

Behavioral Challenges after Brain Injury

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 people 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.

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.

Behavioral terms

- Confused and agitated
- Social skill deficits and/or substance abuse
- Lack of responsiveness to requests (“noncompliance”)
- Resistance to rehabilitation therapies
- Disruptiveness
- Loud verbalizations or threats
- Property destruction, self-injury, physical aggression, etc.

Cognitive terms

- Disinhibition (inability to block or manage drives and impulses)
- Lack of awareness or ability to self-monitor and evaluate
- Personality changes
- Mental inflexibility (rigid or black-and-white thinking)
- Impulsiveness
- Impaired reasoning, judgment, problem-solving, memory, etc.
- Intermittent explosive disorder (a severe inability to resist surges of aggression)
- 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)

Neurological terms

- Frontal lobe syndrome (a set of symptoms associated with impairment of executive functions)
- Injuries to specific regions of the brain, for example the hippocampus, amygdala, temporal lobe, or basal ganglia
- Organic brain syndrome (any physical change in the brain that causes a significant change in mental function)
- Organic personality disorder (a physical change in the brain that causes a significant change in personality or behavior)

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)

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?

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.

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.

Managing Behavioral Problems after a Traumatic Brain Injury

By: Tom Novack, PhD

May, 2002

Behavioral problems following traumatic brain injury (TBI) present tremendous challenges to family members as well as those working with people who have a TBI. These behaviors can interfere with all aspects of individuals' lives, from the rate of recovery, to safety issues, to an ability to socialize.

There is no way to predict if behavior problems will occur or how long they will continue. Some individuals with TBI do not experience behavioral problems, while others exhibit a variety of problems. Typical behavior problems of individuals with TBI include not being able to control their temper, not being aware of proper social behavior, not obeying directions, as well as restlessness and agitation.

All of these problems have one thing in common; they are all caused by the neurological disruption that occurs with a head injury. It is important to understand that when individuals with TBI have behavioral problems, they are not purposely misbehaving. Knowing this can help you understand the behavior of people with TBI. It can also help lessen your concern and anxiety when interacting with them. In working with people with TBI, keep all of your options open as to how you respond to problem behaviors

Understanding Behavioral Problems

It is helpful to understand some general principles about behavior when dealing with behavior problems.

- First, you cannot control other people' lives. You cannot force someone to do something. Each person is responsible herself of himself. Thus, the goal for handling behavior problems is to **manage your own behavior and not that of the other person**. The same applies when dealing with individuals with TBI.
- It is unrealistic to think you can totally do away with negative behaviors exhibited by people with TBI. Expecting to totally eliminate behavior problems will lead to frustration. A more appropriate goal is to **minimize the inappropriate behavior**, even if there are periodic behavior problems.
- Remember to not take the behavioral outbursts of individuals with TBI personally, even though they may behave in a very offensive manner and direct their comments or actions towards you. Try to distance yourself emotionally from this. **Recognize that it is a neurological problem and not a personal issue**. Remain calm and avoid reacting emotionally to what is occurring.

Agitation and Restlessness

Agitation and restlessness displayed by individuals with TBI are the result of injury to the brain.

This type of injury can cause them to have a limited attention span, poor reasoning skills and limited memory. This makes it difficult to stay focused on a particular event or topic and to figure out what to do if a problem arises. All of these factors contribute to agitated and restless behaviors.

Agitation and restlessness are sometimes described as a stage in the recovery process following TBI. However, it is difficult to predict who might experience agitation and restlessness and if it will be a short or long-term problem. The length of time that individuals experience these behaviors varies. Often you need to “ride the storm” for a few days to see if the behavior will be short-lived or if interventions, such as medication, are needed. This means that you must be very patient and know ways to manage agitated and restless behavior.

Approaching & Interacting with Individuals With TBI

How you approach and interact with individuals with TBI can affect their behavior. Keep in mind, they may be confused and react impulsively. How you present yourself can influence how restless or agitated they become.

