplinary treatment staff, and rehabilitation program. As a coordinator of the therapists and an advocate for the patient, the rehabilitation case manager oversees and develops the patient's ongoing treatment plan and discharge goals with the assistance of the interdisciplinary team. The rehabilitation case manager also serves as a liaison between the professional health care staff, family, patient, treatment facility, and funding source or insurance company.

The case manager/social worker performs a general background assessment or psychosocial history. This assessment includes information about the patient's pre-injury personality and lifestyle, emotional and financial resources, educational history, work and leisure interests, special relationships, and previous problems. A psychosocial history often reveals the patient's and family's understanding of the current situation and this often allows the interdisciplinary team to better communicate long-term and short-term goals to families. A social worker is also someone the family can turn to for advice, support, and counseling regarding many issues involved during the recovery process, including economic concerns as well as disability issues.

Therapeutic Recreational Specialist/Recreational Therapist

Evaluating the patient's interests and hobbies and combining them with basic therapy goals is the focus of the therapeutic recreational specialist. This rehabilitation specialist designs programs that give patients an opportunity to enjoy activities of choice, such as sports, crafts, special events, and outside excursions. The focus of therapeutic sessions is often to improve specific physical, cognitive, and social skills, to teach the patient about how to use leisure resources, and to encourage the planning and organization of leisure activities. A primary responsibility of the recreational therapist includes the preparation of the patient for community reentry.

Music Therapist

The music therapist uses instruments and songs to encourage patient involvement in a variety of activities that may help to reinforce various rehabilitation goals. In the early stages of treatment, music therapy heightens awareness and orientation while reinforcing specific therapy goals, such as memory and language skills. As individuals progress, singing songs and playing instruments may help improve fine motor skills, speech and

language abilities, and cognitive skills. Many times, individuals can more easily remember personal history or everyday activities by singing a customized song created in music therapy. Since a music therapist is not an intrinsic member of the comprehensive rehabilitation team, these services are often provided by the recreational therapist.

Life Skills Staff/Rehabilitation Associates

These professionals assist individuals in daily living activities as well as in treatment sessions. They may help with behavioral programs, reteach self-care skills, assist in group therapy sessions, or help carry out treatment plans. The job responsibilities and backgrounds of life skills staff vary. They may be registered nurses, unit staff members, mental health workers, rehabilitation assistants, certified nursing assistants, or specialists with vocational or educational backgrounds. Often the life skills staff are therapists in training. The life skills staff can provide the treatment team with valuable information about how the patient is functioning on a daily basis.

The Family

The family can function as one of the most important aspects of the treatment team. Family members can provide pertinent and valuable information about the patient, such as pre-injury history, likes and dislikes, interests, and motivators. These factors can be crucial to successful rehabilitation. The family can take part in regular team meetings to discuss discharge plans, treatment goals, and future needs of the patient.

Because different members of a family are affected in different ways by the rehabilitation process, family counseling is often available from the clinical psychologist or social worker. A quiet time to talk about pressures, coping strategies, and impending choices helps family members better understand and deal with changes in lifestyles and the needs of the patient. The case manager or social worker can also identify additional resources in the community that may be helpful to the patient. Support organizations, such as the Brain Injury Association (BIA), can provide crucial information and can help families become advocates for the patient.

APPROACHES TO TREATMENT

Neurologic rehabilitation is both an art and a science. However, the quality of treatment often depends on the skills and experience of the professionals who deliver the service as well as the treatment principles and philosophies held by those professionals. These factors may play a major role in determining the success of rehabilitation efforts. Over the past decade, several principles of treatment have been recognized as being effective in the rehabilitation of people with traumatic brain injuries.

- Rehabilitation requires a comprehensive and integrated treatment approach. This element is critical and is discussed in greater detail in the following section, "An Integrated Approach." An interdisciplinary team approach that coordinates the efforts of all therapists is often critical to providing effective treatments to reduce neurologic impairments and to improve functional abilities.
- Treatments should meet the patient's needs at each stage of the rehabilitation process. Delivering therapies at the person's level of functioning and targeting specific skill areas are the goals of the rehabilitation process. Goals are adjusted or redefined as the person improves and demonstrates potential for greater gains.
- Treatments must be consistent, functional, and delivered in a structured environment. After a brain injury, many individuals have problems organizing their thoughts and actions. Establishing various routines usually helps individuals relearn old skills and develop new strategies. Therapists structure functional, real-life activities to help a person progress and return to their community.
- Constant feedback and reinforcement must be given. Persons with cognitive deficits and impaired insight may have difficulty evaluating their performance or recognizing whether they have done something correctly or incorrectly. They may be unable to understand subtle cues or indirect feedback about their performance. Therapists and family members can provide positive feedback and reinforcement by congratulating individuals on their successes, and frequently reminding them of their accomplishments. When an individual needs help, therapists and family members can model the correct behavior in a manner the individual will comprehend.

An Integrated Approach

Clinicians from a variety of professions comprise the interdisciplinary rehabilitation team. A team may include members from any of the following disciplines: medicine, psychology, nursing, physical therapy, social work, dietary, occupational therapy, speech pathology, and therapeutic recreation. Each treatment team member is skilled in specific therapeutic techniques with an emphasis on a particular aspect of function. However, each

"The school teacher and the speech therapist work closely to help me remember facts and things like schedules. The occupational therapist helps me relearn safety habits and daily living skills, like cooking, where I have to organize myself and follow a recipe. These kinds of things are the major things I've had trouble with lately. I'm being taught Algebra II by a math tutor. I don't seem to have a problem with academic facts. It's just the organizational things. This old brain plays funny tricks sometimes."

specialist applies his or her own clinical opinions, expertise, and skills as a part of the overall treatment program in order to achieve the decided goals.

To ensure that all the needs of the patient are met, therapists take an interdisciplinary approach. This approach requires consistency and open communication among team members. Survivors learn, practice, and develop many skills at the same time. Interdisciplinary team meetings are usually held weekly or biweekly to allow all the rehabilitation team members to communicate with one another regarding each patient's

progress. In addition, these team meetings allow therapists to develop treatment strategies with one another, as well as to update the attending physician on any patient specific problems and accomplishments. The interdisciplinary team meetings, also known as care plan staffings, are a key element of the integrated team approach to brain injury rehabilitation.

