

A Family Guide to the Rehabilitation of the Severely Head-Injured Patient

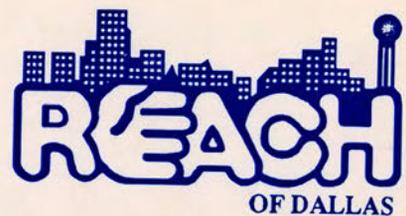
By Lenore A. Hawley

**Coordinator of Neuro-Behavioral Programming
The Ranch Treatment Center**



**Sponsored by
The Ranch Treatment Center
A Brown Schools Psychiatric Hospital
Austin, Texas**

DISABILITY



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Many families find the search for appropriate treatment facilities for their head-injured family member to be a long and frustrating process. With the founding of the National Head Injury Foundation, and its state and local chapters, families and professionals have begun to band together to call for additional services and resources for head-injured persons. New and innovative services have been developed over the past few years in response to this call. One example of services available is The Brown School system of treatment facilities. The Brown Schools currently offers three facilities for head-injured persons (two in Austin, Texas and one in New Kent, Virginia) providing a continuum of treatment which includes long-term rehabilitation, acute medical services, behavior modification programs and programs aimed at reintegrating the patient into the family and community.

For additional information regarding services and resources across the country, contact:

The National Head Injury Foundation
18A Vernon Street
Framingham, MA 01701
(617) 879-7473

For additional information regarding The Brown School's continuum of treatment, contact:

The Ranch Treatment Center
1106 Dittmar Lane
Austin, TX 78745
(national watts line) 1-800-252-5151
(texas watts line) 1-800-252-2878

The Alternative Living Center
1118 Dittmar Lane
Austin, TX 78745
512-447-0744

Cumberland, A Hospital for Children and Adolescents
P.O. Box 150
New Kent, VA 23124
(national watts line) 1-800-368-3472

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INTRODUCTION

You are not alone. It is estimated that over 50,000 people per year suffer a head injury severe enough to keep them from returning to normal lives. (1) And, when one considers the families of the injured -- the parents, spouses, siblings and children -- the actual number of "victims" reaches epidemic proportions.

Families are often left with many unanswered questions when such a tragedy strikes. The medical terminology, the uncertainty and the constant waiting, can be frustrating. Three general questions always seem to arise: (1) What exactly has happened? (2) What do we do next?, and (3) What is the prognosis?

In the following pages we will attempt to answer these questions. We will look at how the brain functions and how it relates to behavior, what kind of disabilities result from head injuries, what is involved in the rehabilitation of the head-injured and how the family can be an active member of the treatment team. Prognosis will be discussed as well. This is perhaps the most difficult question to address, but we will attempt to offer some insights and experiences which may make understanding it less frustrating.

Significant variables exist among head-injured patients, from the person with a minor head injury who returns to his previous functioning level within a few weeks, to the patient who remains comatose for the remainder of his life. This booklet will focus on moderately and severely head-injured patients -- those persons who will be involved in active rehabilitation programs and who may require some level of structure or supervision for most of their lives. Recovering from a traumatic head injury is a slow, uncertain and perhaps lifelong process. Families can more confidently face such a tragedy if they are armed with information, resources and an understanding of what has occurred and what the future may hold.

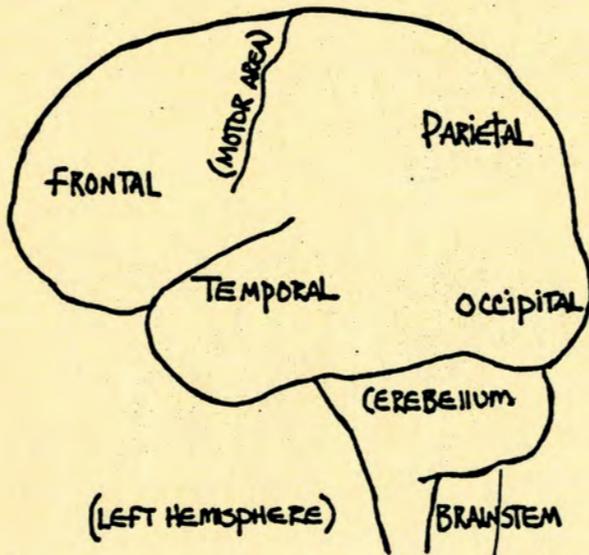
Many of the terms we will use throughout this booklet may be unfamiliar to you. All of the terms which are CAPITALIZED within the text are defined in greater detail in the glossary. For the sake of simplicity, we will use male pronouns (he, himself, his) when referring to the head-injured person.

WHAT HAS HAPPENED?

A. The Brain and How it Works

The brain is the control board for all of the body's functions, including thinking, moving and breathing. It receives messages, interprets them and then responds to them by enabling the person to speak, move or show emotion. (2) The brain is protected by a thick layer of bone (the skull) and is surrounded by cerebrospinal fluid which allows the brain to "float" slightly within the skull. This fluid also fills the open areas within the brain (the VENTRICLES). The brain is comprised of the CORTEX, where most thinking functions occur; the CEREBELLUM, which coordinates movement; and the BRAIN STEM which controls consciousness, alertness and basic bodily functions such as breathing, respiration and pulse.

The cortex is the largest part of the brain and is divided into four "lobes" each of which specializes in particular functions and skills.



FRONTAL LOBE: emotional control, motivation, social functioning, expressive language, inhibition of impulses, motor integration, voluntary movement.

TEMPORAL LOBE: memory, receptive language, sequencing, musical awareness.

PARIETAL LOBE: sensation, academic skills such as reading, awareness of spatial relationships.

OCCIPITAL LOBE: visual perception.

In addition the cortex is divided into two hemispheres. The dominant hemisphere (usually the left hemisphere) controls verbal functions (speaking, writing, reading, calculating), while the right hemisphere generally controls functions that are more visual-spatial in nature (visual memory, copying, drawing, rhythm).

Damage to the brain may occur at the time of impact, or may develop sometime after the injury (due to swelling or bleeding). When the head is hit with sufficient force, the brain turns and twists on its axis (the brain stem) causing a loss of consciousness. If the person remains unconscious for more than a brief period of time he is considered to be in a COMA. (2) When in a coma the person is unable to open his eyes, speak or follow commands. If the injury is severe the area of the brain where the impact occurred may be bruised and damaged. Also, the brain may rebound against the opposite side of the skull resulting in further damage (CONTRA-COUP). It is because of this twisting and rebounding that the traumatically head-injured patient usually receives damage to multiple parts of the brain (DIFFUSE damage).