- **Use a social greeting**, such as “Hi (name), how are you?”, as you make contact. A handshake may accompany the greeting. The handshake and greeting are cues to relax. Remember, introduce yourself each time you make contact. The person may not remember you from previous contacts due to memory problems.
- **Speak slowly and clearly** during your conversations. This gives the person time to process what you are saying if his or her cognitive (mental) processing is slowed by the TBI. Be very direct and brief in what you say. It is better to say, “Can I comb your hair?” than, “You wouldn’t mind if I combed your hair, would you?”
- **Avoid repeatedly disagreeing** with the person. It is important to correct inaccuracies and confusion, but not to an extent that an argument occurs. A good rule of thumb is to correct an error when it first occurs, but do not insist on your viewpoint if an individual with TBI claims he or she is right. It is usually not effective to logically reason with an individual who has a tendency towards agitation. At that point it is helpful to change the subject or make comments that neither agree nor disagree. For instance, he or she may tell you something is lost when you know it is not. If a person is not willing to accept that the item is not lost, just assure him or her that the lost item will turn up shortly.
- **Always explain your intentions** before beginning an activity. Explain in very brief terms what is going to happen. This can prevent a startle reaction that could lead to agitation.
- **Avoid sudden touching or grabbing.** Use a greeting and some conversation before touching a person with TBI. Then you should only touch with a gentle hand pressure on the shoulder or arm. Grabbing and holding firmly should only be used in situations where there is obvious danger to the person or when other interventions do not work.
- **Redirect the attention of a person with TBI.** When a person with TBI shows signs of becoming upset, you can change topics or activities to something less disturbing or confusing. Humor can also be a helpful distraction. Laughter shows that you are not too rigid or formal. It is important, however, that a person with TBI not feel that others are laughing at him or her.
- **Formally end your contact** with a person with TBI. Although we do not commonly do this in our everyday contacts, it is an important step. Often individuals with TBI are not

aware of cues that suggest that you intend to leave or end a conversation. Therefore, it is important to state your intentions, "I have to leave now (name)."

When you use these general rules of contact, your interactions with a person with a severe injury are likely to be smoother. There is less chance for agitation, restlessness or other behavioral problems to occur.

Managing the Environment

Managing the environment can actually be a way to treat behavioral problems and to decrease problems with agitation and restlessness in people with TBI. It is often difficult for individuals with a head injury to remain calm in an active environment. A lot of stimulation, such as loud televisions, loud conversations, and crowds, can increase their restlessness.

- Create a calm environment. This may mean guiding the individual with TBI to a quiet room, closing a door, or turning off the television.
- Stay in control of your behavior. Remember, you need to stay calm and speak in a low, calm voice.
- Use gentle physical contact, such as rubbing the individual's shoulder. Remember that you need to alert the person of your intended actions.
- Physical restraints are sometimes needed if there is significant danger to the injured person or others. You should first discuss the type and use of restraints with the person's doctor. The use of restraints can sometimes increase agitation in individuals with TBI.

Medications

Medications are another treatment used to manage restlessness and agitation. Propranolol is one drug that can have good results. It decreases the behavioral dyscontrol and agitation commonly seen in individuals with TBI. Anti-depressants, such as Zoloft (sertraline) or Prozac, are also prescribed. Occasionally mild tranquilizers, such as Buspara (buspirone), may be beneficial. Another class of mild tranquilizers are benzodiazepines (Ativana or lorazepam). These drugs are used for short periods of severe agitation. However, research with animals shows that their prolonged use can possibly reduce cognitive function and slow recovery from TBI. In extreme cases, such as when individuals with TBI are at risk of harming themselves or others, major tranquilizers are used. Drugs such as Risperdal (risperidone) or Zyprexa are prescribed more often because they have fewer side effects than more traditional drugs (Haldol, Mellaril and Thorazine).

One consideration in using medications to reduce restlessness and agitation is their side effects. These drugs usually affect a person's mental status. This is a problem for individuals who already have significant memory loss due to their injury. Certain drugs may make it more difficult for some individuals with TBI to participate in their daily activities. This can then slow the recovery process. However, there may be situations where medication is desired. For example, you may have a problem getting a person with TBI to stay in bed and go to sleep at night. A mild sedative would be a better choice than restraints.

