

Behavioral  
Challenges  
after  
Brain Injury



Brain Injury Association  
of America



Martin J. McMorrow, M.S.  
Director of National Business  
Development

The MENTOR Network  
Center for Comprehensive Services

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## Introduction

A brain injury can have a variety of effects: medical, physical, cognitive, emotional, and behavioral. Of these, behavioral problems are sometimes the most challenging for persons who are engaged in rehabilitation or attempting to successfully re-enter their communities. Behavioral problems can affect not only a person's success in rehabilitation, but also his or her social relationships, educational or vocational pursuits, safety, and ability to live happily and independently.

An estimated 90% of all people who are severely disabled by a brain injury may experience some related emotional, behavioral, or psychiatric problems. Furthermore, 40% of these individuals may still have behavioral issues five years after the injury, and between 3% and 10% may need intensive ongoing assistance (see Health Resources and Services Administration Federal Traumatic Brain Injury Program Webcast, 2006). People with milder brain injuries may also experience behavioral problems, such as mood changes, irritability and fatigue, although these may be more difficult to identify and it is less likely that these individuals will receive organized support related to their difficulties.

Behavioral problems can range from mild personality changes or periods of disorientation to persistent difficulties controlling emotions, lack of inhibition (an inability to block or manage drives and impulses), and generally managing one's behavior. Often the individual is no better able to control his or her behavior than to control the medical, physical, or cognitive effects of brain injury.

These problems can be very troublesome for the individual and for those who provide services or supports. In fact, they are often identified as the primary reasons for

marital discord, problems with other social relationships, family difficulties, and school or workplace problems. Behavioral problems may result in the need for long-term care in specialized settings.

This booklet will do two things: first, inform people with brain injuries, their families, and caregivers about the kinds of behavioral challenges they may face; and second, offer practical ways to address those challenges.

## **What Causes Behavioral Problems?**

Most behavioral problems after brain injury arise at least in part as a result of damage to the frontal lobe, an area of the brain responsible for “executive functions.” Executive functions include organization, planning, creating, evaluating, reasoning, communicating, and problem-solving skills. All of these are likely to affect how a person behaves.

Human behavior is complex, and it is often difficult to isolate what behaviors directly result from the brain injury. As with anyone, what a person with a brain injury says or does in a given situation is the result of interactions among a variety of contributing factors:

### ***Contributing factors***

- The individual’s pre- and post-injury experience
- The region and nature of the brain injury
- His or her current situation
- His or her history of behaving in a particular situation
- Physical changes such as fatigue, stamina, and sensory sensitivity (such as sensitivity to light or noise)

- Changes in cognitive abilities such as attention, processing of information, memory, and susceptibility to overstimulation
- The behavior of others

These and other causes of behavior interact dynamically over the course of each day. A person can appear to be doing very well one moment and experience tremendous difficulty the next—sometimes due to the cumulative effect of many factors. Individuals may have difficulty remembering the steps to an activity or task and may need to relearn a specific skill. Emotionally-charged behavior, such as confusion and frustration, may also indicate the individual is experiencing depression or mood disorders. Such psychiatric conditions are often a result of the brain injury and appear to be more common in individuals who have been injured than in the general population.

Good neuropsychiatric, neuropsychological, and behavioral assessment can help identify how each of these factors contributes to behavioral problems.

Neuropsychiatrists are medical doctors and therefore able to write prescriptions. Their training focuses on elements of psychopharmacology (the effect of medications on mood, thinking, and behavior). An interview and assessment conducted by a neuropsychiatrist would be similar in length to a typical doctor's visit.

Neuropsychologists are PhDs or PsyDs with expertise in assessing the relationships between the brain and behavior along with elements of cognition. They are trained to conduct detailed assessments using standardized tests, which may take up to eight hours. A neuropsychiatrist will often refer an individual with a brain injury to a

neuropsychologist for such formal testing. Neuropsychologists will issue recommendations that may include a behavior plan.