Bleeding inside the brain (HEMORRHAGE) may also occur, causing a mass of blood to accumulate (HEMATOMA). This mass of blood may put pressure on the brain tissue around it leading to further damage. This is why intracranial pressure is carefully monitored. Blood flow to other parts of the brain also may be cut off due to the bleeding (ANOXIA). Swelling (EDEMA) also may occur following a head injury, and can damage the brain because the skull does not allow the brain to expand.

B. Characteristics of the Head-Injured Individual

Physical, mental and personality changes may occur following a traumatic head-injury. Each patient's recovery is unique due to pre-injury personality and learning style, location and severity of the injury, time elapsed since the injury and the individual's psychological reaction to the injury. Therefore, not all of these changes will occur in your family member. However, in the following paragraphs we will describe some of the characteristics which are commonly associated with head-injured patients.

(a) Motor Deficits: The patient may experience paralysis of one side of the body (HEMIPARESIS), paralysis involving both legs and both arms (QUADRAPARESIS), poor balance, lowered endurance, a loss of ability to plan motor movements (APRAXIA), poor coordination (ATAXIA) and abnormal tone and muscle stiffness (SPASTICITY). The individual also may lose the ability to stabilize his trunk even though his limbs are functional (PROXIMAL

INSTABILITY). Direct damage to muscular and bony tissue may be sustained (orthopedic deficits).

(b) Perceptual Deficits: All sensory systems may be affected, producing changes in hearing, vision, taste, smell and touch. Such changes may involve an increase in sensitivity or a decrease or loss of sensitivity. These changes may include a heightened sensitivity to touch (TACTILE DEFENSIVENESS), loss of sensation to parts of the body, inability to see items on one side of the visual field (VISUAL FIELD DEFICIT), neglect of items located on one side of the body or ignoring one side of the body (UNILATERAL NEGLECT), double vision (DYPLOPIA), difficulty perceiving how far away something is (DEPTH PERCEPTION), decrease in the quality of what is seen (visual ACUITY) or heard (auditory acuity), and loss of the sense of smell or taste. Sensitivity to movement might be heightened (VESTIBULAR deficits) and the person may have difficulty understanding where his limbs are in relation to his body and the space around him (proprioceptive disorder).

(c) Speech and Language Deficits: The patient may have difficulty understanding what is said to him (receptive APHASIA), or difficulty expressing his thoughts (expressive aphasia). Some patients have a specific difficulty recalling nouns or names (ANOMIA). The patient may also have difficulty pronouncing or articulating words (DYSARTHRIA).

Many families find that the COGNITIVE (thinking) deficits and personality changes that occur in their family member are the most difficult to accept. When we can see a disability (for example, a person in a wheelchair) it is easier for us to understand the limitations of the individual and what we can expect of him. The cognitive and personality changes cannot be "seen" easily; therefore, they are often more difficult to explain, understand and accept.

(d) Cognitive Deficits: Patients may often be confused about the current time, where they are, who they are and who the people are around them (DISORIENTATION). In addition, the head-injured person may exhibit an inability to focus on a task without being distracted (ATTENTION deficits), inability to maintain attention to a task over a period of time

(CONCENTRATION deficits), difficulty recalling and "storing" recent information (MEMORY deficits) and difficulty learning new information. He may also display poor JUDGEMENT and an inability to plan events or tasks, difficulty drawing conclusions and making decisions (PROBLEM SOLVING deficits), difficulty switching from one topic or task to another (PERSEVERATION), and may have difficulty adapting to changes in daily routines (INFLEXIBILITY). The patient may be unable to understand ABSTRACT concepts. Intellectual functioning may also decrease.

(e) Denial: Many head-injured patients may lack an awareness or an appreciation of their current situation. This may be caused by both the actual damage to the brain and by the person's reaction to the injury. A patient may completely deny that a disability is present and may consequently reject treatment or attempt to do things that may be dangerous to himself or others. As examples, a patient who is unable to walk may attempt continually to get up from his wheelchair or a patient with a visual field deficit may attempt to drive a car. Denial is particularly difficult for the patient whose deficits are not easy to see. These patients may at first appear to be functioning well, but may have cognitive deficits such as impaired judgement and problem solving. Such patients may leave treatment before they are ready to function independently.

(f) Regulatory Disturbances: The patient may become easily fatigued and require rest periods throughout the day. Because of this he may not be able to sit through long tasks or therapy sessions and may perform better at certain times of the day than others. In addition, the patient may experience changes in sleep patterns, such as not being able to sleep through the night but instead requiring several shorter periods of sleep. Changes may also occur in the patient's ability to regulate his body temperature, as well as his consumption of foods and liquids. Loss of bowel and bladder control also may occur.

(g) Personality Changes: The head-injured patient may show a lack of interest in the world around him (APATHY) and a decrease in motivation. He may exhibit extreme and rapid changes in emotion (EMOTIONAL LABILITY),

irritability, depression and a lack of initiative. The patient may have difficulty inhibiting impulses and emotions (DISINHIBITION) resulting in temper flair-ups, aggression, cursing and a generally lowered FRUSTRATION TOLERANCE. The disinhibited or impulsive patient may act upon sexual impulses inappropriately (while other head-injured patients may have decreased sexual drive). Such patients also may exhibit social immaturity by making "overly friendly" or "silly" comments.

(h) Traumatic Epilepsy: Following a head injury, a patient may experience seizures. Seizures may occur immediately following the injury or may not develop until months or years later. One-fourth of all patients who have early seizures also experience "late-onset" seizures.⁽³⁾ Two types of seizures may occur. The first is a major motor or generalized seizure in which the patient may begin making rapid body movements, lose consciousness, lose bowel and bladder control, and breathe irregularly. The patient may regain consciousness on his own after a few minutes, feel confused and complain of soreness. In some cases the patient may require medication to stop the seizures. A second type of seizure is called a focal motor seizure. A patient experiencing this type of seizure may make odd twitching or jerking movements. The patient usually will not lose consciousness and the seizure will not last long. Often the patient and the people around him are not aware the seizure occurred. It is often difficult to predict if a patient will experience seizures. Many patients are placed on ANTI-CONVULSIVE MEDICATIONS such as Dilantin, particularly during the first two years post-injury when seizures are most prevalent. Medications are prescribed when seizures occur, or as a preventive measure.