Noncompliance with Treatment

Unwillingness to participate in normal daily activities is a common problem when dealing with individuals who have a TBI. This can be anything from refusing to dress, eat, or participate in therapy sessions. Often, this is a sign of confusion or it may be a way of saying that a certain activity is uncomfortable. This can be a difficult situation to handle. While you do not want to force your loved one to do something, you do need to see that he or she completes certain tasks. One way to change his or her mind is to create a situation where she or he wants to participate, even if not enthusiastically.

Determine what activity is being refused and why, if possible. This may be difficult when working with people who are confused. However, it may make the difference in getting them to participate in an activity. An example is when people with TBI refuse to do a simple daily routine, such as getting dressed. You can ask why she or he does not want to get dressed. It may simply be that the color of the clothing is not right or the clothes may be uncomfortable.

Another reason for not wanting to take part in an activity is because she or he is tired and needs some rest periods during the day. If you take time to find out the reasons for refusing to do something, you may find the answer for getting participation in an activity. Remember, something may not seem important to you, but it is to her or him.

Redirect the attention of people with TBI when you want them to take part in an activity and they refuse. Simply move on to a different activity. Then at some point in the future you can return to the refused task. This often works because of her or his limited attention span and memory abilities. One way to create a distraction is to play music during an activity or count during tasks, such as when doing stretching exercises. Be aware, however, that sometimes the distraction interferes with an ability to focus on the task at hand.

Explain activities to people with TBI so they know what to expect. Individuals are usually more likely to refuse to participate when they do not understand what is happening. If an explanation does not work, then you can try changing the order of the tasks. For instance, if dressing is very difficult, then it could be left until the very end of the morning routine. Other tasks can be done first, such as taking medications and eating breakfast.

Provide choices. As the mental abilities improve, individuals with TBI want to have some control over their lives. They may refuse to participate if they think they are being “forced” to do something. You can improve this situation by providing choices. Just be sure that the choices you give are acceptable. For instance, you can let your loved one make choices in what to wear or in his or her daily activities. Present the choices as an either/or decision. For example, ask if he or she wants to wear the blue shirt or the red shirt rather than asking, “What do you want to wear today?” Too many choices make it difficult to decide and can increase confusion and agitation.

Bargaining is another way to get people with TBI to cooperate. This works best later in the recovery process. Bargaining is a way to reinforce their participation in an activity. The “bargaining tool” should be something that a person likes to do, such as watching television. You can encourage getting dressed as quickly as possible so there is time to watch a favorite morning

TV show. It may be possible to get him or her to agree to do one activity if an enjoyable activity follows.

Written goals can give a sense of control. Be sure to post the goals where they are easily seen, such as on the refrigerator or the door to an individual's room. A checklist can be one way to encourage a higher functioning individual to complete his or her activities independently. For example, you can provide a checklist of activities to be completed every day. This makes a person responsible for carrying through with tasks.

Make the tasks meaningful. This can be challenging. Often, routine activities and tasks are not very motivating. In addition, many individuals are limited in what they can do because of their brain injury. Individuals with TBI want to resume their lives and participate in daily activities. For an adult, this means returning to work, being with family, driving a car and engaging in social activities. However, they may first have to re-learn basic skills, such as balance, dressing, and attention skills. Explaining that these basic tasks are stepping-stones to being independent may be helpful.

Provide feedback. You can do this by telling your loved one that he or she has done a good job and provide a smile for reassurance. The impact of such comments should not be underestimated. Positive feedback should be used often.

Temper Outbursts

Everyone's temperament varies. For individuals with head injury, anger and irritability may occur more frequently than with the average person. The cause of these temper outbursts after TBI is related to the type of injury to the brain. Often a TBI occurs to the frontal areas of the brain where the damage causes individuals to be unable to hold back their emotional and verbal responses.

While most people become angry at some point in their lives, they are able to control their anger or "keep it inside." However, individuals with TBI have what can be described as a "quick fuse." It is like the gates fly open and emotions come out. Their temper rises rapidly and outbursts may occur over relatively minor events. These outbursts are often unpredictable. What makes them angry today may not make them angry tomorrow.

