



KentuckyOne Health[®]
Frazier Rehab Institute

*Brain Injury Program:
Handbook
for Families
& Friends*

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To learn that someone you care about has sustained a brain injury is never easy. Many people experience worrisome and confusing thoughts while the uncertainty about the patient's recovery adds to the level of stress and despair.

In recognizing how difficult brain injury is for patients, families and friends, Frazier has developed a comprehensive brain injury treatment program. It is staffed with highly skilled professionals and has been organized to treat each patient according to his/her individual needs.

This Handbook has been prepared for the family and friends of persons with brain injury. It has been designed to provide you with basic information about brain injury, to briefly outline the Brain Injury Program at Frazier and explain how you can assist in the recovery of your family member and/or friend.

The Brain Injury Program at Frazier

The person with brain injury is admitted to the Brain Injury Program by a physiatrist, a physician who specializes in rehab medicine. Once admitted, a specified treatment team of professionals is assembled according to the rehabilitation needs of each patient. Members of the treatment team may include:

	Name
Patient's Name	_____
Family Member	_____
Family Spokesperson	_____
Physiatrist or Rehab Physician	_____
Psychologist	_____
Psychological Associate	_____
Case Manager	_____
Nurse	_____
Occupational Therapist	_____
Occupational Therapy Assistant	_____
Physical Therapist	_____
Physical Therapist's Assistant	_____
Dietitian	_____
Pulmonary Rehab Clinicians	_____
Therapeutic Recreation Specialist	_____
Speech-Language Pathologist	_____
School Tutor/Coordinator	_____

Treatment Guide

Family Spokesperson

The treatment team includes a patient's family or significant others because you have valuable information that is helpful during treatment planning and, you can support the patient in very special ways during the recovery process.

The treatment team will ask that one person in the family be identified as the "family spokesperson." This is the person to whom the treatment staff will communicate all relevant information about treatment goals, patient progress and plans for discharge. Weekly communication between the family's spokesperson and case manager is essential. We ask that the spokesperson then communicate relevant information to other family members.

Getting Started at Frazier

Once the patient has been admitted to his/her room at Frazier, a rehab nurse will begin the evaluation process to determine the patient's level of functioning. Others on the treatment team will begin their evaluation that same day or the day following depending upon the time of day the patient is admitted. Part of the evaluation process will include interviews with you. This helps the treatment team learn about the patient's background, likes and dislikes, and significant events in the past. The team will also want to know what changes the family and patient have noticed since the onset of the injury or illness. The team will ask about the layout of the space in the home to plan for a safe return to home. Providing this information is one important way the patient and family can participate in the rehab process. If you think of relevant information after these interviews, make a note and share that information with the appropriate team member at a later time.

During the initial evaluation, the treatment team will begin to identify the patient's "Functional Problems." These functional problems are caused by the brain injury and could include inability to maintain attention, memory impairment, and impaired self-care or mobility skills. It is these functional problems that clarify the reason that rehabilitation is needed for the patient. Once functional problems are identified, the team will establish a "Treatment Goal" for each problem. The functional problems and the treatment goals are the basic components in the "Treatment Plan." We encourage the patient and family to help create these goals.

Once each week, the treatment team will meet to update and revise the functional problems list and long-term treatment goals. In addition, the team will identify the "Weekly Treatment Priorities" upon which the team will focus during the next seven days. When appropriate, the family will be asked to help the patient and other team members reach these weekly goals.

The treatment team will carefully evaluate the patient's level of functioning according to the Rancho Los Amigos Cognitive Recovery Scale, which defines ten levels of recovery from brain injury. Shortly after admission, you may hear the staff say that the patient is functioning at a Rancho Level between 1 and 10. During a patient's admission, the Rancho Level may change significantly and often. Some survivors move slowly through the Rancho Levels and speed of recovery does not suggest poor ultimate outcome. A summary of the Rancho Scale can be found later in this booklet. As you read further, you will find additional information that will help you during recovery. We encourage you to write down your questions as you proceed so you can ask them when meeting with members of the brain injury team. You may find it helpful to read this material more than once.

Therapy sessions are scheduled at specific times for each patient. There are occasional therapeutic reasons to change a patient's schedule and as a result of timely team communication these beneficial schedule changes will occur. Please be aware that the patient's therapy schedule may change for non-clinical reasons, such as, changes in a therapist schedule or our admission/discharge patterns. A daily master schedule is available by 8:30 a.m. at the nurses' station. You will get an updated daily schedule by 9:00 a.m. Be aware therapists may come to work with the patient at unscheduled times to provide maximum benefit from rehab. Please let the team know how the patient is tolerating their therapy times.

Team Approach.

Case Management: Case managers coordinate discharge planning with the patient, family and treatment team. They schedule family teaching days and team/ family meetings to educate family members about brain injury and to prepare them for discharge. The case manager communicates with your insurance company and can direct families where to get insurance questions answered. The case manager provides information about and makes referrals to community resources. The case manager serves as the family's liaison to the treatment team to ensure that your questions and concerns are addressed as they arise.

Psychology: Psychology services are provided by psychologists and psychological associates who specialize in diagnosing and treating the behavioral, social and emotional problems that result from neurological illness and injury. They provide consultation to the treatment team, educational and support services to families and patients. Comprehensive neuropsychological evaluations are available through Frazier that assess a variety of thinking, memory, sensory, intellectual, academic and vocational skills as well as emotional functioning.

Occupational Therapy: Occupational therapists and occupational therapy assistants help patients improve the skills needed to perform self-care, participate in leisure activities and return to work. Occupational therapists will focus on increasing strength, balance, sensation and coordination. They will also address cognition (thinking) and problem solving abilities. Patients may be encouraged to use adaptive equipment or adaptive techniques in order to become more independent in daily activities.

Physiatry: A physician who specializes in rehabilitation medicine is called a physiatrist. Your physiatrist coordinates the medical and rehab care, outside consultants and referrals for continued services. Upon completion of the brain injury program, some medical rehab services will continue to be provided by your physiatrist. You will need to see your primary care physician within a couple of weeks of discharge from the inpatient stay at Frazier. If you don't have a primary care physician, your physiatrist will help refer you to one.

Physical Therapy: Physical therapists and physical therapist's assistants work with patients to improve mobility, strength, coordination, balance, endurance, flexibility and safety within their environment. The goal is to achieve the highest level of function for each individual both in and outside the home environment. If patients are unable to achieve independence with walking skills, physical therapists recommend and encourage the use of braces, assistive devices or custom wheel chairs to maximize each patient's level of independence.

Therapeutic Recreation: Therapeutic recreational specialists help patients improve their abilities to participate in leisure activities and teach patients how to adapt to recreational skills and attitudes after disability. The recreational therapists plan many activities, indoor and outdoor, so patients can practice being as independent as possible in their own recreational or leisure activities.

Registered Dietitian: Dietitians are part of the multidisciplinary team ensuring adequate nutrition for all patients. An individualized nutrition plan of care is developed and education provided as needed.

Rehabilitation Nurse: The rehabilitation nurse closely monitors, coordinates and delivers nursing interventions designed to restore and maintain maximal health and independent functioning. These interventions vary depending on the individual's physical and mental status, vital signs, level of alertness, nutritional status, bowel and bladder status, sleep/wake cycles, skin integrity, pain levels, medication, and treatment regimen. The rehab nurse is an active member of the interdisciplinary team. The RN and nursing assistant reinforce skills learned in therapy.

Speech-Language Pathology: Speech-language pathologists address communication skills, which involve listening, speaking, reading, writing, and cognitive (thinking) skills. Speech-language pathologists also diagnose and treat swallowing problems.

Brain Injury Services After Inpatient Hospitalization

In most instances, patients are ready to be discharged from the inpatient program before many of the problems associated with the brain injury have resolved. Frazier Rehab Institute offers several therapy alternatives after discharge to meet the needs of the patients with a brain injury. The treatment team will recommend the option that is best suited to the patient's needs.

NeuroRehab Program

This program prepares the patient for a successful return to community life. Located in one of our outpatient facilities, this service has a complete interdisciplinary team that specializes in neurologic rehab. Through individualized case management, the specific and unique needs of each patient are addressed. The team may coach patients at jobsites, school or in their home. The program also offers family education. The emphasis for this part of our continuum is achieving practical, real life goals.

The person with brain injury is ready for the Neurorehab Program - when they demonstrate a readiness for return to unsupervised independence within the home, school, work setting or other productive roles within the community.

Falls, Prevention

Brain injury patients are at high risk for falls. This is due to possible confusion and physical weakness. Falls can lead to serious physical injuries such as cuts, bruises, broken bones, another brain injury, and even death. To prevent falls, an alarm may be placed on the bed or wheelchair that will sound when the patient tries to get out of bed or the wheelchair. Another safety option to prevent falls, is an enclosed bed. Family members should not get patients up. Always call for assistance by using the call light. A patient should not be left sitting at the side of the bed as many falls occur while sitting on the side of the bed. The patient will be assessed for falls risk throughout the stay.

Visitation at Frazier

The treatment team has found that the most productive social visits occur during the evening hours after therapies have been completed. Therefore, we request that extended family members and friends schedule their visits after 4:30 p.m. Monday through Friday. Primary caregivers are encouraged to be present for family teaching throughout the day as often as possible. Weekend therapy may not be as tightly scheduled as on week days so visiting during the day on Saturday and Sunday may be more possible.

Social visits should be limited to brief periods of time with no more than one or two family members or friends present in the patient's room at a time. Questions concerning the patient's readiness for visitors, particularly those who might overstimulate the patient are best discussed with the patient's doctor or therapists. The staff also requests that you respect the rights of other patients to a private, quiet and peaceful hospital environment.

The length and frequency of visits that are most helpful to any given patient varies. Sometimes patients become overstimulated, overly emotional or even lose motivation when family and friends are present. This is not uncommon and should be viewed as a normal part of the recovery process. Accordingly, the treatment team may ask you to limit your visits during this stage of recovery. Similarly, the team may encourage you to increase your visits when this benefits the patient.

The Family as Team Members

The Brain Injury Program Staff views family as important members of the rehab team because you have information about the patient that is important to consider when developing a comprehensive treatment plan. Also, because of your pre-injury relationship with the patient, you can love and support your family member in ways that no other treatment team member can.

Dependency

Patients with brain injury often try to get family and friends to assist them in various ways, e.g., reading a menu, making a decision about clothes or a TV show, or retelling a story. This occurs when the patient finds that performing these "relatively simple" tasks is very difficult.

You and other family members may want to comply with these requests out of kindness and because it is too difficult to stand back and watch a loved one struggle and sometimes fail. However, allowing a patient to try, to struggle, and at times, to fail is often the basis for learning or relearning a skill. Please be open to staff as they offer suggestions about how best to assist your loved one, i.e., maintain the right distance that encourages a sense of personal confidence and independence.

Encouragement

We have found that in some cases, the encouragement given by family members, even when done gently and lovingly, may be experienced by the patient as pressure to perform. Additionally, this can be embarrassing particularly when the patient is aware of his/her inadequacies when performing even the simplest of tasks. In these situations, the family and staff will talk together to try to establish a sound therapeutic plan. The staff will offer you many suggestions about how best to interact with your loved one. Please do not take any comments or suggestions from staff as a personal criticism. They are meant to be helpful.

Family Teaching

Participating in Family Teaching is one of the most important ways family members and caregivers can help the patient. Family teaching includes coming to Frazier for the day and going through occupational, physical and speech therapies in the morning and afternoon. During these sessions, therapists will work with you and the patient to set the treatment plan that is the most functional for the patient and to help you understand the skills that remain intact and the skills that need to be improved. You will have opportunity to try techniques the therapists are using to improve the functional skills. The team is working with you and the patient to transition safely to home and to the next steps in the recovery and rehab process. The family will also have opportunity to gain knowledge and skills through training with the nurses. You may be asked to participate in some basic nursing care, such as bowel and bladder care, feeding tube management, oral care, tracheotomy care, and wound care. The purpose of asking you to do this is not to have you substitute for care provided by our nursing staff, but to prepare you to provide care for the patient at home. Doctors, psychologists, case managers and other team members will also be available for teaching, support, and answering questions as needed.

In most cases, the more frequently family attends family teaching the better. Primary caregivers are encouraged to come as often as possible and spend the day learning. If full days are not possible, you are encouraged to come for half days. Let the team know what days and times you are able to attend. It is crucial for the patient's safety and well being that family is present to learn how to best care for the patient as they prepare for discharge. Recovery from brain injury happens over an extended period of time. Generally you can expect significant changes for the patient at least in the early stages of recovery and attending family teaching will help you to be prepared for changes you may encounter at home.

Another form of family teaching occurs by attending Brain Injury education classes. Frazier offers a twice weekly Brain Injury education class on Monday and Friday from 10:30-11:30 in the 7th floor team and family conference room. A series of topics related to brain injury is covered over a two week period. The topics are relevant to family members of brain injury survivors. Questions are welcomed leading to discussions that enhance the learning. Family members are encouraged to go through the entire two week series beginning the Monday or Friday after the admission to Frazier. This series is open to any number of family members and may be repeated. Patients who have progressed to a level of recovery that would allow them to benefit from classroom style education and discussion are scheduled to attend the classes.

Taking Care of Yourself

You know, caring for a family member with a brain injury presents emotional and physical challenges for you and your family. Normally, family members experience grief, anxiety, sadness, and anger to name but a few emotions. These may contribute to disturbances of sleep, appetite and energy levels. Dealing with brain injury is not easy. These are difficult times.

Clearly, family's health and well-being are critical to the patient's recovery. If you "burn out" or become sick, you will have little to offer the patient or other family members. Unfortunately, the staff sees too many family members sacrificing their health by trying to "Stand Watch" at the hospital many hours each day.

If you are caught in this dilemma, staff will encourage you to view the situation more objectively. You may find it helpful to meet with a psychologist, a trained professional on the treatment team, who has specific knowledge about your loved one. He/she can offer guidance, support and relevant information. Confidential appointments can be made with the psychologist directly or through another team member.

In summary, taking good care of yourself is one of the most helpful things you can do for your injured family member.

Questions and Concerns

You will have many questions and concerns about your loved one during hospitalization. Regular attendance in all Family Teaching activities and attending the Monday and Friday morning education classes, will answer many of your questions and address many of your concerns.

There are two other ways to deal with your questions and concerns. The first is to contact specific members of the treatment team. For example, the nurse can be helpful in addressing questions about daily care, physical functioning, visitation and special precautions for care. The Case Manager can address issues related to discharge planning, community resources and medical insurance.

Secondly, specific concerns about progress and treatment recommendations can be addressed during weekly rounds and during a team and family meeting with all team members present. You may request such a meeting by contacting your Case Manager.

Many variables are considered when deciding upon a discharge date. The most appropriate setting for continued rehab is a primary consideration. Some other factors include the progress the patient is making in treatment, availability of family, the need for further services, limitations of individual insurance policies/coverage, and equipment needs. If persistent one-on-one nursing care and/or constant medical monitoring is needed, a transfer to another facility may occur. Suicidal behavior requires a transfer to a more appropriate setting, and disruptive behavior that interferes with providing rehab services or creates patient safety issues may require discharge from Frazier.