For example, a physical therapist may emphasize and train balancing skills, but he or she also incorporates, applies, and reinforces the manual dexterity skills emphasized by the occupational therapist and the behavioral interventions taught by the psychologist. Each therapist uses specific techniques to concentrate on and improve certain skills. Then, together, they work to combine these skills into functional progress. For example, a person may need to increase knee-bending abilities in order to get in and out of a car. A physical therapist may use specific techniques to increase range of motion, muscular strength, and coordination. Practicing these skills can take place on a mat in a gym and also in a car. The physical therapist tells the occupational therapist which techniques work best. Then, the occupational therapist may use those techniques as part of transfer training; for

example, when showing the patient how to transfer or move from the bed to the chair. In addition to working one-on-one with the patient, the physical and occupational therapists may work together in a session. Similarly, those therapists involved in cognitive remediation, such as the occupational therapist, speech pathologist, clinical psychologist, and recreational therapist, often integrate their efforts and may co-treat patients at times.

The Evaluation Process

Comprehensive rehabilitation treatment plans vary from patient to patient. The rehabilitation process does not involve preset formulas; every treatment goal, therapeutic intervention, and recreational activity is tailored to the individual's skill level. Successful rehabilitation programs involve a detailed and complex, ongoing patient evaluation process, including observation, formal assessments, and an in-depth examination of the patient's history and physical capabilities.

Upon admission to a rehabilitation program, the patient will undergo a comprehensive evaluation conducted by physicians, therapists, nurses, and other rehabilitation specialists. The initial evaluation provides important information on the person's physical, cognitive, behavioral, and psychosocial status.

After completing initial evaluations, treatment team members meet to compare and review information on the person's skills, strengths, and problem areas. These findings, along with the individual's personal history, form the basis of a comprehensive, outcome-oriented plan of treatment, often called the rehabilitation plan. This initial plan of care is formulated during the first week of admission to the brain injury rehabilitation program.

Once a treatment plan has been developed, team members meet regularly to review the person's status, assess progress, and evaluate the success of treatment. Therapists work together to ensure that the individual will relearn skills and that these skills are combined to meet the end goal of purposeful functioning. Short term goals and treatment strategies may be modified by the interdisciplinary team during weekly staffing meetings.

NEUROPHARMACOLOGY

Medications in survivors of traumatic brain injuries (TBI) should be used sparingly with the focus being on ameliorating or decreasing, psychiatric symptoms, behavioral manifestations, and maladaptive behaviors that can interfere or impede the rehabilitative process. Survivors of TBI can present with a myriad of psychiatric symptom manifestations, with the most common ones being depression, explosivity (violent behaviors), which may be situational as well as out of the blue, apathy, lack of interest, anhedonia (lack of pleasure or the capacity to experience it), particularly in individuals with frontal lobe trauma. In individuals with dominant hemisphere trauma, symptoms may include psychosis (being out of touch with reality), auditory or visual hallucinations, delusions (having fixed firm beliefs) which may be paranoid or persecutory in nature, symptoms of bipolarity with manic qualities such as pressured speech, racing thoughts, poor concentration, and increased energy. Alterations in the sleep/wake cycle are common in survivors of TBI with the most common symptoms being insomnia, maintaining sleep, or reversal of sleep-wake cycle. Survivors of TBI may experience a change in personality, either regressive or expansive of underlying pre-morbid personality traits. It is not unusual for survivors of TBI to develop dis-inhibition and may act out in a sexually inappropriate manner towards self or others. From a cognitive stand point, survivors of TBI usually experience deficits in recent memory recall and working memory. With executive dysfunction, i.e. difficulty with organization, there is an inability to complete tasks in a sequential fashion, attention deficit, poor concentration and difficulty with abstract concepts, frequently found as sequelae to TBI, particularly frontal lobe injuries. What the family members or support group of a survivor should remember is that symptoms and behaviors change with time from the date of injury. What is initially seen in terms of symptoms-behaviors will change, improve or fluctuate, as time goes by. Most individuals reach maximum medical improvement 1 ½ to 2 years from the date of injury.

In an effort to help survivors of TBI and their loved ones understand the advantages and disadvantages of psychiatric medications, a brief synopsis has been compiled, with emphasis on how these medications affect an individual who has had a TBI. The emphasis, however, is that there is no such thing as "one size fits all" treatment, and what is effective for one individual may not be effective or even contraindicated in another.

Anti-depressants

Generally, work by increasing serotonin and or norepinephrine in the connection between neurons (synapse), decrease in these neurotransmitters have been implicated in development of mood disorders. Low serotonin levels in the central nervous system (CNS) have also been implicated with violent behaviors to self (suicidality) and others. Anti-depressants are generally classified according to the neurotransmitter they affect such as SSRI

for selective serotonin re-uptake inhibitor or SSNERI mixed type. There are older anti-depressants called tri-cyclic anti-depressants which also have similar pharmacological action depending on whether they are a tertiary or secondary amine such as Amitriptyline (Elavil) and Nortriptyline (Pamelor), respectively. Elavil is sometimes used for its pain management properties as well as an anti-depressant.

- <u>SSRI's</u>: fluoxetine (Prozac), sertaline (Zoloft), paroxetine (Paxil), citalopram (Celexa), escitalopram (Lexapro), duloxetine (Cymbalta), fluvoxamine (Luvox)
 - o *Uses*: depression, irritability, anxiety, obsessive compulsive disorder, trichotillomania, premature ejaculation, social anxiety-phobias, apathy, psychomotor retardation, anhedonia, eating disorders.
 - o *Advantages*: generally work well with therapeutic effects seen in 2-3 weeks, obsessive compulsive disorder may have longer period for therapeutic effect, sertraline (Zoloft) has a low drug to drug interaction.
 - o *Disadvantages*: may lower seizure threshold, can have activating features, i.e. causing increased aggression or even mania, rebound anxiety upon discontinuation especially true of Paroxetine (Paxil), can affect serum levels of other medications such as anticonvulsants, can cause erectile dysfunction, weight gain, reports of increased suicidal ideation, inappropriate antidiuretic hormone (SIADH), decrease in serum sodium, akathisia, motor restlessness (inability to sit still) especially common in the elderly.
- <u>S-NERI</u>: Serotonin Norephinephrine reuptake inhibitor, venlafaxine (effexor) works on the two major neurotransmitters implicated in depression.
 - o *Uses*: depression, anxiety
 - o *Advantages*: may have activating-energizing features, may improve attention and concentration.
 - o *Disadvantages*: may also lower seizure threshold, may cause increase in blood pressure (usually modest), may cause activation-mania, hyponatremia (low serum sodium) due to SIADH, serotonin syndrome, and cardiac arrythmias (rare).
- <u>Buproprion (Wellbutrin)</u> is a miscellaneous anti-depressant which may work by blocking the re-uptake of dopamine.
 - o *Uses*: depression, smoking cessation, attention deficit disorder, short attention span in individuals with Attention Deficit Disorder.
 - o Disadvantages: may significantly lower seizure threshold (5%) and is contraindicated in

individuals with seizure disorder or eating disorder such as anorexia nervosa or bulimia. Should be used with extreme caution in individuals with head injuries. Can be activating but is generally considered to be the least activating for development of manic symptoms.