Behavior analysts usually hold a master's degree. In most states the profession is not licensed or regulated as are physicians and psychologists. (National certification is available for behavior analysts.) A behavioral analysis is a detailed functional assessment examining when and how measurable behaviors occur and what follows them. Some neuropsychologists are trained in behavior analysis and will conduct such assessments themselves, but not all have such training. Many health insurance policies do cover visits to neuropsychiatrists and neuropsychologists, but not to behavior analysts.

More often than not, individuals with significant behavioral issues end up seeing all three types of health care professionals. These professionals may talk about behavioral problems in different ways depending on their area of expertise. The chart on page 5 lists terms that are commonly used.

While your doctor or rehabilitation professional can best explain what he or she means by each, the use of these terms suggests that special attention may be needed to address emerging behavior problems.





<b>Behavioral terms</b>	<b>Cognitive terms</b>	<b>Neurological terms</b>
<ul style="list-style-type: none"> <li>• Confused and agitated</li> <li>• Social skill deficits and/or substance abuse</li> <li>• Lack of responsiveness to requests (“noncompliance”)</li> <li>• Resistance to rehabilitation therapies</li> <li>• Disruptiveness</li> <li>• Loud verbalizations or threats</li> <li>• Property destruction, self-injury, physical aggression, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Disinhibition (inability to block or manage drives and impulses)</li> <li>• Lack of awareness or ability to self-monitor and evaluate</li> <li>• Personality changes</li> <li>• Mental inflexibility (rigid or black-and-white thinking)</li> <li>• Impulsiveness</li> <li>• Impaired reasoning, judgment, problem-solving, memory, etc.</li> <li>• Intermittent explosive disorder (a severe inability to resist surges of aggression)</li> <li>• Dementia due to head trauma (a term indicating that changes due to brain injury are prolonged or permanent—not degenerative as with Alzheimer’s, for example)</li> </ul>	<ul style="list-style-type: none"> <li>• Frontal lobe syndrome (a set of symptoms associated with impairment of executive functions)</li> <li>• Injuries to specific regions of the brain, for example the hippocampus, amygdala, temporal lobe, or basal ganglia</li> <li>• Organic brain syndrome (any physical change in the brain that causes a significant change in mental function)</li> <li>• Organic personality disorder (a physical change in the brain that causes a significant change in personality or behavior)</li> </ul>

Professionals, family members, and caregivers can all provide insight into the behavior of a person with a brain injury. In particular, caregivers and families can help others understand the individual's behavioral problems in context of his or her behavior, experience, and personality prior to the injury. This may help in the development of a more tailored recovery and rehabilitation plan.



Additionally, identifying the five possible contributing factors listed on page 2 may help professionals, family members, and caregivers begin to understand and address the causes of behaviors, instead of merely trying to stop problem behaviors when they occur.

## **What Help is Available?**

People who experience less frequent or intense behavioral difficulties after brain injury may not receive help in overcoming them, especially if these difficulties do not noticeably disturb their ability to socialize, work, and interact in their communities. Sometimes these brain injuries have never been diagnosed, or individuals may not recognize that their difficulties are related to their injuries—particularly if some time has passed. They may not know how to ask for help, and if they do, it is often difficult to recognize that the behavioral problems are actually the result of the brain injury. But even long after an injury

treatment can be helpful and behavior successfully changed. A person should be evaluated by a doctor if he or she experiences the following, even several weeks, months, or more after a blow to the head:

- Attention deficits, difficulty sustaining mental effort
- Fatigue and tiredness
- Impulsiveness, irritability
- Low frustration threshold
- Temper outbursts and changes in mood
- Learning and memory problems
- Impaired planning and problem solving
- Inflexibility, concrete thinking
- Lack of initiative
- Dissociation between thought and action
- Communication difficulties
- Socially inappropriate behaviors
- Self-centeredness and lack of insight
- Poor self-awareness
- Impaired balance
- Dizziness and headaches
- Personality changes

Adapted from Jacques Duff, Post-Concussion Syndrome (Doncaster, Victoria, Australia: Behavioural Neuropathy Clinic, 2005; [http://www.adhd.com.au/Post\\_concussion\\_Syndrome.htm](http://www.adhd.com.au/Post_concussion_Syndrome.htm))