WHAT HAPPENS NEXT?

A. The Rehabilitation Process

The head-injured person goes through a process of SPONTANEOUS RECOVERY -- or natural healing -- which takes place in the first six months following the injury and continues up to two years. Rehabilitation challenges and channels the process of spontaneous recovery.⁽⁴⁾ It involves both relearning skills and learning ways to compensate for skills the patient has lost. The goal of rehabilitation is to return the person to as independent a level of functioning as possible.

The course of rehabilitation varies depending on the patient's needs and the availability of services. We will describe in general the types of programs and procedures which may be involved in your family member's rehabilitation.

Rehabilitation should begin at the scene of the accident, as soon as emergency personnel arrive. In the hospital emergency room the medical team is faced with 1) sustaining life and 2) diagnosing the immediate problem. The patient will be evaluated immediately to determine his medical status. Many hospitals use a rating scale called the GLASGOW COMA SCALE to determine the severity of the neurological damage. This scale rates the patient according to his motor responses, eye opening and attempts to communicate.⁽⁵⁾ A tube may be placed in the patient's throat to assist him in breathing (endotracheal tube), and the patient may be attached to a respiratory machine (ventilator). A series of X-rays (CT-SCAN) may be taken of the brain to help diagnose the exact problem and to determine the need for surgery. Surgery is indicated if there is a need to relieve pressure (intercranial pressure), or if a hematoma is present. Once the patient is somewhat stable, he is moved to the intensive care unit (ICU) for continued close observation and acute care. The patient will remain in intensive care until he no longer requires acute monitoring.

If the patient is comatose, therapists and nursing staff may provide stimulation and exercise the patient even before he regains consciousness. The patient's body may be moved in patterns to normalize muscle tone and prevent deformities of the muscles and bones (orthopedic deformities). Often family members are asked to participate in a program to awaken the patient. This may

involve talking with him, touching him, playing familiar music, and bringing in flowers, perfumes and familiar foods. The patient is routinely repositioned during this time, often in an upright or sitting position, so that skin breakdown does not occur.

Some general hospitals maintain a rehabilitation unit where rehabilitation therapies take place. As the patient becomes ready for more active and intensive rehabilitation, he will be moved to such a unit, or may be moved to a separate short-term rehabilitation hospital. In such settings, the patient will receive additional active rehabilitation involving physical, occupational and speech therapy services as well as continued medical, nursing and social work services. The patient may be evaluated by a neuropsychologist and a vocational rehabilitation specialist. In addition to the patient's schedule of therapies and activities, he should be allowed periods of "quiet time" throughout the day, as he will fatigue easily. However, it is important that the family provide the patient with emotional support and orientation during this period. As he becomes more alert, he may be confused about what has happened and may be angry or fearful.

Many patients require continued rehabilitation and a structured environment beyond the short-term or acute stage. In the past few years programs have been developed to meet this need. Such programs may provide specialized training in vocational rehabilitation, cognitive retraining, independent living skills and behavior management, as well as continued treatment in other therapy areas. These settings also may offer expanded family counseling and psychological services. The length of time a patient remains in such a setting varies, but it may be up to several years, depending on the severity of the injury.

Other treatment programs are being developed for patients who have completed an intensive long-term program, or who do not require such a structured environment. Generally, "group homes" provide a structured and supervised living situation within the community. The patient's day may be structured and planned for him and involve exercise programs, chores and leisure activities. Some patients who live in such settings may be involved in day-treatment programs where therapy services are offered. Group living situations where the patient takes more responsibility for structuring his day often are referred to as

"transitional living centers" or "halfway houses." In such settings, the patient is expected to be more independent, although supervision and support are provided. The patient may work in the community or may attend school, and is expected to make use of community resources including public transportation. The goal of such facilities is to be a "transitional" placement for the patient between the hospital and the home. However, it is important to point out that many patients require continued structure and supervision for the remainder of their lives, and that reintegration into the community is the most difficult aspect of the rehabilitation process.

B. The Treatment Team

A variety of professionals may work with the patient and the family during the rehabilitation process. These may include:

- Neurologist
- Neuropsychiatrist
- Physiatrist / Doctor of Rehabilitative Medicine
- Respiratory Therapist
- Neuropsychologist
- Rehabilitation Nurse
- Dietitian
- Physical Therapist
- Occupational Therapist
- Speech Therapist/Pathologist
- Cognitive Retrainer
- Educational/Vocational Rehabilitation Specialist
- Social Worker
- Recreational/Activity Therapist
- Unit Staff.

Each of these service areas specializes in a specific aspect of the rehabilitation process. To insure that the many needs of the head-injured person are met, many treatment facilities use an "interdisciplinary approach." Such an approach emphasizes the whole patient, stressing communication and consistency among team members. The team is usually led

by a physician who may be a neurosurgeon, neurologist, neuropsychiatrist or physiatrist. Each team member completes a thorough evaluation of the patient and shares this information with the other members of the team so an integrated treatment plan can be developed. Such a treatment plan is based upon an understanding of the individual's unique combination of abilities and disabilities. Here are some examples of how such a team approach can be helpful. An occupational therapist might advise a vocational instructor regarding the placement of work materials for a visually-impaired patient, or might suggest types of work tasks which might be useful in increasing a patient's fine motor skills. A physical therapist may advise the unit staff regarding the proper procedure for transferring a patient from his wheelchair, while the neuropsychologist may assist other team members in understanding the complex cognitive disabilities in the higher-functioning patient.

The team continuously evaluates the patient's progress and discusses long-term goals. In this way, with all members of the team working together, the patient is constantly evaluated as a "whole" person. (That is, even though the person's motor skills may progress to the point where he can move about independently, behavioral deficits may make it necessary that he be under constant supervision.)