Anti-psychotics

Usually classified as typical and atypical:

- Typical anti-psychotics: generally older medications, are generally less expensive, have been proven to be just as effective in the treatment of psychosis (see CATIE trials) but may have more extra pyramidal symptoms (pseudo-Parkinsonian) symptoms i.e. motor restlessness or retardation Akathisia-Akinesia, dystonias and tardive dyskinesia (TD), which are irreversible involuntary movements (note: atypical anti-psychotics such as risperidone (Risperdal) have also been known to cause Tardive Dyskinesia (TD). Typical anti-psychotics may also be less efficacious on negative symptoms such as flattening of affect, social withdrawal and cognitive dulling than some; but not all, of the atypical anti-psychotics. They work by blocking the neurotransmitter dopamine at the level of the D2 receptor.
 - o *Examples of typical anti-psychotics*: chlorpromazine (thorazine), fluphenazine (prolixin), haloperidol (Haldol), perphenazine (Trilafon), trifluoperazine (Stelazine), molindone (Moban).
 - o *Uses*: psychosis, agitated states, tics, Gilles de la Tourette Syndrome, all psychiatric disorders associated with psychotic states, Bipolar Disorder.
 - o *Advantages*: work well on hallucinations, delusions, formal thought disorders, agitation, violent patients.
 - O Disadvantages: can lower seizure threshold, anti-cholinergic side effects i.e. dry mouth paralytic ileus, Tardive Dyskinesia, pseudo Parkinsonian Symptoms i.e. flat affect, shuffling gait (Thorazine shuffle), neuroleptic malignant syndrome, weight gain (exception Moban), hyperlipidemia and diabetes (may be less pronounced than the atypical anti-psychotics, especially when compared to Olanzapine (Zyprexa)), extrapyramidal symptoms, dystonias, cardiac arrythmias, hyponatremia, leukopenia-neutropenia and decrease in white blood cell count.
- <u>Atypical anti-psychotics</u>: block the re-uptake of dopamine at level of D2-D4 (Clozapine) but also block the receptor for serotonin 5-HT which has been linked to hallucinations. They have less cognitive dulling

and pseudo-parkinsonian symptoms than the typical anti-psychotics, and have more therapeutic effect on negative symptoms such as social withdrawal or a flat affect. Clozapine (Clozaril) and Olanzapine (zyprexa) have been known to reverse symptoms of TD (tardive dyskinesia).

- o *Examples of atypical anti-psychotics*: risperidone (Risperdal), olanzapine (Zyprexa), aripiprazole (Abilify), ziprasidone (Geodon), quetiapine (Seroquel), clozapine (Clozaril), paliperidone (Invega).
- o *Advantages*: less extra pyramidal symptoms then typical anti-psychotics, less cognitive dulling, have positive effect on negative symptoms.
- o *Disadvantages*: weight gain, hyperlipidemia diabetes, aripiprazole (Geodon), more weight neutral.

Mood Stabilizers

Anticonvulsants such as valproic acid (Depakote), carbamazepine (Tegretol), lamotrigine (Lamictal), oxcarbazepine (Trileptal), lithium carbonate (Eskalith, Lithobid). These anticonvulsants are useful in the treatment of explosivity, violent behaviors, bipolar symptomatology, manic symptoms such as pressured speech, racing thoughts lability of mood, poor sleep, and increased energy. In addition, valproic acid (Depakote) is useful for treatment of post traumatic headaches, migraines, and hyper-arousability associated with post traumatic stress disorder.

- *Advantages*: useful for treatment of seizures, bipolar symptomatology, post-traumatic headaches, frontal lobe syndrome, intermittent explosive disorder, post traumatic stress disorder, (lithium) treatment resistant depression.
- *Disadvantages*: side effects with anti-convulsants are generally rare and reversible but do occur, frequent blood monitoring is essential. These may include: bone marrow suppression, decreased white blood cell count, decreased red blood cell count, decreased platelet counts, hepato-toxicity, liver failure (especially in children), pancreatitis, cardiac arrythmias and lethal skin rashes are possible, but rare. Lithium can slightly increase white blood cells (leukocytosis) with no clinical significance, can bind to the thyroid gland causing hypothyroidism treated with thyroid hormone supplementation, can cause polyuria, polydipsia (increased thirst and urination) and increase in serum sodium. Both anticonvulsants and lithium can cause a mild essential tremor as well as hair loss.

Anti-Parkinsonian agents (anti cholinergics)

Used to prevent and reverse extra pyramidal symptoms associated with medications that decrease dopamine, i.e. anti-psychotics, generally used in combination with an antipsychotic agent.

- Advantages: work well on dystonias, akathisia, akinesia (EPS).
- *Disadvantages*: cause dry mouth, urinary retention, blurry vision, constipation, will not reverse tardive dyskinesia.
- Examples of anti cholinergics: benztropine (Cogentin), trihexyphenidyl (Artane), diphenhydramine (Benadryl).

Stimulants

Can be useful in treating individuals with attentional difficulties, apathy, psychomotor retardation, stuporous conditions and, of course, attention deficit disorder with and without hyperactivity in children and some adults.

- Examples of stimulants: methylphenidate (Ritalin), dextroamphetamine (Dexedrine), dextroamphetamine/amphetamine (Adderall), modafinil (Provigil), armodafinil (Nuvigil), to name a few.
- *Advantages*: generally medications such as methylphenidate, dextroamphetamine have a short half-life (eliminated quickly from the body), work well on increasing attention and concentration, have a calming effect on hyperactive children, increase alertness, decreased need for sleep.
- *Disadvantages*: can lower seizure threshold, can cause motor tics, decrease appetite, cause insomnia, can cause irritability-mood swings, some individuals can have idiosyncratic responses i.e., can prolong being in a coma rather than reversing it.

Beta blockers _____

Can be useful in the treatment of tremors and headaches, violent behavior.

• Examples of beta blocker: propanolol (Inderal), pindolol (Visken), atenolol (Tenormin).