Individuals with TBI are usually not violent but may make harsh or loud comments and/or show changes in facial expression. Typically the event lasts only two to three minutes at most. After the outburst the person returns to normal rather quickly. She or he no longer seems concerned about what just happened, although she or he may give a short apology.

Remember, these temper outbursts by your loved one are a result of the injury and are not directed at you personally. Your best response is to:

- **Remain calm.**
- **Look for any obvious reason for the temper outburst.** Remove the cause if at all possible or direct the individual away from the stimulus.

- **Do not try to reason or get into an argument** with a person with TBI. This can create more difficulties since many individuals with TBI do not have good reasoning skills. When arguing, these individuals are very emotional. Wait until the temper outbursts are over before trying to talk about what caused the outburst and how it might have been handled differently.
- Get control of the outburst or **“nip it in the bud.”** As you get to know how your loved one reacts to situations, you may be able to tell when she or he is getting anxious or confused. You can then intervene before a temper outburst occurs.
- **Use a reinforcement program** to decrease the number of temper outbursts. This works best with individuals who have higher functioning abilities. You keep track of the number of temper outbursts during the day. If the number of outbursts does not exceed a specified number, then the person can choose an activity. For example, if only one temper outburst occurs in the morning, after lunch she or he can watch a movie or play a video game.
- **Medication.** This should be a final choice to help decrease temper outbursts. These drugs can be expensive and they usually result in some clouding of mental abilities.

Socially Inappropriate Behavior

Sometimes individuals with a head injury say things that are rude or insensitive. Again, you need to remember that this is the result of cognitive problems caused by an injury to the brain. They are unaware how their behavior affects those around them. It is not meant as a personal comment to you. If you react to this behavior personally, it may create more problems.

Crowds and conversations with more than one person often cause individuals with TBI to become more confused. When this happens they are more likely to make inappropriate or irrelevant comments. Some ways to handle this behavior if it occurs in a social setting are to:

- **Redirect attention to another topic.**
- **Try to gently remove the person from the situation.**
- **Use nonverbal cues**, such as a time-out signal. This can let them know that there is a problem with their behavior.
- **Avoid embarrassing a person** with TBI by commenting on his or her behavior in front of others. An individual with TBI is still an adult and wants to be treated like an adult. You need to talk about the improper behavior, but do this one-to-one and in a sensitive manner.
- **Be a role model and teacher.** With daily or regular contact, you have the chance to be a role model and show your loved one proper social behaviors. By being a good listener and not interrupting others, you give a person with TBI clues as to how to behave. You can take turns when speaking and show how this gives everyone a chance to speak. Another activity you can do is practice having conversations. Select topics that will be interesting. This can be on topics like family issues, sports, or the weather. Keep your responses brief so you are understood and the person can “stay in” the conversation.
- **Role-playing** is another activity to help prevent inappropriate behaviors. For example, when a person with TBI makes a sexual comment to others, suggest other responses such as “You have been very nice to me today” or “I like the way you’ve done your hair.” It does not help to correct or criticize the behavior without giving the person some ideas of a better way to respond.

Denial of Disability

Individuals with TBI usually do not fully realize their problems. These problems can include the cognitive, physical or behavioral issues. Once again, this is in part due to the brain injury itself. There are areas of the brain that control ones' abilities to monitor themselves and their surroundings. The area of the brain that controls emotions also directs individuals to not want to accept the major limitations they now have due to TBI.

While you want a person with TBI to understand his or her disability and the difficulties that may be experienced, the person may deny there is any problem. To argue about this may only cause an individual to become more defensive and more strongly deny that there are any problems. This can increase problems with your relationship.

There are, however, some times when you must confront this denial of disability, such as if your loved one is in danger. For example, some individuals with TBI may be non-weight bearing but think he or she can walk and try to do so. They must be confronted directly, but in a nice way. It must be emphasized that the situation may change. Explain that in the future they may be able to walk. You can explain why they cannot do that task at this time, but when their balance improves, they can begin doing things on their own.