People who exhibit more frequent or intense behavioral difficulties after brain injury may encounter a different set of challenges. Although behavioral problems are a common feature of brain injury, relatively

few hospital-based rehabilitation programs have the personnel or environments to respond to them. As a result, people with behavioral problems following brain injury are often discharged from the hospital, transferred to nursing homes, or placed in psychiatric or other treatment settings. In some cases, it may be important to keep this from happening, since any of these changes can disrupt rehabilitation efforts and make it harder for a person to resume a satisfying life. In other instances the changes may help the person get needed behavioral services. Fortunately, there are many residential, community-integrated, and home-based programs for neurobehavioral treatment.

For a family member dealing with behavioral problems soon after brain injury, asking the following questions of the physician, case manager, or member of the treatment team may increase the likelihood of receiving assistance at the hospital or rehabilitation unit:

- Can a psychiatrist experienced in brain injury consult for possible medications that might help?
- Has a neuropsychological assessment been conducted? Are the recommendations of that assessment being followed?
- What other professionals have been consulted (e.g., speech pathologist, behavioral psychologist, behavior analyst, nurse, etc.)?
- Can changes be made in the present environment to help the individual? What, specifically, are caregivers doing to address the behavioral issues?
- If it is determined that the person is not progressing or that the current environment is not equipped to address

his or her problems, is there good reason to expect that things will be different in a new setting?

If it is determined that a different program is needed to address behavioral problems that arise in the hospital, families, caregivers, and medical professionals should remember that not all (neuro)behavioral programs are the same, and keep the following in mind when selecting a program:

- Does the program permit and encourage community integrated activities to increase independence and inclusion?
- Are multiple treatment settings available in the event that the individual's condition improves or deteriorates?
- Is the treatment staff well led, prepared, and experienced in behavioral treatment?
- Is the facility accredited and licensed as a brain injury provider?
- Does the program use a clear treatment model that combines medical, cognitive, behavioral, and rehabilitative approaches?
- What are the specific goals to be addressed at the program?



- Does the program have concise information related to the outcomes of others who have been treated there?

It can be very hard to find the right services, programs, and ongoing supports for persons who experience behavioral problems after brain injury. In many places they simply do not exist. But in places where they do, the Brain Injury Association of America's (BIAA) annual Directory of Brain Injury Rehabilitation Services can be a very useful resource (visit [www.biausa.org](http://www.biausa.org) and click on "Bookstore"), as it identifies programs that offer specialized behavioral intervention services.

Hospital discharge planners, state BIA affiliates, independent case managers (nurses or social workers assigned by insurance companies or others to guide care), and representatives of the National Association of State Head Injury Administrators (NASHIA) may also be able to assist you in your search.

Finding the right services or programs is only one part of the equation. You will also have to find the financial resources to pay for them. In many situations, a person with a brain injury will have exhausted his or her insurance benefits long before deriving the maximum effects from rehabilitation.



Furthermore, since many insurance plans still view “recovery” as primarily related to medical/physical stabilization, walking, and speech, it can be difficult to justify costly treatment on the basis of cognitive and behavioral problems. The following suggestions may help you during this process:

- Keep all physician reports and written recommendations related to behavioral issues. Make special note of behaviors that have changed since the injury. Similarly, make a copy of the neuropsychological assessment and learn its recommendations thoroughly.
- Learn your state’s Medicaid eligibility standards and, if appropriate, apply quickly. Many states have made great progress in developing systems of care for people who have experienced brain injury. In fact, more than half of all states now have dedicated brain injury waivers that may provide help with funding (see NASHIA in Resources for more information).
- Learn to “advocate for outcome.” Making the choice early to invest in outcome-oriented rehabilitation—rehabilitation that promotes personal independence and autonomy—can significantly reduce the long-term costs of care.

### ***How Do I Interact with a Person who Has Significant Behavioral Problems?***

Many people who experience behavioral problems after brain injury will not receive the professional rehabilitation and supports they need. As a result, they, their families and caregivers and others around them may need to become very active participants in rehabilitation, advocacy, and life processes.

