



**BRAIN INJURY
ASSOCIATION
OF NEW JERSEY**

825 Georges Road, Second Floor
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Helpline: 1-800-669-4323

No Brain Injury is
Too Mild to Ignore,
or Too Severe to
Lose Hope

Impaired Cognition and Behavior Problems—Double Trouble

By Carolyn Rocchio

Brain injury has a very unpredictable course of recovery. Many factors contribute to the ultimate outcome, such as, pre-morbid personality and goal direction of the individual, the length of coma, areas of the brain or brain stem damaged, family support, age at which the injury occurs, emergency medical services (admission to a trauma center vs. nearest hospital), and of course, funding to provide specialized rehabilitation services.

No family is ever prepared to comprehend the full magnitude of the life changes the injury creates. Most manage from day to day, learning on the go and drawing on reserves to get them through what they hope will be a short term situation with a satisfactory conclusion. Everyone rejoices with the first signs of awakening, thrills at the first attempts to communicate or walk, and feels very confident that rehabilitation can restore functional abilities. However, the physical recovery may be very misleading in some cases and families may not be adequately prepared for the cognitive and behavioral changes that may persist and be difficult to manage.

Once the medical and rehabilitative process is completed, it doesn't mean that your family member will resume life as it was before. Fortunately many, with good support systems will enjoy a near normal life and other family members will perhaps be inconvenience only briefly. However, for those whose family member sustains severe damage to the frontal and temporal lobes of the brain, life may never be the same. Physical limitations are more widely understood and accepted by the general public but few understand and/or tolerate behavior that is the product of severe cognitive impairment.

There are no easy answers to managing the long term affects of brain injury, but the best method is a proactive approach. That requires preparation on the part of the family, a discharge plan that provides good information the family can follow, and the cooperation of the individual to agree to the plan. Everyone needs a "what do I do if this happens?" book, but often the most frustrating problems surface after rehabilitation, insurance and the family are all exhausted.

Some common problems experienced by individuals with brain injury are inability to consistently plan and organize the day, recall information in a functional manner, stay on task while bombarded with external stimulation, and in general to make sense of the world in which one lives. Is it any wonder that the response is often negative? Unwanted behavior does not



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develop over night, nor does it disappear overnight. I urge all families still involved in a rehabilitative setting to ask, "Is my family member likely to have difficulty with cognitive and behavioral issues once reintegrating into the community?" If the answer is yes, make sure that the facility provides practical strategies for managing the behavior to keep things from getting out of control. Also be alert to the fact that undesirable behaviors may develop some months or even years after the injury and still be directly related to the insult to the brain.

It is particularly frustrating for families of children reentering the school system when assuming the educators understand brain injury and will appropriately provide for their child. Unfortunately, nothing could be further from the truth in most school systems.

Brain injury is uniquely different from other disabilities and needs to be addressed as such. The same holds true for adults attempting to return to the job setting only to discover the job is the same but the "employee" is different. Brain damage affecting cognitive skills and abilities ultimately becomes the most disabling residual effect of brain injury. The manner in which the family deals with these changes will determine the quality of life for the person with the injury as well as those family members in supportive roles. The amount of time you spend gathering information and preparing to help your family member through the maze of reintegration and possible lifelong support, the more positive results can be expected.

The time spent learning about ways to help your family member through reentry into the community will pay off in easier to manage behavior.

Most individuals are very happy to come home after rehabilitation, not only is home a safe and secure place but it is often perceived as a place where one will find one's old self. Friends and family are happy but after a period of welcoming friends may soon return to their old routines of school, work, and leisure activities leaving the person with brain injury isolated. Brain damage involving frontal or temporal lobes of the brain resulting in confusion, memory loss, poor organizational skills, disinhibition, poor reasoning skills and judgment can change the individual dramatically and it is very difficult for others to understand these changes.