With so many different people working with your family member, it may at times be difficult to understand who is doing what and to whom specific questions should be directed. The following are descriptions of some of the professionals who may be working on your patient's team:

Neurologist

A neurologist is a physician who specializes in disorders of the nervous system, including disorders of the brain. The neurologist may be involved in initial evaluation of the patient's neurological status. He may diagnose the type of injury the brain has sustained and make recommendations regarding the need for surgery or medications. The neurologist may be requested to reevaluate a patient if he begins to show signs of regression during the recovery process. Neurologists are particularly important to the treatment of seizure disorders.

Neuropsychiatrist

A neuropsychiatrist is a medical doctor who specializes in the relationship between the neurological system and psychiatric/psychological disturbances. Such a physician may provide direct therapeutic services, including individual and family therapy. He also may prescribe medications to aid the treatment of agitation, depression or moodiness.

Physiatrist/Doctor of Physical Medicine

The field of physical medicine and rehabilitation involves aspects of medical orthopedics and neurology. A doctor of physical medicine is often referred to as a physiatrist. In some hospitals, such a physician directs the therapy services including physical therapy, occupational therapy and speech therapy.

Respiratory Therapist

The respiratory therapist is usually involved in the early stages of recovery when the patient may experience difficulty breathing. The therapist is responsible for maintaining the ventilator, and assisting the patient who is unable to cough up secretions ("suctioning").

Neuropsychologist

A neuropsychologist is a PhD psychologist who has specialized training and expertise in the interrelationships between the brain and behavior. The neuropsychologist performs a variety of tests to determine the patient's intellectual, cognitive and personality functioning. This information is then shared with the patient, family and other members of the team so that a treatment program can be developed which is tailored to the specific patient's needs. The neuropsychologist also may provide individual and group therapy to the patient and/or the family, to address their adjustment to the injury, their denial of deficits and redevelopment of the patient's social interaction skills.

Rehabilitation Nurse

The duties of the rehabilitation nurse vary, depending on the stage of treatment. If the patient has acute medical needs, the nurse is responsible for evaluating the patient's daily needs in relation to

positioning, bowel and bladder functioning, hygiene, physical health and neurological status. The nurse relays information daily to the attending physician so that necessary changes may be made in the patient's medication or treatment. In later stages of treatment, the nurse also may be responsible for providing bowel and bladder training, and assisting in the retraining of self-care skills. Rehabilitation nurses also may be employed by funding sources (such as insurance companies) or by individual families, to coordinate the patient's course of rehabilitation. This will be addressed further in the section entitled "Resources for Financial and Placement Assistance."

Dietitian

The dietitian evaluates the patient's nutritional needs, taking into consideration the patient's pre-trauma weight and eating habits, as well as extensively investigating the patient's nutritional history since the injury was sustained. Following a traumatic head injury, a patient's nutritional needs may change drastically. He may lose considerable weight during the early stages of recovery when the body requires a higher caloric input because of the need for physical recovery from the trauma. Patients also may lose the ability to control their appetites. The dietitian may devise a special diet for the patient to help them gain weight, lose weight or to aid in bowel and bladder functioning. In addition, a special diet may be necessary for patients with difficulty swallowing or chewing. The dietitian also may provide nutritional education to the patient (in individual or group settings) to help him regain control of his nutritional needs and understand the necessity for dietary interventions.

Physical Therapist

The physical therapist's goal is to return the patient to the highest level of motor functioning possible; for one patient this may mean learning to walk again, while for another it may mean maintaining normal sitting posture in his wheelchair. For still another patient the goal may involve higher-level skills such as being able to manipulate large equipment or to play basketball. The physical therapist extensively evaluates the patient's muscle tone, movement, balance, endurance, ability to ambulate, ability to plan motor movements, strength and coordination. If the patient

requires special equipment (such as a wheelchair, walker or splint) the therapist evaluates the patient's ability to use the equipment, as well as determining the correct size and type of equipment for the specific patient. The therapist constructs a program of exercises and movements to develop the patient's motor skills. A wheelchair is often used not only for the patient who is unable to ambulate, but for others as a therapy tool. The recovering patient needs all the energy he can get, as each small task which was once be performed automatically may now take considerable cognitive and physical energy. The patient may be able to endure a more extensive therapy schedule if a wheelchair is used.

Occupational Therapist

The occupational therapist focuses on the physical, cognitive and perceptual disabilities which influence the patient's ability to perform functional tasks. The therapist evaluates the patient's ability to use his fingers and hands (fine motor skills), perceptual skills, cognitive functioning, eye-hand coordination and "self-care skills" such as dressing, dining and bathing. Therapy sessions may involve the use of mats, balls, peg boards, puzzles and physical movement exercises. Functional tasks also may be used such as cooking, working with tools, using art materials, swimming or taking trips in the community. The therapist also may perform splinting of the patient's arms or hands and may provide the patient with special equipment (such as adaptive eating utensils, large print reading materials, dressing aids or adaptive seating devices).

Speech Therapist/Pathologist

A speech therapist evaluates the patient's motor-speech skills, expressive and receptive language skills, writing and reading skills, and determines whether the patient requires an extensive hearing evaluation by an audiologist. The therapist also evaluates the patient's cognitive functioning, as well as his social interaction skills (such as whether he can maintain eye contact and initiate conversation). If indicated, the therapist may refer the patient to an ear, nose and throat specialist (Otolaryngologist).

Therapy may involve developing the patient's speech, listening and conversational skills, and higher level cognitive skills (such as understanding abstract analogies, making decisions, etc.). It also may involve social interaction or conversational skills. Patients may be recommended for speech therapy even though they do not have apparent speech problems, but because they have deficits in "higher-level" language functioning which could inhibit their ability to be reintegrated into the community and the work environment.

Cognitive Retrainer

Cognitive retraining is a new field of study developed in the last few years, specifically to meet the special needs of the brain-injured patient. To define cognitive retraining we should first define cognition. Cognition refers to knowing, awareness, perception of objects and remembering ideas; it is the learned set of rules by which we think -- the rules on which all learning is based. Cognitive retraining can be defined as the relearning of cognitive skills disrupted after brain damage, and/or the learning of methods to compensate for disruption of cognitive skills, based on assessment of the individual's set of abilities and disabilities. Put simply, it could be defined as "relearning how to learn".