- *Advantages*: works well on essential tremors, vascular headaches may respond to this medication, some violent individuals with episodic dyscontrol may respond to high doses of beta blockers.
- *Disadvantages*: may cause bronchial constriction, may mask hypoglycemia, contraindicated in asthmatics and diabetics, may decrease heart rate (bradycardia), lowers blood pressure. Not always effective, may require doses to achieve therapeutic results in violent behavior that the individual cannot tolerate because of side effects.

Benzodiazepines

Useful in the treatment of anxiety, seizures, insomnia (short term), violent behavior agitation as needed. Some benzodiazepines such as alprazolam (Xanax) can have antidepressant properties, used for withdrawal states.

- *Advantages*: short half-life, i.e. benzodiazepines such as lorazepam (Ativan) are very useful in short term treatment of agitation and aggression. Long half-life benzos, such as Klonopin are useful in the treatment of seizure disorder, Benzodiazepines are not irritants to the central nervous system.
- *Disadvantages*: have abuse potential, cause tolerance, can cause memory loss, disinhibition.
- Example of benzodiazepines: clonazepam (Klonopin), lorazepam (Ativan), diazepam (Valium)

Hypnotics

Individuals who have had a TBI are prone to sleep disturbances primary - secondary insomnia, reversal of sleep wake cycle etc. Hypnotics are useful for short term management of sleep disorders. Some individuals may require longer treatment due to chronic insomnia. The main issue is the development of tolerance such as in the use of benzodiazepines with a short half-life, i.e. triazolam (Halcion). Medications that work on re-establishing circadian rhythms such as rozerem and melatonin may be useful.

- *Advantages*: helps re-establish normal sleep patterns, establishes sleep-wake cycle.
- *Disadvantages*: can cause tolerance, some individuals have amnesia and will even drive cars or perform other chores while asleep.
- Examples of Hypnotics: zolpidem (Ambien), triazolam (Halcion), temazepam (Restoril), trazodone (Desyral) though an antidepressant is often used as a hypnotic.

Cognitive Enhancers_

There have been some studies showing mild improvement in cognition (memory) in individuals with TBI who were treated with medications for Alzheimers. Some of these medications such as donepezil (Aricept) work by decreasing the degradation of acetylcholine the major neurotransmitter implicated in memory storage.

- *Advantages*: may help in improving recent memory.
- *Disadvantages*: not always effective, may lower seizure threshold, can cause insomnia, depression, anorexia, urinary frequency, headaches, syncope.
- Example of cognitive enhancers: donepezil (Aricept), rivastigmine (Exelon), memantine (Namenda)

Antihypertensives (alpha 2 agonists)_

Clonidine (Catapres) and guanfacine (Tenex) are used (off label) in children with hyperactivity and poor impulse control. They work by down regulating the neurotransmitter norepinephrine. They work synergistically when used with lithium carbonate.

- Advantages: have therapeutic effect on motor tics, decrease hyperactivity.
- *Disadvantages*: may cause irritability, sedation, lowers blood pressure, reports of cardiac arrythmias, rebound hypertension if abruptly discontinued.
- Examples: clonidine (catapres) guanfacine (Tenex).

In conclusion, survivors of TBI should be treated if at all possible with the least amount of medications. Symptoms and maladaptive behaviors that interfere with the rehabilitative process should be treated. Initial reasons for treatment will usually change as the survivor undergoes rehabilitation and nears maximum medical improvement (MMI). Attempts (when possible) to taper or wean off of psychiatric medications as the individuals date of injury progresses should be made. Polypharmacy (excessive or unnecessary medications) and the use of two or more medications of the same class should be avoided. The clinician and the loved ones of the survivor should be cognizant of the fact that psychiatric manifestations are common in TBI and not always permanent, but may represent a bump in the road in the rehabilitative process.

VOCATIONAL ELEMENTS

The ability to work successfully often plays a central role in the self-esteem of individuals in our society. Work provides economic, physical, social, and personal benefits. A career often brings routine and structure, shapes a sense of personal identity, and provides a sense of worth. People who sustain brain injuries face enormous challenges and barriers to re-entering the workforce. Comprehensive rehabilitation often includes pre-vocational and vocational training for those individuals who are able to participate. Once in a rehabilitation setting, appropriate individuals often receive a vocational evaluation. This evaluation includes an assessment of work abilities and skills, and the identification of potential functional barriers to employment. The vocational evaluation allows therapists to develop a customized vocational plan.

Vocational plans often include a gradual work reintegration strategy. A vocational plan incorporates strategies for enhancing many functions critical for successful return to work; these include cognition, physical abilities, communication skills, and behavioral control. As a result, many members of the interdisciplinary rehabilitation team participate in an individual's vocational plan.

Vocational rehabilitation is geared toward survivors with good insight and those who have met many of their rehabilitation goals. The vocational trainees explore job opportunities matched to their capabilities. In addition they are given aptitude tests and work sample tests to determine whether they are capable to return to their prior vocation or another suitable alternative. Vocational trainees may also be provided various standardized tests to help identify specific capabilities and interests. Team members administer and interpret these tests very carefully, since the injury related deficits are unique from individual to individual. In many instances, they may modify the tests to meet individual needs. Standardized testing can provide evaluators with valuable information about an individual's ability to learn and to make sound judgments and decisions. These tests can also provide information about the person's productivity, punctuality, reaction time, distractibility, and tolerance for frustration.

At the rehabilitation facility, individuals may participate in situational assessments that evaluate their ability to perform a variety of tasks in simulated work settings. As they progress, survivors participate in customized assessments at real work settings in the community. These assessments give the vocational evaluator an opportunity to observe an individual over an extended period of time in an actual work setting. Vocational therapists provide frequent feedback and design strategies to help individuals compensate for their deficits.

Vocational rehabilitation may also include work adjustment training, educational training, a driver's evaluation, community exploration, and training in job-seeking and interviewing skills. If a job site is chosen before the patient leaves the rehabilitation facility, a job coach may accompany the person to the job site to help him or her learn new tasks and to smooth the transition back to work.

An important part of successful vocational reintegration is a commitment to education and advocacy on the part of the rehabilitation facility and the family. Actively participating with in-service training, brain injury support groups, and state-level conference presentations can go a long way toward educating potential employers and other members of the community about the process of reintegrating survivors of brain injury into the work force.

Comprehensive Rehabilitation Evaluation

A Comprehensive Rehabilitation Evaluation, known as a Life Care Plan, is a document that summarizes the medical, psychosocial, educational, vocational, and daily living care needs of an individual after sustaining a brain injury. A certified life care planner or board certified physiatrist or neurologist with experience in treatment of brain injuries may perform this evaluation. A Comprehensive Rehabilitation Evaluation is a comprehensive report that defines a patient's impairment, disability, and the cost for future medical care.