Since discharge needs vary from patient to patient, each case is addressed individually. The case manager will coordinate the discharge plan and discuss the development of discharge plans weekly with the family spokesperson. The entire treatment team will participate in this planning. Our goal is to prepare for a well organized transition to home.

As a general “rule of thumb” a patient will need to demonstrate progress on a weekly basis in order to remain in the rehab hospital. Insurance companies require that the treatment team report weekly on the patient’s progress or lack of progress. The criteria that insurance companies use to determine coverage and length of time they will pay for services varies from company to company. Any questions or concerns about continued coverage should be directed to your Case Manager.

Discharge planning may also be discussed when you meet with the rest of the treatment team during the Team & Family meeting.

Transition from Rehab to School

Following a brain injury, your child may have special needs in relation to school. Often changes in the school program will be necessary for your child to progress academically. A team effort is required for a smooth transition. You as parent/guardian will be a vital member of the team.

Currently, there are two Federal laws that set the standard for services within each state. Keep in mind however, that there are variations in educational services from state to state. The Individuals with Disabilities Education Act (IDEA): Public Law 101- 476 makes certain that federal funds are available. This law sets guidelines for delivering services to children from ages 3 – 21 years who are in need of special education services. There are four steps to this process:

1. Identify the need for special services. A doctor, parent or agency can make the referral.
2. Evaluation to determine the child's learning strengths and weaknesses. A parent/guardian must give permission for this step.
3. Individual Education Plan – Goals and objectives are created by a team of professionals including the parents/guardian. All services will be delivered in a setting that is least restrictive for the child.
4. Review -The plan (IEP) is to be reviewed at least annually but more frequent reviews are usually recommended for a child with brain injury.

The second federal law is listed under section 504 of the Rehabilitation Act. A 504 plan is less formal but provides a list of accommodations to help the child succeed in the school setting.

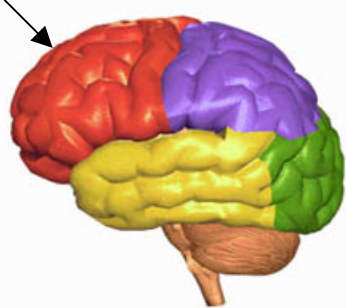

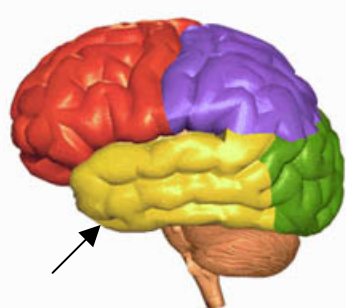
In the event that your child attends a private school, the rehab team will work with the school and provide essential information for the reentry process. Private schools are not subject to Federal Law requirements for special education.


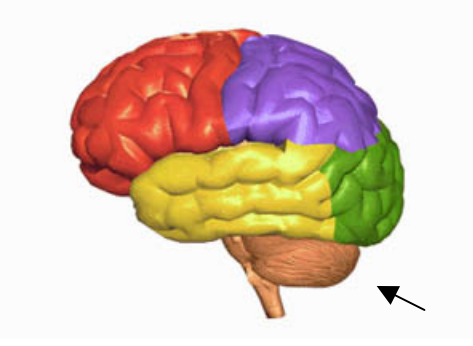
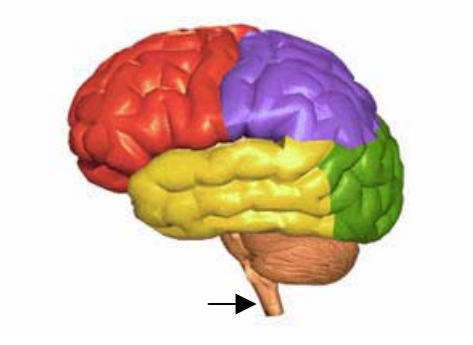
For children under the age of 3, the rehab team will contact the federal program called First Steps. First Steps is an early intervention program for children with developmental delay or a particular medical condition that is known to cause a developmental delay. Services are coordinated through the Cabinet for Health Services in each state.

You are encouraged to speak to the case manager and ask questions about the school re-entry process. You as parents/guardians are the most valuable ongoing source of information. The key to successful reintegration of your child back into the school system is communication and education about brain injury for all parties involved.

Areas of the Brain

Areas of the Brain

Frontal Lobe	Location	Function
	<p>The frontal lobe is located in the area around your forehead.</p>	<ul style="list-style-type: none"> Emotional control Reasoning & judgment Voluntary movement Motivation & Initiation Social behavior Creativity Expressive language Problem solving Planning & Decision making
Parietal Lobe	Location	Function
	<p>The parietal lobes are located behind the frontal lobes, above the temporal lobes, and at the top back of the brain.</p>	<p>Related to the tactile senses:</p> <ul style="list-style-type: none"> Touch Pain Taste Pressure Temperature Spatial relationships
Temporal Lobe	Location	Function
	<p>The temporal lobes are located on both sides of the brain and just above the ears.</p>	<ul style="list-style-type: none"> Hearing Memory Meaning Language comprehension Learning Interpreting auditory stimuli Processing auditory stimuli.

Occipital Lobe	Location	Function
	<p>The occipital lobe is found in the back of the brain.</p>	<p>Related to the brain's ability to recognize objects</p> <ul style="list-style-type: none"> Visual perception Visual input Reading
Cerebellum	Location	Function
	<p>The cerebellum is located at the base of the brain, underneath the occipital lobe.</p>	<ul style="list-style-type: none"> Balance Equilibrium Coordination of voluntary movement
Brain Stem	Location	Function
	<p>The brain stem is located at the bottom of the brain and connects the brain to the spinal cord.</p>	<p>Related to life-sustaining actions:</p> <ul style="list-style-type: none"> Breathing Heart rate Temperature Level of alertness

Rancho Los Amigos Cognitive Recovery Scale

RANCHO LOS AMIGOS COGNITIVE RECOVERY SCALE

The Rancho Los Amigos Cognitive Recovery Scale (RLA) is one of several scales developed to identify stages or levels of brain injury recovery. This scale begins with Level 1 and progresses through Level 10. The treatment team will use this scale as a guide when developing each patient's treatment plan. The team's treatment strategy will change if the patient progresses from one Rancho Level to the next. Each person with a brain injury will move through the Rancho Levels at various speeds. Patients will be discharged from the hospital prior to progressing through all of these levels. Therapy services often continue after discharge.

Most patients do not require a lot of stimulation during mid range Rancho Levels (4,5,6). Instead they usually get more than enough stimulation for the whole day by attending therapies. Brief, quiet visits are most helpful. Stimulation can be anything that excites the patient, such as TV, radio, lights, talking, seeing several people at once, being in a hallway or noisy place. The patient may not outwardly show over stimulation and their expression may be blank but still be over stimulated on the "inside". They may, for example, sweat or breathe rapidly when over stimulated.

Recovery Levels

- Level I (1). **No response:** (to any stimulus): Total Assistance – the patient appears to be in a deep sleep or coma and does not respond when presented with visual, auditory, tactile, proprioceptive, vestibular or painful stimuli.
- Level II (2). **Generalized response:** Total Assistance – the patient moves around, but movement does not seem to have a purpose or consistency. This reaction may be due to deep pain. Patient may open their eyes but do not seem to be focused on anything in particular.
- Level III (3). **Localized response:** Total Assistance – the patient begins to move their eyes and look at specific people and objects. They turn toward or away from loud voices or noise. The patient at level 3 may follow a simple command such as, "squeeze my hand." Responses are inconsistent and directly related to the type of stimulus.
- Level IV (4). **Confused and agitated:** Maximal Assistance – the patient is very confused and agitated about where he or she is and what is happening in the surroundings. At the slightest provocation, the patient may become very restless, aggressive, or abusive (verbally and/or physically). The patient may enter into incoherent conversation in reaction to inner confusion, fear or disorientation. Motor activities that could be detrimental are attempted. Safety and deficit awareness are important issues.
- Level V (5). **Confused, inappropriate, non-agitated:** Maximal Assistance – the patient is confused and does not make sense in conversations, but may be able to follow simple directions. Stressful situations may provoke some upset, but agitation is no longer a major problem. Patients may experience some frustration as elements of memory return. Follows tasks for 2-3 minutes but is easily distracted by environment.
- Level VI (6). **Confused, appropriate:** Moderate Assistance – the patient's speech makes sense, and he or she is able to do simple things such as dressing, eating, and teeth brushing. Although patients know how to perform a specific activity, they need help discerning when to start and stop. Learning new things may also be difficult. The patient's memory and attention are increasing and he or she is able to attend to a task for 30 minutes.
- Level VII (7). **Automatic appropriate:** Minimal Assistance for daily living skills – the patient can perform all self-care activities and are usually coherent. They have difficulty remembering recent events and

discussions. If physically able, can carry out routine activities. Rational judgments, calculations, and solving multi-step problems present difficulties, yet patients may not seem to realize this. Needs supervision for safety.

Level VIII (8). **Purposeful, Appropriate: Stand-By Assistance**: The patient is independent for familiar tasks in a distracting environment for one hour. He or she acknowledges impairments but has difficulty self-monitoring. Emotional issues such as depression, irritability and low frustration tolerance may be observed.

Level IX (9). **Purposeful, Appropriate: Stand-By Assistance on Request**: The patient is able to shift between tasks for two hours. Requires some assistance to adjust to life demands. Emotional and behavioral issues may be of concern.

Level X (10). **Purposeful, Appropriate: Modified Independent**: The patient is goal directed, handling multiple tasks and independently using assistive strategies. Prone to breaks in attention and may require additional time to complete tasks.

Description and family strategies for each RLA Level

Level I - No Response: Total Assistance

- Complete absence of observable change in behavior when presented visual, auditory, tactile, proprioceptive, vestibular or painful stimuli.

Level II - Generalized Response: Total Assistance

- Demonstrates generalized reflex response to painful stimuli.
- Responds to repeated auditory stimuli with increased or decreased activity.
- Responds to external stimuli with physiological changes generalized, gross body movement and/or not purposeful vocalization.
- Responses noted above may be same regardless of type and location of stimulation.
- Responses may be significantly delayed.

Level III - Localized Response: Total Assistance

- Demonstrates withdrawal or vocalization to painful stimuli.
- Turns toward or away from auditory stimuli.
- Blinks when strong light crosses visual field.
- Follows moving object passed within visual field.
- Responds to discomfort by pulling tubes or restraints.
- Responds inconsistently to simple commands.
- Responses directly related to type of stimulus.
- May respond to some persons (especially family and friends) but not to others.

Family Strategies for Level I-III

Family members should not interpret the agitation and confusion as regression, but rather as progress. The individual is not aware of what he/she is doing and is likely to remember little of this period of time.

When relating to a person at a low Rancho level, family and friends should:

- Use calm, reassuring tones, and in a normal tone of voice
- Tell the person what you are going to do before you do it. For example, “I’m going to move your leg.”
- Speak in short phrases, keeping comments and questions short and simple. For example, instead of saying, “Can you turn your head to me?” say, “Look at me.”
- Allow the person extra time to respond. Sometimes responses are inconsistent, incorrect or do not occur.
- Have one person speak at a time.
- Tell the person who you are, where they are, why they are in the hospital, and what day it is.
- Speak in concrete terms. Discuss things that are happening near the person.
- Bring in favorite belongings and pictures of family members and close friends.
- Bring in familiar activities, such as favorite music, talking about family and friends, reading favorite magazines or books out loud, watching favorite TV shows or videos to stimulate senses and memory.
- Gently massage lotion on the person’s arms, legs, back and stomach. This not only increases the person’s tactile awareness but also helps prevent skin breakdown.
- Touch the person on the face, arm, or leg with various textures like a washcloth, fuzzy toy, flannel, plastic, rubber, etc. for sensory stimulation.
- Use a variety of soaps, fragrances and lotions to stimulate smell.
- Keep a notebook nearby for family and visitors to sign. Instruct them to log in any noticeable responses to stimuli.
- Limit the number of visitors to 2-3 at a time.
- Keep the room calm and quiet.
- Maintain rest periods.
- Always assume the person with brain injury can understand what is being said. Never discuss subjects that may be upsetting in front of the person.

Level IV - Confused/Agitated: Maximal Assistance

- Alert and in heightened state of activity.
- Purposeful attempts to remove restraints or tubes or crawl out of bed.
- May perform motor activities such as sitting, reaching and walking but without purpose or upon another's request.
- Very brief and usually non-purposeful moments of sustained alternatives and divided attention.
- Absent short-term memory.
- May cry out or scream out of proportion to stimulus even after its removal.
- May exhibit aggressive or flight behavior.
- Mood may swing from euphoric to hostile with no apparent relationship to environmental events.
- Unable to cooperate with treatment efforts.
- Verbalizations are frequently incoherent and/or inappropriate to activity or environment.

Family Strategies for Level IV

Rancho Level IV is characterized by: Emergence of Agitation and Confusion

Family members should not interpret the agitation and confusion as regression, but rather as progress.

The individual is not aware of what he/she is doing and is likely to remember little of this period of time.

When relating to a person at Rancho Level IV, family and friends should:

- Tell the person where they are and reassure them that they are safe.
- Bring in family pictures and other personal items. These may make the person feel more comfortable as well as stimulate memory.
- Allow the person as much movement as is safely possible; Take person for rides in a wheel chair, if permitted.
- Not force the person into activities; listen to them and follow their lead, as is safely possible
- Provide frequent rest breaks to minimize episodes of increased restlessness and agitation.
- Keep the room quiet and calm; if the person is agitated, turn off the TV and radio.
- Limit visitors to 2-3 at a time.

Level V - Confused, Inappropriate Non-Agitated: Maximal Assistance

- Alert, not agitated but may wander randomly or with a vague intention of going home.
- May become agitated in response to external stimulation, and/or lack of environmental structure.
- Not yet oriented to person, place or time.
- Frequent brief periods, non-purposeful sustained attention.
- Follows tasks for 2-3 minutes before being easily distracted
- Severely impaired recent memory, with confusion of past and present in reaction to ongoing activity.
- Absent goal directed, problem solving, self-monitoring behavior.
- Often demonstrates inappropriate use of objects without external direction.
- May be able to perform previously learned tasks when structured and cues provided.
- Able to respond appropriately to simple commands fairly consistently.
- Able to converse on a social, automatic level for brief periods of time.
- Verbalizations about present events may become inappropriate and confabulatory.

Family Strategies for Level V

Rancho Level V is characterized by Continued Confusion with Inappropriate but Non-Agitated Behavior. Conversations can be confused, unusual, insistent, humorous or bizarre.

When relating to a person at Rancho Level V, family and friend should:

- Avoid a tendency to reward or play into inappropriate behavior.
- Use redirection and distraction to stop inappropriate behavior. Due to cognitive limitations, reasoning at this stage is not successful, but redirection is often easy and effective, since the patient is so easily distracted.
- Not assume that the person will remember what you tell them. Persons at Rancho Level V often require frequent repetition
- Keep comments and questions short and simple.
- Remind the person of day, date, name and location of the hospital as well as why they are in the hospital.
- Help the person get organized for tasks and activities.
- Bring in familiar pictures and personal objects from home.
- Limit visitors to 2-3 at a time.
- Give patient frequent rest periods.