If denying the disability does not put a person at any danger, it may be easiest to simply ignore it. Change the topic and move on to another activity. In most cases, a person's understanding of his or her abilities will improve with time and as he or she participates in more activities. Experiences in trying to do an activity will often have more effect than simply talking about the problems. You can gently explain this, but avoid any arguments. There are usually few benefits from arguing. In most cases, a lack of awareness by the individual is a sign of limited reasoning skill. Remember to avoid embarrassing comments. Do not comment on the disability in front of others or address them in a teasing or demeaning manner.

You can watch for signs of positive growth, such as when a person with TBI does something that you did not think she or he could do. When a person with TBI insists on doing something, it is usually best to let her or him try it with supervision. For example, if a person believes she or he can do some chores in the kitchen, start with an easy chore. First begin with activities like simple food preparation, setting/clearing the table, or putting dishes away. This shows you what the individual can actually do in a safe setting.

Final Words

The most important thing to remember in living and working with an individual with TBI is to remain calm and be flexible. Do not take it personally when she or he exhibits behavioral problems. You need a calm and sensitive approach as you help your loved one, who has a TBI, as she or he struggles through a difficult time.

Additional Resources

Guide to Traumatic Brain Injury Resources

By: The National Center for the Dissemination of Disability Research (NCDDR) and the Research and Training Center (RTC) on Community Integration of Individuals with Traumatic

Brain Injury.
2002

<http://www.ncddr.org/du/products/tbiguide/>

This Guide includes resources produced by NIDRR Grantees, including the TBI Model System Centers.

Home Based Cognitive Stimulation Program

By: Tom Novack & Jacqueline Blankenship
2002, UAB Model TBI Care System, Birmingham, AL

<http://main.uab.edu/show.asp?durki=49377>

Booklet of activities to use with individuals following their brain injury designed to assist in the recovery of thinking skills. Activities grouped by levels of difficulty and different thinking skills. 56 pp. \$3.

Living with Brain Injury: A Guide for Families, 2002

By: Richard C. Senelick, MD and Cathy E Ryan, MA

This book will help families, people with brain injury or professionals. Topics include: Causes and treatments; physical, cognitive and behavioral symptoms; & questions family members commonly ask. 145 pp.

To order call 800-321-7037 \$10.95

Management of Behavioral Problems during Acute Rehabilitation of Individuals with TBI

By Tom Novack, PhD

2002, UAB Model TBI Care System, Birmingham, AL

<http://main.uab.edu/show.asp?durki=47778> A paper for rehabilitation staff who work with individuals with TBI that suggest ways to manage their own behavior in relation to behavioral problems of individuals with TBI.

Understanding Brain Injury: Guide for the Family

By: Mayo Clinic Model TBI Center, Rochester, MN

<http://www.mayo.edu/model-system/navpos5b.html>

A booklet to help families adjust including topics such as: the structure and function of the human brain; causes of brain injury; the recovery process and behavior and communication changes after TBI. 34 pp.

This paper is published by the UAB Traumatic Brain Injury Model System, supported by grant #H133A980010 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, Dept of Education, Washington, DC. Opinions expressed are not necessarily those of the granting agency. Permission to reprint this newsletter, in part or completely, is granted for educational purposes. Published by the UAB-TBIMS, Birmingham, AL. 2002 Board of Trustees, University of Alabama. UAB-TBIMS Project Director: Thomas Novack, PhD Editor: Linda Lindsey, MEd Email: tbi@uab.edu Visit our web site at www.uab.edu/tbi

BEHAVIOR MANAGEMENT IN RESIDENTIAL BRAIN INJURY SETTINGS

Judith Falconer, Ph.D.

WHO IS THE BRAIN INJURED INDIVIDUAL?

Until the injury, the person was like you and me. He/she probably worked or went to school, contributed to society, loved and was loved, had fears and worries, experienced pain and joy. We frequently fail to understand that until the injury, the person was a fully functioning member of a family, work group, and society. Until we understand the person behind the brain that was injured, we can do little to restore that person to a more functional life. We must delve beyond the current behavior and discover hidden strengths and weaknesses, pride and sorrow, accomplishments and failures.