This booklet cannot cover all the medical and behavioral assistance that persons with brain injury with behavioral issues may need. But it can provide some brief guidelines regarding the two key time periods in recovery: (1) soon after an injury; and (2) later on, as an individual demonstrates increased ability to learn new skills.

## **Soon After the Injury**

Soon after an injury, behavioral problems are likely to become apparent when a person is confused, disoriented, and unable to communicate effectively. This is sometimes referred to as an “agitation phase” of recovery. During this time, people with brain injury may struggle to understand what has happened, where they are, and whom they are with—let alone the multitude of expectations that others may have in a hospital or rehabilitation setting. It is common, therefore, for individuals to be frustrated and agitated.

It can be very hard to interact with a person with brain injury during this time, particularly when that person may be perseverating (continually repeating the same actions or phrases), urgent, and physically strong. Here are some ways to help:

### **1. Get involved with people and activities.**

Behavioral problems can be very hard to deal with. But it is important to resist the impulse to avoid difficult situations. A person with a brain injury is not likely to become better oriented or less confused if left alone.

### **2. Comfort appropriately while encouraging independence from the start.**

It is only natural to want to comfort a



family member, but providing comfort at the wrong times can actually make problems worse. Encourage increased independence from the start, as people with brain injuries can begin to feel helpless.

### **3. Coach, encourage, and reinforce positive behavior.**

Things that used to be easy are often extremely hard after a brain injury. Focus on what the individual is doing well, rather than just correcting mistakes or directing behavior.

### **4. Help the person get physically involved in his or her environment.**

Many rehabilitation professionals believe that restrictions, particularly physical restraint and isolation, prolong behavioral difficulties after brain injury.

### **5. Adjust your expectations to the new situation.**

Brain injury can have serious, lifelong effects. While it is reasonable and healthy to expect the very best, understand that the person with the injury may already be doing as well as he or she can do.

### **6. Develop a characteristic style of interacting.**

People with brain injuries may need to be reminded regularly whom they are with, where they are, and what has happened to them. Provide verbal descriptions of people and places as situations change. Understand that the person may be having trouble with memory and keep providing the information as often as it is needed.

## **7. Encourage safe exploration.**

Although you may wish to keep the individual from doing anything potentially dangerous, remember that in order to become more independent the person will need assistance to rediscover his or her environment.

## **8. Gradually raise expectations.**

While it is important to raise expectations over time, it is also important not to raise them too fast, as the person with brain injury could become overwhelmed or frustrated.

## **9. Discover the person's preferences.**

Be alert to the individual's wants and needs. Find ways in which he or she can engage in desired activities. Mix difficult tasks with more desired ones. Encourage the individual to engage in activities rather than assuming that he or she is unable to participate.

## **10. Listen with all your senses.**

It can be difficult to communicate with a person with a brain injury. So pay attention to everything in the person's behavior. What is the behavior communicating? It is almost always saying something.

## **11. Bounce back quickly from problems.**

You may encounter very serious behavioral problems. Try not to get stuck attempting to teach new skills while the person is upset, as most people do not learn well at those times.

## 12. Reach agreements.

When difficulties arise, use negotiation skills. Helping someone requires a partnership, not giving orders.

### Later On: Developing Improved Self-Management Skills

In most cases the person will gradually begin to make sense of his or her situation, learn to communicate needs, welcome assistance from others, and participate in the process of recovery. Sometimes, however, a person will have continual or long-term problems, such as confusion, disorientation, and an inability to communicate effectively. These may lead to behavioral problems that intensify, disrupting recovery and rehabilitation. In these cases the individual and his or her family and caregivers need a plan to cope with unwanted behaviors.

Although some people with brain injuries may be able to develop good self-management plans on their own, more often it will be useful for them to work closely with partners or teams. Sometimes external perspective can help one better understand one's own behavior.

Developing the plan is not simply a matter of making a few notes about what caregivers will



do when a particular unwanted behavior occurs. The process involves many people (the person with the injury, medical professionals, clinical specialists, other caregivers, and families) working together to devise a meaningful approach to behavioral problems. All involved must remember that:

- The plan is for a specific person with unique strengths and needs
- Ultimately the plan is for that individual, not anyone else
- The most effective behavioral plans are created with the help of the brain injured person, and focuses on supporting behavior in positive ways, through rewarding good choices and making changes in the environment that increase the likelihood the person will succeed.