Level VI - Confused, Appropriate: Moderate Assistance

- Inconsistently oriented to person, time and place.
- Able to attend to highly familiar tasks in non-distracting environment for 30 minutes with moderate redirection.
- Remote memory has more depth and detail than recent memory.
- Vague recognition of some staff.
- Able to use assistive memory aide with maximum assistance.
- Emerging awareness of appropriate response to self, family and basic needs.
- Moderate assist to problem solve barriers to task completion.
- Supervised for old learning (e.g. self care).
- Shows carry over for relearned familiar tasks (e.g. self care).
- Maximum assistance for new learning with little or no carry over.
- Unaware of impairments, disabilities and safety risks.
- Consistently follows simple directions.
- Verbal expressions are appropriate in highly familiar and structured situations.

Family Strategies for Level VI

Rancho Level VI is characterized by Continuing Confusion but Emergence of Appropriate Behavior.

When relating to a person at Rancho Level VI, family and friends should:

- Expect the person to be unaware of their deficits and the need for increased supervision and rehabilitation. They may insist nothing is wrong with them and that they can go home and resume their usual activities.
- Realize that redirection is not effective and arguments can be frequent and prolonged.
- Encourage the person to participate in and continue to stay in rehabilitation services.
- Understand that the person may react to their head injury in a non-emotional manner and may appear not to care that they are injured. Family should know that this behavior is related to their stage of recovery.
- Realize frequent repetition may be necessary.
- Discuss and journal activities that have happened during the day, to help the person improve his/her memory.
- Help with starting and continuing activities.

Level VII - Automatic, Appropriate: Minimal Assistance for Daily Living Skills

- Consistently oriented to person and place. Some assistance for orientation in unfamiliar environment.
- Able to attend to highly familiar tasks in a non-distraction environment for at least 30 minutes.
- Minimal supervision for new learning and demonstrates carry over of new learning.
- Initiates and carries out familiar personal and household routine but has poor recall for activities.
- Superficial awareness of his/her condition but unaware of specific impairments and disabilities and the limits they place on his/her ability and safety in carrying out household and community activities.
- Minimal supervision for safety in routine home and community activities.
- Unrealistic planning for the future and overestimates abilities.
- Unable to think about consequences of a decision or action, appears oppositional/uncooperative.
- Unaware of others' needs and feelings Unable to recognize inappropriate social interactions.

Family Strategies for Level VII

Rancho Level VII is characterized by Automatic, Appropriate Behavior. Most persons at this level are at home, and are returning to school and possibly work environments. Deficits in memory, information processing, fatigue, behavioral control, and social interactions may hamper performance in these settings, and may be perceived as intentional. Intervention at this level should include persons involved at the school, community, or work environments. Family members should know that judgment may still be impaired and close supervision may still be necessary. Support is important due to the transitional nature of this level of recovery.

When relating to a person at Rancho Levels VII, family and friends should:

- Treat the person in the same way as they did before the brain injury. For example, provide guidance and assistance in decision-making but respect the individual's opinions.
- Speak with normal speech patterns and vocabulary. Simple words or phrases are no longer needed.
- Be careful about teasing or using slang, as they may misunderstand. Sometimes humor is not understood.
- Talk through problems about the person's thinking skills, problem solving or memory challenges without criticizing. Reassure the individual that problems may persist because of the brain injury.
- Encourage the person to remain in therapy, to improve their cognitive skills.
- Check with the physician regarding any restrictions on driving, sports, drinking.
- Encourage the person to use note taking and tape-recorders to help with memory deficits.
- Discuss situations where the person may have had difficulty controlling emotions.
- Talk with the person about feelings and offer outside support such as counseling and/or support groups.

Level VIII - Purposeful, Appropriate: Stand-By Assistance

- Consistently oriented to person, place and time. Able to recall and integrate past and recent events.
- Independently attends to and completes familiar tasks for 1 hour in distracting environments.
- Uses assistive memory devices to recall daily schedule, "to do" lists and record critical information.
- Initiates and carries out steps to complete familiar personal, household, community, work and leisure routines with stand-by assistance and can modify the plan when needed with minimal assistance.
- Requires no assistance once new tasks/activities are learned.
- Aware of and acknowledges impairments and disabilities when they interfere with task completion but requires stand-by assistance to take appropriate corrective action.
- Thinks about consequences of a decision or action with minimal assistance.
- Acknowledges others' needs and feelings and responds appropriately with minimal assistance.
- Low frustration tolerance/easily angered. Argumentative. Self-centered. Depressed. Irritable.
- Uncharacteristically dependent/independent. Overestimates or underestimates abilities.
- Able to recognize and acknowledge inappropriate social interaction behavior and takes corrective action.

Family Strategies for Level VIII

Rancho Level VIII is characterized by Purposeful, Appropriate Behavior. The person can initiate and carry out steps to complete familiar personal, household, community, work and leisure routines and can modify the plan when needed with minimal assistance. Family strategies are similar to those at level VII. When relating to a person at Rancho Levels VIII, family and friends should:

- Treat the person in the same way as they did before the brain injury. For example, provide guidance and assistance in decision-making but respect the individual's opinions.
- Speak with normal speech patterns and vocabulary. Simple words or phrases are no longer needed.
- Be careful about teasing or using slang, as they may misunderstand. Sometimes humor is not understood.
- Talk through problems about the person's thinking skills, problem solving or memory challenges without criticizing. Reassure the individual that problems may persist because of the brain injury.
- Encourage the person to remain in therapy, to improve their cognitive skills.
- Check with the physician regarding any restrictions on driving, sports, drinking.
- Encourage the person to use note taking and tape-recorders to help with memory deficits.
- Discuss situations where the person may have had difficulty controlling emotions.
- Talk with the person about feelings and offer outside support such as counseling and/or support groups.

Level IX - Purposeful, Appropriate: Stand-By Assistance on Request

- Independently shifts between tasks and completes them accurately for at least two consecutive hours.
- Uses assistive memory devices to recall daily schedule, "to do" lists and record critical information for later use with assistance when requested.
- Initiates and carries out steps to complete familiar personal, household, community tasks independently, and unfamiliar personal, household, work and leisure tasks with assistance when requested.
- Aware impairments and disabilities when they interfere with a task and takes appropriate corrective action, but requires stand-by assist to anticipate a problem before it occurs and take action to avoid it.
- Able to think about consequences of decisions or actions with assistance when requested.
- Accurately estimates abilities but require stand-by assistance to adjust to task demands.
- Acknowledges others' needs and feelings and responds appropriately with stand-by assistance.
- May have low frustration tolerance and may be easily irritable. Depression may continue.
- Able to self-monitor appropriateness of social interaction with stand-by assistance.

Level X - Purposeful, Appropriate: Modified Independent

- Able to handle multiple tasks simultaneously in all environments but may require periodic breaks.
- Able to independently procure, create and maintain own assistive memory devices.
- Independently initiates and carries out steps to complete familiar and unfamiliar personal, household, community, work and leisure tasks but may require more than usual amount of time and/or compensatory strategies to complete them.
- Anticipates impact of impairments and disabilities on ability to complete daily living tasks and takes action to avoid problems before they occur but may require more than usual amount of time and/or compensatory strategies.
- Able to independently think about consequences of decisions or actions but may require more than usual amount of time and/or compensatory strategies to select the appropriate decision or action.
- Accurately estimates abilities and independently adjusts to task demands.
- Able to recognize the needs and feelings of others and automatically respond in appropriate manner.
- Periodic periods of depression may occur.
- Irritability and low frustration tolerance when sick, fatigued and/or under emotional stress.
- Social interaction behavior is consistently appropriate.

**RANCHO LOS AMIGOS MEDICAL CENTER
PEDIATRIC LEVELS OF CONSCIOUSNESS
INFANT TO 2 YEARS**

- | | | |
|------|---|--|
| V. | NO RESPONSE TO STIMULI | A. Complete absence of observable change in behavior to visual, auditory, or painful stimuli. |
| IV. | GIVES GENERALIZED RESPONSE TO SENSORY STIMULI | A. Gives generalized startle to loud sound.
B. Responds to repeated auditory stimulation with increased or decreased activity.
C. Gives generalized reflex response to painful stimuli. |
| III. | GIVES LOCALIZED RESPONSE TO SENSORY STIMULI | A. Blinks when strong light crosses visual field.
B. Follows moving object passed within visual field.
C. Turns toward or away from loud sound.
D. Gives specific, localized response to painful stimuli.
E. Spontaneous, nonpurposeful movement of extremities. |
| II. | RESPONSIVE TO ENVIRONMENT | A. Responds to name.
B. Recognizes mother or other family members.
C. Enjoys imitative vocal play.
D. Giggles or smiles when talked to or played with.
E. Fussing is quieted by soft voice or touch. |
| I. | INTERACTS WITH ENVIRONMENT | A. Shows active interest in toys; manipulates or examines before mouthing or discarding.
B. Watches other children at play; may move toward them purposefully.
C. Initiates social contact with adults; enjoys socializing.
D. Shows active interest in bottle.
E. Reaches or moves toward person or object. |

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**RANCHO LOS AMIGOS MEDICAL CENTER
PEDIATRIC LEVELS OF CONSCIOUSNESS
PRE-SCHOOL AGE 2-5 YEARS**

V. NO RESPONSE TO STIMULI

A. Complete absence of observable change in behavior to visual, auditory, or painful stimuli.

IV. GIVES GENERALIZED RESPONSE TO SENSORY STIMULI

A. Gives generalized startle to loud sound.
B. Responds to repeated auditory stimulation with increased or decreased activity.
C. Gives generalized reflex response to painful stimuli.

III. GIVES LOCALIZED RESPONSE TO SENSORY STIMULI

A. Blinks when strong light crosses visual field.
B. Follows moving object passing within visual field.
C. Turns toward or away from loud sound.
D. Gives specific localized response to painful stimuli.
E. Spontaneous, nonpurposeful movement of extremities.

II. RESPONSIVE TO ENVIRONMENT

A. Follows simple commands.
B. initiates purposeful activity.
C. Refuses to follow commands by shaking head or saying "no".
D. Imitates examiner's gestures or facial expressions.
E. Responds to name.
F. Recognizes mother or other family members.

I. ORIENTED TO SELF AND SURROUNDINGS

A. Provides accurate information about self.
B. Knows he is away from home.
C. Knows where toys, clothes, etc. are kept.
D. Actively participates in treatment program.
E. Recognizes own room, knows way to bathroom, nursing station, etc.
F. Is potty-trained.
G. Initiates social contact with adult.
Enjoys socializing.

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Frequently Asked Questions

Frequently Asked Questions

Friends and family of newly injured patients often have many questions about recovery stages, rehabilitation and adaptation. Answers to many of the frequently asked questions are discussed below.

What is a brain injury?

A brain injury is a physical and chemical event that is often the result of a blow to the head sustained from a fall, an automobile accident, sports injury, etc. However, brain injury can also occur when there is a lack of oxygen to the brain (anoxia), with brain tumors, when certain illnesses or infections are present, and following certain types of cerebral hemorrhage. An individual does not have to lose consciousness to sustain a brain injury.

In situations where brain injury results in a very brief period (minutes) of unconsciousness or coma, the recovery may be complete or nearly complete. When the duration of the coma extends to hours, days, and weeks, the person is increasingly more likely to be left with a range of deficits in physical, intellectual, communicative, behavioral and/or emotional functions. Even mild brain injuries may produce changes in reasoning, perception and person-to-person relations. Such changes can compromise work-related abilities as well as family interaction. Such problems can have a devastating impact on both the patient and their family.

Can a person recover from brain injury?

Yes, but in contrast to the short time it takes to become injured, the recovery from a brain injury is measured in weeks, months and even years. Recovery is usually most rapid shortly after the injury (the first six months) and slows down with the passage of time. Though some people with severe brain injuries appear to have no noticeable problems and may function relatively independently, many subtle problems are usually present. Others require constant care for the rest of their lives. Our experience is that individuals continue to show improvements years after the injury or illness.

What should I expect from myself?

Most people are shocked by the news that a loved one has suffered a brain injury. Most experience a flood of thoughts and feelings, some of which may be disturbing. Some examples of these feelings are:

- Guilt is a common reaction to a loved one's brain injury. It often comes with the idea that "If I had done something differently, the brain injury wouldn't have happened." Often, it is best to acknowledge such feelings (perhaps with a member of the Treatment Team or another loved one) and put them aside until they can be viewed in a broader perspective.
- Anger is often directed at other family members, the doctors and other caregivers. Anger is a strong emotion and sometimes is justified. Frequently, the anger one feels after such a tragedy is misdirected. Again, it is helpful to become aware of the anger, and discuss your feelings with a trusted person or therapist.
- Shock affects people differently. Some people show their emotions outwardly; others appear outwardly calm yet hide inner turmoil. For many who experience shock, they may feel anxious, as if they were having a bad dream. Experiencing shock is a normal response and it takes time to resolve. Not progressing past the "shock" can be troublesome.

Where do I turn for answers if I have additional questions?

Members of the Brain Injury Team at Frazier will try to thoroughly answer any questions you may have today or in the future.

If I need guidance, where should I turn?

Stress is commonly experienced by families of a brain-injured patient. Accordingly, families must take good care of themselves so that they remain healthy and able to participate in the recovery process of their loved one. Families often become “overwhelmed” and may benefit from talking with the team psychologist for counseling and support. Signs of stress may include:

Poor self-care

An overwhelming sense of guilt or worthlessness

Change in sleep or appetite

Feeling lost or alone with no one to turn to for help

Excessive use of alcohol or drugs

A sense of helplessness and a belief that nothing helpful can be done

Inability to comprehend what is being said about the patient

What is a brainstem injury?

The brainstem is part of the brain that connects the larger portion of the brain with the rest of the spinal cord. Many functions are tightly packed in the brainstem and its position at the base of the brain leaves it quite susceptible to injury. The brainstem controls consciousness, breathing, heartbeat, eye movements, pupil reactions, swallowing, facial movements, thirst, hunger, wake/sleep cycle, and equilibrium. Furthermore, all sensations going to the brain, as well as signals from the brain to the muscles, must pass through the brainstem. The brainstem is often damaged in severe brain injuries, but is almost never the only part of the brain which is injured.

Temperature control is a common problem with brain injury survivors, i.e., the person’s normal response to changes in temperature is interrupted, and the brain responds in an abnormal way. Temperature elevations without clinical correlation, such as infection, are often seen. Severe sweating without a rise in temperature is also seen frequently. Accordingly, the body temperature of a person with a brain injury is monitored throughout the course of recovery. Elevations in temperature are attended to systematically to rule out the presence of an infection.

What is a coma?

Coma is defined in a number of ways. One of the most useful ways to define coma is that it is a sleep-like state in which the injured person does not speak and cannot obey commands. People are usually no longer considered to be in a coma if they open their eyes, speak, or can obey simple commands.

Coma in people with brain injury almost always results from injury to several parts of the brain. In very rare circumstances, a major portion of the brain is spared and only the brainstem is injured. Prolonged coma in the vast majority of cases implies injury to all parts of the brain including the brainstem.