All members of the treatment team actually do cognitive retraining, since throughout the patient's rehabilitation program he is being prompted to think, respond and learn. Some facilities now have cognitive retraining departments or programs. The staff who work in these departments may have a background in neuropsychology, speech therapy, occupational therapy or education. In addition, they have experience and training in the rehabilitation of the head-injured patient. Cognitive retraining addresses problems in orientation, concentration, memory, judgement, sequencing, problem solving and other cognitive skills. Cognitive retraining also may address perceptual problems. Often, cognitive retraining involves the use of computers and video games. They have been found useful since they motivate the patient, give him immediate feedback on his performance and can be programmed to focus on a specific skill and demand that the patient remain attentive. As the patient progresses, the programs can be made more systematically difficult.

Educational/Vocational Rehabilitation Specialist

If the patient is of school age when the injury occurs, he may require reintegration into an educational program. Often, due to cognitive and behavioral changes, the patient is unable to return to his former school environment and may require tutoring or special education services. The instructor evaluates the patient's academic skills (including reading, writing and math) and develops an individualized educational program for the patient. If the patient is an adult, "reeducation" in basic everyday skills may be necessary. This may include such functional skills as making purchases, balancing a checkbook, using community resources and obtaining loans. The adult patient also would receive vocational rehabilitation services. These would include evaluating the patient in the areas of work skills and interest, ability to follow directions and routines, work habits and attitudes, work endurance and the ability to work cooperatively with others. If a vocational or prevocational program is offered within the treatment center, the patient may be enrolled in a series of work stations or prevocational classes. A prevocational program focuses on the underlying skills necessary to enter a working situation (concentration on a task, cooperative work, endurance, following directions), while a vocational program teaches specific job skills (such as typing, welding, printing, etc.).

Social Worker

The social worker serves as a liaison between the professional team and all other parties concerned with the patient including the family, funding sources, friends and past or future placements. The social worker completes an assessment of the patient's history, particularly the psychological and social history ("psycho-social assessment"). This assessment will include the patient's pre-trauma personality style, educational history, developmental milestones (when he took his first step as a baby, etc.), and leisure interests and skills. The assessment will outline the family structure (number of children, marital status, names of siblings, etc.), the family's reaction to the injury, and the goals that the family has for the patient. Such information can help the staff better understand the patient and treat orientation and memory deficits. The team needs to understand the family's

goals before setting rehabilitation goals for the patient or discussing long-term plans.

Recreational/Activity Therapy

The recreational therapist may evaluate the patient's leisure interests and skills, ability to initiate leisure activities, group interaction skills and skills in the community. Therapy often takes place in a group setting focusing on such activities as cooking, gardening, exercise, games, arts and crafts, music, shopping, attending community events and using community resources (such as libraries, public transportation, community centers). Sessions also may focus on group interaction skills, increasing leisure initiative, decision making skills and "dating" skills.

Unit Staff

Many treatment teams include staff who work with the patient on the living unit and are responsible for structuring, advising and teaching the patient when he is not in therapy sessions. These team members may be called "mental health workers", "child care workers", "nurses aides", or "rehabilitation assistants". Usually these staff come from a variety of backgrounds; they may have a degree in psychology, social work or education, or their backgrounds may be in areas unrelated to the rehabilitation field. In some facilities the unit staff may include registered nurses (RN) or licensed vocational nurses (LVN). The job responsibilities of the unit staff vary, but often they are involved in carrying out behavioral programs, reteaching self-care skills, and helping the patient relearn how to use leisure time. The unit staff works closely with other members of the treatment team to insure that the patient's therapy programs are followed throughout the day. Unit staff may attend therapy sessions with the patient and may assist in therapy. The unit staff can provide the team with valuable information regarding the patient's functioning on the unit and in the community. Unit staff can be especially helpful to the family in providing information on the patient's overall progress.

The Family

The family is one of the most important components of the rehabilitation team. They are the one continuous support system which follows the patient through the rehabilitation process. The family is the team's historian, providing detailed and insightful information regarding the patient's history. Such information is vital to the rehabilitation process as the team needs to be aware of the patient's pre-trauma personality, interests and learning style. The team will use this information to determine what treatment strategies should be used and what goals should be set for the patient. The family also provides a psychological support system for the patient. They are familiar faces and provide reassurance and motivation to keep the patient going. In addition, the family can give the patient constant feedback on his progress. A third role the family can fill is an advocacy role. The family can identify additional resources in the community which may be helpful in the patient's rehabilitation. In the advocacy role, the family can help raise the awareness of the general public as to the needs of the head injured population. Many families do this through organized groups such as the NATIONAL HEAD INJURY FOUNDATION (NHIF). A final role of the family is that of a planner. Other team members can develop plans for the patient, but only the patient and the family can decide if those plans are financially and emotionally realistic for the family. (6)

C. Principles of Treatment

The study of rehabilitation of the head-injured individual is currently in the developmental stages. In the past few years many new ideas, theories and strategies have been presented at conferences, in professional journals and in texts. This sharing of information has produced a variety of "principles of treatment." A set of such principles will be presented here. They may help you to understand the approach taken by rehabilitation professionals and also may serve as guidelines for you in your interactions with (and expectations of) your family member. It should be noted that principles and philosophies of treatment vary among facilities. The information presented here represents one model of rehabilitation.

1. Treatment Must Begin At the Patient's Level (4,8)

One of the difficult aspects of treating the head-injured patient is determining at what level he is currently functioning in a specific skill area. The instructions and/or cues and assistance given to the patient may need to be altered to teach the patient successfully. Tasks may need to be broken into "steps," beginning just above the step where the patient is currently functioning. If a task is too simple for the patient he will not be challenged or motivated and no learning will take place. He also may feel insulted, angry and frustrated. Likewise, if a task is too difficult he will feel unsuccessful and anxious, and no learning will occur.

We have noted that the head-injured patient is quite variable and unique. The head-injured patient varies not only from other patients, but also varies from one skill to another (being independent in one area and requiring significant assistance in others). In addition, the patient's skills may vary over time. He may make rapid and dramatic changes, particularly in the early stages of recovery. The patient may reach "plateaus", where progress ceases for a period of time, or he may actually regress. Such regression may occur as the patient becomes more aware of what has happened to him and becomes frustrated with the changes that have taken place.

2. Treatment Must Be Consistent, Repetitious and Structured

When a person sustains a severe head injury, he loses some of the internal structure upon which learning and thinking are based. Therefore, he must obtain this structure externally from his environment. It could be said that treatment of the head injured involves changing the environment as much as it does changing the patient. (7) An environmental structure can be built around the patient that "fills in the gaps" left by his disabilities so that he can use the skills he does have to continue growing and learning.