It doesn't take long for the individual with brain injury to discover that there's no longer the same reasons to get up in the morning, there's no one to hang around with and familiar things just aren't the same anymore. Friends quit coming around, driving privileges are gone, and in general life is a real drag! Boredom can lead to overeating, weight gain, disagreements within the family about anything and everything and a vicious cycle of behavioral deterioration begins. The goal should be to circumvent this cycle by advance planning. Some suggestions about this planning include:



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1. Learn about your family member's deficits by close involvement in the rehabilitation process. Have a clear understanding about ways your family member's deficits will affect his abilities and ask about compensatory strategies you can implement in your home to lessen the impact of these deficits. Start planning for homecoming as far in advance of discharge as possible.
2. Have ready the room your family member will be using upon arriving home (many individual's living independently of the family may need to return to the family home, perhaps temporarily, to meet their care needs.) Plan the room arrangement so the individual can function as independently as possible. This may mean that drawers are thoughtfully arranged with stickers on the outside to describe the contents; a divided tray, properly labeled to hold wallet, watch, coins, glasses, etc. placed on the nightstand to ensure that personal items are not misplaced; and a notebook or cue cards available with steps for completing tasks as simple as showering or other personal care routines.
3. Establish a schedule that includes as much activity as the individual can tolerate without becoming overly fatigued. This may mean an outpatient therapy, schedule, a day activity program in the community or even a volunteer "job." Everyone needs a reason to get up in the morning and something satisfying to look forward to. Many families complain that the individual never wants to do anything. However, the problem may be inability to initiate and plan, so the family should help with planning activities. Deciding on the plan is the first step but reminders, written and verbal, keep the plan in motion. Equally important is the follow-up which may require cueing to help the person "remember" the event. Don't make the mistake of asking, "What did you do last night?" Instead ask, "Did you enjoy the concert last night, tell me about it?" By cueing you are helping the person retrieve the information from long term storage and integrate it into the conversation.
4. If social problems such as drugs/alcohol were a problem before the injury, they are likely to be a greater problem afterward. As long as your family member is dependent on the family then the family is in the best position to prevent this from happening. A hard line approach now may make life easier later. It is important to be aware that use of medication, i.e., anti-seizure medication, can be a dangerous combination with the use of other non-prescription substances.
5. External cueing is very helpful. If the individual is constantly faced with situations in which he has no recall and those around him



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constantly remind him of his lack of memory, it may eventually cause an erosion of self-esteem. Create some strategies for compensating for this problem by developing lists, post-it notes, or cue cards or any other strategies that help the person feel more independent and less likely to make mistakes and be nagged or scolded.

6. Structure, structure, structure and consistency! The importance of a structured environment cannot be over emphasized. There's nothing more frustrating and frightening than being an adult and not knowing what you're supposed to be doing. Structuring helps offset some problems by giving the individual a consistent and dependable way of life.
7. Always check with your physician when behavioral changes occur. Seizures can develop after brain injury and it is not uncommon that they occur some months or years after the injury. They are frequently called "silent seizures" because they do not involve convulsions; however, they often create changes in behavior. Monitor your family member's behavior and note any changes, e.g., random and restless pacing, staring into space, complaints of foul odors or taste changes, and/or hallucinations. These symptoms can indicate seizure activity and warrant testing to determine if there is abnormal electrical activity in the brain which is commonly controlled with the use of anti-seizure medications.

It is not easy but individuals with brain injury can be helped to control behavior and lead socially fulfilling lives. When behavioral problems become unmanageable, families are encouraged to seek outside help, ideally through contact with professionals and rehabilitation facilities familiar with brain injury. Lacking that option, community mental health facilities are alternatives. The family will need to work closely with the professional staff at mental health facilities to ensure that the problems are addressed appropriately. Also contact your state's Brain Injury Association office for further information about cognitive and behavioral problems after brain injury.

Carolyn Rocchio is the parent of a son with a brain injury sustained in a 1982 automobile crash. She is the founder of the Brain Injury Association of Florida and a former Board member of the Brain Injury Association.

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*Additional information can be found at: Helpline: 1.800.444.6443
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