What is a vegetative state?

The term vegetative state is used to describe someone who is awake but unaware of themselves or their environment. A person in a vegetative state will open their eyes, demonstrate sleep-wake cycles and basic reflexes, such as blinking when they are startled by a loud noise or withdrawing a hand when a painful stimulus is applied. However, they do not demonstrate any purposeful response to sensory or cognitive stimuli, such as following an object with their eyes or responding to command.

What is a minimally conscious state?

The term minimally conscious state describes a person who shows intermittent but clear evidence of awareness of themselves or their environment. This classification is given if they can respond to command; for example, moving a finger reliably when asked to do so.

What is locked-in syndrome?

This term is used when someone has had a specific type of injury resulting in damage to the brainstem. Someone who is locked-in is both awake and aware, but they are unable to respond because they are paralyzed and unable to speak. Typically, persons in this condition are able to communicate only by up and down eye movement.

Does good nutrition help recovery?

Adequate nutrition is very important for maximum recovery from a brain injury. Brain injured persons need a tremendous amount of calories, and it is not unusual for a brain injured person to lose as much as 25% of his/her body weight. Providing adequate nutrition can be very difficult. Nutritional needs are assessed immediately after injury and the doctor orders a proper diet and the method of feeding. Often supplemental vitamins and minerals are needed. Oral diets (eating by mouth) may vary from a pureed diet to a regular diet. Various types of tube feedings are used for those patients who are not able to handle oral diets. For example, a person may be fed by a nasogastric tube (feedings administered by a tube inserted into a person's nose, down the back of the throat, and to the stomach), a gastrotomy tube (a tube surgically placed through the abdominal wall directly into the stomach) or via a jejunostomy tube (a tube surgically placed through the abdominal wall directly into the small intestine). Occasionally, a brain-injured person may need to be fed through an IV (intravenous) line. Medicines can be administered through IV lines or feeding tubes too.

Nutritional evaluations are performed by a dietitian throughout the recovery process. The patient's weight, caloric and fluid intake, urinary output and bowel function are monitored and assessed frequently. Optimal nutrition remains a high priority throughout the recovery process.

It is important to understand the type of diet the patient is on and to feed them only the appropriate types of food. Feeding a patient regular food or liquid when they have a weak swallow can lead to medical complications. Please discuss swallowing and diets with your nurse and speech language pathologist.

What is a seizure?

A seizure is the result of abnormal brain activity and is common in persons with severe brain injury. Seizures are not good for the brain and it is desirable to control them. Medication will be used to control seizures. Some people with brain injury continue to take medicine to prevent seizures for several years after injury. Seizures, which can start long after the injury, are referred to as posttraumatic epilepsy. These are seen more frequently in people who have had a penetrating injury to the brain, people who have had blood clots in the brain and those who have had seizures in the first weeks after the injury. Blood levels of anticonvulsant medications are routinely monitored in effort to prevent seizures. Suddenly stopping seizure medication can bring on seizures in people who would not otherwise have had them; therefore, it is important to take these medications as directed. The physician will advise the patient when it is time to reduce or eliminate a medication.

Alcohol and seizure medicine do not mix!

What can I do to help?

Frazier Rehab Institute's Brain Injury Program encourages the family to become involved in the daily care of their loved one. It is important to let the nursing staff and physician decide when and how much care is helpful. Family members need to be asked how much they wish to be involved so that adequate decisions can be made. Formal opportunities for such discussions occur at Frazier Rehab Institute during Family Teaching, and weekly Educational Group classes.

What therapies are best?

The "best" therapies for a brain injury survivor can only be determined after careful assessment. Most patients will require many different types of therapy. However, a therapy that is essential for one person may not be necessary for another. The Frazier Rehab team stays current with evidence based practice to be sure that the treatments given each patient are appropriate and maximally therapeutic.

How is brain injury measured?

Certain tests, such as a CT (computerized tomographic) scan, EEG (electroencephalogram) or BAER (brainstem auditory evoked response) provide some information about the extent of the injury. Neuropsychological evaluation is the most sensitive assessment in determining the extent and type of brain behavioral disturbances and strengths. However, much can be learned about brain function by careful observation of speech, behavior, physical movement, learning, memory and judgment.

Does the brain heal itself?

Current research indicates that even though parts of the brain may be damaged, destroyed or missing, remaining parts can learn how to take over the functions that were lost. It appears that the brain cells called neurons that are next to damaged brain areas can reconnect pathways between other neurons, forming new circuits that can resume some of the lost function. This is called neuroplasticity. Also, so-called "mirror neurons" located on the opposite side of the brain from the damaged area, can become involved in roles that the injured region used to have. A goal of rehabilitation is to stimulate the brain to re-form lost circuits.

What is posttraumatic amnesia?

Coming out of coma is not just "waking up" as people often imagine or as television often depicts. Most typically, it is a gradual process of regaining contact with the world. The kind of memory that is most often affected is the ability to continuously remember the events of the day.

Posttraumatic amnesia is a state when a person with brain injury is awake but unable to recall what happened just a few hours or even a few minutes ago. A person in this state may appear confused and occasionally disoriented. People who have fully recovered from their injury usually have only confused perceptions at this stage of recovery, if they remember it at all.

What causes agitation?

When the brain is injured, it is unable to accurately process information, to filter out distractions and to plan appropriate responses to people and surroundings. In essence, the brain has lost the ability to guide the person's actions. During this stage of recovery, states of extreme irritability are often present. Verbal and physical aggression are common at this stage and are often distressing to family and friends.

It is important for family to remember that these states are beyond the patient's control. Moreover, they do not imply that there has been a permanent personality change or that the survivor is in severe pain. This stage may last for weeks or until the person begins to comprehend what is happening to him/her. This stage is very taxing on family members and caregivers. The team at Frazier Rehab Institute will teach family members methods to minimize or redirect this behavior.

When does recovery stop?

Gradual recovery from brain injury may continue for several years. It is important to note, however, that recovery may stop at any stage. In the most unfortunate cases, people may survive for many years and yet be totally dependent with no awareness of their surroundings. Our experience is that this is rare.

Is all well when my loved one leaves the hospital?

Many people with brain injury have continuing problems even after they leave the hospital. This is particularly true for those who have had a prolonged period of coma. Problems with complex thinking, emotional control, personality change and memory are common. Both the patient and the family may be frustrated and disturbed by these continued difficulties.

Setbacks in self-care, independence and life-style goals are not unusual. To assist with some of these setbacks, the rehab treatment team will likely recommend outpatient therapies or a comprehensive, day treatment program.

Is there anything my loved one should avoid following brain injury?

Activity Precautions Following a Brain Injury:

Brain injury results in changes in thinking and coping. Recovery spans years. In order to maximize recovery and minimize the chance for a second injury the following precautions are strongly recommended. In addition, if you notice physical or emotional symptoms or behaviors that are concerning to you, contact your doctor.

This is a general list of recommendations for a person with a brain injury. Your doctor and team may give you specific and additional recommendations that vary on an individual basis. If you are interested in an activity that may place you at risk for an injury or re-injury, please contact your rehabilitation doctor for direction.

The following precautions are strongly recommended for all persons who have sustained a brain injury:

1. Always wear a seat belt.
2. Children should be placed in a car seat.
3. Adolescents and adults who plan to drive must complete (or re-complete) the driver's evaluation course for individuals who have sustained brain injury.
4. Always wear a helmet when biking, roller-skating, roller blading or skate boarding.

The following precautions are examples of activities that your doctor may recommend that you avoid for an extended period of time following a traumatic brain injury. Please consult with your rehab doctor regarding your ability to participate in such activities now or in the future.

1. Riding mopeds, 4-wheelers, motorcycles, jet skis, etc.
2. Diving into water.
3. Water/snow skiing or “tubing”.
4. Contact sports including football, basketball, soccer, volleyball, wrestling, hockey, boxing, etc.
5. Amusement park rides.
6. Use of illicit drugs and/or alcohol.

Medications to Avoid Following a Brain Injury:

The following precautions are recommended for all persons who have sustained a brain injury.

1. Avoid medications with alcohol content
 2. Avoid medications with pseudophedrine listed as an ingredient
 3. Avoid medications that may cause a sedative-type effect
 4. Avoid antidepressants (unless prescribed by your doctor)
 5. Double check all allergy medications with your doctor before taking
- * If you or your family doctor have any questions about medications, have them contact your rehab doctor.
- * Remember; never stop any medications that were prescribed by your rehab doctor. Contact that doctor first.
- * This is a general list of recommendations; specific recommendations vary on an individual basis.

What can families do to help?

Frazier Rehab Institute’s Brain Injury Program encourages the family to become involved in the daily care of their loved one. Families often decorate the patient’s room with photos of family and friends, cards, or favorite belongings. The therapists may ask you what type of music or leisure activities the patient enjoys. You could bring in items to use during therapy sessions. Many families have found it helpful to keep a journal or scrapbook recording the day-to-day or week-to-week recovery process. When visiting, avoid talking about the injury, accident or rehabilitation but instead talk about everyday life such as news, neighborhood gossip or sports.

Learning as much as you can about brain injury and recovery is essential. Attend scheduled team and family meetings and family teaching, as well as the educational classes.

During family teaching, the staff will educate you about different ways to interact with your family member as they progress in therapy. It is important to know about overstimulation. Learning the signs and symptoms of overstimulation can help you know when to turn off the lights and television, leave the room, limit visitors and allow the patient downtime to relax. It is also important to learn about redirection. Redirection is a technique the team uses to prevent inappropriate behaviors or to change the subject of inappropriate conversations.

There are many ways you can learn to help. The Frazier Rehab Institute team believes family and caregivers are essential. We invite you to take advantage of our family and caregiver educational opportunities to learn more about brain injury and recovery.

Resource Guide

Resource Guide

Where To Start

1) Education

The Frazier Brain Injury team has found that education regarding brain injury is essential for preparing families for discharge and managing future recovery needs. We encourage you to take advantage of our family and caregiver educational opportunities to learn more about brain injury and recovery.

Attend twice weekly educational series on Monday and Friday mornings at 10:30 am.

Attend family teaching days

Attend any Team and Family meetings

Research outside brain injury resources

2) Personal/Family

In the early phase of recovery, caregivers are the Brain Injury team's primary target for education and information. Caregivers will be involved in decision making and coordinating recovery efforts. If you need to take time off from work to participate in the brain injury program, ask your employer about signing up for Family Medical Leave.

It is very important for caregivers to take good care of themselves by eating right, getting good rest and taking time out for themselves. The caregiver role will be more prominent after discharge and we want you to be prepared for the transition to home.

3) Financial

Read your health insurance policy and learn the vocabulary to better understand the benefits and limitations of the policy. For example, do you know?

- What is the lifetime maximum your policy will pay?
- What are the benefits for outpatient therapy?
- What are the benefits for the Durable Medical Equipment needed at discharge?
- Do you have an out of pocket maximum?

If the brain injury survivor is without an income, check with his/her employer for possible short or longterm disability coverage. Also initiate a disability application for Social Security Disability. Your Frazier case manager is available to help you understand this information.

4) Community

If extended family, friends or neighbors offer to help, give them something to do. For example, ask them to feed the dog, run an errand, make a donation to your state's brain injury association or another charitable organization that may be assisting you.

Frazier Rehab Institute/Southern Indiana Rehab Network

Frazier Rehab Institute _____ 502 582-7400
220 Abraham Flexner Way
Louisville, KY 40202
www.frazierrehab.org

NeuroRehab Program _____ 502 429-8640
4912 Highway 42
Louisville, KY 40222
www.frazierrehab.org

Southern Indiana Rehab Hospital _____ 812 941-8300
2104 Blackiston Blvd.
New Albany, IN 47150
www.sirh.org

Brain Injury Support Group Information

NeuroRehab Program “8-9-10” _____ 502 429-8640
Third Wednesday of each month 5:30-7:00 pm
Survivors only

NeuroRehab Program
Family and Caregiver Support Group
First Wednesday of each month 1:30-2:30 pm
Third Tuesday of each month 1:30-2:30 pm

Southern Indiana Rehab Hospital _____ 812 283-8545
Support Group
Third Thursday of each month 7:00 pm
Contact Ray Maag, secretary

Baptist Hospital East Debbie Nelson _____ 502 896-7456

Financial Programs

ABI Waiver Program serves adults with brain injury ages 21 to 65 years old. Qualifying individuals must meet the nursing facility level of care and financial guidelines. The program is short term, designed to help individuals transition to existing community resources and live as independently as possible in the community. To initiate an application, contact the Kentucky Medicaid Office. 502-564-5198 or 866-878-2626.

TBI Trust Fund serves children and adults with brain injuries. This fund was designed to supplement existing resources to provide services not covered by other sources (i.e. health insurance, vocational rehab). There are no income criteria to be eligible for this program. There is a limitation of benefits of \$15,000 per person per year, with a lifetime maximum of \$60,000. For more information or to initiate an application, contact the Kentucky Department for Aging and Independent Living 502-564-6930.

The following is a list of services that may be provided by the ABI Waiver Program or the TBI Trust Fund:

- Behavior Programming
- Case Management
- Community Residential Services
- Companion Services
- Counseling and Training
- Environmental Modifications
- Occupational Therapy
- Personal care services
- Prevocational and Supported Employment Services
- Psychological Services
- Respite Care
- Specialized Medical Equipment and Supplies
- Speech and Language Services
- Structured Day Program

Disability Income

Social Security Administration _____ 800 772-1213
Department of Health and Human Services 800 325-0778 TTY
Baltimore, MD 21235
www.ssa.gov

Social Security Administration Main Office _____ 502 582-6690
601 W. Broadway
Louisville, KY 40202

Social Security Administration Federal Building _____ 812 948-5288
121 West Spring St.
New Albany, IN 47150

Contact the 800 # or visit your local Social Security office to request an application. Ensure all requested information is submitted with the application and deadlines are followed. The SSA will consider all applicants for disability. The decision is based on the SSA opinion that the applicant will be disabled (unable to work) for greater than one year. The application process can take several months for the initial decision. Some applicants are deferred and progress reviewed after a specified period of time before a decision will be made. Many applicants are denied. The appeal process is explained in the denial letter. The appeal process can take 1 to 2 years. Individuals have found that legal assistance can facilitate this process. If you are declared disabled, you will be awarded disability based on the amount of money you have contributed to the Social Security tax system from your work history.

Social Security Disability Insurance (SSDI) www.medicare.gov

Monthly payment based on your tax contributions
Eligible for Medicare—2 year waiting period

Supplemental Security Income (SSI) www.chs.state.ky.us/dms

Standard payment for eligible recipients
Automatically eligible for Medicaid in most states (not Indiana)
Household income is considered

Numbers that may be helpful to complete application:

Medical Records

Frazier (Jewish Hospital) _____ 502 587-4416
Kosair Children's Hospital _____ 502 629-8700
University of Louisville Hospital _____ 502 562-3062

Legal Documents (Birth, Death, Marriage & Divorce)

KY Bureau of Vital Statistics _____ 502 564-4212
IN Bureau of Vital Statistics _____ 317 233-2700
National Record Network _____ 800 255-2414

Legal Assistance

Lawyer Referral Service _____ 502 583-1801
Legal Aid Society _____ 502 584-1254

Federal Tax Benefits

Internal Revenue Service _____ 800 829-1040

www.irs.gov

When building ramps or modifying your home, save your receipts. Home modifications for the disabled and some medical expenses are tax deductible. Check with your tax advisor or contact the IRS to determine your eligibility for excluded income, itemized deductions and/or tax credits.