Such a structure may include placing items in the same place every day so the patient can find them, giving the patient a written schedule of the day's events, posting signs on the wall as reminders ("take glasses to reading class," or "call mom on Thursdays") or giving the patient a list of

things he can do in his leisure time. The structure also may involve having consistent strategies that team members use when interacting with the patient. For example, the team may decide to praise the patient when he greets people who pass him to increase his initiation of social interactions. Such a strategy will be successful only if it is used consistently throughout the patient's day. If a patient is reinforced for a behavior in one situation but not reinforced for the same behavior in another environment, the likelihood of that behavior becoming learned is reduced.

The saying "practice makes perfect" is basic to learning, and is particularly relevant to the head-injured patient. The patient may learn a task one day and be totally unable to perform it the following day. Treatment must be repetitious, to the point of "over learning."

3. As the Patient Progresses, the Difficulty of the Task Must Increase and the External Structure Must Decrease

As the patient progresses he will begin to internalize skills and abilities. As this occurs, the external structure built around the patient must be slowly removed so that learning can continue. (8) There must be a need or demand for learning to take place. For example, when a child is first learning to ride a bicycle, he needs some external assistance; a parent's steadying hand or perhaps a set of training wheels for extra support. As the child begins to learn, the external aids are slowly taken away. If they are not the child will never master the skill and will always need assistance. Retraining after a head-injury can be quite similar, even though the end result may not be complete independence. Whether the skill to be learned is improved judgement, memory or balance, the external treatment structure built around the patient must slowly be removed or the patient will remain dependent on it. However, it must only be removed when the patient is ready; for just like the child learning to ride a bicycle, if the assistance is removed too quickly he will falter.

4. Consistent Feedback and Reinforcement Should Be Provided

An important aspect of learning is knowing what we have done right and wrong so that we can be as successful as possible in the future. Each of us is constantly using the responses of others, our interactions, our experiences, our successes and failures, to determine what we will do in the future. Without such feedback, we would make mistakes over and over. We would never learn. The head-injured patient often lacks an awareness of what is going on around him. He may not pick up on the subtle cues and feedback in the environment which help him evaluate his performance. If the patient forgets to go to therapy and it is not pointed out to him, chances are he will forget again the following day. Likewise, if a patient is successful at a task, he is more likely to use the same strategies in the future if his successful behaviors are acknowledged. (9)

5. Information Should be Presented in More Than One Sensory Modality

The brain is complex enough that one sensory modality (vision, touch, taste, hearing or smell) may be severely disabled while another is functioning normally. The treatment team will evaluate which type of input is most successful for the individual patient, and channel information through that sensory system. For example, "Joe" may have poor visual memory skills, while "Tom" has poor auditory memory skills. Tom may have difficulty recalling the names of his therapists, but may be able to learn them if the names are paired with visual cues (pictures, name cards). If maximum learning is to take place, information should be presented in a variety of modalities.

6. Information Must Be Motivating and Relevant to the Patient if it is to be Learned

When a person has deficits in attention, concentration or motivation, information must be highly relevant to be noticed and attended to. Each of us learn and work so we can reach specific goals. Tasks which are goal-related, having a concrete observable end in sight, can be attended to easier to attend to and can be more motivating. It is important to keep in mind that a head injury may severely limit a person's ability to achieve

his former goals. If those goals are unobtainable, new ones must be developed.

HOW MUCH CAN WE EXPECT? - THE QUESTION OF PROGNOSIS

"First they told us he wouldn't come out of the coma, but he did. Then they said he would be a vegetable, and would never be able to walk or talk; but he regained those skills. Now they tell me he'll never be exactly like he was before the accident, and I just can't believe it; I can't believe that one last miracle won't come true." (10)

The families of head-injured persons are frequently frustrated by the degree of uncertainty accompanying the injury, not knowing what level of recovery to expect and therefore being unable to adjust or make plans for the future. Three basic factors make it difficult to predict recovery: many variables affect recovery, many of these variables are difficult to measure and every individual is unique. Despite these problems in predicting the level of recovery, it may be helpful to get some general ideas about several of these factors and what to expect regarding recovery.

The rate of recovery is most rapid during the initial weeks and months after the head-injury, or after the person awakens from the coma. The relatively rapid recovery during this early period often leads both the family and the treatment staff to predict continued rapid, perhaps complete, recovery. Unfortunately, recovery does slow down after a time and this is often a disappointment to families. However, this slow down in progress does not mean an end to recovery -- rehabilitation professionals have reported continued gains in functioning even several years post-trauma.

Several factors should be considered when making prognostic statements. These include the nature and extent of the injuries, pre-injury personality and level of functioning, opportunity to receive appropriate rehabilitation, length of coma, quality of early medical care, the amount of time that has passed since the injury, the rate of recovery and the "recovery environment" (social, family and self-imposed demands). (11)

Although many of these factors are beyond the family's control, the family can facilitate recovery by finding rehabilitation resources and using some of the treatment principles described earlier.

THE RECOVERY OF THE FAMILY

When a severe head injury occurs, the family is traumatized as well as the patient. Some family members have claimed that a severe head-injury is not unlike a death in the family. The person whom you loved and depended on is no longer the same. His personality, his abilities, his interaction styles and his goals may no longer exist in the way that did before. In fact, some families have stated that a severe head injury is more difficult than a death; a loss has occurred but there there is no time to grieve because a "new" person has developed and his needs are immense and immediate. The family therefore is placed under emotional, physical and often financial stress. Other family affairs and needs may go unattended. Psychologically, people often react to traumas in their lives by experiencing a series of stages of grieving. (12) These stages include:

1. DENIAL: "No this couldn't have happened to us...", "The doctors are wrong - everything will be fine soon..."
2. ANGER AND FRUSTRATION: Family members may feel anger toward anyone who could be seen as the cause of the injury, or anger toward the hospital staff; feelings of being victimized may arise.
3. DEPRESSION AND WITHDRAWAL: Family members may withdraw from friends and social contacts, and may lack the motivation to take care of their own needs and relationships. Family members may stop eating properly, not get enough sleep and be ineffective in their jobs.
4. ACCEPTANCE: Hopefully, with time, the family will come to accept the changes that have occurred in their loved one and in their lives. Only after acceptance can the family begin to tend to it's own recovery.