The Life Care Plan defines the capacity for future gainful employment and rates the impairment and disability. Future medical needs and the costs associated with these needs are accurately defined. The methodology utilized used to determine the costs for future medical care includes the evaluator's knowledge, training, and clinical practice experience in caring for geriatric, adult, adolescent, and pediatric patients who have suffered from all types of injuries. These injuries include, but are not limited to, traumatic brain injuries, spinal cord injuries, strokes, amputations, burns, and multiple orthopedic traumas.

The spirit and intent of the Continuation of Care Plan is to accurately define the cost of future medical care to maximize the patient's functional potential and reintegrate the patient back into society at their highest functioning level, to the best of their ability. The Comprehensive Rehabilitation Evaluation Report is utilized by insurance companies, attorneys, and state agencies to better understand the individual's disability, medical requirements, and projected long-term costs associated with care of the patient over the course of their lifetime.

CHILDREN & ADOLESCENTS

Each year, over one million children are seen in emergency rooms with head trauma. Most of the injuries result from accidents involving motor vehicles, bicycles, sports, and falls. More than 150,000 children are hospitalized, and over 20,000 sustain moderate to severe brain injuries annually.

In many instances, children who sustain a brain injury early in life may look "well" after recovering from the injury. However, as these children get older and their brains mature, more serious behavioral and cognitive consequences can emerge.

Children and adolescents with brain injuries should receive care at facilities that specialize in pediatric neurologic rehabilitation. A child's brain often is still in the process of growing and developing when an injury occurs, therefore, brain growth and development are often interrupted. Pediatric brain injury rehabilitation is designed to help the child get back on track in the areas of learning and development and to help retrain skills lost as a result

"School is most important to me. I'm now a candidate for going into the public school. When I do attend public school, it'll just be for three hours a day at first. This is to see how I perform with the schedules and the homework. I'll take my memory notebook to school and a staff person stays with me. The point is that I'm beating this brain injury. I've been helped by so many people. I'm thankful for having a second chance at life."

of the brain injury. Children require a specialized rehabilitation environment where they can recover from their injury, regain skills, and learn at an age-appropriate level.

Pediatric rehabilitation often emphasizes the three basic components of a child's life: family, school, and recreation; the environment in which rehabilitation services are delivered often resembles a child's world. For example, therapy rooms with chalk boards and

colorful surroundings resemble classrooms for school-age children. Bedrooms filled with toys, games, and pictures, recreate a warm, home-like environment.

If a lengthy rehabilitation stay is needed, families may consider a facility that offers educational services or has an accredited school program with classes conducted by certified special education teachers. These settings can offer a natural and comfortable environment in which children can learn skills and gain knowledge. Oftentimes, pediatric rehabilitation programs allow the public or private school system to provide special educational instructors at the rehabilitation facility within a specialized time slot during the child's therapy schedule.

Facility staff members often work closely with teachers from the child's home school. Teachers receive information on brain injury, the potential physical, cognitive, and behavioral problems, and rehabilitation techniques. To prepare for a child's return to school, teachers may visit the facility to meet with therapists to discuss progress, problems, and rehabilitative strategies that can be used in the classroom.

Families should seek out a facility that provides flexibility for visits and outings, responds to family needs, and most important, treats family members as members of the treatment team, and provides parent-child caregiver training. Many programs encourage families to be with their child as much as they can and to work side-by-side with therapists as long as it does not interfere with the child's functional progress. When the facility is not close to home, families should have the option to have frequent discussions with the health care team and their child so that they may continue to have involvement in the rehabilitation process.

A DAY IN THE LIFE

Below are sample daily schedules for two patients receiving neurologic rehabilitation. Scott is at an acute rehabilitation facility. Terri receives continued rehabilitation and training at a post-acute facility. (Both Scott and Terri are recovering from a traumatic brain injury.)

Scott's treatment plan focuses on active involvement in a variety of therapies including:
occupational therapy (OT),
physical therapy (PT), cognitive remediation activities of daily living (ADLs), classroom sessions in the enrichment center and therapeutic recreation (TR).
This rehabilitation program is designed for the remediation of problems involving physical, cognitive and behavioral dysfunction.

Time	Monday	Tuesday	Wednesday	Thursday	Friday
7:00	ОТ	OT	ОТ	OT	ОТ
7:30	ADLs	ADLs	ADLs	ADLs	ADLs
8:00 9:30	BREAKFAST				
9:00	Cog/Ed	Good Morning	Good Morning	PT	Good Morning
9:30			ORIENTATION		
10:00		Movement	Speech	Movement	Music Group
10.30	ОТ	Group	PT	Group	
11:00 12:00	Life Skills	Life Skills	Life Skills	Life Skills	Life Skills
12:00 1:00					
1:00		Enrichment	Speech	Enrichment	ОТ
1:30	PT	Center	ОТ	Center	Enrichment
2:00	Speech				Center
2:30	Psych	ОТ		ОТ	
3:00	Cog/Ed	PT		PT	Psych
3:30	TR			Cog/Ed	
4:00				Speech	
6:00	DINNER				
6:30	EVENING ACTIVITIES				

Terri's rehabilitation program focuses on successfully re-entering society. She is living semi-independently in her own apartment and responsible for preparing most of her own meals. This advanced program of rehabilitation is designed to enhance skills necessary for community reentry, vocational reintegration, physical reconditioning and stress management.

Time	Monday	Tuesday	Wednesday	Thursday	Friday
7:30 8:30			BREAKFAST		
9:00 10:00	Stress Mngmt	PT	PT	Voc Group	PT
10:00	Reasoning Group	ST	Reasoning Group	ST	Reasoning Group
11:00		Voc	RT	Leisure	Voc Group
11:30	Goal Adjustment	Group		Planning	Goal Adjustment
12:00 1:00			LUNCH		
1:00	Community	Planning & Org	Community		
1:30	Integration		Health	Planning &	Community
2:00	Meal Planning	Swimming	Money	Organization	Integration
2:30			Management		
3:00	Grocery		Memory	Social	Memory
3:30	Shopping		Group	Skills	Group
4:00				Psych	
4:30			ST		ST
5:00 6:00	DINNER				

OUTCOMES & CHALLENGES

In the past, many individuals who suffered traumatic brain injury didn't survive. However, with advances in medical technology, emergency treatments, and neurosurgical techniques, many victims of serious accidents resulting in brain injury now live, and in many cases, their long term functional outcomes are better than ever before.