Advance Directives

Advance Directives are documents, which allow you to make decisions regarding your future medical treatment.

A Living Will tells health care professionals and your family whether or not you want life-prolonging treatment if you are in a terminal condition or a permanently unconscious state. Hospitals and doctors offices are required by law to ask you if you have this document.

A Health Care Surrogate is a person you select to make health care decisions if you are unable. You can designate a health care surrogate within your living will document.

Financial Planning

The following are documents you can draft to prepare for the management of your personal affairs, financial holdings or debts and/or medical treatment decisions. You must be competent to draft these documents.

A Will directs how you would like your personal belongings and financial holdings managed after your death.

A Power of Attorney designates a person to handle your financial affairs in your absence. This document is only valid while you are competent.

A Durable Power of Attorney designates a person to act on your behalf at the time you become incapacitated. It allows your designated person to make personal, financial and medical treatment decisions on your behalf. If you have this document, there is no need to pursue guardianship should you become incapacitated.

** If you do not have a Durable Power of Attorney in place at the time you become incapacitated, a person who wishes to assist you with your affairs must pursue guardianship.

Guardianship

Disability Court for Jefferson County _____ 502 595-4933

514 W. Liberty St. (Old Jail Building)

Louisville, KY 40202

Process (Evaluated by court appointed interdisciplinary team)

Evaluations reviewed by judge—makes decision

Time periods for hearings

Emergency Guardianship 48 hours to 7 days

Guardianship 30 to 60 days

Protective Services

Most commonly, victims of abuse are children under the age of 18 years, spouses or significant others, disabled adults and the elderly. There are 5 types of abuse: physical, sexual, emotional/psychological, neglect (including self-neglect), and exploitation. State law requires that all abuse, even suspected abuse be reported. You can make an anonymous report. The Cabinet for Human Resources will not reveal the source of the referral. When reporting, provide as much information as possible regarding the situation, abuser, victim and demographics. To make a report, please call:

Kentucky	
Adult Protective Services _____	502 595-4803
Child Protective Services _____	502 595-4550
	800 752 6200
Indiana	
Adult Protective Services _____	812 285-6364
Child Protective Services _____	812 288-5444

State Assistance Programs

Department of Social Insurance _____	502 595-4238
Jefferson County	
908 W. Broadway	
Louisville, KY 40203	
KY Temporary Assistance Program	
Food Stamps	
Medicaid/KCHIP	

Division of Family and Children
 Floyd County
 824 University Woods, Suite 9
 812 948-5480
 New Albany, IN 47150
 Aid to Families with Dependent Children
 Food Stamps
 Medicaid

Information and Hotlines

Alcoholics Anonymous _____	502 582-1849
Alcohol Hotline _____	800 331-2900
Crisis and Information Center _____	502 589-4313
	800 221-0446
Narcotics Anonymous _____	502 499-4423
Narcotics Abuse Hotline _____	800 234-0420

Housing

Kentucky Housing Corporation _____ 800 633-8896

1231 Louisville Road

Frankfort, KY 40601

www.kyhousing.org

Lower-than-market-rate home mortgages

Homeownership education and counseling

Rental assistance

Housing rehabilitation and repair programs

Independent Living Centers

These centers provide people with disability assistance to help you live independently. Services include: advocacy, information and referral, independent living skills, counseling, technical assistance, and benefit counseling.

Center for Accessible Living

Louisville, KY _____ 502 589-6620

305 W. Broadway, Suite 200 888 813-8497

981 South Third St. 40203 TTY: 502 589-6690

Louisville, KY 40202 Fax: 502 589-3980

www.calky.org

Murray, KY _____ 270 753-7676

1051 N. 16th Street, Suite C 888 261-6194

Murray, KY 42071 TTY: 270 767-0549

Fax: 270 589-3980

BEST Center for Independent Living, Inc.

624 Eastwood Avenue _____ 270 796-5992

Bowling Green, KY 42103 TTY: Use Relay Service

Bestcil@bestcil.org Fax: 270 796-6630

The Center for IL Options (Satellite)

525 West 5th Street, Suite 218 _____ 859 341-4346

Covington, KY 41011 TTY: none

ciloky@cilo.net Fax: 859 341-1252

Disability Coalition of Northern Kentucky

1032 Madison Avenue _____ 859 431-7668

Covington, KY 41011 TTY: 1-800-648-6057

dcnky@fuse.net Fax: 859-431-7688

Pathfinders for Independent Living, Inc.

105 East Mound Street _____ 606 573-5777

Harlan, KY 40831 TTY: 606 573-5777

pathfinders@harlanonline.net Fax: 606 573-5739

Advocacy
 Employment Programs
 Housing
 Independent Living Skills
 Peer Counseling
 Personal Care Attendant Program (Extensive waiting list)
 Ramps (Waiting list)

Persons with brain injuries may require 24 hour supervision or assistance from a caregiver initially at discharge or indefinitely. There are no immediate programs that provide personal care at no cost to you. The personal care attendant program coordinated by the Center for Accessible Living has an estimated waiting list of 10 years in the Louisville area.

The Center for Accessible Living and other organizations continue to advocate for additional federal funding for the personal care attendant program. You can help by contacting your state and federal representatives to voice your concern for the need for adequate funding. There are agencies that provide caregiver services for specified rates. If you are interested in hiring assistance, please discuss with your Frazier case manager.

Home Accessibility

In preparing for discharge, make sure you complete and turn in the Patient Home Accessibility Form to your therapy team. The information you provide on this form will allow your physical and occupational therapists to make recommendations for equipment or modifications needed in the home to maximize safety and independence after discharge.

Ramps

Center for Accessible Living _____ 502 589-6620
www.calky.org 888 813-8497
 TTY: 502 589-6690
 Fax: 502 589-3980

New Directions Housing Corporation _____ 502 589-2272
 1000 E. Liberty Street 888 757-8790
 Louisville, KY 40204 Fax: 502-589-3256

701 E. Spring Street, Suite 208
 New Albany, IN 47150
www.ndhc.org

KATS Network _____ 800 327-5287
www.katsnet.org

If you have steps to enter your home, you may need to make your home accessibility a priority for discharge planning. Insurance companies do not provide coverage for ramps. The above resources have financial assistance available but are very limited in funding and have extensive waiting lists. You may need to have a ramp built by a private contractor. The Center for Accessible Living can give you the names of contractors who may be available and have reasonable costs. The KATS Network may be able to assist you with locating used portable ramps or other sources of funding. The case management department has a ramp building guide if you have family or friends skilled in this area. The Center for Accessible Living also has lists of area apartments that are wheelchair accessible should you need to consider alternative housing. Ramps take time to coordinate and you should discuss with the team if one is needed and start right away.

Transportation

KY Disabled Parking Permit _____ 502 574-5700

Obtain via County Clerk's Office Jefferson Co.

Temporary (6 months)

Permanent (6 years)

Requires physician signature and must be notarized.

www.jeffersoncountyclerk.org

IN Disabled Parking Permit _____ 812 282-1862

Obtain via License Bureau Clark Co.

Temporary (6 months)

Permanent (2 free in 4 years)

Requires physician signature and must be notarized

www.in.gov/bmv/branches

Driver's Evaluation _____ 502 451-6886

Frazier Rehab Institute/Newburg

3430 Newburg Rd.

Louisville, KY 40218

Requires physician order when appropriate

Evaluated by Occupational Therapist

Some insurance plans will cover via OT benefit or may be eligible via Department of Vocational Rehabilitation

TARC 3 via TARC's ParaTransit Department _____ 502 585-1234

1000 W. Broadway

Louisville, KY 40203

TTY: 502 587-8255

www.ridetarc.org

Must be unable to use fixed-route services due to a disability or functional limitations.

KY Medicaid has cab vouchers available for physician or clinic appointments

KY Medicaid Members Services _____ 800 635-2570

Passport Health Plans (KY Medicaid Health Maintenance Organization)

o Non ambulance transport _____ 800 485-6531

o Ambulance transport _____ 800 296-0517

IN Medicaid has transport service available for physician or clinic appointments

Mainstream Transport Service _____ 812 288-1135

Wheelchair Van Transport Services

Vans with wheelchair lifts will provide transportation for specified rates

Care A Van _____ 502 634-4444

Mainstream _____ 812 288-1135

Wheels _____ 502 561-3690

Travel

Access-Able Travel Source _____ 232-2979
www.access-able.com

Provides free travel information for the disabled

Internet Access

Louisville Free Public Library _____ 502 574-1611
Main Branch
301 York St.
Louisville, KY 40203

If you do not have access to a computer with internet capacity, visit your local public library. The internet has massive amounts of informational materials available regarding traumatic brain injury from all over the world.

Assistive Technology

Assistive Technology Resource Center
Frazier Rehab Institute
220 Abraham Flexner
Louisville, KY 40202
(502) 582-7660 or (866) 540-7719
www.kentuckyonehealth.com/assistive-technology

The Assistive Technology Resource Center uses technology to maximize function for individuals being treated for disabling conditions such as spinal cord injury, movement disorders, brain injury, stroke and developmental disabilities. The services offered by ATRC include:

- Seating and mobility
- Adaptive computer access
- Electronic aids to daily living
- Home and work modification

Kentucky Assistive Technology Services Network (KATS)
Coordinating Center
200 Juneau Drive
Louisville, KY 40243
(502) 489-8258
(800) 327-5287
www.katsnet.org

KATS Network seeks to “connect individuals with disabilities to the appropriate organizations that can improve the quality and productivity of their lives through assistive technology.” The KATS Network provides the following services and more:

- Assistive technology services
- Loan of assistive devices
- Funding information and referrals
- Assessments and evaluations
- Consultations on appropriate technologies

Kentucky Assistive Technology Loan Corporation
275 East Main Street
Mail Stop 2 E-K
Frankfort, KY 40621
(877) 675-0195
www.katlc.ky.gov/

The Kentucky Assistive Technology Loan Corporation (KATLC) offers low interest loans for qualified applicants with disabilities who need assistive technology.

Enabling Technologies (enTECH)
845 South Third Street
Louisville, KY 40203
(502) 585-9911
www.spalding.edu/academics/entech/

EnTECH provides consultation, assessment, material development, training, resources, and a lending library among other services

RETURN TO SCHOOL AND/OR WORK

Education and School Re-entry

Frazier's Academic Re-integration coordinator will work with the family, school, and rehab team of each brain injured child to identify, design and implement services to meet the needs of the child for a successful school re-entry.

Legislation, such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, provides all children with the right to a free and appropriate education. The law says that children with disabilities must be provided the same opportunity to learn as children without disabilities.

Indiana Department of Education
Room 229 State House
Indianapolis, IN 46204
(317) 232-0588
www.doe.state.in.us

Kentucky Department of Education
500 Mero Street
Frankfort, KY 40601
(502) 564-3141
www.education.ky.gov

Indiana and Kentucky Departments of Education provide assistance with:

- Exceptional children services
- Individual Education Plan (IEP) and 504 plans
- Home/hospital tutoring programs
- Early childhood education programs for 3 and 4 year olds.

If you have questions regarding school related services, you can contact Frazier's Pediatric Academic Coordinator, Lisa Schmitt, at (502) 582-7417 for assistance.

Early Intervention Services

First Steps serves children age birth to three who have developmental delays. Services include the following:

- Evaluation and development of an individual family service plan
- Nursing and nutrition assessments
- Physical Occupational and Communication development
- Assistive technology
- Skill development services
- Vision and hearing services
- Transition services to early childhood education programs

Southern Indiana Cluster I
P.O. Box 547
Corydon, IN 47112
(812) 738-1975
(800) 674-2285 - other state offices
<http://www.in.gov/fssa/ddrs/2815.htm>

Kentuckiana District - Seven Counties
3717 Taylorsville Road
Louisville, KY 40220
(502) 459-0225
(877) 417-8377 - other state offices
<http://chfs.ky.gov/dph/firststeps.htm>

Health Care Assistance for Children

The following agencies may assist in funding for services, testing or equipment not covered by health insurance. Families will need to meet specified income criteria.

KY Commission for Children with _____ 800 232-1160
Special Health Care Needs
1405 E. Burnett
Louisville, KY 40217
www.chfs.ky.gov

IN Children's Special Health Care Services _____ 800 475-1355
(CSHCS) TTY 866 275-1274
Espanola 800 433-0746
<http://www.iidc.indiana.edu/irca/ServArticles/CSHCSprogram.html>

Vocational Rehabilitation Services

Vocational Rehabilitation assists people with disabilities in making informed career choices and utilizing available support services to prepare for, obtain or retain employment. Vocational Rehabilitation services include:

- Counseling and guidance
- Physical and mental restorative services
- Vocational training
- Placement and job coaching
- Transportation (driver's evaluations and vehicle modification)
- Telecommunications
- Other rehabilitation technological aids and devices

After a referral is made to your area Vocational Rehabilitation office, a counselor will contact you to schedule an appointment and begin the application process. If you are determined eligible, the counselor will work with you to determine which programs are appropriate to help you meet your vocational goals.

For more information regarding Vocation Rehabilitation services, contact your local Vocational Rehab office.

Indiana Division of Disability and Rehabilitation Services
(800) 545-7763 choose option 2 for Vocational Rehab
www.in.gov/fssa/ddrs/2636.htm

Indiana Area 25 Vocational Rehab Office
Serves Clark, Floyd, Harrison and Scott counties
452 Vaxter Avenue
(812) 288-8261

Kentucky Office of Vocational Rehabilitation
800 372-7172
www.ovr.ky.gov

Louisville Regional Office of Vocational Rehabilitation
410 West Chestnut, Suite 100
Louisville, KY 40202
(502) 595-4173

Return to Work for Agricultural Occupations

Kentucky AgrAbility _____ 800 333-2814
N 106F AgScience North
University of Kentucky
Lexington, KY 40546-0091
<http://ces.ca.uky.edu/agrability/>

Provides education and technical assistance to agricultural operators and farm families.