Ultimately, if a person is to live independently, he or she will need to relearn how to manage emotions and behavior, rather than indefinitely counting on others to manage these issues. For this reason, it is useful to approach behavioral problems after brain injury just like the physical, speech, or cognitive problems: by developing a specific strategy that the injured person can use on his or her own or with assistance, step by step, when difficulties arise.

The key components of a self-management plan include the following:

- 1. Identify what a person can do when he or she notices a trigger or recognizes a sign of becoming upset.**

This is the key component of the plan. Often it includes things like taking deep breaths, counting to ten, using distractions like music, removing oneself from the

situation, remaining silent, or repeating things to oneself like “now it is time to relax.” Arrange these actions in a stepwise fashion with the participant, so that if one alternative is not effective there are others to try. If together you can identify something that has worked in the past, it may be useful to include that as step one.

**2. Learn to recognize when behavioral issues are most likely to occur.**

Can the person communicate how he or she is feeling? Are there specific times of the day or particular situations that increase the likelihood that problems will occur (being tired, feeling ill, or recently having experienced a seizure)? Get a piece of paper or go to a computer, and with the participation of the person, write these things down in his or her own words.

**3. Identify specific events or triggers that seem to make a person upset.**

Everyone is likely to be upset more by some things than others. For a person with a brain injury these can include being corrected or criticized (particularly in public), dealing with difficult tasks, time pressures, handling transition times, getting out of routine, and not being acknowledged or praised when it is expected. As above, write these down under the category “things that make me upset.”

**4. Recognize what has happened in the past when the individual has become upset.**

Behavioral problems start somewhere and end somewhere. They are not a single event. What is the first sign that

an individual notices when he or she is becoming upset? For example, does he or she start breathing faster? Notice tension in specific part of the body? Blush? Make repetitious movements? If the person doesn't get control of himself or herself, what is likely to happen next? Try to describe the pattern of a typical upset, including the most intense behavior that has occurred in the past.

## **5. Identify what others can do to provide assistance if needed.**

This part of the plan allows the individual to play a very active role and actually direct his or her family and caregivers.

Ask questions like, "What would you like others to do if they notice that you are having problems?" A person may ask not to be corrected in public, or to be redirected to a particular activity or removed from a situation. If information is sparse, keep asking, "What else can others do to help you?" With time, the person may identify that the best thing others can do is remind him or her to "use the plan."

Every individual's plan is different. Some are very simple, some are more complex. Working together on the plan or talking about it more broadly can help the individual educate others about his or her difficulties and enlist their support. It is important to practice the plan before the triggering event or upset occurs, in order to build up the coping strategy. With practice, it is far more likely that these coping skills will be effective when a person begins to become upset.

Approaching behavioral problems after brain injury with the goal of helping a person manage his or her emotions can completely

change the way that person interacts with others. Instead of focusing on unwanted behavior with the goal of stopping it, a self-management approach lets the person focus on developing new skills and advance toward greater independence.

## **Expect the Extraordinary**

Consider the situation of a man in his mid-forties who experienced a severe frontal lobe brain injury as a result of a car crash.

This man had been living in a reputable neurobehavioral rehabilitation program for nearly a year. He used a wheelchair to get around, spoke unintelligibly, was extremely loud and resistant to assistance, had what appeared to be seizures, and slept in a restraint bed to protect him from falls.

Professionals in the program, the family, and other caregivers believed he was doing about as well as he could, considering the severity of his brain injury. This was not unreasonable, since many people with brain injuries function similarly.

At the urging of an insurance case manager and with the agreement of a reluctant family, the man was moved to a new program, which used different approaches to his behavioral problems. Within two weeks he was walking. Within one month he was speaking clearly and the seizure-like activity (which actually reflected his attempts to walk) had completely disappeared. The environment in the new program was more normal and homelike, and he never displayed any significant behavioral problems there. Within four months he had developed a self-management plan (which he rarely needed to use) and was discharged to a rehabilitation program focused on community re-entry. Within seven months, he returned home to his family and job. Although he is now divorced, five years

after his injury, he is retired and living happily and independently in his home.