The future holds many possibilities for survivors of brain injury. However, there is no typical outcome that a family may rely on since each injury affects each individual in a different way. Some survivors return to their families and resume their lives with residual deficits under control. Yet for other survivors, the return home will require adjustments in family life, family member roles, and relationships. Some survivors successfully return to their former jobs, many others re-enter the work force in a different capacity or on a reduced schedule; and some will not be able to work at all.

Clearly, the future for the survivors of a traumatic brain injury is not without challenges. During and following the transition back home, many individuals may experience setbacks and encounter new difficulties as problems and barriers to independence emerge. This is natural. What is important is that the family members work together to reach new goals. Strategies learned in the rehabilitation environment can be invaluable in helping solve or compensate for many problems at home. Families should also feel free to seek the help and support of professionals as well as friends. It is important to keep in touch with the rehabilitation facility and to seek outpatient therapy, counseling, in-home care, and other professional services as needed.

Successful outcomes after brain injury require a consistent commitment and a belief in rehabilitation, support, communication, and adaptation on the part of the survivors and their families. Perhaps the greatest challenge is striking the balance between having faith that progress is always possible and accepting and adapting to a new way of life.

PART III

For Families & Friends

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FAMILY ADJUSTMENT

When a brain injury occurs, the family suffers along with the patient. Many family members and friends may experience reactions that are quite similar to the feelings of grief that occur after a death. In fact, some may find that a severe brain injury can be more difficult to deal with than a death. Families often find that the person they love and may have depended on is alive, but different. Family members may spend day after day at the hospital and see little improvement, or they may see the person emerge from coma only to be aggressive, agitated, and confused.

In the first few weeks and months after the injury, family members and friends often experience a range of emotions as they try to come to terms with the overwhelming crisis. Strong feelings, that are difficult to accept or express, seem to inundate them. Although these experiences are quite normal, family members may feel guilty and confused by these feelings.

Family members may experience feelings of panic, fear, anxiety, hope, and denial as they first come to grips with a sudden brain injury. As the patient's condition stabilizes and rehabilitation begins, these feelings often give way to anger, frustration, and sorrow. These all are very normal reactions for family members to experience after a loved one suffers a serious injury. Family members and close friends should allow themselves to experience these emotions while avoiding the tendency to keep their feelings hidden or to feel guilty about emotions they experience. Repression of emotions can lead to depression, more anger, and feelings of inadequacy and helplessness.

Successful adjustment and recovery for families can come from giving support and communicating openly with all family members, including the survivor, as well as rehabilitation professionals such as the attending physician and the team psychologist. Successful adjustment may also stem from developing the strength and stamina to persevere through the good and bad days, and from having faith that improvement is always possible. Most importantly, family members need to care for themselves in order to be able to care for their loved one.

TIPS FOR CAREGIVERS

Some of the ways family members and friends can care for themselves are to:

- **Eat properly.** Skipping meals, eating on the run, or filling up on junk food will lessen energy reserves. Family members who function as caregivers should eat a regular diet rich in nutrients and vitamins.
- **Get enough rest.** Balance the time spent at the hospital and rehabilitation facility with other aspects of life. Families need to be rested and ready for the challenges that rehabilitation brings. Take time for exercise or to have a meal with a friend.
- Express feelings. Discuss positive and negative feelings with trusted friends, family members, or staff. Many people find it helpful to keep a diary or journal of their feelings and experiences. (Use the blank page in this booklet if you like. List your problems and worries and then ask yourself three questions: What things can I change and how can I change them? What do I need more information on and where can I get that information? What items are beyond my power and control to change? This exercise may help one to clear the mind, to feel more in control, and to take action when possible.)
- Avoid excessive use of alcohol. Instead of eliminating problems and relieving stress, alcohol can create
 more problems.
- Seek professional help. Psychologists, physicians, nurses, therapists, social workers, and other members of the treatment team are good resources for talking things over and getting answers to questions. These professionals can also direct families and friends to other sources of help.
- Ask questions. Families and friends should write down questions as they think of them and ask treatment team members for answers. Although many questions may have no clear-cut answers, a more thorough understanding can help families better deal with many issues.
- Maintain close family relationships. Try not to neglect other family members, especially children. Small children may not understand the sudden unavailability of a parent. Make time for personal contact with close family members. The telephone and e-mail are options when time away from the hospital to see other family members may not be possible.

SUPPORT & RESOURCES

Brain injury brings a great deal of change to the lives of family members and close friends – changes in lifestyles, daily routines, careers, and even in social relationships. In the initial days after the injury and during the rehabilitation process, family members may feel alone, isolated from friends, neighbors, and colleagues whose lives continue on "normally." This is partly because family members frequently engross themselves in their loved ones daily rehabilitation process, often for eight to ten hours a day, leaving little time for anything else.

Also family members may find it difficult to explain the complexities of brain injury, its wide range of problems, and the rehabilitation process to those not directly involved in the day-to-day situation. Close friends may remain in touch, but after such a dramatic event people often change their priorities and find they have less in common with those they were close with in the past. As a result, families and friends involved closely in the rehabilitation process may have less contact with their social networks.

Families and friends can pursue many avenues to build new networks of support. Most rehabilitation facilities have social workers or family advocates on staff who can help families and friends to find the support and resources they need. Many rehabilitation programs also coordinate a support group for families and friends of survivors.

Throughout the country there are networks and organizations that assist persons with brain injuries and their families to band together to share information and offer support. People new to the rehabilitation arena should seek out local and state brain injury support groups. These organizations provide families, close friends, and survivors with a forum to talk about what they are doing, problems they are having, and the coping strategies and techniques that work for them. Social workers or other rehabilitation professionals can help families identify local support groups.

On a larger scale, the Brain Injury Association of America (BIAA) has a network of state affiliates and support groups nationwide, and offers a wide variety of research and educational resources. Local libraries can also offer a wealth of information and resources on a wide range of topics, including how to choose a facility, pay for rehabilitation, and obtain grants and scholarships for brain injury survivors. They can be reached at 703-761-0750 or www.biausa.org. (Some resource references are listed in the back of the book.)

QUESTIONS & ANSWERS

How long do cognitive deficits persist following brain injury?

Some cognitive deficits can last forever; some will only last a few days or a few weeks. The recovery process and functional improvement may continue over several years. The future potential for additional recovery depends on the severity and type of brain injury as well as the amount of time that has elapsed since the initial injury.

DO COGNITIVE DEFICITS IMPROVE WITH REHABILITATION?