Equal Opportunity Agencies

The Rehabilitation Act of 1973 and the Americans with Disability Acts of 1990 and 1995 prohibit discrimination on the basis of disability. The ADA addresses equal opportunity for:

- Title I Employment
- Title II Public Services
- Title III Public Accommodations
- Title IV Telecommunications
- Title V Miscellaneous

To learn more about the ADA contact:

Southeast Disability and Business _____ 800 949-4232 Voice/TTY
Technical Assistance Center
1419 Mayson St.
Atlanta, GA 30324
www.ADAsoutheast.org

Architectural and Transportation Barriers _____ 800 872-2253 Voice/TTY
Compliance Board
1331 F. Street, NW, Suite 1000
Washington, DC 20004-111

Brain Injury Associations

Brain Injury Associations are available to assist survivors and families and may provide the following:

- Legislative and public advocacy
- Prevention and understanding of brain injury
- Information and resources
- Networking and support groups
- Educational seminars
- Provider Directories
- Conferences and much more

Brain Injury Alliance of Kentucky _____ 502 493-0609
7321 New LaGrange Road, Suite 100 866 854-4246
Louisville, KY 40222 Fax: 502 426-2993

Brain Injury Association of Indiana _____ 317 356-7722
9531 Valparaiso Ct., Suite A 866 854-4246
Indianapolis, IN 46268
www.biausa.org/Indiana/bia.htm

Brain Injury Association of America _____ 703 761-0750
8201 Greensboro Drive
McLean, VA 22102
Brain Injury Information Center _____ 800 444-6443
www.biausa.org

International Brain Injury Association _____ 703 960-0027
MCC Association Management
5909 Ashby Manor Place
Alexandria, VA 22310
www.internationalbrain.org

Resources for Brain Injury Information

Brain Resources and Information Network _____ 800 352-9424
National Institute of Neurological Disorders and Stroke
NIH Neurological Institute
P.O. Box 5801
Bethesda, MD 20824
www.ninds.nih.gov

Brain Injury Society
1901 Avenue North, Suite 5E
Brooklyn, NY 11230
www.BISociety.org
Newsletters
Brain Injury awareness information

Brain Trauma Foundation _____ 212 772-0608
7 World Trade Center Fax: 212 772-0357
34th Floor
250 Greenwich St.
New York, NY 10007
www.braintrauma.org

National Resource Center for _____ 804 828-3704
Traumatic Brain Injury
Virginia Commonwealth University
P.O. 980542
Richmond, VA 23298
Education materials
Brain Injury events

National Rehabilitation Information Center _____ 301 459-5984
1010 Wayne Avenue, Suite 800 346-2742
Silver Spring, MD 20910-3319
www.naric.com
NARIC is a government-sponsored information resource center
Collects and disseminates the results of federally funded research projects
Extensive literature collection

Centre for Neuro Skills _____ 800 922-4994
3501 North MacArthur, Bldg. 200 800 554-5448
Irving, TX 75062
www.neuroskills.com
On-line articles to read
Glossary of rehabilitation terms

****Please see the Community Resource Packet in your Frazier education binder for additional community resources.**

Glossary

Glossary

ABNORMAL MUSCLE TONE - A disturbance in the amount of tension normally found in a muscle. The tension may be "too tight" (hypertonicity or spasticity) or "too loose" (hypotonicity or flaccidity).

ABSTRACT THOUGHTS-Ideas or concepts that are not explicitly stated or provided; "thinking outside the box".

ACTIVE RANGE OF MOTION (AROM) - The amount of movement in a joint that a person can achieve by using their own muscle strength.

ACTIVITIES OF DAILY LIVING (ADL) - Activities, include feeding, dressing, personal care, homemaking and community reintegration.

ADAPTIVE EQUIPMENT - Any device used for the purpose of improving one's ability to perform a task (in other words, button hooks and reachers, built-up utensils, walkers, large computer screens).

AFFECT- Following brain injury many people have a "flat" or "blunted" affect. This means that their faces don't show what they are feeling.

AFO - Ankle-foot orthosis; any brace, which controls the ankle and foot.

AGITATION- Being uncontrollably restless, upset or overly excited by things going on inside of or around a person.

AIR SPLINTS - Plastic splints that are formed to fit around the disabled limb and inflated to full capacity to exert a pressure on the tissues, which facilitates the flow of circulation and reduces spasticity.

ALERTNESS - Refers to consciousness or wakefulness.

AMNESIA - Lack of memory for periods of time.

ANOMIA - Inability to find the correct word. Problems with naming objects, person or events; often the person will recognize the word when it is given.

ANOXIA - A condition resulting in insufficient oxygen to the brain.

ANTI-CONVULSIVE MEDICATIONS - Medications that prevent or relieve convulsion/seizures. Such medications include: Dilantin, Tegretol, Depakote and others.

ANXIETY - Motor tension caused by physical and psychological tension (i.e. worry, fear, upset stomach, heart pounding, lack of concentration, difficulty sleeping, etc.)

APATHY - A person exhibiting apathy may refuse to participate in or be disinterested in activities and spend time sitting or lying around. Disinterest or lowered activity is the result of impaired brain function not under the voluntary control of the person with brain injury.

APHASIA - Speech and language problems caused by damage to the brain. People with aphasia may have problems in speaking, understanding, reading and writing.

APRAXIA - Partial or complete inability to carry out a planned, purposeful, learned sequence of movements, in the absence of paralysis. Sensory changes or deficiencies in understanding.

AROUSAL - One part of the attention stage of information processing. It is the ability to stay awake. An early problem for survivors is that they can be constantly drowsy, sleepy or not very alert. This often improves with time.

ASPIRATION - The passage of foreign material, such as food and liquid, into the lungs.

ASSISTANCE LEVELS

Dependent - survivor who makes no voluntary effort to assist.

Maximal Assistance - survivor who participates minimally and another person (or persons) does most of the work.

Moderate Assistance - survivor and another person (or persons) participate about equally in performance of the activity.

Minimal Assistance - survivor performs most of the activity and another person (or persons) assists minimally but constantly.

Supervision - survivor requires observation by another person to ensure consistently safe performance of an activity.

Independent - survivor requires no assistance or supervision to perform an activity.

ATAXIA - Interruption of smooth muscular movements characterized by incoordination usually associated with damage to the cerebellum.

ATTENDING PHYSICIAN - The doctor ultimately responsible for the care of the person with brain injury.

ATTENTION SPAN - The length of time a person can concentrate on a task or event.

AUDIOLOGY - Study of hearing and balance disorders.

AUDITORY COMPREHENSION – The ability to understand what is heard.

AUGMENTATIVE COMMUNICATION DEVICES AND SYSTEMS - An alternative or supplemental communication device for non-verbal persons (i.e. alphabet board, picture board etc.).

AWARENESS- understanding the problems you are having because of a brain injury.

BEHAVIOR MODIFICATION PROGRAM - A program for intensive behavioral intervention in a controlled setting. The purpose is to develop adaptive behavior in a less structured environment. Persons with brain injury often need to relearn accepted behaviors in this manner. The Neuropsychologist is instrumental in developing these programs.

BODY SCHEME - The knowledge of how one's body is put together and the relationships of body parts to one another (i.e. a person may not know that their hand is at the end of their arm).

BOWEL AND BLADDER PROGRAM - Brain injury often causes impairment in bowel or bladder function. Activity, medication and diet are used to reestablish a routine for bowel and bladder regulation.

BRAIN STEM - This portion of the hindbrain is the main "highway" for information flowing between the brain and the rest of the body. All signals from and to the brain must pass through the brain stem. The brain stem controls consciousness, swallowing, heartbeat, body temperature, breathing, eye movements, etc.

CARRYOVER - Refers to the ability to retain newly learned skills or information and apply them from situation to situation.

CATHETER - Catheters are thin tubes, which may be placed in several parts of the body to put material in, drain body fluid out, or to take samples or measurements.

CEREBELLUM - That part of the brain, which coordinates movements; located in rear of the skull.

CEREBROSPINAL FLUID, (CSF) - The cerebrospinal fluid surrounds the brain and spinal cord and fills the ventricles (cavities) in the brain.

CEREBRUM - This is the largest portion of the forebrain and is the center for rational thought and creativity. Its capabilities give humans the capabilities that no other creature will ever possess.

CHEMICALLY DEPENDENT - Drug or alcohol dependent.

CHEST TUBES - Tubes inserted between the ribs and lungs to remove air and/or fluid.

CLONUS - Quick stretch of a muscle producing a sustained series of rhythmic jerks.

CLOSED HEAD INJURY - A brain injury that does not include a fractured skull.

COGNITION- How our brain processes information. The process of thinking.

COMA - People with severe brain injuries often slip into long periods of unconsciousness. The depth of coma can vary from no response to stimulation, while for others a slight awakening may be observed.

COMMUNITY REINTEGRATION/VOCATIONAL PROGRAMS - Community re-entry/vocational programs offer intensive retraining in the life skills brain injured persons need in order to function as independently as possible. Training includes emphasis on self-care, activities of daily living and physical mobility designed to teach patients and their families about community resources and how to use them (i.e. transportation services, recreation programs and support groups).

COMPENSATION – Learning to use other than normal means to achieve a goal.

COMPUTERIZED TOMOGRAPHY, CAT SCAN, CT SCAN - A series of x-rays of the brain at various levels to show its structure; a CT SCAN shows the more obvious changes (e.g. bleeding, enlarged ventricles or atrophy/shrinkage).

CONCENTRATION - The capacity to deliberately maintain one's attention on specific stimuli excluding others from awareness.

CONCEPT - General idea or meaning usually mediated by a word, symbol or sign. An idea that combines several elements from different sources into a single notion.

CONCRETE THOUGHTS-Ideas or concepts that are easily identified or given.

CONCUSSION-This is an injury to the head often mild, causing momentary or no loss of consciousness, sometimes referred to as a mild TBI.

CONFABULATION-Making something up that is not true.

CONFUSION - The state of being “mixed-up” relating to time, place or person.

CONTINENT - Ability to control bowel and bladder functions.

CONTRA-COUP INJURY - Injury to the brain opposite the side of the head, which was hit.

CONTRACTURE - Loss of range of motion in a joint due to insufficient movement.

CONTUSION-Medical term for a bruise.

CORTEX - The cortex is the largest portion of the brain and is where most thinking and cognitive functioning takes place.

CRANIOTOMY - Any surgical opening into the skull performed to relieve intra-cranial pressure, to control bleeding or to remove a tumor.

DEFICIT AWARENESS- The ability to recognize how an injury has affected one's ability to perform certain tasks (being unaware of one's deficits is not the same as being in denial).

DIAPHORESIS - Excessive sweating.

DIFFUSE AXONAL INJURY (WHITE MATTER SHEARING) - Microscopic tears of the nerve fibers that may have a more significant impact on functional abilities than the more obvious damage to the brain.

DIPLOPIA - Seeing two images of a single object. Also referred to as double vision.

DISINHIBITION - The inability to control or inhibit impulses and emotions. The person may say or do things impulsively.

DISTRACTIBILITY- The inability to hold your attention on an activity.

DYSARTHRIA - Difficulty with talking due to weakness or poor coordination of the muscles of the lips, tongue or jaw. Speech may sound “slurred”.

DYSPHAGIA - Inability or difficulty in swallowing.

ECHOLALIA - A parrot-like repetition of words spoken by others.

EDEMA – Swelling.

ELECTROENCEPHALOGRAPHY (EEG) - An electrical test of the functioning of the brain.

ENCEPHALOGRAPHY - Non-invasive use of ultrasound to record echoes from brain tissue. Used to detect hematoma, tumor or ventricle problems.

ENCEPHALOPATHY - Any abnormal condition of the structure or function of tissues of the brain.

ENDOTRACHEAL TUBE (ET TUBE) - A tube inserted into the patient's trachea (windpipe) to control their breathing and prevent foreign material from entering the lungs.

ENDURANCE - The ability to maintain an activity for a length of time. This applies both to physical and cognitive activities. Reduced endurance is very common for survivors of brain injury.

EUPHORIA - An exaggerated feeling of well-being or elation.

EXECUTIVE FUNCTION-The cognitive skills that help people do goal-directed activities such as making a meal, driving, or managing money.

EXTERNAL FIXATION DEVICE - A special splint that holds broken bones in place, these devices are connected to pins through the bones.

EYE-HAND COORDINATION OR VISUAL-MOTOR INTEGRATION - Is the use of the eyes and hands together in which visual information guides the motor response of the hand.

FAMILY TEACHING - Formal or informal scheduled meetings with families to assist them in understanding the patient's problem areas and suggestions for recovery.

FAMILY CONFERENCE - A meeting between the family and members of the rehab team to discuss progress, concerns or discharge plans.

FINE MOTOR ACTIVITIES - Activities involving small complex movements such as writing and manipulating small objects.

FLACCIDITY - Lack of muscle tone, which results in the inability to perform any movement.

FRONTAL LOBE - The area of the brain located in the front left and right sides. This area plays a role in controlling emotions, motivations, social skills, expressive language, working memory and new learning.

FROZEN SHOULDER - Pain and stiffness of the shoulder resulting in limited range of motion.

FRUSTRATION TOLERANCE - The ability to deal with frustrating events in daily life.

GASTROSTOMY TUBE (G-TUBE) - Surgical insertion of a feeding tube into the stomach through the abdominal wall.

GLASGOW COMA SCALE - Defines the level of consciousness with three factors: motor responses, eye opening and verbal responses. Range is from 3 - 8 (severe), 9 - 12 (moderate) and 13 - 15 (mild).

GROSS MOTOR ACTIVITIES - Large movements of the body involved in rolling, sitting and standing.

GROUP HOME - A closely supervised living situation for disabled individuals that focuses upon the development of self-help skills to prepare individuals for semi-independent or independent living.

HALO - A metal ring fixed to the skull of patients with spinal injuries to prevent head and neck movement.

HEAD CONTROL - The ability to maintain the head in an upright position and move it independently of the body, arms and legs.

HEMATOMA, SUBARACHNOID, SUBDURAL, EPIDURAL - Trauma to the head, which causes blood vessels to rupture. Blood accumulates and may put pressure on the brain.

HEMIANOPSIA - Blindness of one-half of the visual field caused by brain injury.

HEMIPARESIS - Muscle weakness of one side of the body.

HEMIPLEGIA - Paralysis of one side of the body caused by an injury to the opposite side of the brain.

HEMORRHAGE - The escape of blood from a ruptured vessel.

HIGHER COGNITIVE FUNCTIONS - Usually refers to judgment, abstraction, organization, problem-solving or planning.

HOYER LIFT - A mechanical device used to transfer a person safely to and from bed or wheelchair.

HYDROCEPHALUS - Excess accumulation of cerebrospinal fluid, causing increased intracranial pressure.

HYDROTHERAPY - Treatments using water as a means of promoting relaxation and healing, increasing flexibility and decreasing pain. May involve use of pools, walking tanks, or whirlpools.

HYPOTHALAMUS - Part of the forebrain, this tiny brain section handles basic needs such as hunger and thirst. It also plays a role in several emotional states.

HYPOXIA - A decrease in oxygen supply to tissue.

IMPULSE CONTROL-The ability to stifle inappropriate behavior.

IMPULSIVITY - Attempting with confidence unfamiliar tasks or responses that are beyond one's capabilities or knowledge. Acting without first thinking.

INCONTINENT - Inability to control bowel and bladder functions.

INFARCT – A tissue area deprived of blood flow.

INHIBITION-The ability to filter thoughts and expressions.

INITIATION - The ability to start an activity or conversation with little or no prompting.

INSIGHT - Understanding and integrating factors of a situation.

INTENTION TREMOR - A tremor that occurs only with voluntary, planned (intentional) movements.

INTERMEDIATE CARE FACILITY - A facility, which provides personal care with an intermediate degree of physical and/or social dependence.

JARGON – Nonsensical words or sounds used in place of real words.

JUDGEMENT-The ability to know the dangers of certain activities and to make appropriate decisions.

LABILITY - Inappropriate emotional expression and control such as exaggerated laughing or crying.