Many family members may find it difficult to accept such feelings and psychological reactions within themselves. They may feel guilty and that they must remain strong. It is important to point out that such psychological reactions are normal and quite "acceptable." After all, the family is recovering from a trauma too.

Many people in the community are unfamiliar with head injury. Therefore, family members often may feel isolated, and may find it difficult to get support from their friends and the community. Many families of the head-injured have banded together for support and sharing of information. The National Head Injury Foundation now has chapters in almost every state, and provides information and support through it's national office in Framingham, Massachusetts. In addition, family members may seek professional help through counselors, social workers and other mental health professionals in their community. The social worker assigned to your patient's rehabilitation team may be able to assist you in locating such services.

RESOURCES FOR FINANCIAL AND PLACEMENT ASSISTANCE

The financial cost of rehabilitation is beyond the means of most families, requiring that some kind of "third-party" financing be involved. Third-party payers may include private insurance companies, workman's compensation insurance (for patient's injured in work-related accidents) and legal settlements. Patient's also may qualify for Social Security benefits.

The involvement of insurance companies depends on the nature of the accident, the policies of the individuals involved and the laws of the state. "Re-insurance" companies also may become involved. These are companies which basically "insure" the insurance companies and become a secondary source of payment. The amount of coverage provided by insurance varies among companies. For some patients, only medical costs will be covered and other therapy services will be excluded. Other companies will pay for specific therapy services but will not pay for others, e.g., they may cover physical therapy, but not cognitive retraining. Workman's compensation insurance usually covers the person's rehabilitation needs until he is able to return to gainful employment. For the severely head-injured individual, this often means the remainder of his lifetime.

The pursuit of a legal settlement is often a lengthy and difficult process. It is important that the patient continue to receive rehabilitation during the time that such a settlement is being pursued. Your lawyer may be able to give you more information regarding this.

Deciding what course of rehabilitation would be best for the head-injured individual is a difficult task for the family. Usually the family has had no previous experience with the field of rehabilitation and does not know where to go when looking for the proper program for the patient. Several sources of assistance are available in this area. Some insurance companies employ "rehabilitation consultants" or "rehabilitation nurses" whose job is to decide what course of rehabilitation would be most beneficial for the patient. Such consultants have a background in rehabilitation and can provide advice and information

to both the family and the insurance company. There also are private rehabilitation consultants and consulting firms which may be hired directly by the family. As mentioned in the section on educational and vocational services, the state rehabilitation commission may be of assistance in locating job placements for the head-injured person. In addition, The National Head Injury Foundation can be a resource in locating programs and facilities. NHIF has published a National Directory of Head Injury Rehabilitation Services which is available through their office.

GLOSSARY OF TERMS

ABSTRACT: Refers to concepts that may be difficult to understand; concepts that are theoretical or detached, dealing with things that cannot actually be seen. Some patients with cognitive deficits can only understand concepts that are "concrete," or related to something tangible in the environment.

ACALCULIA: Loss of ability to do simple arithmetic.

ACUITY: Sharpness or quality of a sensation.

AGNOSIA: Loss of ability to recognize things through a particular sensory system. For example, VISUAL agnosia refers to the inability to put together visual information so that it makes sense; the parts of an object may be seen but the person is unable to put it together as a "whole".

AGRAPHIA: Inability to express thoughts in writing.

ALEXIA: Inability to read.

ANOMIA: Loss of the ability to recall the names of objects. Patients who have this disability often can speak fluently but have to use other words to describe objects. For example, a patient may say, "It's one of those things that you hold and you move it like this" (describing a hair brush).

ANTI-CONVULSANT MEDICATIONS: Medications that prevent or relieve convulsions. Such medications include Dilantin, Tegretol and Phenobarbitol. A patient may be placed on such medications as a precaution against seizures, or the medication may be administered to halt a lengthy seizure.

ANOXIA: A lack of oxygen which can cause damage to the brain. This can result when blood flow is reduced, (such as when electrocution has occurred).

APATHY: A lack of interest or concern.

APHASIA: Loss of the ability to express oneself and/or to understand language. There are many different kinds of APHASIA. RECEPTIVE APHASIA refers to the inability to understand what someone else is saying. This is often associated with damage in the temporal area of the brain. EXPRESSIVE APHASIA refers to an inability to express oneself. Some patients may know what they want to say but may not be able to form the words. Other patients may be able to form the words but many of the words they say may not "make sense." Expressive aphasia is often associated with the left frontal area of the brain.

APRAXIA: Inability to perform purposeful movements when paralysis is not present. Particularly refers to inability to use objects. For example, a patient may be unable to put together the proper movements to sit crosslegged on the floor or may not know what to do when handed a broom.

ASTEREOGNOSIA: Inability to recognize things by touch.

ATAXIA: Inability to coordinate muscle movements or having irregular muscle movements. This can interfere with the person's ability to walk, talk, eat, perform self-care tasks and work.

ATTENTION: The ability to focus on one subject or bit of information; being able to filter out the relevant from the irrelevant information in one's environment.

BRAIN STEM: The lower portion of the brain which connects it to the spinal column. The brain stem coordinates the body's vital functions (breathing, blood pressure and pulse). It also houses the reticular formation which controls consciousness, drowsiness and attention.

CEREBELLUM: The portion of the brain which is located below the cortex. The cerebellum is concerned with coordinating movements.

CORTEX: The largest portion of the brain consisting of two cerebral hemispheres which are connected by a band of tissue (the corpus callosum). This is the area where most "thinking" and cognitive functioning takes place. It is sometimes referred to as the "cerebrum."

COGNITION: Knowing, awareness, perceiving objects, thinking, remembering ideas. The learned set of rules on which all thinking is based.

COMA: Unconsciousness lasting for more than a brief period of time. A state of unconsciousness where the person cannot be aroused and/or does not respond.

CONCENTRATION: Sustaining attention to a task over a period of time; remaining attentive.

CONTRA-COUP: When the brain is hit with sufficient force, causing it to "bounce" against the opposite side of the skull; thereby causing injury to both the site of impact, and the part of the brain opposite the impact. (For example, if the impact is to the left frontal area, contra-coup damage may occur to the right occipital area).