Had no one ever tried anything different with this man, it is very possible that nothing would have changed. Those around him might have continued to believe he was doing as well as could be expected. While his situation may be unusual, the bottom line is clear: expect the extraordinary. Trying may not always produce the desired result, but if you do not try you will never know.

## **Internet Resources**

Brain Injury Association of America  
[www.biausa.org](http://www.biausa.org)

National Association of State Head Injury Administrators  
[www.nashia.org](http://www.nashia.org)

National Disability Rights Network  
[www.ndrn.org](http://www.ndrn.org)

Centers for Disease Control and Prevention/Traumatic Brain Injury Website  
<http://www.cdc.gov/ncipc/tbi/TBI.htm>

### ***Written Materials:***

Lash and Associates Publishing and Training  
[www.lapublishing.com](http://www.lapublishing.com)

National Association of State Head Injury Administrators  
[www.nashia.org](http://www.nashia.org)

Traumatic Brain Injury Facts:  
Neurobehavioral Health.



Neurobehavioral Issues of Traumatic Brain Injury: An Introduction.

National Association of State Head Injury Administrators, Neurobehavioral Health Committee. March, 2006.

### ***Health Resources and Services Administration***

Reducing the Use of Restraint and Seclusion of Individuals with Traumatic Brain Injuries. Health Resources and Service Administration, Federal TBI Program Webcast. (Harvey Jacobs, Martin McMorrow, and Jane Hudson) Available at <http://www.ndrn.org/issues/an/rs/resources.htm>.

### ***Some Additional Materials Written by this Author***

McMorrow, M.J., Braunling-McMorrow, D., & Smith, S. (1998). Evaluation of functional outcomes following proactive behavioral residential treatment. *Journal of Rehabilitation Outcomes Measurement*, 2, 22-30. (Journal is now out of print. Copy is available at [www.mentorabi.com](http://www.mentorabi.com).)

McMorrow, M.J., Guercio, A, & Guercio, J. (1998). Interacting with persons who are confused and agitated. *Brain Injury Source* 2: 32–45.

McMorrow, M.J. (2003). *Getting Ready to Help: A Primer on Interacting in Human Service*. Baltimore, MD: Brookes Publishing.

McMorrow, M.J. (2005). *The Helping Exchange: PEARL*. Wake Forest, NC: Lash and Associates Publishing.

## **About the Author**

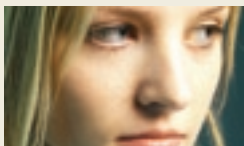
Marty McMorrow is currently the Director of National Business Development for the MENTOR Network. He has over 35 years experience in program design and delivery of human services, has published more than 60 professional papers, and presents often to public groups. Marty co-developed the social skills training program *Stacking the Deck*, and the language training program *Looking for the Words*, which were supported by the Illinois Department of Mental Health and Developmental Disabilities. He also designed the Personal Intervention Neurobehavioral Program at the Center for Comprehensive Services in Carbondale, Illinois which is now a part of the MENTOR Network. Marty's primary interest is in translating behavioral technology into proactive and applicable human service programs.

Tina Trudel aided greatly in the editing of this booklet. She is President/COO of Lakeview Healthcare Systems, Inc. & Lakeview Virginia Neurocare, LLC; Senior VP of Clinical Operations, Lakeview Management, Inc.; and Assistant Professor of Clinical Psychiatric Medicine, University of Virginia Medical School.

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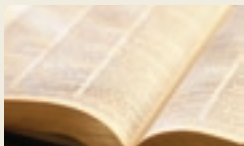
*Behavioral Challenges after Brain Injury* is one in a series of brochures on “Living with Brain Injury.”



Overcoming Loneliness



Preparing for Life after High School



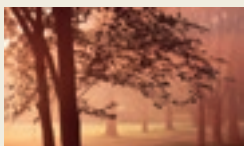
A Basic Legal Glossary



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