WHAT CONTRIBUTES TO BEHAVIOR PROBLEMS FOLLOWING BRAIN INJURY?

1. Pre-injury variables:

- Age
- Intellectual skills (communication skills, learning style, etc.)
- Personality traits (dependency, assertiveness, motivation, etc.)
- Health
- Social support
- Education/work patterns

2. Acute medical treatment variables:

- Severity and length of coma
- Nature of injury (diffuse plus localized effects)
- Other medical complications (orthopedic, respiratory, etc.)
- Medical environment
- Family involvement

3. Post acute treatment variables

- Time since injury
- Physical recovery
- Treatment environments (physical & psychological)
- Nature and involvement of family
- Financial status
- Motivation for recovery

4. Additional critical variables

- Staff burnout level
- Family burnout level

- Availability of treatment options
- Availability and implementation of behavior management strategies
- Availability of cognitive retraining strategies

WHAT IS BEHAVIOR MANAGEMENT?

1. A way to analyze behavior and modify maladaptive behavior
2. A frame of mind which assumes that all behavior is learned and that all behavior is maintained through reinforcement

OBJECTIONS TO BEHAVIOR MANAGEMENT:

- Dehumanizing
- Too time consuming
- Too complex
- Not necessary
- Only a gimmick
- Fear of being disliked by client/family/other staff

HOW TO DO BEHAVIOR MANAGEMENT: THE NUTS AND BOLTS

1. Be patient. Change will occur very slowly.
2. Be consistent
3. Expect the unexpected
4. Don't overstimulate
5. Treat adults as adults
6. Remember, rehabilitation is a learning process
7. Reinforce appropriate behavior
8. Ignore inappropriate behavior unless it is dangerous to the brain injured individual or others
9. **YOU ARE THE MOST POTENT REINFORCER AVAILABLE TO THE INDIVIDUAL.**

BEHAVIOR MANAGEMENT PROCEDURES:

1. **ANALYZE TOTAL BEHAVIOR PATTERN** --- Determine which behaviors:
 - a. occur with excess frequency, intensity, or duration
 - b. fail to occur with sufficient frequency, adequate intensity, or appropriate form
 - c. the individual can do particularly well
 - d. the individual did particularly well in the past
2. **SPECIFY PROBLEM BEHAVIORS & SITUATIONS**
 - a. when/where they occur

- b. frequency of occurrence
- c. length of occurrence
- d. intensity
- e. individuals present during occurrence
- f. what precedes them
- g. consequences
- h. what has already been tried

3. SPECIFY CURRENT/POTENTIAL REWARDS/PUNISHMENTS

- a. Material Time Out
- b. Activity Restraints
- c. Social Withdrawal of social contact
- d. Token Loss of privileges or reinforcers
- e. Covert

4. ESTABLISH BEHAVIORAL GOALS

- a. Select specific behaviors to be increased, decreased and/or added
- b. Do not leave behavior void
- c. Do not attempt to change multiple behaviors simultaneously

5. SELECT APPROPRIATE INTERVENTIONS

- a. Utilize client's strengths
- b. Minimize effects of client's deficits
- c. Decide to change:
 - 1. Environment
 - 2. Other people
 - 3. Client
- d. Establish realistic time frames
- e. Be realistic about expectations of:
 - 1. Self
 - 2. Client
 - 3. Other people
 - 4. Environment

6. IMPLEMENT BEHAVIOR PROGRAM

- a. Inform/train everyone involved
- b. Give program a chance to work before giving up or changing it
- c. Expect client to test your determination to succeed
- d. Be consistent

- e. Be patient

7. MONITOR PROGRESS

- a. Keep detailed records
- b. Be consistent
- c. Involve client in monitoring
- d. Fade reinforcers gradually
- e. No holidays allowed

8. MAINTAIN NEW BEHAVIOR PATTERN

- a. Prayer may be appropriate
- b. Recycle if necessary