LACK OF INITIATION AND FOLLOW-THROUGH - The inability to start, continue and carry through actions without structured supervision.

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

LONG TERM MEMORY - The ability to remember things over a long period of time. This type of memory is usually preserved after a brain injury.

MAGNETIC RESONANCE IMAGING (MRI) - The process of creating images of the body without the use of ionizing radiation. During MRI, a magnet is used to pull on the nuclei of the body's hydrogen atoms. This magnet causes the nuclei to line up and repeatedly absorb and raise radio waves. A computer then translates these radio waves to images of the areas examined. The images are projected on a video screen and recorded on film for interpretation by a radiologist (a physician specializing in diagnostic imaging). MRI scans are capable of better resolution than CT scans and can image deeper in the brain.

MEMORY - Recording new information. Many types of memory are recognized, e.g., 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).

MINIMALLY CONSCIOUS STATE - The term minimally conscious state describes a person who shows intermittent but clear evidence of awareness of themselves or their environment. This classification is given if they can respond to command; for example, moving a finger reliably when asked to do so.

MOTOR CONTROL - The ability to selectively contract or relax a muscle or group of muscles at will for a purposeful movement.

MOTOR PLANNING PROBLEM - Difficulty starting, continuing and stopping movements when there is no actual muscle weakness or damage. Also referred to as APRAXIA.

MUSCLE TONE - The amount of tension (continuous contraction) in a muscle at rest. The quality or quantity of muscle tone has an effect on the efficiency of voluntary muscle contraction.

NASOGASTRIC TUBE (NG TUBE) - A tube which passes through the patient's nose and throat and ends in the stomach. This tube allows for feeding to maintain nutritional status or to remove stomach acids.

NEGLECT, HEMI-NEGLECT -Severe lack of awareness of the side of the body or environment opposite the side of the brain injury. May occur in any sensory modality.

NEURON - The basic operating unit of the brain. Billions of them interconnect inside the brain to send thoughts, feelings and information throughout the brain and the body.

NEUROPSYCHOLOGICAL EVALUATION - An evaluation using psychological tests, interview and behavioral observations to determine a person's cognitive abilities, emotional and behavioral state. These evaluations focus on relationships between the brain and behavior.

NEUROPSYCHOLOGIST - A psychologist with special training and skills in dealing with people with

neurological impairments and brain-behavior relationships. Neuropsychologists often administer special evaluations of brain function and coordinate the rehabilitation of persons with brain injury.

NEUROSURGEON - A surgeon who performs surgery on the brain and nervous system.

NURSE - A staff nurse who coordinates the patient's care. Typically interacts closely with the patient and family in providing direct nursing care and education..

NUTRITIONIST - An expert in the feeding and nutritional needs of people.

NPO - A physician's order that the patient is to receive "nothing per oral," i.e., "nothing by mouth."

NYSTAGMUS - Involuntary movement of the eyeball.

OCCIPITAL LOBE - The back part of the brain involved in perceiving and understanding visual information.

OCCUPATIONAL THERAPIST (OT) - The occupational therapist works on routines of self-care activities and retraining to improve a person's independence.

ORGANIZATION-The ability to arrange your thoughts to make them sensible and orderly.

ORIENTATION – The ability to know one's location in time, space, and relationship to other people.

OUTPATIENT REHABILITATION - This program is for patients who no longer need a hospital environment and may benefit from living in the community with retraining received at rehabilitation centers.

PARALYSIS - Inability to move a muscle or group of muscles voluntarily.

PAREISIS - Partial or incomplete paralysis.

PARIETAL LOBE - The upper middle lobe of the brain involved in perceiving and understanding sensation and relates to speech and writing.

PASSIVE RANGE OF MOTION (PROM) - The amount of motion at a given joint when it is moved by another person or another functioning limb. See Active Range of Motion.

PERCEPTION - How the various senses receive information and make sense of them.

PERSEVERATION - Meaningless repetition of a verbal or motor response or repetition of answers that are not related to successive questions asked.

POSITRON EMITTED TOMOGRAPHY (PET SCAN) - Imaging procedure that allows the brain's metabolism to be pictured so that areas of greater and lesser brain activity can be discerned.

PHYSIATRIST - A physician who specializes in physical medicine and rehabilitation, who has overall responsibility for directing the rehabilitation program.

PHYSICAL THERAPIST (PT) - Treats a patient with a program formulated from an evaluation of the individual's motor functioning to correct and improve areas of impairment.

PLATEAU - A continued absence of significant improvement.

POSITIONING - Placing a person in a position and changing that position so that muscle and joint flexibility is preserved and skin breakdown prevented.

POST TRAUMATIC AMNESIA (PTA) - That period of time following an accident when there is no memory. This period includes the coma and any time after awakening when nothing can be remembered. The length of the PTA is a partial predictor of the quality of the recovery. PTA ends at Rancho Level 6.

PRAGMATICS-The behaviors behind what you say or communicate, such as eye contact, gestures and facial expressions.

PREMORBID – Patient’s condition before the injury.

PROBLEM SOLVING - The ability to use cognitive processes in a task in a practical way using reasoning and judgment.

PRONE - Lying face down.

PROSTHESIS - An artificial limb, any artificial device, which replaces the function of a body part or system, i.e., an artificial limb.

PSYCHIATRIST - A physician who specializes in the medical management of mental illness.

PSYCHOLOGIST - A mental health professional with expertise in the diagnosis and treatment of mental, emotional and behavior disorders.

PTA - See AMNESIA, POST-TRAUMATIC

PULMONOLOGIST - A physician who specializes in problems of the lungs.

QUADRIPARESIS - A weakness that involves all four limbs.

RANCHO LOS AMIGOS COGNITIVE RECOVERY SCALE - A ten level scale of cognitive recovery ranging from I (No Response) to X (goal directed, appropriate interactions with the environment.) A five level scale of cognitive recovery is used for children approximately five years old and younger.

RANGE OF MOTION - Refers to the specific angles of movement of which a joint is capable.

REASONING - Drawing logical conclusions with analysis and support of given facts. Includes drawing inferences, recognizing cause/effect, and understanding relevancies and relationships. Critical thinking skills in problem solving include: (1) Ability to define a problem, (2) Selecting pertinent information in solving it, (3) Recognizing stated and unstated assumptions, (4) Formulating and selecting relevant hypotheses, and (5) Drawing valid conclusion and judging validity of inferences.

REHABILITATION - The restoration of maximum independence to a disabled individual with his limitations by developing his residual capabilities.

RESIDENT - A physician who has finished his medical training and is taking additional training to specialize while being supervised by the Attending Physician.

RESPIRATOR - See VENTILATOR.

RESPONSE - How you act, what you say or do. Your reactions to what is happening around you.

RIGIDITY - Difficulty in conforming or changing attitudes or actions; tenseness or immobility of muscles due to extreme increase in muscle tone.

SEIZURE/SEIZURE DISORDER - A seizure is a disturbance in the electrical chemical activity of the brain due to nerve cell damage or electrolyte imbalance.

SELF-AWARENESS - One of the more common problems among survivors is the ability to really be aware of what they are saying and doing and their impact on others. People with self-awareness problems may not be aware of some of their major impairments.

SEMICONSCIOUS - Not completely aware or responsive.

SENSORY INTEGRATION - Interaction of two or more sensory processes in a manner, which enhances the adaptiveness of the brain's response.

SENSORY STIMULATION - A treatment that stimulates all the senses designed to encourage the coma or vegetative patient to respond to their environment.

SEQUENCING SKILLS - The ability to put time or events in the correct order, e.g., motor (sequencing motor movements smoothly) or linguistic (sequencing words appropriately into sentences) as well as keeping track of the correct order of stimuli.

SERIAL CASTING, INHIBITIVE - A technique used to reduce contracture and control hypertonicity in and around a joint, usually the ankles, wrists and elbows. A series of casts are applied to the area every few days. When the casts are changed, the joint should be recasted in an improved position.

SHUNT - A procedure to drain off excessive fluid in the brain.

SOCIAL SECURITY DISABILITY - Monthly income granted to persons who have paid into the social security system and are confirmed disabled and unable to work for at least one year. Coverage also provides health insurance through the Medicare program if the disability continues beyond two years.

SPASM - A sudden involuntary contraction in muscles or blood vessels, which disrupt function.

SPEECH-LANGUAGE PATHOLOGIST - Speech-language pathologists address communication skills which involve listening, speaking, reading, writing and cognitive thinking) skills. Speech-language pathologists also diagnose and treat swallowing problems.

SPLINT - An external device used to provide positioning to help prevent or correct contracture of an extremity.

SUB-ACUTE REHABILITATION PROGRAM - This program is designed for patients slow to recover and for which more time is needed to decide the best treatment.

SUBLUXATION - A partial or incomplete dislocation of a joint.

SUPINE - Lying on one's back.

SUPPLEMENTAL SECURITY INCOME - Refers to a federal income maintenance program for the aged, blind and disabled who have limited income and resources. Administered through the Social Security Administration. People who receive supplemental security income usually receive Medical Assistance also.

SWELLING - Just as an ankle swells if it gets turned wrong, the brain can swell following an injury. Because the brain is encased within the skull, swelling can put enormous pressure on the brain.

SYNERGY, MOVEMENT - Action of two or more muscles that forms a pattern of movement. In brain injury, synergy refers to abnormal stereotypical patterns of movement.

TEAM ROUNDS - A weekly meeting of an individual's Rehabilitation Team. At the team conference, the person's progress, rehabilitation goals and estimated length of stay are discussed and documented.

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

TILT TABLE - A table, which has the capacity to raise and lower a person from the horizontal to the vertical position and vice versa.

TONE - The tension for resting muscles and the amount of resistance that is felt when a muscle is moved.

TRACHEOSTOMY - A hole made in a patient's neck, which will allow them to breathe with a ventilator. A surgical procedure, which creates an opening into the windpipe (trachea) through the neck.

TRACKING - The ability to follow moving objects with the eyes.

TRANSFERS - The ability to move from one surface to another. Basic transfers include movement to and from a bed and chair; advanced transfers refer to movement to and from a toilet, car, tub/shower, and floor.

TRUNK CONTROL - The ability of a person to maintain proper alignment of the trunk and pelvis; to move and bring the trunk back into alignment after movement.

VEGETATIVE STATE - the term vegetative state is used to describe someone who is awake but unaware of themselves or their environment. A person in a vegetative state will open their eyes, demonstrate sleep-wake cycles and basic reflexes, such as blinking when they are startled by a loud noise or withdrawing a hand when a painful stimulus is applied. However, they do not demonstrate any purposeful response to sensory or cognitive stimuli, such as following an object with their eyes or responding to command.

VENTILATOR - A mechanical device designed to qualify (humidify, warm and adjust oxygenation) the air, which is then delivered to the patient by assisting or controlling pulmonary ventilation, either intermittently or continuously.

VERBOSITY - Inability to control the amount of verbalization. Verbalization is often disorganized.

VESTIBULAR SYSTEM - This system is responsible for maintaining balance and equilibrium. The system receives information from the inner ear, the eyes and sensory receptors in the joints of the body; dysfunction in this system will result in unsteadiness, imbalance or spatial disorientation.

VIDEO FLUOROSCOPIC SWALLOW STUDY - A video x-ray study that is performed to determine any difficulties a person may have in swallowing in order that appropriate therapeutic measures may be taken.

VISUAL FIELD DEFICIT - The inability to visually perceive information in a specific area of the visual field. This may involve left, right, one half or one quarter of the visual field.

VOCATIONAL REHABILITATION COUNSELOR - A counselor who assesses a person's employment potential and helps the person prepare for employment.

WORD FINDING – The ability to search for and locate words from the learned vocabulary when they are needed.

Scope of the Frazier Rehab Institute Brain Injury Program

FRAZIER REHAB INSTITUTE SCOPE OF THE BRAIN INJURY PROGRAM

Introduction to Frazier

The Frazier Rehab Brain Injury Program provides comprehensive services to the individual who has experienced a brain injury and to the individual's family and other members of their support network. Frazier Rehab Institute has achieved CARF (Commission on Accreditation of Rehab Facilities) Accreditation for the Brain Injury Program.

Frazier's admission nurses and affiliated physiatrists (doctors specializing in rehab medicine) are either present in the local hospitals or available through phone and email contact to work closely with the acute care hospital team and the family to transition the patient into rehab. At Frazier we are always willing to open our doors for family tours. We are pleased to show families what is available at Frazier and to introduce them to key team members who will be responsible for the patient's care.

Frazier introduces the family to rehab while the patient is recovering in the acute care hospital. We then provide our brain injury program to the patient and family through our continuum from inpatient rehabilitation through post-acute outpatient rehab. The intent of the Frazier Brain Injury Program is to provide intensive and comprehensive services designed to prevent or minimize chronic disabilities of persons with a primary diagnosis of acquired brain injury. The program aims to restore the person to optimal levels of physical, cognitive, behavioral, social, and emotional functioning within the context of the person, family, and community.

Goals of the program are:

1. To provide a formally organized program for support and advocacy for the brain injured individual and family.
2. To educate families to understand the effects of the brain injury and the recovery process.
3. To improve behavioral problems, address personality changes, educate the patient and family about self-awareness deficits associated with brain injury through psychological intervention and an interdisciplinary approach.
4. To improve the patient's thought processes, memory skills, perception and judgment through cognitive retraining activities.
5. To improve the patient's mobility and self-care skills through focused therapy and care promoting physical recovery.
6. To encourage active participation and education of the patient's family through attendance at the patient's therapy sessions and through routine scheduled family teaching sessions.
7. To develop a comprehensive discharge plan for the patient by working closely with the patient and family to identify needed resources and services and make appropriate referrals.
8. To restore each person served to his or her fullest potential of independence and productivity at home, in the workplace, at school and in the community.

Persons Served

Frazier Rehab Institute's Brain Injury Program offers comprehensive services to patients of all ages. Our rehab team has clinicians specializing in pediatric and adult brain injury treatment. Many are certified brain injury specialists. The Brain Injury Program is available to patients at any level of recovery after injury – from coma to mild brain injury. The Brain Injury program offers services to people who have had a traumatic brain injury or a non-traumatic brain injury such as anoxic or hypoxic events, exposure to toxic substances, brain tumors, infections, and metabolic disorders.

To be admitted to the Frazier inpatient program, an individual must have family or other caregivers available to participate in the family teaching program with the goal to care for the patient in the home setting; be medically stable and able to participate in 3 hours of therapy per day. To be considered medically stable, a patient must meet all of the following:

- All vital signs stable
- Free of fever for at least 48 hours
- Adequate nutrition/hydration (orally or by feeding tube)
- All medications adjusted/finalized and plans for use defined
- Must not require one-on-one nursing care
- All work up procedures and surgical interventions completed (or definite plans finalized)
- Participation restrictions and activity limitations defined.

To be admitted to the inpatient Brain Injury Program, the patient must not require constant psychiatric intervention or active treatment for chemical detoxification. Further, infectious disease must be absent or controlled so that the safety and health of other patients are not compromised and so the patient is not prevented from participating in the rehabilitation program.