Individuals with brain injury usually learn to compensate for deficits. Compensation allows for an improvement in functional performance, which is the essence of post-acute rehabilitation. In addition, some cognitive deficits resolve from the natural healing process.

Do cognitive deficits influence personality or behavior?

New challenges can affect a person's mood, which, in turn, can affect their behavior and consequently their personality. Sometimes coping with and adjusting to cognitive impairments make very outgoing people become quiet and quiet people may become aggressive. A survivor's change in personality and behavior may also result from injury involving the brain centers which control the modulation of behavior and emotional function.

How long will post-acute rehabilitation last?

The purpose of brain injury rehabilitation is to help a person to become as independent and functional as possible. For some patients, that may take several weeks or months; for others it can take over a year. However the average length of an inpatient stay for most individuals is from two to six months. Following a course of inpatient brain injury rehabilitation, many individuals will often require a continuation of treatment in an outpatient therapy program or a transitional living program.

WILL MY SPOUSE BE ABLE TO WORK FOLLOWING VOCATIONAL REHABILITATION?

Variables that predict the potential for employment are socially appropriate behavior and the ability to learn work skills. If these skills can be achieved, there is a strong likelihood patients can go back to work; however, it may not mean returning to their former job.

How many hours of therapy will my son receive in post-acute rehabilitation?

Generally, individuals are provided with the maximum duration of daily therapies they can realistically tolerate each day. Although this will vary from patient to patient, the goal to strive for is six to eight hours of therapy a day sessions. Factors that may limit the amount of therapy received range from physical and mental fatigue, limited frustration tolerance, and behavioral outbursts.

WHY DOES MY DAUGHTER NEED POST-ACUTE REHABILITATION?

An injury to the brain that has caused cognitive or physical deficits may result in a loss of functional independence necessary to perform daily living skills. These impairments may cause an individual to lose the ability to ambulate, transfer, and to perform basic activities of daily living such as self-feeding, grooming, dressing, or bathing. They may also lose the ability to perform higher level activities of daily living such as the ability to manage finances, daily schedules or work responsibilities. People who have sustained brain injury need to relearn the skills necessary to function outside a hospital setting.

WILL WE BE ABLE TO BE INVOLVED IN OUR DAUGHTER'S REHABILITATION?

Family is the patient's best historian, and often knows better than anyone else how to motivate a patient in therapy. The clinicians will usually incorporate these motivational strategies into the patient's treatment plan. At times, family and friends may become a distraction and actually hinder therapy progress. Family members should be attentive to these cues and remove themselves for the benefit of the patient.

WHY DOESN'T OUR DAUGHTER REMEMBER THINGS FROM ONE HOUR TO THE NEXT?

Memory deficits are among the most common problems individuals have after a brain injury. However, during the rehabilitation process individuals learn to overcome memory deficits by using compensatory strategies such as taking notes and using a daily reminder schedule. In addition, as the parts of the brain involved in the memory process heal, the capacity for memory also improves.

WHAT TYPE OF REHABILITATION FACILITY IS NEEDED? HOW DO I CHOOSE ONE?

The patient's limitations that have resulted from a brain injury, as well as his or her strengths determine the type and level of care that is necessary. Patients having limited functional deficits may only require the reduced services provided in an outpatient program. Those patients having multiple areas of functional impairment will require inpatient comprehensive rehabilitation care at either a sub-acute inpatient unit or a post-acute residential facility. Those patients having serious medical problems may require acute rehabilitation services in a hospital based facility. Once the type of facility has been established, families should consider the staff's expertise in

dealing with neurologic injury. The family's confidence and comfort with the rehabilitation staff are also important considerations. All rehabilitation program options should be considered prior to choosing a program or facility.

How will rehabilitation be paid for?

Dependent upon the types of funding accepted by the individual programs, rehabilitation may be funded by Medicaid, Medicare, health insurance, or Workers' Compensation. Some states have special programs designed to assist families obtain financing for rehabilitation of individuals who sustained a traumatic brain injury that resulted from violence or motor vehicle accidents. Most facilities have professional staff that assists families in identifying alternative funding sources that may help alleviate the cost of rehabilitation.

APPENDICES

59 GLOSSARY

- Rehabilitation & Medical Terms
- Insurance Terms

65 RESOURCES

66 SUGGESTED READINGS

The following glossary contains many terms that one may encounter in the field of Brain Injury Rehabilitation. This glossary is divided into three sections; rehabilitation and medical terms, names of medications, and insurance terms. Some, but not all, of these terms are discussed in sections of this booklet.

Rehabilitation & Medical Terms

ABNORMAL POSTURAL SWAY - Greater than normal tone of muscles used to maintain the body in ordinary postures.

Abstract Thinking - Style of thinking in which concepts and ideas are understood and later applied in problem solving.

ACALCULIA - Inability to solve simple arithmetic problems.

Acute - Sharp, severe, having sudden onset and short course.

ACUTE REHABILITATION PROGRAM - Primary emphasis is on the early phase of rehabilitation, which usually begins as soon as the patient is medically stable.

ADL's - Activities of daily living. Routine self-care such as feeding, grooming, dressing, bathing and toileting activities.

AGNOSIA - Loss of the ability to recognize the meaning of a sensory stimulus. For example, visual agnosia is the inability to recognize familiar objects by sight.

AGRAPHIA - Inability to express thoughts in writing. The inability to write words, numbers or letters.

Anosmia - Loss of smell.

APHASIA - Loss of the ability to verbally express oneself and/or to understand language.

Behavior Disorders - Abnormal patterns of behavior, such as violent, destructive actions, that prevent acceptable participation in a social setting.

BIOFEEDBACK - A process in which information, such as heart rate, skin temperature, or electrical activity of muscles, is recorded and then relayed back as a signal on a computer screen so that the individual becomes aware of any alteration in the activity.

CASE MANAGEMENT - The process of facilitating the access of a patient to appropriate rehabilitation and support programs and coordination of the delivery of services.

CLOSED HEAD INJURY - Trauma to the head that does not penetrate the skull, but injures the brain.

Cognition - The conscious process of the mind by which individuals perceive, think, and remember.

COMA - A state of unconsciousness from which the patient cannot be aroused, even by powerful stimulation. The unawareness of self or environment.

DAY CARE - A service provided during ordinary working hours for the patient who requires supervision, including assistance with medication, meal preparation, dressing or moving about.

DIFFUSE AXONAL INJURY (DAI) - The widespread structural injury and disruption of axons, the wires of communication that exist between brain cells, that results from the forces of trauma.