CT SCAN: A series of x-rays taken at different levels of the brain. A scan often is done soon after the injury to determine whether surgery is needed. Repeat scans are done later to see how the brain is recovering.

DIFFUSE: Brain damage which covers many areas of the brain rather than one specific location. Diffuse damage is common in closed head injuries due to the brain moving about and tissue being torn, stretched and bruised.

DISORIENTATION: Not knowing where you are, who you are or the time. Often professionals use the term "oriented in all three spheres" or "oriented times three", which refers to person, place and time.

DIPLOPIA: Seeing two images of a single object ("double vision").

DYSARTHRIA: Difficulty forming or articulating words. This may be caused by damage to the motor areas of the cortex or damage to the brain stem. Dysarthria may include speech that is slurred, talking extremely fast or slow, or improper pitch.

DISINHIBITION: The inability to control or inhibit impulses and emotions.

EDEMA: Collection of fluid in the brain tissue causing swelling.

EMOTIONAL LABILITY: Exhibiting rapid and drastic changes in emotions; quickly becoming angry, sad, silly or happy, and being extreme in showing these emotions.

FRONTAL LOBE: The area of the brain located at the front on both the left and right sides. This area plays a role in controlling emotions, motivation, social skills, expressive language (in an area on the left side referred to as Broca's area) and inhibition of impulses. The motor strip, controlling movement and motor integration, runs along the posterior (back) of the frontal lobe.

FRUSTRATION TOLERANCE: The ability to deal with frustrating events in daily life; the point at which a person can no longer control his anger in a situation and responds by yelling, throwing things or becoming aggressive.

GLASGOW COMA SCALE: A scale of severity of injury developed by B. Jennett, MD, and G. Teasdale, MD (13). This scale relates the level of consciousness with three factors: motor responses, eye opening and verbal responses.

HEMIPARESIS: Weakness of one side of the body (or part of it) due to injury to the motor areas of the brain.

HEMISPHERIC ASYMMETRY: Differences in the types of functions for which the two sides of the brain are responsible. (For example, the left side is usually associated with verbal functions, while the right is associated with spatial abilities).

HEMORRHAGE: Bleeding that occurs following trauma. Bleeding may occur within the brain when blood vessels in the skull of the brain are damaged.

INFLEXIBILITY: The inability to adjust to everyday changes in routines, usually related to injury to the frontal lobes. Some head-injured persons may have

little difficulty following a structured routine but may exhibit sudden frustration and confusion when their routine is changed.

JUDGMENT: The process of forming an opinion, based on an evaluation of the situation at hand. "Good" judgment refers to choosing the most optimal course available. Judgment involves cognitive skills, personal values and preferences, and insight into what your abilities and disabilities are. For example, a patient with judgment deficits may be able to make decisions, but the decisions may be unsafe or unsuccessful.

LIMBIC SYSTEM: A set of structures (usually considered part of the temporal lobe) which play an important role in memory, attention, emotions and behavior.

MEMORY: The process of perceiving information, organizing and storing it, and retrieving it at a later time as needed. Memory is a complex function that involves many parts of the brain working together. There are different "types" of memory including immediate (repeating a phone number), recent (recalling what occurred the previous day), and remote (recalling the name of a childhood friend).

NATIONAL HEAD INJURY FOUNDATION (NHIF): An organization of families and professionals concerned with the needs of head-injured persons. The organization provides information and support, and has chapters in many states. The national office is in Framingham, Massachusetts.

OCCIPITAL LOBE: The posterior (back) part of each side of the brain, involved in perceiving and understanding visual information.

PARIETAL LOBE: The upper middle lobe of each side of the brain, involved in receiving and understanding sensations, and closely linked to speech fluency and writing.

PERSEVERATION: Becoming "stuck" on one word or task and not being able to switch back and forth or go on to the next word/task. (For example, a patient may be asked to draw a circle on a piece of paper. He may then be asked to draw a square, but instead will continue drawing circles).

PROXIMAL INSTABILITY: Impaired strength or muscle tone of the trunk, shoulder girdle or hip girdle. This can cause poor posture, abnormal movement of the limbs, inability to sit up and inability to hold one's head up. Caused by damage to the motor strip of the brain.

PROBLEM SOLVING: The ability to evaluate all of the factors involved when faced with a problem, and to generate and evaluate possible solutions. Patients with deficits in this area may "freeze" when faced with a problem; that is they may not be able to think of possible solutions and instead will respond by doing nothing.

POST-TRAUMATIC AMNESIA (PTA): A loss of memory that occurs immediately after injury, and which may continue for weeks or months. During this time many patients are unable to organize or retrieve information. The length of PTA is regarded as an indicator of eventual recovery.

QUADRAPARESIS: A weakness which involves all four limbs.

SPASTICITY: An abnormal increase in muscle tone, causing the muscles to resist being stretched. A patient with spasticity may look "curled up", with his arms held close to his chest, or he may appear very stiff.

SPONTANEOUS RECOVERY: The recovery which takes place spontaneously as the brain heals; this type of recovery occurs with or without rehabilitation and it is often difficult to know how much improvement is spontaneous and how much is due to rehabilitative interventions. It occurs early in the recovery process.

TACTILE DEFENSIVENESS: Being overly sensitive to touch; withdrawing, crying, yelling or striking out when touched.

TEMPORAL LOBE: The lower middle part of each side of the brain, involved in receiving information from the auditory system and involved in memory.

UNILATERAL: Pertaining only to one side.

UNILATERAL NEGLECT: Not responding to things on one side. This usually occurs on the opposite side from the location of injury (right side brain injury, neglects left side). Some patients will only exhibit this when both sides of the body are being touched at once. In extreme cases, the patient may not bathe, dress or acknowledge one side of his body.

VENTRICLES: Four cavities in the brain which are filled with cerebro-spinal fluid, serving as a cushion when the brain is impacted. These cavities may enlarge when brain tissue is damaged.

VESTIBULAR: Awareness of movement involving the head. Disorders of the vestibular system can lead to a lack of awareness of movement, a lack of awareness of direction of movement or hypersensitivity to movement.

VISUAL FIELD DEFICIT: Not visually perceiving information in a specific area of the person's visual field. Often this involves either the left or right half of the visual field, but may involve a quarter of the visual field, etc.

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