Inpatient Rehab

Frazier offers inpatient rehabilitation to individuals who are recovering from brain injury either on the adult neurologic floor or the pediatric floor. Each of these inpatient floors has been specially designed for patients' and families' comfort, privacy, and care needs. Patients are provided rooms that are well equipped to manage medical and nursing care and to allow family and friends to visit comfortably. The patient rooms are wired for internet access for family members' convenience and are equipped with large flat screen televisions. Wireless internet access is available to our guests throughout the Frazier building. A family member is permitted to stay overnight if the patient is staying in a private room. A patient dining room is available on the floor for meals and for recreational activities. Families are welcome to reserve a dining room for a special family occasion.

The adult neurologic unit has treatment areas on the floor that have been especially designed with the therapy needs of the neurologic patient in mind. The therapy space on the floor is comprised of:

- Therapy gym for Occupational and Physical Therapy
- Speech-Language Pathology offices
- Private treatment room for use when distractions need to be minimized
- Practice kitchen area for daily living skills
- Practice bathroom area for daily living skills
- Splinting room

What We Offer

The equipment available in the neurologic therapy areas can be used for general rehab purposes, but was primarily selected because of the needs of the neurologically involved patient. Our therapeutic approaches and equipment address difficulty with balance, sitting, mobility, self-care, vision, cognition, behavior, emotions, communication and swallowing. A few examples of the technology and techniques we have available to the brain injury patient are:

- Dynavision™ for visual perception
- Biometrics™ for upper extremity rehab
- Robots for improving shoulder/elbow, wrist and hand movement
- Overhead lifts for transfers, standing, and walking
- Motomed™ for exercise and retraining
- Nusteps™ for exercise and retraining for functional electrical stimulation
- Deep physical agent modalities including ultrasound, electric stimulation, and anodyne
- Bioness™ for functional electrical stimulation
- Dynamic splinting for upper extremity functional return
- Serial casting and medications for spasticity management
- Modified constraint induced movement therapy
- Fluoroscopy for the swallow evaluation
- Endoscopy for the swallow evaluation
- Swallow therapy including neuromuscular electrical stimulation
- Frazier Water Protocol
- Aphasia therapy and cognitive rehabilitation
- Ramps, curbs, stairs, and parallel bars for ambulation therapy,
- Therapy pools
- Animal assisted therapy
- Assistive technology and wheelchair seating resource center
- Car – parked in the 9th floor gym for practicing getting in and out of a vehicle.

The pediatric floor also has patient rooms with the same comfort and care features as the adult floors. The pediatric therapy areas are equipped for children with special emphasis on the needs of children with neurologic injuries and illnesses. The beautiful therapy gym has a wide array of specialized equipment including parallel bars, ramps, curbs, stairs, Motomed, Nustep, standing frames, and gross motor play equipment. Adjacent to this space is a sensory integration gym which is equipped with swings, slides, and climbing apparatus. Sensory integration therapy is available to our children with brain injuries. There are speech-language pathology offices and a private treatment room located in the therapy area as well. Our Academic Reintegration Coordinator arranges for tutoring through the Jefferson County Public School System (JCPS) as appropriate. She also coordinates record exchange and return to school with JCPS and other school districts.

The Snoezelen room is located on the pediatric floor where patients are provided sensory stimulation in a calm, non-distracting environment. The pediatric floor has the Ronald McDonald Family Room for family relaxation. The LaRosa Lounge is a recreational space for structured activities and for down time.

On the Frazier grounds we have built an outside therapy area that contains playground equipment and mobility space. The pediatric patient has access to any equipment located on the adult neurologic floor or elsewhere in the building if the clinical need is present.

The Frazier inpatient rehab program operates seven days per week. Adult and pediatric patients should expect to receive at least 3 hours of therapy five of every seven days. Inpatient therapy begins as early as 7:30 am and can continue until approximately 4:30 pm. Each patient's schedule is adjusted as needed to best suit his/her progress and needs. Some therapy may take place in the patient's room, for example basic self-care activities involving grooming, dressing, and hygiene. Other activities are better suited to spaces where the specialized therapy equipment is located. Some therapy activities might occur in other parts of the building and campus including the outdoor therapy area. On occasion, the therapists may accompany the patient on a community outing.

Most therapy sessions are provided one-on-one with patients. We may offer co-treatments by two therapy disciplines teaming up to treat the patient together. Some therapies may best be provided in a group format. Group therapies typically are provided in addition to the three hours of individual therapy patients receive five of every seven days.

The **Social Daily Living Skills Group** is led by an inter-disciplinary team to take individual therapy a step further by promoting social interaction while doing physical, cognitive and recreational therapy activities. Examples of activities include planning and carrying out a social event, playing Wii, or cooking a meal.

The **Lunch Feeding Group** is held weekdays during the lunch hour to assist patients with swallowing and feeding problems to feed themselves, practice safe swallowing, and achieve good nutrition in a social setting.

Getting Started

Upon admission each rehab team member completes an evaluation and works with the patient, family, and other team members to develop an individualized and integrated treatment plan. The patient and family are considered essential team members in this planning process. Our goal is to get the patient home and the family often holds the key to making this happen. We need to understand how the family functions, and what is considered important by the family and the patient. Our team will use information about your family's lifestyle and personal goals to help craft a plan for promoting the smoothest recovery and return to home. We will continuously complete individualized assessment, intervention, and evaluation throughout the patient's rehabilitation to achieve the goals that are set.

A person coming to Frazier for brain injury rehab is usually showing physical, cognitive, emotional, social and/or behavioral changes. The individual with a brain injury may not be responding to others, or may be confused and agitated. The person may be saying things that he/she normally wouldn't say and might be having memory problems. The person might not be able to walk or swallow. There are many different problems a person with a brain injury might have. No two people with a brain injury show exactly the same problems or impairments. This is because everyone's brain is different, and the extent and type of brain injury varies amongst individuals. Despite the differences, there are predictable patterns of recovery that people with brain injury typically experience. The Rancho Los Amigos Cognitive Recovery Scale is utilized as a guideline for progression of the treatment plan. Our

team understands brain injury recovery and we teach the family to have an ongoing understanding of the patient's level of recovery and the best intervention approaches at each stage of recovery.

The rehab team will provide family members written information, education, and support as the patient goes through rehab. We will conduct team and family meetings as needed to ensure the family and the rehab team goals are aligned. Our program has team members who are specialized in brain injury rehab. In fact, many of Frazier's brain injury program staff have earned brain injury specialist certification (CBIS/CBIST) through the Academy of Certified Brain Injury Specialists. The entire team will provide relevant education to the patient and family throughout the rehab stay. A brain injury education and support group for family meets twice a week. The patient is welcome to attend if able to benefit from the sessions. We want you to always feel comfortable to ask questions of any of our team members.

The Frazier Team

The Frazier inpatient team members include:

- Psychiatrist (rehab doctor)
- Consulting physicians
- Case managers
- Rehab nurses
- Nursing assistants
- Psychologists
- Neuropsychologists
- Occupational therapists
- Occupational therapy assistants
- Physical therapists
- Physical therapist's assistants
- Speech-language pathologists
- Dietitians
- Pulmonary rehab clinicians
- Recreation therapists
- Rehab aides.

Spiritual Support

The team can assist in addressing spiritual needs by connecting the patient and family with available religious and spiritual support and services provided through the medical center. If preferred, an individual's personal religious ministers may be called in for spiritual support.

Case Management

Our case managers are the team coordinators. A case manager's role is to link the family, patient, and rehab team. The case manager is the team member who works with the insurance companies to report progress and to advocate for the continuing stay in Frazier while progress is occurring and hospitalization is medically necessary. The case manager coordinates and schedules family education and team and family conferences. The case manager supports the patient and family in discharge planning by identifying services, support and equipment that will be needed after inpatient rehab. The case manager is an expert on community resources including post-acute rehab services, transportation

agencies, brain injury support groups, and financial programs. We have a commitment to our patients to assist them in conserving their financial resources to meet their long-term care needs. Our case managers provide the patient and family with recommendations relative to their existing financial resources and relative to alternative financial programs such as the Traumatic Brain Injury Trust Fund, Acquired Brain Injury Waiver program, and Vocational Rehab services.

The case manager works closely not only with the family and patient but also the rehab team. There is frequent communication between team members about patient issues and progress so that all are updated routinely. Great communication leads to the best care and optimal rehab outcomes. We designed our Frazier inpatient floors and established our teams with great communication in mind. The team meets formally at least every 7 days to gauge overall progress toward discharge goals and to update the discharge plan as needed. More frequent, informal meetings are held to coordinate care.

The Downtown Medical Campus

Frazier Rehab is located in a thriving medical community. Acute care hospitals surround Frazier including the Kosair Children's Hospital attached by pedway, Jewish Hospital also physically attached, Norton Hospital across the street, the University of Louisville Hospital and the James Graham Brown Cancer Center down the street. The University of Louisville (UL) Neurosurgeons and Physiatrists reside in Frazier's building. Medical consultation by a variety of specialties is available as needed. A UL Neuro-Optometrist runs a weekly clinic at Frazier for inpatients experiencing visual impairments after brain injury. She is available to follow patients when discharged as needed.

Family Teaching

Family teaching is essential to the patient's safe and successful discharge to home. We expect the family to attend therapy sessions to learn how to best care for the patient and to support what the patient is learning. New learning is more likely to occur and become stable, when the family helps the patient carryover the techniques or recommendations that were taught in therapy or at the bedside. Families are expected to attend the Brain Injury Education and Support group offered two times each week.

Brain Injury Support and Advocacy

A representative from the Brain Injury Alliance of Kentucky (BIAK) visits Frazier weekly and is available to meet patients and families. The BIAK's mission is to serve Kentucky citizens whose lives have been affected by brain injury through advocacy, education, prevention, research, service and support.

After Inpatient Rehab

Recovery from brain injury is a long-term process lasting several years. Inpatient rehab is typically a short stay and patients are discharged after a few weeks. The rehab team generally makes recommendations for continued therapies after inpatient discharge. Many patients are able to return home and resume therapies in an outpatient setting.

Outpatient Services

Frazier operates the **NeuroRehab Program** located at 4912 US 42 in Louisville's East End, which is a comprehensive outpatient program that specializes in managing the rehab needs of patients with cognitive deficits after an acquired brain injury. The NeuroRehab Program accepts patients from adolescence through the geriatric years. Admission criteria include:

- Medical stability
- Continent of bowel and bladder
- Rancho Los Amigos Cognitive Recovery Scale score of 5 or above
- Ability to learn and progress toward goals
- Willingness to attend and participate reliably
- Willingness to address substance abuse if needed
- Willingness to address psychiatric conditions if needed

The team approach offered to the brain injured outpatient in the NeuroRehab Program is individualized to decrease the level of disability and the need for assistance, while increasing productivity in the home, workplace, and community. The NeuroRehab Program offers a comprehensive, holistic, day treatment program and traditional outpatient therapies.

Services offered at the NeuroRehab Program include:

- Cognitive, behavioral, and emotional treatment
- Physical conditioning
- Vocational preparation
- Psychological counseling
- School re-entry
- Substance abuse counseling
- Driving skills training
- Bioptic Driving Program
- Home evaluations
- Home management
- Concussion management
- Visual-perceptual treatment
- Job analysis
- On-site work evaluations
- On-site work re-entry
- Brain injury survivor support group
- Caregiver support group
- Preparation for independent living
- Prevention and wellness education.

The NeuroRehab Program team also has achieved brain injury specialist certification (CBIS) and consists of:

- Psychiatrists (rehab doctors)
- Occupational Therapists
- Speech-Language Pathologists
- Physical Therapists
- Psychologists
- Case Managers
- Rehab Aides

The NeuroRehab Program works closely with the Frazier Neuropsychology department to make appropriate referrals for and to obtain information from neuropsychological evaluations. Neuropsychological evaluations provide valuable information to the patient, the family, and the therapists working with the patient. These assessments are part of the outpatient treatment program. The information gained from the neuropsychological assessment can help determine the individual's current level of functioning and learning abilities for school or work, and home environment, in addition to identifying cognitive skills that need to be addressed in therapy. The rehab doctors follow patients in clinic at the NeuroRehab Program for ongoing medical management.

The NeuroRehab Program also collaborates with the Kentucky Department of Vocational Rehab which is a state funded agency that provides vocational counseling to assist patients with return to school or gainful employment. A vocational rehab counselor is on site at the NeuroRehab Program twice weekly. Vision therapy is offered at the NeuroRehab Program by a neuro-optometry practice.

KentuckyOne Health offers concussion management services that encompass a variety of options including a Concussion Helpline, medical appointments with a concussion specialist, neuropsychological evaluation, and evaluation and treatment by member(s) of the NeuroRehab team. Clinicians working at the NeuroRehab Program answer the Concussion Helpline seven days per week triaging calls to identify needs and assist in navigating services if needed.

Traditional Outpatient Rehab Services

Some brain injury survivors will not need the comprehensive services offered at the NeuroRehab Program. Others may prefer to get their rehab in an outpatient clinic closer to home. Frazier offers outpatient rehab at multiple sites throughout the Louisville Metro area. Young children are best served in our downtown outpatient pediatric program. The children are treated on the pediatric floor in the specialized therapy spaces with the appropriate equipment and expert therapists. The case manager helps the patient and family to identify the most suitable location to receive outpatient therapy based on convenience or specialized services available.

Home Health Care

Patients may require therapies be provided in the home for a period of time. Traveling to an outpatient setting may be too difficult for them or home health nursing care may be needed. Frazier can arrange for rehab in the home through the VNA Nazareth Home Care, a service of KentuckyOne Health. We also can make referrals to other home care agencies if preferred by the patient and family.

Residential Placements

Some patients may continue to require 24 hour nursing care and a less intense level of therapy and may be discharged to a skilled nursing facility. While other patients may need a more intensive, longer term residential treatment program to achieve more progress before being able to return to the home setting. We are connected to the rehab world at large and can make appropriate referrals for skilled nursing facility placements and specialized residential brain injury programs if necessary.

Ongoing Support Systems

Frazier Rehab Institute hosts a monthly Brain Injury Survivor Support Group at the NeuroRehab Program, 4912 US 42. This community based support group offers education and social networking and is available to Frazier patient and anyone in the community who has sustained a brain injury. Peer support has proven invaluable to many people who have survived a brain injury. The Frazier NeuroRehab Program also offers a support group for caregivers of acquired brain injury survivors.

Maintaining Wellness and Fitness After Brain Injury

Frazier has developed the Community Fitness and Wellness Center within the downtown Institute. Individuals with disabilities can become members of this program to improve cardiovascular/aerobic fitness, muscular strengthening and flexibility. The Community Fitness and Wellness Center is staffed by exercise science professionals and equipped with state of the art equipment.

Our Commitment to You

The Frazier Rehab Institute Brain Injury Program provides intensive and comprehensive services designed to prevent or minimize chronic disabilities while restoring the person to optimal levels of physical, cognitive, social, and behavioral functioning. The clinical team is both competent and compassionate. We are committed to providing the best environment, services, and education to assist the patient to achieve the highest level of independence possible.

We understand that a brain injury can prove traumatic to the patient, family and network of friends. We try very hard as a team to be aware of the difficulties each one is experiencing and to help you feel comfortable with and knowledgeable about the services we are providing you.