DIFFUSE BRAIN DAMAGE - Injury to the brain in many different areas rather than in one location. Diffuse damage is common in severe traumatic brain injuries.

DIPLOPIA - Double vision; the perception of two images of a single object.

DYSARTHRIA - Difficulty in forming words and articulating often because of disturbances of oral muscle control when speaking.

Dysmetria - Inability to coordinate a movement of the extremities.

EXECUTIVE FUNCTION - An organizational cognitive brain function that allows for available information to be used in planning, prioritizing, sequencing, self-monitoring, self- correcting, inhibiting, initiating, controlling, or altering behavior.

EXTENDED CARE FACILITY - A residential facility for the patient who requires 24-hour nursing care or rehabilitative therapy on a less intensive basis than in an inpatient comprehensive rehabilitation center.

FLACCID - Lacking normal muscle tone; limp.

GLASGOW COMA SCALE - A standardized measure used by paramedics, nurses, and emergency physicians to establish the level of awareness in neurologically impaired persons following an acute traumatic brain injury by assessing responsiveness in three areas: eye opening, motor response, and verbal response.

HEMIPARESIS - Weakness of one side of the body.

HEMIPLEGIA - Paralysis of one side of the body.

IMPULSE CONTROL - The ability to withhold socially inappropriate verbal or motor responses.

INDEPENDENT LIVING PROGRAM - Community-based living to maximize a person's ability to be self-directed; allows an individual to live in his or her own home; usually combined with the opportunity to work when possible.

LogBook - A diary-like listing of an individual's daily activities, which can be used to help remind the person of upcoming events.

MILD TRAUMATIC BRAIN INJURY - A concussion. A concussion is manifested at the time of trauma by confusion and amnesia of less than 24 hours of duration often without a preceding loss of consciousness. Loss of consciousness, if any, does not exceed the duration of 1/2 hour.

Moderate Brain Injury - Brain injury manifested at the time of trauma by loss of consciousness of more than 1/2 hour but less than 6 hours in duration.

MOTOR CONTROL, FINE - Delicate, intricate movements used in such activities as writing, buttoning buttons, or piano playing.

MOTOR CONTROL, GROSS - Large, strong movements used in such activities as chopping wood, grasping large objects or kicking a ball.

Non-ambulatory - Not able to walk.

Orthosis - Splint or brace designed to improve function or provide stability.

OUTPATIENT - The patient residing outside the hospital but returning on a regular basis for more therapeutic services

PARAPARESIS - Weakness affecting the lower limbs.

PARAPLEGIA - Paralysis of the lower half of the body.

PERSISTENT VEGETATIVE STATE - A condition in which the patient is unable to speak or follow simple commands and does not respond in any psychologically meaningful way. The transition from coma to one of vegetative condition reflects changes from a period of no response to the internal or external environment, other than reflexively, to a state of wakefulness but with no indication of awareness. Normal levels of blood pressure and respiration are automatically maintained. Sleep-wake cycles may also be maintained.

PLATEAU - A temporary or more permanent leveling off of the recovery process.

PRE-MORBID CONDITION - Characteristic of an individual present before a disease or injury.

QUADRIPLEGIA - Paralysis of both arms and legs.

RANDOM MOVEMENT - An action of moving without obvious reason, purpose, or conscious effort.

RANGE OF MOTION - The range of movement at a joint.

Rehabilitation Engineering - Use of technical advances to help improve the quality of life for persons with disabilities

RESPITE CARE - Program that allows person and family to adapt to the residual deficits of brain injury; noninterventinal model to address socialization and recreation.

SEIZURE - An uncontrolled discharge of nerve cells, which may spread to other cells throughout the brain. The sudden attack may be accompanied by loss of bowel and bladder control, loss of awareness, and abnormal movements

Shunt, CSF - A procedure for draining excessive fluid from the brain. A surgically placed tube that drains spinal fluid from the brain ventricles to the abdominal cavity, heart, or large veins of the neck.

SPECIALTY SERVICES - These are rehabilitation services or programs developed for patients having special needs such as programs for those patients who are respirator- dependent, visually-impaired, or those requiring substance abuse treatment services.

Spontaneous Recovery - Recovery that occurs as damaged tissue heals.

Transitional Living - Training for living in a setting of greater independence; typical lengths of stay vary with an individual's ability to acquire community reentry skills.

UNILATERAL NEGLECT - Impaired attention to one side of the body. This usually occurs on the side opposite the area of the brain injury and usually in association with right parietal lobe brain injuries.

VEGETATIVE STATE - A state of survival after brain injury in which consciousness is altered to the degree that apparent wakefulness is regained but without conscious purposeful mental function. The patient is wakeful but is unaware and unresponsive to his or her surroundings. (See also persistent vegetative state.)

VISUAL FIELD DEFICIT - Inability to see objects in a specific region of view ordinarily perceived by both eyes.

Insurance Terms

ADJUSTER - A person who handles insurance claims. (see also Claims Service Representative).

AGGREGATE INDEMNITY - The maximum dollar amount that may be collected for any disability.

CARRIER - The insurance company responsible to pay the losses or for coverage of medical costs.

Case Reserve - The dollar amount stated in a claim file that represents the estimate of the amount to be paid.

CLAIMS SERVICE REPRESENTATIVE - A person who investigates losses and settles claims for an insurance carrier or the insured

DOUBLE INDEMNITY - A policy provision usually associated with death, which doubles payment of a designated benefit when certain kinds of accidents occur.

ELIMINATION PERIOD - A period of time between the period of disability and the start of disability income insurance benefits, during which no benefits are payable.

MEDICAID - A government funded program for persons, regardless of age, whose income and resources are insufficient to pay for health care. Qualification requirements are defined by the federal and state government.

MEDICARE - A government funded insurance program for disabled or aged persons. Qualification requirements are defined by the federal government.

Premium - Periodic payment needed to maintain an active insurance policy.

RESIDUAL DISABILITY BENEFITS - A provision in an insurance policy that provides benefits in proportion to a reduction of earnings that result from a partial disability.

RIDER - A document that amends the policy or certificate benefits or provisions. It may increase or decrease benefits, waive the condition of coverage, or in any other way amend the original contract.

THIRD PARTY FUNDING - Reimbursement for services rendered to a person in which an entity other than the recipient is responsible for the payments, e.g. an insurance company.

UNDERWRITER - A company that receives premiums and accepts responsibility for the fulfillment of the insurance policy contract; or the company employee who decides whether or not the insurance company should assume a particular risk; or the agent who sells the policy.

WAIVER - An agreement attached to a policy that exempts from coverage certain types of disabilities or injuries.

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